

Chapter 1

[00:00:06] Narrator:

Hello and welcome to the Palliative Care Project, [00:00:10] a series of podcasts for culturally and linguistically diverse speaking carers. You're listening to the English version of the podcast. We have also recorded this podcast in Arabic, Chinese and Hindi and we welcome our listeners to jump online to hear this in language. All podcasts are available on the Carers New South Wales website. This recording was made with the help of carers and families from different language and cultural backgrounds. They're people who have experienced firsthand what it means to care for someone towards the end of their life.

[00:00:47]

They agreed to share their comments, and for us to hear their voices in the hope of helping other carers and their loved ones who are about to embark on their palliative care journey. Through their own voice, we will hear them share their experiences, what they found helpful, what they wish they had done differently, and their advice to carers in a similar situation. You will also hear from doctors and nurses who will provide information about palliative care. We hope you find this helpful, whether you are caring for someone now or perhaps in the future.

[00:01:30] Carmen - Palliative Care Nurse:

When someone is diagnosed with a life-limiting illness, it can be a very distressing time. Often people avoid talking about it until it is too late, and as a result they don't find out what help is available from palliative care in Australia. The carers we talked to all said they wish they knew more about palliative care before they actually experienced it themselves. That way they could have better prepared and understood how it could help them.

[00:02:10] Michael – Carer's Experience:

You know, after so many years sitting down and talking to someone about palliative care, I realised now there was so much I could have asked. They would have helped me look after my mother back then. I believe this conversation with our community is very important.

[00:02:40] Carer's Experience

During the time I was looking after my father. I found it so difficult I thought at the time it was best not to ask too many questions and upset my family. But you know, now after looking back, asking and learning more about palliative care at the time, would have made such a big difference to not only my sister but for me, her children, husband, and the entire family.

[00:03:18] Carmen - Palliative Care Nurse:

I felt people from culturally diverse communities generally fear talking about death itself. It is part of the cultures and is often a taboo subject. Consequently, I've met many people who are shocked and upset when I start talking about palliative care to them, but they all realise later it is an important conversation. I really hope this recording will help you, as the listener, to reach out to the doctors and nurses who may talk to you about palliative care. We just want to help you, your family and your loved one to have the best possible care and support you're entitled to.

[00:04:05] Mina - Carer's Experience:

My advice is that doctors should introduce palliative care concept to carers and the relatives of cancer patients as early as possible, so carers and relatives can start to educate themselves and be mindful about what services are available. Otherwise, when a doctor suddenly suggests it, the first usual reaction is, "Oh, my, the patient will die soon." It is not the case.

[00:04:25] Carmen – Palliative Care Nurse:

Our Palliative Care Team understands the importance of respecting our culturally diverse patients through the whole palliative care journey. We are trained to respond to all different communities, and know that in the various cultures, family, community, and even community leaders play a very important role in their care. We encourage our listeners to approach the Palliative Care Team and have a conversation about what you and your family's wishes are and begin to get to know your Palliative Care Team who will be with you along the way.

[00:05:14] Panama - Carer's Experience:

Being part of this conversation has been so rewarding. I encourage you as a carer, or if you are a family member, to take the time to listen in on the conversation and just know you're not alone and there are people around you today who can help you. Looking back, I wish I knew then what I have learned today during this interview about palliative care. You know, taking that first step to talk to someone outside the family is hard, but trust me, it will make such a difference.

[00:05:54] Narrator:

Let us begin with Chapter 2, as we hear from our doctors, nurses and other carers discussing exactly, what is palliative care?

END

Chapter 2

[00:00:02] Narrator:

Hello and welcome to the Palliative Care Project, a series of podcasts for culturally and linguistically diverse speaking carers.

[00:00:13] Narrator:

Welcome to Chapter Two. In this chapter, we will explore exactly what palliative care is. We will also hear our guests talk about some of the decisions and choices they had to make during this time, particularly as culture plays such an important part in their family life. Let us begin by hearing a nurse from the palliative care unit, explain exactly what palliative care is.

[00:00:50] Carmen- Palliative Care Nurse:

Palliative care is all about promoting the best possible quality of life. Palliative care is for someone who is living with an illness that can no longer be cured, but what we as a team do is to improve the person's quality of life by managing their symptoms well.

[00:01:10] Rosie - Carer's Experience:

It is strange, but I know many years ago, I went through palliative care when I looked after my mother, and after so many years now, uh, in preparation for this interview, if someone was to ask me what that was called, I guess, I wasn't able to tell them. In our community and in my family, we don't often use the name palliative care. We don't really refer to it either. I suppose it's kind of difficult at the time to have that conversation, but I guess looking back now, it would have helped me understand the process a little better.

Now, from what I have learned today, in my own words, I would say palliative care, it's really a stage in someone's life, where their health is affected by serious illness, that's kind of progressing and needs different care to the normal support that you get in hospital.

[00:02:09] Mina - Carer's Experience:

A Chinese doctor mentioned that we could have tried palliative care. As soon as we heard it, we were all very shocked. As we thought palliative care meant there was no cure. This is not the case.

[00:02:30] Carmen- Palliative Care Nurse:

So in palliative care, we work with the whole team. In the team, there are medical specialist, specialist nurses, physiotherapists who maintain your independence, occupational therapists to make sure you are safe at home and able to stay at home for as long as possible. Social worker for all your other social needs, counsellor, they're very important because we need--

we really need to look after your emotional and spiritual needs, dietitian, to make sure that you're-- you've maximised your calorie intake.

A speech pathologist for your swallowing and many volunteers who will help us all to aim to improve the quality of life for you and your family.

[00:03:15] Rosie - Carer's Experience:

For many years after looking after my mother, to this day, I still continue to wonder, could I have done something different? I think back now that all these questions are still in my mind because I really didn't understand what palliative care was and how the treatments and doctors and medicine all work together. If I knew more then, I would have picked up the signs, how she was progressing, how at times she was getting worse, at times better, and what she needed during these different stages.

I would have also quietly spoken to one of the nurses and asked more questions, but at the time I thought, "Well, what do they know about cultures and traditions?" I was a little bit confused.

[00:04:01] Mina - Carer's Experience:

On Saturday, the nurses told us that mum would not wake up again. By Sunday noon, she had gone in her sleep. We felt comfort that she did not suffer anymore, but I wish we knew what medicine was used. For Chinese people, I heard a saying that morphine speeds up one's death. Not sure if it is true or not. But like I said, we were comforted that in mum's last moment, she was asleep without any more suffering.

[00:04:50] Carmen - Palliative Care Nurse:

Sometimes people think palliative care is just for end-of-life and get very distressed when it is suggested as they think the person is about to die or their life will be shortened just by accepting palliative care. This is far from the truth. Palliative care does not mean that there is no hope, does not mean that you have given up or the family don't care about you anymore. Palliative care does not lead to an early death and it is certainly not euthanasia. Just like for example, morphine. Morphine, we use it to relieve pain or to relieve shortness of breath. Morphine itself is well-researched and there are strict guidelines on how to use morphine to relieve someone's discomfort correctly.

[00:05:39] Michael – Carer's Experience:

When palliative care was suggested, it was such a relief. With dad's illness, he would have 39 degrees temperature all of a sudden in the middle of the night. It was quite frightening, you know, so we felt he was in safe hands and also took a huge weight off our shoulders. I do not feel there was a cultural barrier to stop us from using palliative care. My brother and I were

really grateful for the help and time they offered to us. The nursing staff were quite supportive and helped us through the whole process.

[00:06:23] Rosa, Carer's Experience:

Palliative care nurses and doctors understand different cultures more than you'd think and back then, I would have liked to have had a talk and to understand more. It would have meant I would have had more quality time with her in the end.

[00:06:48]

Carmen - Palliative Care Nurse:

Once you accept the palliative care, the team will ask you about your individual needs and cultural needs and what is important to you. You're welcome to ask any questions and make any requests because we want to provide you the best possible care. There are also after-hours services available. So, in the middle of the night, or over the weekend, you and your family are not being left alone. We continue to support the family after the person dies or passes away through our bereavement services and these services are really well recommended.

[00:07:24] Rosa – Carer's Experience:

I have realised it's about comfort, care, being physically and mentally comfortable so that the focus isn't on your medical condition or getting worse, but rather your health and feeling as well as, and as comfortable as you can be. It's just a different way of looking at it now.

[00:07:51]

Carmen- Palliative Care Nurse:

When we meet people early in their illness, it gives us an opportunity to get to know each other before they become too unwell. We try to individualise our care. We really listen to what they want and need and how we can best provide this. In some circumstances, the terminally ill patients may prefer for us to talk to the family directly about their illness. We just need to get the person's permission to do this as long as we have their consent. So, it's good to have this conversation with the doctors and nurses early on.

When you're first told about palliative care, it is good to find out more about it from a recommended source. We see so many people who jump online to get information, but it really worries me because most of the information is not correct. Again, it is very important to get the correct information from a recommended source.

[00:08:51] Rosa - Carer's Experience:

I was shocked after a few weeks my uncle passed away, and the family was very angry. I understand now that my uncle had not accepted palliative care treatment until the very end,

that was why he passed so quickly, and that it wasn't because of medication or anything else. I think back if he had known more about his condition, I think he would have made a different decision and accepted palliative care support. It would have helped him with his pain, uncomfortableness, and the shock of leaving so soon.

[00:09:35] Michael- Carer's Experience:

I was first introduced to palliative care when we were in the hospital, and we just immediately thought that, you know, "This is it really, my dad is going to die," and my first question was like, when? and don't tell him, absolutely don't tell him, that - they were our two most important concerns at the time, and my reaction was absolute fear and loss. You can imagine that. The other thing is even in our culture we-we absolutely don't talk about death, and-and dying, you know.

[00:10:20]

You just- you just don't bring death into the family or talk about death at all. Looking back now, I would have asked different questions about palliative care. You know, m-maybe not in front of my family, or my mother as that would not have been acceptable by the family, but, you know, in hindsight, like I said, I would've gone back separately, discreetly, to learn more. I would have asked more questions about the signs, physical symptoms, you know, and, how-how to make him, my dad, comfortable instead of putting up a wall.

[00:11:07] Cindy- Carer's Experience:

At the beginning, I felt very alarmed. I did not know there were helpers out there I could reach out to for help. He often fell and I could not easily lift him up. We were often stuck in awkward situations; I did not know how to shower him safely. I was physically exhausted most of the time.

[0:0:11:40] Carmen - Palliative Care Nurse:

Caring for someone with a life-limiting illness is not easy, and it is very frightening, and you can feel very alone. Reaching out for help will let you feel more able to manage. It is important to take care of yourself, and your needs as it will give you more strength to care for your loved one.

[0:0:12:05] Cindy- Carer's Experience:

Our family GP sensed I needed help, from him I got various help, including a gentleman came to shower papa, and also made me realise that in Australia, not only papa got looked after. They also look after carer's wellbeing, so when you, as a carer, feel alone, please reach out and seek help.

[00:12:32] Carmen - Palliative Care Nurse:

The patients and the family always remain the centre of our decision-making, and in control of decisions of their health, medical treatments, and their whole well-being. Please make sure you let us know if you have any special requests so that that your care and your care plan are culturally appropriate to your family at all time.

[00:13:10]

Narrator:

We have come to the end of Chapter Two.

[END OF AUDIO]

Chapter 3

[00:00:03] Narrator:

Hello and welcome to the Palliative Care Project, a series of podcasts for culturally and linguistically diverse speaking carers.

[00:00:14] Narrator:

Welcome to Chapter Three. In this chapter, we will explore palliative care and the cultural influences which may affect how we respond and how we receive palliative care treatment.

[00:00:35] Carmen - Palliative Care Nurse:

As a palliative care nurse practitioner with Chinese background, I know firsthand the challenges and the community experience due to our cultural beliefs and traditions, which date back thousands of years. Some of these traditions, while it is cultural and needs to be considered, may at times affect the care and level of support a family may be able to receive. It is important that you let someone know immediately if you feel the information were way too challenging for your family.

[00:00:55]

Many non-English speaking families do not talk about death or dying, or even consider having end of life in a home, because, many will say it is a bad omen, but it is sometimes unavoidable. Our concern is the health and wellbeing, not only of the patient, but also for the carer who is often exhausted or not heard.

[00:01:33]: Rosa - Carer's Experience:

My family, we did not talk about palliative care, death or even dying. Culturally, it's really not appropriate to talk about death in a traditional or cultural Arabic family, and it's like you're inviting trouble into your home or something. As a carer, I was concerned to talk about it in front of my family, but I found I could ask the nurse in my own time or while I was at the hospital, it really helped me. I didn't have to tell my family I was doing this, or else they would just not understand, but I'm so glad I did.

[00:02:00] Carer's Experience:

My grandmother died when I was younger. I didn't know much could come out in the open as to how she felt. Nobody wanted to talk about it. They pretended things are okay. It's a sign of weakness if you talk about it. They hide in corners and talk to domestic workers as no one can know I am crying or that I'm grieving. Grandmother was hidden away in the room when visitors came. She died with dementia and no one knew.

[00:02:50]: Carmen -Palliative Care Nurse:

Many people wait till too late to accept palliative care and coincidentally, because they wait too long, the person passes away soon after. And the family think it was all because of palliative care, but in actual fact, medications that were used don't speed up death. It just makes them more peaceful while they're reaching the last stage on their own naturally. The body decides what it will do. Everyone is different and responds differently no matter what your culture's background. Being pain-free and free from distress in a dying phase during this last stage is important for everyone, and it is really what every patient is entitled to.

[00:03:45] Rosa - Carer's Experience:

I had not heard much about palliative care before. My community heard and they advised people not to take medication or else the person will die earlier. I was very afraid, I didn't know who to believe, but I was happy I asked the nurse so she could explain this to me. I now understand that the medication will not make the person die earlier.

[00:04:15] Semi - Carer's Experience:

My father hated the hospital food, and my concern was, he was losing weight. As his daughter, I had a responsibility to feed him good home-style chicken soup the way grandma would make it. The nurses would give us access to the kitchen, and we could warm it up in the microwave. Once he had a few spoonful's, he wouldn't want anymore. I was so worried he wasn't eating. My sister, uncles and aunties kept saying it was a bad sign and I should force him to eat.

The nurse assured me that it was sometimes better not to force the body to eat if it didn't want to. He had fluids through the machine, but I couldn't see how that was enough. Of all the responsibilities I have, as the oldest daughter, I felt I was letting him down by not being able to give him our culture food from home to nourish him. This was a huge emotional challenge for me.

[00:05:40] Carmen - Palliative Care Nurse:

People might continue treatment if it is helping them, and food is not stopped unless the person is unable to eat. Food means different things to our body while someone is in the dying phase. Feeding someone who has no appetite can actually cause more harm and worsen the symptoms. People need very little food if they are not very active as the illness progresses, but enough to maintain their body. Speak to your nurses about this. They will guide you how to look after your loved one.

[00:06:20] Michael - Carer's Experience:

I was worried because dad was always sleeping when he was taking, uh, morphine. And we thought, you know, we thought they were giving him medication to make him go to sleep. And

we asked them to stop the medication. They explained to us that without the medication, dad was going to suffer even more. And so, then I realised that, you know, we're having him alive with no medication, and at the same time, in a lot of pain. That was really like, it was also not fair for him. It was good to be able to talk to the doctors, to be honest, and the nurses on my own to have this explained to me, and my priest was also with me while I had this conversation, it really helped me talk and open up and be a bit more open-minded about things.

[00:07:22] Eliza - Carer's Experience:

My grandmother deteriorated quickly. Our community had visited daily, but this was getting a bit much. I know in our culture, visiting the sick and asking for forgiveness was a part of our faith and customs. But by this stage, Teta was exhausted. And at times, wasn't able to speak or to read the Koran. The Palliative Care Team at the hospice were really good. They gave us a private room with an extra bed where I or my sister could sleep at night. We read the Koran for Teta when she wasn't able to, even throughout the night. And we called Imam when the time was right. It was peaceful. And I felt the staff were very respectful of our choices.

[00:08:27] Rosa - Carer's Experience:

We couldn't get my sister comfortable at home. So, the nurse suggested she come into hospital for a few days. Well, we felt very upset as we thought that if she went to hospital, that means she was dying, but she did come home again, and she was much better. Her pain was more controlled by the medication, and she was much more comfortable. It helped us to keep looking after her at home.

[00:09:07] Panama - Carer's Experience:

I do not see any cultural barriers to stop us accepting palliative care. As soon as they offered palliative care, it immediately eased my burden, more in psychological and emotional way to support me as a carer. I immediately felt safe for my dad. There were all these professionally trained medical staff to take good care of dad.

[00:09:40] Carmen - Palliative Care Nurse:

Specialist palliative care is usually called in when the person has complex symptoms from the life limiting illness. Palliative care doesn't mean you are giving up on living. It is not about stopping all treatment, stopping food or stopping to drink. It gives the person the opportunity to focus on what is most important to them, and what brings the most joy.

[00:10:050] Narrator:

We have come to the end of Chapter Three.

Chapter 4

[00:00:04] Narrator:

Hello and welcome to the Palliative Care Project, a series of podcasts for culturally and linguistically diverse speaking carers.

[00:01:13] Narrator:

Welcome to Chapter Four. In this chapter, we will discuss how palliative care works, who organises palliative care, and the various options provided by palliative care services.

[00:00:30]: Carmen- Palliative Care Nurse:

Well, palliative care can be organised in several different ways. Mostly it will be initiated by your treating specialist because the doctors will know what stage your illness is at and then a referral will be made to your local Palliative Care Team. Actually, any health professional, who knows you well can make the referral with your permission. Once the referral is received by the team, then one of the specialist nurses will have a look at your referral and they will contact you directly.

[00:00:55] Mina - Carer's Experience:

We started using palliative care once a month. There was community nurses who came to do home visits. Once she even brought a Mandarin speaker nurse to help out. Palliative care was not really for curing patients but gave us emotional and psychological support. Also, it was helpful as it was hard to see the doctor any time we wanted. These community nurses worked with the doctors and follow-up mum's case quite well. For example, in mum's case, she was suffering from constant diarrhea.

The community nurses always carried a booklet of a series of stool sample images. Mum was able to point hers out. The nurse would then suggest appropriate medication to ease the condition.

[00:02:10] Carmen- Palliative Care Nurse:

Palliative care service differ from one location to the next, but usually, there will be a team of medical professionals and allied health members. They may be based in a hospital or in a community. So when the referral is received by the team, it will be triaged by the specialist nurse, and they will make contact with you and that is where the specialist nurse will explore the appropriateness of the referral. When someone from palliative care first meets you and your family member, they will usually have information about the illness and the treatment from the referral.

They will talk to you in more detail about how the illness is affecting you, the different stages, what is expected to go through, and they will ask you what your wishes are and how you would like to be cared for. Palliative care service differs from one location to the next, but usually, there will be a team of medical professionals and allied health members. They may be based in a hospital or in the community.

[00:03:15] Michael - Carer's Experience:

So I really-- I've got to say, the Palliative Care Team, they had done so much for dad. Although we didn't see the doctors often, you would always see the nurses around showering dad, changing him, making sure he's okay, he's comfortable and then there was also all the church people, the people coming from our local church, they came to pray for us. That was very helpful too. So we felt that in palliative care, really, to be honest, dad would keep some dignity with a nasty cancer he was suffering. They reduced his pain and relaxed dad, made him as comfortable as possible.

[00:04:00] Mina- Carer's Experience:

There were doctors, nurses showering mum and changing the beds. Volunteers came to do massages for mum. Mum was 73 and some of her friends were in their 80s. They came to visit my mum. They were impressed by the facility. Although they were visiting mum, they were actually looking and checking for their future needs. Half year later, after mum passed away, they even held a memorial service for families who lost their loved ones in the same hospital around the same time. My dad wanted to go, but I was not so eager.

But we went along with my dad. I'm glad I went. There were poems read, candle lighting, mum and other names were read out. They set pigeons, flying away, symbolising our loved ones forever in our hearts. It was a moving scene and it was comforting. We were very touched.

[00:05:10] Irene - Carer's Experience:

Palliative care greatly helped us. Before dad became an in-patient. I had to look after him 24 hours a day. It was hard, really, really hard. When he was in hospital, my daughter would be able to come in the morning and the three of us together finished our breakfast. My daughter then was able to come in the evening and have dinner together in the hospital. Then, my daughter would drive me home for a while as I needed to do washing, get everything organised. Then I returned at 11:00 PM and be with my husband through the night.

[00:05:50] Mina - Carer's Experience:

Our entire family were grateful to palliative care. Mum was sent to the hospital by ambulance. In contrast to our imagination that palliative care hospital might be dark and depressing. It was a new hospital ward with one patient per room. There was a corridor outside our rooms to a pleasant garden. It was a serenity that we really needed.

[00:06:10] Cindy - Carer's Experience:

At dinner time, I sensed that something was really wrong with papa, but could not pinpoint it, so I called an ambulance. While waiting for the ambulance, papa was very scared. As soon as the ambulance arrived, papa was relieved. They put an oxygen mask on. He drifted into sleep. I did not realise that he would never wake up again from that sleep. When the doctor sat me down in a quiet room and asked me if papa's condition worsened, would it be okay not to pump his heart up and not insert any tubes? "Oh, yes, yes, yes."

I heard these exact words before and papa had pulled through it before. So, I didn't really catch on. But I did take his advice. And at midnight, I went home to fetch mum to the hospital and rang my sister in China to let her know just in case. I am glad I did that. A nurse whispered to me that hearing usually was the last to go. I took that advice as well. I held papa's hand and sang quietly into his ear as he loved singing. At one stage, papa sweated profusely, and we all noticed his clothes were soaking wet and it also soaked all his bedsheets.

Several nurses kindly offered to help. Mum and I wiped papa gently and we changed him into dry clothes. The nurses even changed the whole bedding without much fuss, all so gentle towards papa. Papa did not get disturbed much. Papa peacefully passed away in the early morning, gone so fast that mum and I were stunned. All hospital staff quietly went out the room to leave us with papa in private. Because we did not prepare for this, it was extremely hard for us to accept it. No one came to hurry us up. We were in the room with papa for a very long time until we felt that we were ready.

We came out to tell the staff. All years since that night, I still cannot help but sometimes recall and relive that night. Papa had a good death. He simply fell asleep and never woke up again. This has given us comfort to deal with it easier. The hospital really treated us with humanity and were very kind indeed. The hospital provided the family member emotional support when we most needed it.

[00:09:35] Carmen- Palliative Care Nurse:

There are different levels of service available in different areas. It is important to explore what is on offer in your locations because each area is very different. It is very important that, for us to know what their needs are, so, for the family to open up and let us know and discuss with us, very helpful. For example they might need help with showering or with some housework. Some family members or some carers are actually reluctant to ask for sharing or ask for help because they think, they think they are failing the patients and that is not the case at all.

There are services even available for someone who allows the carer to go out for shopping and have someone to rest by in the home to look after the patients at home. This service will ask you what your needs are and help in the way that works best. We understand and we know it is very tiring and it's physical and emotionally demanding when caring for someone

you love is unwell, even with life-limiting illness. We're here to help you to get this service if you allow us to.

[00:10:44] Panima – Carer’s Experience:

I tried not to upset him by talking about his condition. I wanted to be positive and hide as much from him as possible. We did get some care at home for him. This really helped me care for him. My advice would be to always keep an open mind about what is offered. Get educated about things, seek help focussed on physical condition.

[00:11:20] Carmen - Palliative Care Nurse:

Palliative care is really, it's a whole team effort. So in our team, we've got physiotherapists and occupational therapists. These are the health professionals that can help with the equipment to be placed at home and help you to care for your loved one at home. Things like wheelchairs, hospital beds, bathroom aids, your safety, how to transfer properly so that you do not hurt yourself at home.

[00:11:50] Rosa - Carer’s Experience:

It was so much easier to shower mum once they lent us a special chair that sits in the shower. Mum couldn't manage to stand for long so the chair meant that she could sit down to have her shower. The wheelchair was also great as we could take mum out and she did not get exhausted just walking to where we were going.

[00:12:30] Irene - Carer’s Experience:

Palliative care was really a great help to my family in so many ways. For example, my husband, he has a brother, he flew in from Hong Kong. He arrived at 11.00 AM. My husband was able to spend his last 30 minutes talking to his brother before he died. And that's really all thanks to the palliative care doctors. They told us that we only had about two days left. That alert was really enough for us. After my husband passed away, I watched how the Palliative Care Team worked for us. He was washed by nurses. They changed him into decent clothes, and there were candles and flowers. I was speechless. It was so beautiful and peaceful.

[00:13:45] Narrator:

We have come to the end of Chapter 4.

Chapter 5

[00:00:04] Narrator:

Hello and welcome to the Palliative Care Project, a series of podcasts for culturally and linguistically diverse speaking carers.

[00:00:010] Narrator:

Welcome to Chapter Five. In this chapter, we will explore decision-making during the palliative care journey. We will also explore how to facilitate conversations when discussing issues with family. Let us begin by hearing from a nurse from a palliative care unit.

[00:00:30] Carmen - Palliative Care Nurse:

So, palliative care is all about respect, the choice of the terminal inpatients and the family, what they want, how they want to be cared for. And it means the decision 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 the decision, while they can, but as their condition progresses, they might need someone else to make the decision for them. Then we need someone to be their voice.

In some cultures, it may be certain members of a family who are the decision maker. It is important to discuss this with the person that you care for while they are well enough to find out how they want decision to be made. If they prefer the doctors to talk to the family members, then they will have to let the doctors know who they can talk to and who can make decisions on their behalf.

We understand palliative care can be daunting at first, but it is about guiding and preparing you for the journey.

[00:01:50] Mlna - Carer's Experience:

Yes, we were able to talk openly in our family. I have a sister in China. All of us felt shocked by mum's cancer news, but we did not deny it. We accepted the news, and they were mentally prepared.

[00:02:15] Michael - Carer's Experience:

My dad told the nurses that he wanted them to-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 me such questions, and always gave me advice to help me make decisions.

[00:02:40] Carmen - Palliative Care Nurse:

So, some of the questions that may be asked by us, the Palliative Care Team, uh, may include, one of the most important and most frequent questions we ask is, what is important to you and your family? We'll also ask if you have any pain, we aim to improve your quality of life, minimise your symptoms. So, the answers to these questions will help us to review and explain medications or other ways to manage your symptoms the best that we can.

We also ask about who in the family do you prefer we talk to if your condition, uh, deteriorate further, uh, or become too unwell to talk, or don't want to talk, too weak to talk. Where do you want to be cared for, is a question that we will ask you quite early on when you are less unwell, because it's very important that you get to be cared for in the place that you want at the end of life. It could be home, it could be hospital, and it could be hospice as well.

And the whole reason why we ask so many questions like this, is to really explore and secure the goal of care so we will know what the options are available for you, and we can plan with you and your family.

[00:4:12] Cindy - Carer's Experience:

When my dad was dying, we didn't prepare at all for his end of life. I felt too overwhelmed to talk about these things. I regret I didn't talk about it with dad. It seemed bad luck and a bad omen to talk about dying, so I avoided talking about it.

My advice, to prepare for end of life early. Now I'm caring for mum, I need to talk in a subtle way and ask her what she really wants. She said she doesn't want to suffer too much. She wants quality of life. You need to find your way to have these conversations in ways that are okay for the person. It is a very sensitive topic, and the choice of words is very important.

It is a blessing to be able to look after parents. It helps one to feel good in the future. It is important to love, touch, and hug our aging parents a lot.

[00:05:35] Carer's Experience:

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 there talking together

[00:05:45] Irene - Carer's Experience:

My regret that I did not let my husband die naturally and I reluctantly let him go. I insisted the nasal gastric tube insertion from the hospital. I felt he suffered longer unnecessarily. My husband himself was pulling tubes off.

He had enough. He was tired and hard, very hard.

[00:06:50] Cindy - Carers experience.

Chinese rank filial piety as a number one virtue. Some Chinese still believe filial piety means to keep their parents alive at any cost. Extending parents' lives has the potential to extend suffering, and I don't believe this is true filial piety. To these people, I would like to say, please let your parents die peacefully and naturally. Please do not let them suffer unnecessarily. One should grow old with dignity. One should have quality end of life. One deserves to have as much comfort as possible, and the least pain possible. It is extremely hard and extremely emotional to let your loved one go, but sometimes you do have to make the decision because you love them.

[00:08:10] Irene - Carer's Experience:

As caregivers, we need to pay attention to diet, sleep and rest. There are other supports that can help you. I realise that I don't have to do this alone. Palliative care social workers helped us organise some help at home. I don't know how I have continued this without their help.

[00:08:35] Cindy - Carer's Experience:

When mum was so engaged in choosing that cemetery, I was really puzzled. Normally, mum is frugal and does not like to waste money. By chance, I got insight out of her. She believes that a good cemetery will bring good luck and prosperity to her children. That is not only mum's belief, many Chinese believe that. Chinese are quite eager to arrange their own cemetery. However, to write a will is taboo.

[00:09:20]: Mina - Carer's Experience:

Because mum's illness was quite a sudden one, mum did not have wills, health plans or enduring power of attorney done before she fell ill. We did not discuss any of them either during the time I was caring for her. In my family, we did not talk about power of attorney or wills, but we openly discussed choosing which cemetery would be the best.

[00:09:58] Carer's Experience:

"Plan ahead," and so 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.

[00:10:20] 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.

[00:10:45] Michelle - Carer's Experience:

No. Chinese people don't like making wills. After mum passed away, my dad has signed power of attorney with me, but dad has not made his will. When dad visited some of his friends in China, they all warned him not to make a will. Around a dining table with his friends, they would discuss about the wills. Someone felt that it was a bad omen that if a person had written a will, he or she might die suddenly, or the person might feel that his or her offspring would rather him/her die quickly to inherit the wealth.

Do you know why people believe we don't need these things? Because in the old days, it was very clear who did what in the family and who inherited what from the 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.

[00:12:10] Narrator:

We have come to the end of this chapter-

[END OF AUDIO]

Chapter 6

[00:00:03] Narrator:

Hello and welcome to the Palliative Care Project, a series of podcasts for culturally and linguistically diverse speaking carers.

[00:00:17] Narrator:

We have come to the end of our conversation on palliative care. We hope that this podcast has been really helpful to you and hope that you were able to connect with some tips and suggestions made by our speakers. We hope that the different stories and community voices have helped you learn more about palliative care.

If you are a carer and listening to this podcast, we encourage you to reach out and speak to your palliative care nurse about your concerns.

If you have specific cultural needs, speak to them about how they can tailor the support provided so that you can spend quality time with your family member.

[00:01:07] Rosa – Carer’s Experience:

I have learned so much from not only telling my story, but meeting others who have experienced palliative care. I hope by telling you about our stories it has helped you too.

[00:01:26] Panama - Carer’s Experience:

The hardest part is having a conversation with your family members. Sometimes it's easier to talk to the nursing staff and doctors at palliative care. They know how to help you, and it is confidential.

[00:01:52] Carmen – Palliative Care Nurse

We thank you for listening to this podcast, and encourage you to reach out and speak to your local Palliative Care Team. The team is there to help answer any of your questions and concerns, particularly if cultures and tradition plays an important role in the way you receive treatment and healthcare.

We are there to help you and your loved one to spend good quality time together while living with a terminal illness till the very end.

[00:02:25] Narrator:

Thank you for listening to the palliative care program, a conversation about palliative care for culturally and linguistically diverse communities. The project was funded by New South Wales Health and auspiced by Carers New South Wales. We would like to acknowledge the support

provided by the palliative care advisory committee for this project. We would also like to thank Calvary Health Care Kogarah, the Multicultural Communities Council of Illawarra, Ethnic Community Services Co-operative, and Ethnic Communities' Council of New South Wales.

A great thank you also to the health professionals and guest speakers who have joined us in the conversations today. You will find their names and profiles on the website. Most importantly, the many carers who spoke with us and shared the experiences so that other carers would be able to understand more about palliative care. We thank ECC New South Wales and their bilingual workers and researchers for their collaboration and partnership.

For more information, please contact Carers New South Wales website www.carersnsw.org.au or contact the Carer Gateway on 1800 422 737, or visit www.carergateway.gov.au.

For more information about this recording or other materials, please contact Carers New South Wales. Thank you.

[00:04:08]
[END OF AUDIO]