

Chapter 1

[00:00:06] Narrator:

The Palliative Care Project, an audio recording program in the Arabic language.

Hello and welcome to the Palliative Care Project, a podcast series for linguistically and culturally diverse caregivers.

You are listening to this podcast created for the Arabic-speaking community. We have also recorded podcasts in English, Chinese and Hindi. We would like to say welcome to our listeners on the Internet. All of these recordings are available on the Carers New South Wales (Carers NSW) website.

To our listeners today, we hope you will find this conversation in Arabic about palliative care valuable. We think that it might help you, as a carer, in providing end-of-life care for someone.

This recording was made with the help of Arabic-speaking people who have used palliative care. They will share their experiences, and what they found useful, with you; giving advice to other caregivers in similar situations.

The recording aims to give you and the person you care for a good understanding of palliative care. You will also hear from doctors and nurses who will provide information on palliative care. We hope you will find this helpful, whether you are providing care to someone now, or perhaps in the future.

[00:01:53] Mira - Palliative Care Nurse:

When someone is diagnosed with a life-threatening disease, it can be very devastating news. In some Arab families, it is very difficult to speak openly about terminal illness or death. People often avoid talking about it until it is too late. As a result of that, they may suffer without knowing what type of help is available. All carers with whom we spoke in this podcast said that they wished they had known more about palliative care before they experienced it first-hand; because then they would have been more prepared.

In Arab societies, the concept of palliative care may be non-existent within health care terminology. Sometimes, people might have misconceptions about palliative care and associate it solely with the end of life. However, in my job, every day, I see that it is much more than that as I witness the benefits of palliative care and support before disease progresses to its final stages.

[00:03:36] George - Carer's Experience:

In my personal experience, people have fear or apprehension when it comes to talking about death openly. It could be because it is taboo to talk about it in their culture, or perhaps it is a community thing. I mean, usually, it is considered a taboo.

[00:04:01] Mira - Palliative Care Nurse:

In my experience, I have found that people from an Arab background are generally afraid to talk about the subject of death itself. It may be culturally inappropriate to talk about such topic or more often than not, it is a taboo subject. Some Arab families are reluctant to talk about death outside the immediate family. More often than not, there are many strict customs and traditions pertaining to this subject, which deem discussing it with 'strangers' (anyone who is not an immediate family member) unacceptable. The family will most likely keep to itself and handle the issue internally.

I have met a lot of people who were shocked and expressed their discomfort when I first spoke to them about palliative care, but they realised later how important this conversation was. I really hope this recording will help you, as a carer, to seek out your doctors and nurses and open up to talking about palliative care. We really want to help you, your family, and the person you are providing care to, so that you can have access to the best care and support possible.

[00:05:44] Rima - Carer's Experience:

The most difficult thing was: What to ask? And who should I ask? I encourage people to learn from our previous experiences and to ask as many questions as possible, so that they understand how to live comfortably with the patients they are caring for.

[00:06:09] Ragheed - Bilingual Facilitator:

I learned a lot from my experience in setting up interviews with people who have experienced palliative care. Bear in mind that I have used the service myself, with one of my family members. Now, as a researcher, to conduct these conversations, I cannot stress enough how much I have learned and how much I wish I had known this information before, when I was personally in need of it; because the more information we have, the better our choices are.

I am happy that you will be part of a program that will help our Arab community. I invite you to seize the opportunity and benefit from this recording, which will answer your questions and dispel your worries because, based on my personal experience, had I had sufficient knowledge at that time, I would have asked the doctors and nurses many questions that didn't cross my mind then. Now, after this experience, I have more information related to this subject, and I hope you find this recording helpful.

[00:07:20] Narrator:

You have been listening to *In My Own Voice*, a palliative care project. We have come to the end of Chapter 1. In the next chapter, we will explore specifically what palliative care is, the medical definition, and how to introduce (the concept of) palliative care to our community members. We'll hear more about the palliative care team from doctors and nurses, and how they can help an Arabic-speaking family throughout this journey.

Chapter 2

[00:00:00] Narrator:

The Palliative Care Project, a voice recording program in the Arabic language, Chapter Two.

Hello and welcome to The Palliative Care Project, a podcast series for linguistically and culturally diverse carers.

Welcome to Chapter Two.

In this chapter, we will explore what palliative care is and listen to our guests talking about some of the decisions and choices they had to make, especially since tradition played an important role in their family life.

Let's start by listening to a nurse from the Palliative Care Unit explain exactly what palliative care is.

[00:00:56] Mira - Palliative Care Nurse:

Palliative care revolves around promoting the best quality of life possible. Palliative care is for people with terminal illness. It provides them with medical care that relieves pain, symptoms and stress caused by their serious illness. Palliative care is provided by a team of professionals, who provide specialised support focussed on improving a person's quality of life, by meeting their physical, social, emotional and spiritual needs.

In palliative care, we work with a full team of specialised doctors, nurses, physiotherapists and occupational therapists, social workers, counsellors, dieticians, speech pathologists and even volunteers. The patient and their family always remain the decision makers, when it comes to their health, medical treatment and well-being. We consider an individual's cultural needs, as we ask about your cultural requirements and preferences. This is the time to let us know if you have any special requests, so that the arranged care is also culturally appropriate.

[00:02:54] Bashir - Carer's Experience:

I have no regrets because as a family, with the help of treating doctors, we did everything possible to keep my mother comfortable. We learned about palliative care from the oncologist. Our oncologist explained what palliative care is, and what they could provide to keep her comfortable in her last days.

[00:03:25] Mira - Palliative Care Nurse:

In some Arab families, it is believed that palliative care is only related to end-of-life care, and they feel very upset when it is suggested to them because they think that the

person is about to die, or that the countdown to the end of their life will start the moment they accept palliative care, which is not true. Palliative care does not mean losing hope, or that you have given up, or that the family no longer cares.

In addition, if someone needs to be hospitalised to receive palliative care, it does not mean that they are dying and their days are limited. Maybe they only need to check the symptoms of the disease and change medications. Once that is done, in most cases, they can return home knowing that they are receiving treatment to reduce their pain. Palliative care does not lead to premature death, and it is not a form of euthanasia. Medications such as morphine can be given to relieve pain or 'treat' shortness of breath. Correct use of morphine helps patients. The doctors are highly trained, the medication is well researched, and there are strict guidelines on how to use medications to relieve someone's discomfort properly.

[00:05:22] Fatima: Carer's Experience:

Years after my mother's death, I, to this day, still think about how that happened? Could I have done something different? All these questions are still on my mind because at that time I didn't understand that the palliative care team and doctors all work together to provide the best care and treatment for a patient. Of course, had I known this, I would have easily understood what was required of me. As my mother's carer, I would have been able to recognise all the signs during the stages of her illness.

Had I known about this (palliative care), I would have spoken to the doctors about everything that was on my mind, but at the time, I thought to myself, "They know nothing about our customs and traditions". I was very pessimistic... but contrary to what I had believed, they knew more about our culture than we thought they did. I encourage you to ask the doctors and nursing staff who specialise in palliative care all your questions.

[00:06:56] Maya: Carer's experience

I couldn't stand talking to him about his condition, but I noticed that he wanted to stay close to me and his daughters... but at that time, our house was very small and (un)furnished. So, the situation was very difficult, we couldn't stay at the house, and he was so sick... Our situation was very difficult.

[00:07:24] Mira - Palliative Care Nurse:

You can start palliative care at any stage of your illness, even from the time you get diagnosed and start treatment. You don't have to wait until your disease is advanced, or until you are in the last months of your life. In fact, the earlier you start palliative care, the better. When you are first told about palliative care, it is good to find out more about it from a recommended source. There is a lot of misinformation, especially on the Internet. It is best to ask your doctor or the palliative care team any questions you may have. Do as much research as possible so that you can share the correct information with the person you are providing care to, and your family.

[00:08:43] Elias: Carer's Experience

I was talking with my brothers about my father's condition, but they couldn't help me with anything, with the exception of emotional support, because they were living abroad. It was okay for us to talk about these things in our community because we believe that life is a short journey and that it will end when God wills it to end. It was difficult, but I was able to get through it with the help of palliative care.

They supported me a lot in my journey as a carer. I was the one making all the decisions in our family because my other family members were abroad... and having support from palliative care helped me with this. I advise others to be strong, talk openly with their loved ones and decide what they want to do. I thank God for giving me the opportunity to take care of my late parents until the last day of their lives.

[00:09:59] Mira - Palliative Care Nurse:

The health professionals understand how difficult it is to have these conversations. We are there to help you and your family understand how to provide care to a person who is receiving treatment. A family meeting can be arranged by the palliative care team. Family gatherings/meetings are considered a way of empowering and supporting the family, and providing an opportunity to share and clarify the care goals, stages of treatment and people's wishes.

[00:10:38] Narrator:

You've been listening to *In My Own Voice*, a palliative care project. We have come to the end of Chapter Two. In the next chapter, we will explore palliative care and how cultural traditions affect how we respond to and receive palliative care support.

Chapter 3

[00:00:03] Narrator:

The Palliative Care Project. Audio recording program in the Arabic language,

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

[00:00:24] Narrator:

Welcome to Chapter Three. In this chapter we will explore palliative care and the cultural influences that may influence how we respond to and how we receive palliative care support.

[00:00:51] Mira - Palliative Care Nurse:

As a practicing Palliative Care Nurse, and as a person who comes from an Arab background, I know first-hand the challenges and cultural barriers that can affect families' perceptions of palliative care and death. The roots of these cultural beliefs and traditions, sometimes, go back thousands of years. Some of these traditions, while cultural and need to be considered, can sometimes affect the care and level of support the family may be willing to accept or receive. It is important to inform the relevant person as soon as you feel that the information provided to you about palliative care might be a major challenge for you and your family. It is important that these concerns are made clear from the get-go.

[00:02:04] Assad - Carer's Experience:

Frankly, my family members did not talk about palliative care, or death in general, as it is not desirable to talk about these topics, or to talk about death in our Eastern culture, and so I was afraid (hesitant) to talk about such topics with my family, but I realised that I could ask a nurse and get answers to my questions. This step helped me a lot to understand the fast-paced events that were taking place around me, but I did not tell my family members. I was talking to the nurse about these matters because they would not understand it, and the nurse was very understanding, she even arranged appointments with volunteers to massage my father's feet at that time. This, kind of, made me feel relieved and reassured because my father was in a lot of pain, and massage helped him overcome this-- even a small part of this pain, and made him feel physically relieved, it rid him of the pain.

[00:03:30] Mira - Palliative Care Nurse:

Let's talk about the myth that palliative care accelerates death. Studies have shown that people with advanced illness who receive palliative care improve in terms of quality of life, and in fact, it has been proven that they live longer than people with the same

advanced illness who do not receive palliative care. The reason people believe this acceleration myth is that in many cases, people wait until it is too late to accept palliative care. Consequently, because they waited so long before accepting palliative care, the person dies soon after, and the family believes it was because of the palliative care treatment. Remember, normally, medications are used to help reduce pain and suffering throughout a patient's journey, all the way to the last stages. Regardless of your cultural background, not experiencing pain or distress during these last stages is important for everyone, and is the right of every patient.

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

I hadn't heard much about palliative care before. Society and people say that medication makes the patient die prematurely. I was so scared; I didn't know who to believe. I asked the nurse, and she explained everything to me in detail. Now I understand that the medication they prescribe does not make a person die prematurely.

[00:05:44] Mira - Palliative Care Nurse:

Usually, specialists get involved in palliative care when a person has complex symptoms. Palliative care does not mean giving up life, nor is it related to not taking medication, or not eating and drinking. It gives a person the opportunity to focus on their comfort without pain, and preserve what is most important to them and what brings them the most joy.

People can continue to receive treatment, as long as it helps them, and they do not stop eating, unless they are unable to eat. When the condition of people with advanced illness deteriorates, it is common that they feel less hungry and thirsty because the body realises that it is nearing the end. People who do stop eating die of their disease, not of starvation. Hunger is often absent at the final stages of life, so feeding to prevent hunger is not usually recommended unless the person craves food.

Sometimes, this can be difficult to understand for families who believe that a carer should cook and serve meals to the end, but food has a different meaning to the body when a person is dying. Feeding a person who has no appetite can harm them and can lead to symptom aggravation. People need less food during periods of inactivity when their disease progresses, as they only need the minimum amount (of food) to maintain (the functionality) of their bodies.

[00:08:05] Maya - Carer's Experience:

My dad hated hospital food, and my concern was that he was losing weight. As his daughter, it was up to me to make/feed him homemade chicken soup the way my grandmother used to make it. The nurses allowed us into the kitchen, so we could microwave it. After a few sips, he no longer wanted to eat. I was so worried because he wasn't eating. My sister, uncles and aunts kept saying, "It's a bad sign," and that I should force him to eat.

The nurse assured me that sometimes it is best to not force the body to eat if it does not want to. He had nutritious liquids (solution) going into his body through the tube, but I couldn't see how that was enough. As this was one of the many responsibilities that I had as the eldest daughter, I felt like I let him down because I could not provide him with our traditional/regular homemade food to feed him. This was a huge emotional challenge for me.

[00:09:27] Hilda - Carer's Experience:

Talking about death is a very sensitive topic in our Arab culture although some people talk about this subject more frankly, because they have faith and beliefs that make them stronger than other people and the rest of society. If they see that palliative care is needed, especially for people who are, for example, I mean, those who are in the hospital, or those who are at home, I always advise them that they consider the benefit of palliative care because it will certainly help them a lot in their lives, and it will also help their patients. I also advise them to appreciate the support provided to them.

[00:10:29] Assad - Carer's Experience:

I was able to discuss my mother's needs with my family members. In my community, I think it's uncommon to talk about these things openly, but we can talk about it with our older family members. In my community, the man is the decision maker in his family. When my mother was sick, I did not call my brother in America because I did not want to bother him. My brother arrived in Australia a day before my mother died. In the Arab society, it is taboo to talk about death, but we need to build up the courage to talk about it.

[00:11:19] Narrator:

You have been listening to the "In My Voice" project, which is a palliative care project. We have come to the end of Chapter Three. In the next chapter, we will discuss how palliative care works, who regulates palliative care, and the different options and services offered through the Palliative Care Program.

Chapter 4

[00:00:02] Narrator:

The Palliative Care Project, a voice recording program in the Arabic language.

Hello and welcome to The Palliative Care Project, a podcast series for linguistically and culturally diverse carers.

[00:00:23] Narrator:

Welcome to Chapter Four. In this chapter, we will discuss how palliative care works, who manages/regulates palliative care and the different options and services provided through palliative care.

[00:00:48] Assad - Carer's Experience:

As for us, we tried palliative care because when the doctor who was treating my late mother-in-law decided to stop cancer treatment, because she used to take medication and because the medication was not producing any result, her condition kept getting worse day after day. So, the doctor decided to try palliative care. At first, we were shocked as we did not know what palliative care was, and we did not know what to do. Also, we did not expect that the (palliative care) treatment would work in any way, not even in 'controlling' the disease (stabilising her condition). So, one doctor from palliative care came to our home and explained to us what palliative care is and what was going to happen next. The doctor was very kind and helpful, she wanted to really help-- because she saw the (patient's) condition, and since she had experience in these matters, she knew that we would lose the patient, who was my mother-in-law. So, she explained to us how we could help her, and of course, she didn't stop there, she helped my mother-in-law a lot and relieved her pain a lot. Even my mother-in-law, may God have mercy on her, had no fear of palliative care. All she wanted was to have us around in her last days.

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

When the palliative care specialist first meets the patient and the family, they (the specialist) will give information about the disease and the treatment prescribed, they will need enough time to tell you, in more detail, about the different stages of palliative care and how the disease will affect the patient, as well as provide information on how to help the family through these stages. They will ask you if you have any special wishes on how you would like to receive palliative care services. Palliative care services vary from place to place, but they are usually provided by a team of medical professionals and allied health professionals that may be based in or out of the hospital. Palliative care treatment plans can also vary from patient to patient because treatment plans are based on individuals' circumstances and needs. This is why we tell people not to

compare their palliative care treatment plans to other patients. What may be the right plan or approach for one person, may not be the right approach for another.

[00:04:33] Assad - Carer's Experience:

You know those who suffer from incurable diseases, especially cancer, and reach the final stages of chemotherapy, where it is not even helping them anymore. I asked the doctor, "What is the best thing that we can offer to our father?" He said, "The best thing is to take him home where he can stay until he passes away". Frankly, what eased the burden and what eased the suffering, was the palliative care team who kept supporting me until the last day.

[00:05:18] Mira - Palliative Care Nurse:

There are different levels and types of services available based on each region. These services range from home services such as showering or cleaning, transport services that help you to attend your doctor's appointments, to emotional support and giving the carer a break. These are called respite services. It is important to see what is available for you in your location because each area is completely different. The carer role can be very tiring and physically demanding, therefore taking care of the carer is just as important as taking care of the ill person.

[00:06:21] George - Carer's Experience:

It was much easier to shower my mum while she was sitting in a special chair because she couldn't stand for long. So, with that chair there, it meant she could sit down and take a shower. The wheelchair was great and comfy for my mother whenever we went to the market.

[00:06:51] Mira - Palliative Care Nurse:

Palliative care services can also help with equipment that help provide care in the home; things like wheelchairs, hospital beds, toiletries, etc. That will help you take care of the patient who is receiving treatment safely. Sometimes, just having a piece of equipment, like a rail in the bathroom, or a toilet seat lift can make all the difference, in which case an occupational therapist will be on hand to advise you on what can help you the most.

[00:07:48] Kareem - Carer's Experience:

My dad always suffered from convulsions, and his feet used to tremble after lying in bed for a long time. Palliative Care sent me a volunteer to give my dad a foot massage, and this, for sure, helped me personally to take a break, even if it was only for an hour. Also, it greatly helped my father sleep better. I did not know that such services were provided through palliative care, until I discovered and experienced it first-hand. I thought that such services were only provided at the hospital, along with services like injections and

sedative drugs to 'control' pain. I want everyone to have complete knowledge of what palliative care offers them.

[00:08:54] Narrator:

You've been listening to *In My Own Voice*, a palliative care project. We have come to the end of Chapter Four. In the next chapter we will explore decision-making during the palliative care stage, and we will also explore what is referred to as 'advance planning.'

Chapter 5

[00:00:01] Narrator:

The Palliative Care Project, a voice recording program in the Arabic language,

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

Welcome to Chapter Five. In this chapter, we will explore the decision-making process during the palliative care stage. We will also explore what is referred to as 'planning ahead'. Let's start by listening to a nurse from the Palliative Care Unit explain what is meant by 'planning ahead.'

[00:00:54] Mira - Palliative Care Nurse:

The palliative care approach respects the choices of a terminally ill person and their family with regard to providing care (to the terminally ill person), meaning that decision-making must be done based on what's in the patient's best interests, taking into consideration their wishes regarding the way they want the care to be provided. Usually, the patient is the one who makes the decisions as long as they are able to. However, as their condition worsens, they may need someone else to help them make these decisions. In some Arab families, the decision maker role may be assumed by a certain family member. It is important to discuss this with the person you are caring for early, when they are still healthy, in order to get their opinion on how decisions should be made. If they prefer that a doctor speaks with a certain family member, then they should tell the doctor who the person whom they think should make decisions on their behalf is.

[00:02:20] Assad - Carer's Experience:

My father asked them to talk to me instead of talking to him. They asked me many questions about my father's wishes and were very friendly and kind. They gave me a lot of advice so that I could make the right decision.

[00:02:47] Mira - Palliative Care Nurse:

Some of the questions the palliative care team might ask include: What is important to you at this stage in your life? Do you feel pain? Which family member would you like us to talk to about your condition when you are unable to speak due to your illness? Where would you like to receive end-of-life care? Home? The hospital? An aged care (nursing) home? We will need to know the person's wishes. When their condition worsens, the team will read you the care goals and inform you of the available options.

[00:03:41] Fadia - Carer's Experience:

The doctors and nurses asked my husband about the amount of pain he was experiencing, they didn't want him to feel the pain, and they assured us that the medication would reduce the pain a lot.

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

The doctor asked us during a meeting he had with me and the family when we were discussing at the time, the end-of-life care issue. He was like, "Would you prefer palliative care to be provided at home or at the hospital?" We certainly preferred the hospital because the necessary equipment, services, doctors, and nurses were available at the hospital, so they would definitely take care of her more, and this helped her during her last days.

[00:04:50] Abdullah - Carer's Experience:

Many patients have pride and prefer not to suffer or burden their families; they wish to sleep and never wake up from their sleep.

[00:05:10] Mira - Palliative Care Nurse:

The palliative care teams have a lot of experience in helping families discuss and define their options and wishes. We can have these discussions in private with the patient, or we can include the family in these discussions. We always aim to determine what suits and meets the patient's wishes and needs, to help them make the decision to continue treatment that relieves them of pain, discomfort or stress.

Sometimes, people feel an obligation to keep trying to extend a person's life because they consider caring for them a burden that they have to shoulder. As a team, we help the family determine what is best for their loved ones, and what are the patient's options, wishes and needs. Talk to the palliative care team if you feel that this topic is a challenge for you.

[00:06:36] Ragheed- Arabic Speaking Facilitator:

In our Arab communities, we consider caring for the elderly a virtue, and we want to preserve our parents as much as possible, even if this calls for a 'difficult' (challenging) medical intervention, which could make them suffer from pain. We don't think of anything other than preserving them. I would like to say to these people, let your parents 'leave' (pass away) peacefully and naturally.

[00:07:08] Mira - Palliative Care Nurse:

Sometimes, decision-making can be complicated if the extended family are involved and don't all agree on one course of treatment. For example, if a person needs

morphine for pain relief, many people from different cultures believe that morphine will cause the patient to die faster. This can cause conflict within the family. There are clear instructions on how to properly use medications such as opioids. Our goal is not to sedate anyone or accelerate the end of their life.

[00:08:05] Abdullah - Carer's Experience:

Frankly, having someone from palliative care with me was very necessary. It helped me a lot and reduced my struggle a lot because I needed to have my own time to 'practise' my life, i.e. time to sleep, eat, take care of myself. Frankly, one gets tired if one is alone, or perhaps they can no longer bear it because of the amount of pressure. I think that having another person to help with providing care is necessary and a very good idea.

[00:08:48] Mira - Palliative Care Nurse:

Sometimes, the decision maker is neither the patient, nor the carer. In some cultures, a different family member may be the one who makes the decisions. Our desire as a team is to see how we can support the family and the carer in making these difficult decisions, with the patient's best interest in mind. These conditions can be very stressful for the carer, and we want to offer them support to help them during this journey.

[00:09:36] George - Carer's Experience:

Planning ahead. So, a friend told me I needed to get what they call a 'power of attorney' and I did, but then when my mum got really sick and couldn't make decisions regarding her health on her own because she was in a coma, I thought I could intervene and make decisions on her behalf, since I was her son, but they told me I needed to obtain permanent guardianship. I didn't know they were two different things. The power of attorney was for the financial decision(s), but for her health-related decisions, obtaining the guardianship was needed. I wish I had known that beforehand.

[00:10:24] Mira - Palliative Care Nurse:

People's wishes can be explored through a process called advance planning. The palliative care team can have discussions with the patient about things such as, who they would like to make decisions about their health care if they can no longer make those decisions. You can ask your palliative care team for more information about this. They may also consider writing a will. In some cultures, wills are not considered important, but under Australian law it makes it much easier for the family after a person passes away. There are online resources to help you prepare it in your own language through an organisation called Advance Care Planning Australia.

[00:11:34] Narrator:

You have been listening to *In My Own Voice*, a palliative care project. We have come to the end of Chapter Five. In the next chapter, we will look at 'where to from here?' and

hear how you can receive help if you are caring for someone who has or needs palliative care.

Chapter 6

[00:00:02] Narrator:

The Palliative Care Project, a voice recording program in the Arabic language,

Chapter Six. Welcome to the Palliative Care Project, a podcast series for linguistically and culturally diverse carers. We have reached the end of our palliative care recording, and we hope that this podcast will be helpful to you, and that you benefit from some of the advice and suggestions provided by our speakers.

Don't be afraid to start a conversation with your loved ones. If you need any help, we recommend that you talk to the Palliative Care Team and your family. We know this is a difficult time for you, but you cannot overestimate the importance of having a conversation with your Palliative Care Team, so they can provide you with the right support. Regardless of your cultural background and your traditions, they are experienced in providing care to families from different cultural backgrounds.

[00:01:29] Mira - Palliative Care Nurse:

We thank you for listening to this podcast, and we encourage you to communicate and talk to the Palliative Care Team. The team is there to help answer any of your questions and concerns, especially if culture and tradition play an important role in the way you receive treatment and health care. We are here to help you and the patient to live with the disease comfortably and without pain. The focus is also on helping the family have quality time with the terminally ill person as they near the end-of-life phase.

[00:02:29] Ragheed - Arabic speaking facilitator:

I learned a lot from my experience in setting up interviews with people who have used palliative care. Bear in mind that I have tried the service with one of my family members, previously. Now, as a researcher, to conduct these conversations, I cannot express how much I have learned and how much I wish I had known this information before, when I was personally in need of it; because the more information we have, the better our choices are.

I am happy that you will be part of a program that will help our Arab community. I invite you to seize the opportunity and benefit from this recording, which will answer your questions and dispel your worries because, based on my personal experience, had I had sufficient knowledge, I would have asked the doctors and nurses many questions that didn't cross my mind at the time. Now, after this experience, I have more information related to this subject, and I hope you find this recording helpful.

[00:03:47] Elias - Carer's Experience:

The most difficult thing I have seen in this field, when you're following up with a patient, is that you face some difficulties that are, for example, confidential and private in nature, so you cannot discuss these things in front of the family or a family member, for example. Therefore, the best thing to do is talk with palliative care because they have the professionals and the doctors who can provide you with the necessary advice. I think talking to them is easier; and it's less embarrassing, so one would be inclined to talk about things that one would otherwise not disclose. In a nutshell, communicating with palliative care doctors is much better.

[00:04:50] Assad - Carer's Experience:

If I went back in time to be with my father during his last days, I would have searched more for palliative care in Arabic because I have learned a lot of things that changed the perception I have of this service from that which my family, friends, and I used to have of it in the past.

[00:05:21] Mira - Carer's Experience:

There are many things that we can do as carers. On the Internet, there is a lot of information, but it's not always true. I always advise you to reach out to palliative care workers and professionals to get the correct and detailed information.

[00:05:45] 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 (NSW Health) and sponsored by Carers New South Wales (Carers NSW).

We would also like to thank Calvary Health Care Kogarah, the Multicultural Communities Council of Illawarra, the Ethnic Community Services Cooperative (ECSC), and the Ethnic Communities' Council of New South Wales (ECCNSW). Also, thank you very much to the health professionals, speakers, and guests who joined us in the talks today. You will find their names and profiles on the website, and most importantly, you will be able to find many carers who have spoken to us and shared their experiences so that other carers can understand more about palliative care. Also, thank you very much to the health professionals and guest-speakers who have joined us. More importantly, thank you to the many carers who have spoken to us and shared their experiences so that other carers can understand more about palliative care.

The resource was designed with the support of the Ethnic Communities' Council of New South Wales (ECCNSW). We thank ECC New South Wales and their bilingual workers and researchers for their cooperation and participation in this resource. For more information, please contact Carers New South Wales on the website: www.carersnsw.org.au or call the Carer Gateway on 1800 422 737. Monday to Friday from 8:00 a.m. to 5:00 p.m. You have been listening to a conversation about palliative

care for Australia's culturally and linguistically diverse communities. For more information about this recording or other materials, please contact Carers New South Wales (Carers NSW).