Palliative Care

Hello everybody. I've been asked to speak to you for module five specifically on palliative care. My name is Cathy Strachan and I am a palliative nurse and a qualified pastoral carer and have some experience with dementia care and I was asked to speak to you specifically about what palliative care is for this module.

How would I, if I was a visitor coming into palliative care, prepare myself to visit somebody if they were at end of life and what do I think are the most important skills that would help you in these circumstances? So that's what we're going to have a look at today.

The World Health Organization defines palliative care, this is a new definition for 2023, as a specialized medical care for people living with a serious illness.

This type of care is focused on providing relief from the symptoms and the stress of the illness and the goal is to improve quality of life for both the patient and the family. So palliative care is quite a large encompassing model of care and the reason that I noticed that it's changed in 2023 is that the old definition of palliative care said giving quality of life to those people who have a life-limiting illness. So palliative care really is a general type of care or plan of care that is given to people when they have got a serious illness which is going to lead to death, even if that death is in a few years' time.

Moving towards the end of life

So the kind of visiting that we are talking about today is not just visiting somebody that is sick because that applies to a lot of people but specifically those people that are moving towards the end of life and that can be in the last month, the last week, the last days, everybody will be different and unique.

So why is it important for us to have a discussion about visiting in palliative care? If I was going to visit somebody in palliative care or end-of-life care, so possibly they are dying at home or they are nearing death at home or in a hospice or in a hospital, how would I make sure that I'm 100% ready to go and visit these people? The question I would ask myself is how do I feel about death and dying? Have I come to terms with how I would feel if I was in those circumstances? Because how can you go into the hospital situation or visit the person at their bedside when you've got no idea how you're feeling about it, never mind how they might be feeling about it, or you're going to be shocked and unprepared for what they may say or not say when you haven't considered it for yourself? These are the kinds of questions I think you need to put some time aside and think about seriously.

Do you find death and dying terrifying concept? Do you find it really confronting? Is there something about death and dying that you haven't resolved for yourself? Are you in the process of going through grief because you've lost somebody that's passed away or a loved one or a close friend? Has it been a traumatic death? All of these kinds of things will impact your feelings and experiences about death and dying. If you've never experienced anything like that yourself, then up until this point you're very fortunate and very blessed, but you still need to think about if you were in that situation, how do I think I would feel about it? Am I prepared for these sorts of things? Because you can't go and help somebody else prepare for it if you aren't prepared for it yourself. A second thing is, how do I feel I would cope if I walked into somebody's room and they are dealing with really difficult and deep emotions? So strong emotions, don't have to be negative.

The sick person may be grieving for their issues, or the family may be grieving for the person that is at the end of life. Or there may be other strong emotions involved. There may be a lot of unresolved issues. They may be arguing and family fights, which is quite a common thing around the deathbed, particularly if you have children who have different views about how mum and dad or the loved one should or shouldn't be treated. Or, God forbid, there's issues around money and fighting about money and inheritance, and you haven't looked after dad for the last 10 years and now you're just here because you want money. It's incredible the kind of things that come up at death.

Being prepared to help family and friends

So, you have to be prepared when you go into this situation, firstly for the patient, most important, and secondly for the family around them. How are you going to handle all these strong emotions? And if you feel that you're not really prepared to deal with their issues, then you might want to take somebody with you that can be a support to yourself so that you can be a support to the others, or perhaps delay the visit until you're feeling a little bit stronger and more secure in yourself and how you are feeling and dealing with strong emotions from other people. And then another really important preparation for going into a situation like this is what are you going to expect to see? If you have never seen a person that is at end of life, somebody that is dying, or if you've never seen a dead person, how do you think you're going to respond? And perhaps going into that situation for the first time on your own may be more confronting than you realize, and it might be an idea to go in with somebody else for the first time because you don't want to fall apart when you are supposed to be there to support either the family and or the patient.

I don't think it's wrong to show emotion, that's not what I'm saying, but you need to be prepared to deal with the confronting situation that you're going to find. I'm going to describe a little bit to you what I think, in my experience, dying looks like for somebody. And these are the most common things which people find distressing.

Possible symptoms of someone dying

So breathing patterns change and often it becomes very noisy. So when I say breathing patterns change, the breathing can become gaspy, like that kind of breathing, or it can have long gaps between the breathing. Sometimes they're deep breaths, sometimes it's fast breathing, which is a little bit distressing to see.

And if you did see somebody in a situation like that, I would call in the palliative nurse and ask them if they can give them something to help the patient relax and breathe a little bit more regularly. What’s actually happening for the patient is that their heart is slowing down. So often if you feel the pulse, you will notice that the pulse has got a little bit weaker and softer, and that the heart is probably working harder to try and get the blood pumping around and the patient's not getting enough oxygen, which is why they're breathing quickly.

Sometimes you will see patients with nasal prongs where the oxygen is fed from the wall into the patient's nose so that they're getting enough oxygen so that the breathing isn't as stressful and strenuous for them. It can actually be very distressing to observe somebody who is dying of any lung condition or breathing condition, because the breathing becomes very, for want of a better word, tortured, where it's almost like, where they're desperately trying to get in air.

And that is very distressing, even for us who've been nursing with people and looking after people for a long time. You just need to be prepared for these sorts of things. The other thing is that sometimes the breathing can get very noisy. It sounds like they've got a lot of phlegm or moisture

in their throats because their muscles are all relaxing in their throat and in their oesophagus because they don't have the strength to swallow normally. So all the moisture in their mouth, which they would normally swallow, is difficult to swallow for the patient. And it starts sounding quite gurgly, like they've got a lot of mucus in the back of their mouth.

It's not distressing for the patient, but it doesn't sound very pleasant. They're trying to breathe through bubbles because of all the liquid in the back of their throat. And that can also be very distressing. In fact, the noise of that is more distressing to visitors and family than it is to the patient. So we often lie the patient on the side on the pillow with a towel underneath their cheek because you get quite a lot of the fluid will dribble out of the side of their mouth. It's not an issue, but it's something which you need to be aware of.

Pain

The other thing which can be really distressing to visitors and family is if the patient's pain is not well controlled. Now, normally when they're in a hospice, the pain is well controlled because we have regular medications or we have medications which drip slowly into the body so that they have a fairly steady pain medication regime.

But if a patient is experiencing pain and grimacing and very agitated and shifting in the bed because they can't get comfortable, that can also be quite distressing to watch because sometimes they will moan and groan in pain. Again, if that situation happens, you really do need to get the palliative nurse to come in. And often we will have family members that will push the buzzer and go, it's obvious mum's in a lot of pain, please can you come and help her? And we can give extra medications.

Agitation can also be, there is a condition called terminal agitation where the patient tries to sit up and their arms are flailing or they're trying to pull at their clothes and they're trying to take their clothes off, that sort of thing. This is also very distressing to watch because you don't really know what they're agitated about. Sometimes the agitation is from pain.

Sometimes the agitation is what we call cerebral irritation. And because the brain's getting swollen, particularly if there's cancerous growth or there's swelling from edema or anything like that, the patient can have a lot of headaches, but they get kind of agitated and they're sort of reaching up to their head, but they're not really quite sure where the pain is. Also quite distressing to watch. And again, call for the nurse or get the doctor to come in and get the patient to calm down.

Exhaustion

Another very common symptom, which because their body is putting so much energy into getting oxygen and keeping the blood pumping and the body pumping, these patients generally are very, very tired. So when I say drowsy and exhausted, having a visit can't be too long, particularly if you're talking, because they do get very tired.

On the other hand, if you do want to be there and you want to actually be present with the person, you can be quiet with them and just hold their hand so that they know that you're there because that can be just as comforting as talking. And then the patient doesn't feel like they've got to put out a lot of energy and effort into talking to you or to listening to you or to absorbing the social situation.

You know, families come and visit because they want to be with their loved one, but the children are running around and people are talking to each other. And there's not a lot of focus and attention on the person that is sick and is actually really exhausted. So sometimes it's nice to have it peaceful and quiet when the patient's really tired or is very drowsy.

And then the other thing, which isn't so traumatic, but it is something to be aware of, is that often the hands and feet are the first things that you notice. Sometimes the lips, you know, when somebody gets very cold and their lips go blue or their fingers go blue and mottled or their feet do, exactly the same kind of thing happens when they're getting towards end of life, because the blood is being withheld from the periphery and is being kept for the vital organs like the heart and the liver and the lungs and the brain. And fingers and toes and lips and nose and sometimes ears are not as important as the vital organs.

So they tend to go bluish or sort of like a bluey purple colour or very blotchy, so that it's red and white blotches, which you notice more on the legs when the circulation is decreasing. So those are some of the physical changes that you will notice. Sometimes the skin goes a funny sort of a yellowy grey colour and they look unwell.

It's not as distressing as some things but these other things which I've mentioned here are things which you need to prepare yourself for. And perhaps if you're finding those things confronting, perhaps look some of them up on the internet and have a look at a video or photographs of people that are going through these things, so that when you are confronted with it for the first time when you visit somebody, it's not as shocking and as possibly scary for you when you go and visit these people.

Visiting skills?

So what skills do I need as an individual to help the person that is palliative? By far and away the most important thing is that you are going to visit this person to be the hands and feet of Jesus to them. So you go there with prayer and you ask the Father to help you in preparation to give you the strength, to give you the comfort that you can pass on to other people, to be what the person needs you to be in that visit, not what you think you should do, because everybody will be in a different place when you go and visit them. Sometimes I go there and I just stand at the bedside and hold the hand and beg God to take the person, not loud, because they are either so uncomfortable or they are so lonely because they've got no visitors or no family or they've been suffering for so long. Or sometimes you just pray for comfort or that the family will be there when they go or whatever it is that the person needs, but to give you the strength to pass that love and comfort on to the patient and or the family, whoever is there.

The other thing is that something that goes without words is your unconditional love and support, the warmth of your presence when you go there. And just being there can be a comfort and a support to the family or the patient or both. And sometimes you don't actually have to say a lot; they're just so grateful to see you. Maybe all they needed was a hug, maybe all they needed was you to sit quietly next to the bed and hold their hand and talk gently and softly in their ear, because even when a patient is unconscious, the very last sense that goes is hearing, because often patients will, if they're drowsy or they've been unconscious, they may wake up and they can remember conversations that have been had, they can answer questions that they've been asked.

And I always say to all family members, keep talking, just gently and quietly, say whatever it is that you want to say to the person and encourage family members, if you're the visitor going in, encourage family members to say goodbye, to say the things that they loved about them, to say

the things that they've always wanted to say, not to upset the patient, but to comfort the patient and for them to have long conversations with them about happy memories and things that they enjoyed doing together, so that the person knows that they are loved and appreciated. And in some instances, lots of children have said this or spouses have said this to patients, “Just let go, I'm going to be okay, I'm going to be looked after, everything is all set up for me, it's okay, I'm going to be okay, you need to let go.”

Letting go

And often sometimes people just need to hear that reassurance from somebody that it's okay for them to go and then they will die. It's incredible how many people will hang on until child arrives and then will die the next day, if the child's coming from overseas or from another state, they know you’re there. And one of the things, I must mention this because I found it absolutely fascinating, but one of the things which medical researchers have done is measure the brain activity of patients that are not fully alert and awake to see the difference in brain activity and recognition of family members versus staff or unknown people that walk into a patient's room. A patient's brain waves and brain activity when a nurse walks into the room or a doctor or an unknown person is fairly normal and will continue as it was when they were drowsy. But should a family member or a loved one walk in or a family pet or something like that, when they walk into the room, the brain activity changes completely. And I think it's incredible that even when you're unconscious, the person is recognizing the voices and the warmth of somebody that they know and love.

Patience and non-judgemental and unconditional love

So, the other things which I think is really important include patience. Obviously for me, non-judgmental goes with unconditional love, that it doesn't matter what the person says or what the family members say, they are going to be experiencing the turmoil of loss and grief around this time, even if the person hasn't gone yet, it's called anticipatory grief or shock that they've got to the situation so quickly. And sometimes the things that they say, you think are like, oh, absolutely outrageous. How could they possibly say that? But you are not in their shoes and you are not experiencing what they are experiencing. This is not necessarily your loved one who's going and you might be going there to support the family or to support the individual who's going through some really traumatic processing of information, of trauma that's happened in their lives and they just want somebody to talk to before they get to the point that they can no longer deal with these issues and pass away. So for me, non-judgmental and unconditional love go very strongly hand in hand.

And patience, because you might be there a long time, just being there, and you might also be having to put up with people saying the same thing over and over and not making any progress because they're going round and round in a situation over which they have no control. It can be family members, it can be the person who's dying. Some people get incredibly agitated, and they ask you the same questions over and over or they say the same things and you thought you'd resolved an issue and nobody can give you a time. They're going to die at 12 o'clock tomorrow. It doesn't work like that. Sometimes we think they're going to die overnight and then they perk up in the morning and they're bright and breezy and they're actually even speaking again.

So it's very, very difficult to tell unless the patient's become completely unconscious and you can feel that their heart rate's dropping and that their breathing's changed and things like that. Coming back from very close to the edge is much more difficult than when people are kind of going in and out of consciousness or delirium or anything like that.

Silence

And then together with patience is the use of silence and that's got to do with you being present there, allowing the person to be where they are, to give them the space to talk if they want to or the space to just rest with their eyes closed if that's what they want. Some people need to talk, some people need to be quiet and you need to give them whatever space it is that they need.

And then the other thing is, I just threw this in at the end, is that you can never fully prepare yourself. So there will be something that somebody will say or the patient will do or it could be anything.

They've lost control of their bowels and you can't handle the smell or they vomit everywhere and you can't handle vomit or they start raging at you about their child. And people say the weirdest things. I had a young lady, she was in her 60s and she said she was playing off her two children against each other. Oh, one daughter's so warm and loving and the other one's cold and callous and calculating. And you know, that's her judgment and that's her speaking. I don't know the daughters from a bar of soap and they may very well be like that.

And the fact that I think it's unpleasant for her to be comparing her daughters to a stranger has got nothing to do with anything. So you've got to learn to hold your tongue and be prepared to be uncomfortable or to disagree with what they're saying. But this is their journey, this is not yours.

So you need to be ready to be made to feel uncomfortable. I'm not saying you will, but there's a possibility that you may be, and you may be confronted with situations that you don't feel you're prepared for. And there's nothing wrong with saying to somebody, "I'll find out for you or let me think about that or can we pray about together?"

You don't confront the person, because there's no point in getting into an argument or an emotional discussion with somebody about something over which you have no control and over which they can't change because the person in the bed is dying or they are the person that is passing away.

God will wipe away all tears

So those are just some of the tips that I thought would be quite important. And at the end of the day, we are all waiting for the day when death and dying will be a thing of the past and God will wipe away every tear from their eyes and there will be no more death or sorrow or crime because all these things have gone forever.

Thank you and I hope I pray everything of the best for you for your adventure in going to be caring visitors for people at end of life. Thank you.

Cathy Strachan