Respect client preferences for quality of life choices

Introduction

Every person has his/her own preferences for the place and manner in which they would like to die. As a nurse working in aged care, I have heard many variations on these. Some people say that they would like to die ‘suddenly’, ‘in my sleep’, ‘with my family around me’, ‘at home’, ‘in hospital’. Let me share with you that one of my clients died several years ago watching the sunset with a glass of wine in hand. Other clients have died watching TV in their favourite lounge chairs. Not every person can choose the place of death, nor the manner in which they die but many like to have control over the quality of their lives, right up to the end.

This reading will enable you to communicate with clients about their wishes at the end of their lives and to respect the choices they are able to make to give them as best quality of life as possible.

Encourage client, carers, family members and/or significant others to share information regarding changing needs and preferences through a supportive environment

Open communication about the changing condition of the client is the key to providing ongoing care which supports both client and his/her family. Ineffective communication causes distress to clients and their families, and may make it more difficult to provide care for the client who is dying.

Providing a supportive environment

In our society we place great value on telling the truth about the nature of an illness and its likely prognosis. Clients and families often want more information than the doctor or health professional can give them eg they may want an exact estimate of the time the client has left before death. Additionally, some people from other cultures hold a different view and believe that telling the older person how serious their condition is, may cause them to give up hope and die sooner.
Withholding the truth about the client’s prognosis has an impact on ethical decision-making, treatment decisions and planning care. In most cases where the person is of sound mind, we believe that the person should be given information about their condition so that they can make decisions about their ongoing care. Usually there is a family member or two who have been given permission by the client to participate in information-sharing, and care giving and who support the client through the last phases of life. Family members who do this often say that the experience gives them satisfaction, pays back love which they have previously received from their loved one, and gives them a sense of inner strength.

Therefore, communication with the client and family should be open and honest, culturally relevant, and ongoing, in order to know about and meet the needs of the client as they change.

**Case study**

Mrs Lee, who originally migrated from Hong Kong, has asked you several times what her doctor was saying when he visited. Although she speaks English, Mrs Lee’s doctor is from South America and she finds him hard to understand. Mrs Lee’s son and daughter spoke to the doctor outside the residential aged care facility and he told them that Mrs Lee has metastases in her brain from her lung cancer. This diagnosis means that Mrs Lee has limited time to live. Mrs Lee’s son and daughter love and respect her. They do not want her to lose hope. They ask you not to explain to Mrs Lee what the doctor has said.

A good response from you as an aged care worker to Mrs Lee’s family would be:

> ‘Your mother has asked me to explain what the doctor has said. It is important that Mrs Lee has the opportunity to finalise anything she needs to, before it is too late. Can I make an appointment for you all to meet with the doctor again so that he can explain things to your mother while you are present to support her through this circumstance?’

**Respect client’s lifestyle, social context and spiritual needs and document observations in line with care plan**

Each person lives within a social context which is personal and uniquely relevant to that person. That social context is influenced by culture, values, friendships, family support etc. Unfortunately for very old people, they often have few social resources to draw on for support at the end of their lives. Particularly they may have lost friends and family members, spouses are often frail and cannot care for them or the spouse has died or separated
and there is no one at home to provide care. Staff members and volunteers try to fill this void wherever possible.

As it has become acceptable to ‘come out’ in our society, there are more same sex couples who are ageing and who will support each other in the terminal phase of life. Additionally, there are many combinations of ways in which families are constructed in our society. Whatever the situation, the people involved in your client’s end-of-life, must be respected.

Support the person at the end-of-life by encouraging family and friends to support the person by reinforcing their value to the older person. Provide opportunities for them to be helpful. This might involve an activity such as taking the dying person into the sunshine on a fine day or reading to him/her. Occasionally a family member offers assistance with washing the dying person. Check with your supervisor before you accept this offer as your organisation may have a policy about this.

As a person reaches the end of his/her life, he/she will withdraw from life, and lose interest in visitors. If this happens, ensure that the family members know that this is ‘normal’.

As older people move towards the end-of-life, they generally come to terms with their own mortality. Most will reflect on the ‘meaning of life’ and those who have strong religious faiths will use that faith for spiritual support. Spiritual support can be given by a religious leader, but also by any person willing to ‘be there’ and listen to the older person. When a person accepts that he/she is dying, there is a reduction in anxiety and a sense of purpose in getting the last things done before death.

The expression of spirituality may vary depending on ethnicity, gender, social class and personal experience.

Spiritual support can be given by a carer by encouraging the client to reminisce or review life. Reminiscing provides the client with an opportunity to reflect on parts of his/her life which were meaningful. Life review can help the client come to terms with past conflicts and find forgiveness. Even clients who say that they are not aligned with any particular religion will often find comfort in a familiar prayer or poem or reading from a holy book. Don’t be afraid to offer this when you sense that your client is anxious about death.

Spiritual and social needs are an important component of any care plan, and should be reviewed regularly, goals re-evaluated and new strategies put in place to meet those goals.

Respect cultural choices in line with care plan

‘Culture’ refers to the distinctive customs and way of life of a society or group. In Australia there are many groups of people, who have immigrated
here as post-war migrants to find a new way of life, and those who have joined other family members here. All have distinctly different customs and values which need to be appreciated when a client is at the end of his/her life. Importantly, although a person may belong to a particular culture, that person also has his/her own beliefs and practices which may be quite different from those of the culture from which he/she originates.

Australian Aboriginal communities may differ in cultural characteristics, language and location. Some Aboriginal people may not know the concept of palliative care, and for remote communities, palliative care at home may be difficult to maintain.

There are some important considerations about providing palliative care for an Aboriginal client:

- Communication is often through a respected person in the Aboriginal community or an Aboriginal health worker. Aboriginal health workers are trained in liaising with traditional healers and white health professionals.
- There is a widely held belief that a person should go back to their community to die or to be buried. This can cause a significant drain on financial resources if the person has to be transported home with an initiated ceremony person accompanying the person.
- There are important issues around death, including correct ceremonies. The whole person must be buried with all body parts present.
- If a person dies in a house, it cannot be occupied for some time. Sometimes a smoking of the house purifies it of bad spirits.

The National Palliative Care Program has three Practice Principles for providing palliative care to Aboriginal and Torres Strait Islander people. These are:

1. Include Aboriginal and Torres Strait Islander organisations and/or personnel in the planning, provision and monitoring of palliative care to ensure culturally relevant requirements are addressed and preferences of the patient and/or family are considered.
2. Communicate with the patient and their family and community in a sensitive way that values cultural difference.
3. Provide training to all personnel to enable the provision of culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples.

Most importantly, never assume that all Aboriginal and TSI people are the same. Give respect to each individual by taking time to communicate with your client and with those who are important to them.

*If you do not understand the culture of your client, never be afraid to ask questions. Your world will expand if you try to*
**understand the ways and values of those in your care.**

Wherever possible, provide information about a palliative approach to those from culturally and linguistically diverse backgrounds in their own language because this enhances cultural sensitivity and ensure that appropriate care is provided.

Support the freedom of the client, carer, his/her family and/or significant others to discuss spiritual and cultural issues in an open and non-judgemental way within scope of own responsibilities and skills

It isn’t necessary for you to belong to any religious faith for you to engage in communication with your client and/or his family about spiritual issues. Religion and spirituality are closely related but are distinctly different concepts. Spirituality is generally viewed as broader than religion. Some people include religion as part of their spirituality, others see spirituality as being about a sense of purpose in life, a transcendent relationship with a higher power, connectedness with nature, people and the universe, or feelings of hope, love, trust and forgiveness.

Expressions of spirituality include prayer, meditation, storytelling and reminiscence, rituals, loving and caring, being outside with nature, and other activities that nourish the spirit. In older adults, having a sense of religious or spiritual connectedness is associated with improved emotional health.

Talking to an aged client about their spiritual needs can often be daunting for a young person. Answer your client’s concerns in whatever terms you find most comfortable. For concerns which are outside your scope, refer to your supervisor who can make a decision which person would be the most appropriate to assist the client and his/her family. Ministers of religion, priests, pastoral care workers, tribal elders are examples of people experienced in spiritual and cultural issues.

An aged care worker is in an ideal position to listen to a client who may be troubled, and to ask questions as to what might be troubling him/her. Then, if the answer is outside your own comfort zone, speak to your supervisor about the issue.
Refer further needs and issues to appropriate member of the care team in line with organisation protocols

In most organisations, the supervisor is the appropriate person to whom referrals are made. The supervisor is able to call upon which ever pastoral support person is necessary to meet the need.

Case study

Mrs Poulos, an 88 year old Greek lady, has been unhappy ever since she was admitted to the facility. She cries a lot and will not leave her room for meals. Some evenings when you are on duty you hear her weeping inconsolably and admonishing God for leaving her to die alone in a nursing home. Whenever you help her undress for bed, she tells you of the sad life that she has had, and then starts weeping again. You feel helpless. When you read her care plan you note that she has nominated ‘Christian’ as her religion.

A response you might give could be:

‘Mrs Poulos, I can see that you really need someone to talk to about your unhappiness here. There are several people who could help you, such as our chaplain or the local priest. We also have a pastoral care committee whose members can just come to talk with you, and read some texts from the Bible for you. Do I have your permission to ask the supervisor to contact one of these people?’

And of course, do whatever you say you will do.

Using a reassuring tone of voice, gentle touch and not rushing your client are great skills to use when you are unsure about what to say in a situation.

Provide emotional support using effective communication skills

Empathic communication is at the core of providing emotional support for the palliative care client. You should:

- watch and listen for cues that the person wants to talk about what is happening to him/her
- ensure that the setting is appropriate ie it’s a topic that is best discussed in private
- check that you are talking about the same thing – explore their current understanding of illness
- ask open-ended questions appropriately in order to explore how the person is feeling about his/her situation
• be open and honest – if you are concerned about the questions being asked of you, let your supervisor know
• reassure the client that he/she will have strategies in place to deal with severe pain and other symptoms
• follow up any promises you make – if you promise to inform someone of the client’s concerns, do so
• use the non-verbal communication skills of touch and silence appropriately.

When working with people with advanced dementia at the end of their lives, good communications skills are even more important, as is your ability to know and understand your client. Even when clients have advanced dementia, they are able to understand and react to your tone of voice, facial expressions, body language and touch. So if you enter the room with a smile, reassuring voice, and gentle, appropriate touch, your client is more likely to respond to you positively, even if all that person can do is show a more relaxed face and body. If you enter the room to care for a client with advanced dementia and you wear a scowl and either don’t speak at all, or speak without a gentle tone, then the person will become anxious, fearful, confused and may respond aggressively.

People with advanced dementia often respond to gentle music played softly and to aromatherapy. Pets bring great joy to most people with dementia as long as they are not boisterous. Many facilities have a ‘pets for therapy’ program where specially trained pets make regular visits to the residents. Residents of aged care facilities may grieve for the pet that they have had to leave when they entered the facility.

Wherever allowed, encourage family to bring that pet in for a short visit. It will do wonders for the resident’s peace of mind. Remember – check your facility’s policy first!

If you already have some knowledge of caring for people with dementia, you will know how important the following strategies are for communicating with a client with advanced dementia:

• introduce yourself every time you see the person – he/she won’t remember you from day to day
• use the person’s name, and explain what you are doing before you do anything
• maintain eye contact at all times
• remain calm and speak in a calm, matter of fact tone
• keep sentences short and simple
• ensure that your non-verbals (body language, facial expressions) match what you are saying
• focus on one instruction at a time
• give time for responses, if the person can still verbalise
• repeat yourself—don’t assume that you have been understood
• don’t give more than two choices.
• respond to the client’s non-verbal behaviour – agitation and pacing up and down can mean that the person is in pain; withdrawing the body part or screwing up the face can also indicate pain.
• use gentle and appropriate touch to let your client know that you are there for him/her.

When caring for a person with advanced dementia, understanding the person’s background or social history will help communication.

The care manager will have a social history of the client and this will be used to add information to the client’s care plan. Social history of the client will detail the family of origin, marital status, children, past employment, education details, place of birth, religion, likes and dislikes of things (such as meals, pets etc), health status, fears, characteristics of the client’s personality (such as shyness, friendliness, musical tastes, war service, normal hobbies) and anything else the person or carer is able to offer to help form a profile of the client.

This information is invaluable to all staff and carers who deal with the client. Firstly, it helps to give a full picture of the client so they can be approached in a manner that will be acceptable, and so activities and conversation can be tailored to meet their individual needs. Also, social histories will often highlight situations which would be best avoided. For example, the client may have been in a concentration camp during World War II so that person may believe that he is back in the concentration camp if bedrails are placed on his bed – and his behaviour may become aggressive. One way of managing this situation could be to adjust the height of the bed to its lowest possible point and place a mattress beside the bed in case the client tries to get out of bed.

As the client’s memory deteriorates so will their ability to plan, think and cope with emotions. The individual client’s ability to function may vary day-to-day and at different times of the day, so the carer will need to have strategies for the best way to react and know what activities will please and distract a particular client.

Any strategies which work in enabling better care for the client should be recorded on the care plan and updated whenever necessary.

**Case study**

When you are attending Tricia, a terminally ill client, she asks you quietly:

‘Am I dying?’
An appropriate response might be:

‘All signs are that you are dying. Is there someone whom I could get to talk to you about it, or is there something that I can do for you?’

This opening allows further discussion or for you to get an appropriate person to talk to Tricia about her fear, and about any specific wishes she may have.

Demonstrate respect for the relationship between the client and carer

Respect is shown for the client and carer by your attitude and your behaviour. Respect is shown by:

- not judging a person
- considering each person as a unique human being
- viewing the person as being capable of making his/her own choices about the end of his/her life
- expressing warmth and friendliness
- providing encouragement and support.

A previous and ongoing relationship between the client and his/her carer should be cherished. This relationship will help you understand your client and give you valuable insights into your client’s physical, social, cultural and spiritual needs. Allow the client and his/her carer time to have privacy as they wish. In the case of a couple who have been in a marital-type relationship, close the door and make other staff aware of the need for privacy.

Reference: NEALS NSW DET 2009