

## **Palliative Care and Buddhist Cultural Sensitivity**

by Diana Cousens

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First of all I would like to thank you very much for inviting me to come here today and to share in the discussion of helping the dying. My involvement in this field came about through developing the booklet, 'Buddhist Care for the Dying'. I understand everyone has a photocopy of it.

Palliative care is a difficult topic but it's important. Preparation will make a lot of difference to the quality of care that people receive. When Ian Gawler launched the booklet he talked about the death of his mother when he was a teenager, and said that if anyone wanted to write a book about how to handle death badly, they could just follow what happened in his family. The loss was not discussed and everybody was just expected to get over it.

The booklet does not talk about how to manage grief and loss, but perhaps by learning to provide better care for the dying, those who remain behind will not be haunted by anxieties about all the things they should have done but didn't. A large proportion of people born in Australia are born to parents from other countries. Many of these people do not remember traditional cultural practices related to dying because, as the second generation, they have assimilated into the mainstream. And those of us who have become Buddhist by choice are still very much in the process of learning.

Issues around culturally sensitivity often come into visibility when there is a situation of insensitivity. Perhaps the starting point for Buddhists in Australia to put forward their voice arose on the occasion of a death of a Tibetan lama in Canberra. In 1993 Gyalsay Rinpoche died suddenly in the night from a stroke. His students found him in the morning and rang the lamas in India who advised that he should not be moved and that prayers should be performed. There should be no autopsy. The students also rang the ambulance which came very quickly. The ambulance wished to remove the body immediately and then the students advised the police that it should not be moved. The removal time was negotiated.

After a few hours some lamas came from Sydney who advised that the nature of the death had been instant, that he had died of a wind stroke and that the consciousness had left the body immediately. Therefore it would not be too bad to do an autopsy, but the lamas in India had advised against it. After discussions between the students and the Attorney General's Office, representatives from the Office of Tibet, and the lama's own doctor, it was agreed to limit the autopsy to the head. The Attorney General announced that there would be an inquiry into the ACT Coroner's Act. The body was embalmed, with students performing Buddhist prayers in the funeral parlor

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during the embalming. The body was then flown back to the lama's monastery in India for burial.<sup>1</sup>

This episode came as a shock to the whole Australian Buddhist community. We had no preparation for the death of a lama. Australian law and customary practice did not favour a Buddhist point of view or Tibetan cultural expectations. The key Buddhist concerns were not to move the body, to provide an opportunity for religious practice, and to avoid an autopsy. Other concerns were that primacy be given to the preferences of Buddhist spiritual leaders, such as the head of the Sakya tradition, and the lamas who came from Sydney. Australian law gives rights to family members, whereas from a Tibetan Buddhist perspective the responsibility for ensuring appropriate practice lies with religious authorities. In the case of the death of a Buddhist monk or a nun who has left the household life, family members may be fairly peripheral in the scheme of things. There is a parallel in Australia, in that exceptions are given to Aboriginal and Torres Strait Islanders, among whom custom and tradition may also give responsibility to a person outside the family. Another consideration is that many Australians also have spiritual beliefs which are not shared by their family members.

The Inquiry into the Coroner's Act resulted in amendments that reflect some of these concerns that were put into effect in 1997. In determining whether the coroner should order an autopsy or the removal of a body, the statute now reads that the Coroner may "have regard to the desirability of minimising the causing of distress or offence to persons who, because of their cultural attitudes or spiritual beliefs, could reasonably be expected to be distressed or offended."<sup>2</sup> This is a big step forward, but an awareness of the importance of spiritual authority for Buddhists at the time of death remains unlegislated.

This is an example of a really big event that highlighted questions of cultural expectation and customary practice. It also helped inspire the preparation of the booklet. It became obvious that there was much to know and much that could be done better. I created a questionnaire which was sent to all the temples in Victoria that asked quite simple questions. Questions like, what are good things to do around or for a dying person and what things should you avoid doing around a dying person? One of the things that you will find out as you work with people from many countries, is that Buddhism itself is not monolithic. There are substantial variations in ideas of what is good and what is not good between Buddhists of Sri Lanka, Vietnam, China, Japan and Tibet. Much of what people believe to be 'Buddhist' is quite culturally specific. There are also wide variations between different types of Buddhist practice. Some Buddhists enjoy long chanting ceremonies and elaborate rituals, some prefer absolute simplicity and an emphasis on quietude. It's all authentically Buddhist.

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<sup>1</sup> Ann Pickering, "Respecting Spiritual and Cultural Beliefs About Death – An Australian Buddhist Case Study," a talk delivered to the Conference on Human Rights, Faith, and Culture, hosted by the Association for Baha'i Studies in Canberra, Australia, November 7-8, 1998.

<sup>2</sup> The Coroners Act, Section 28. Quoted in *ibid.*, p.6.

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I think it is also important that you are able to understand some foundational Buddhist ideas. The first is that we believe that this life is one of an infinite series – a dying person is therefore not about to become nothing but is about to go on to another life.

We also believe that if we die well, with a peaceful mind, that will beneficially influence our next life. There are some transition periods at the time of death and the capacity to harness and focus the mind during these transition periods determines the kind of future life that will occur. It is thought that without the burden of sense consciousnesses the mind becomes extremely subtle and there is a chance to recognise its true nature at this point. If that occurs then the person reaches liberation – however, this is also understood to be extremely rare.

Buddhists also do not believe in a creator God. Buddhists believe that everything in the world is created by causes. We say that things don't happen by themselves, or through chaos, or for no reason, we say that things are caused by actions. Our life experience is largely determined by our own actions and in a sense, that gives us some responsibility for what we experience.

When we talk about karma, we are talking about the results of the actions of body, speech and mind. Nobody has perfect karma because nobody has lived in a perfect way. However, everyone has done some good things, as well as some bad things. Karma is created not only by actions but by the way we think about actions. Therefore the attitude of rejoicing in good actions itself creates enormous karma. For a dying person, it is crucial for them to remember all the good actions that they have performed and to feel good about them. If a person has done some kind of bad action in their life, then it is important to remind them that there is no karma that cannot be purified. Karma is not destiny but energy. It's like the ripples of water in a pond after a stone has been thrown in. The ripple is just a movement of energy. The ripple does not exist forever. If a person feels strongly that they wish to purify a past karma then they need to confess the action, strongly regret it, recite a purification prayer if possible, and determine not to do it again.

The most positive karma comes from love, compassion and wisdom. In order to create a positive state of mind at the time of death for Buddhists most of the interviewees for my booklet talked about creating a sacred atmosphere. They advised placing a Buddha statue in a place where the dying person can see it, playing tapes of chanting, inviting monks and nuns to come and say prayers, and generally doing things to inspire a mind of faith. You, as secular palliative care workers, may not feel comfortable constructing shrines and playing chanting tapes, etc., I don't know, but perhaps if you are aware that the families and care givers of Buddhists may find benefit in these things you may be able to enable them in some way.

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Another key concept in Buddhism is impermanence. One of my lamas once said that the good news about impermanence is that it means that if you don't own a Ferrari now, you may own one in the future. Because we believe in beginningless time and an uncountable series of lives we also believe that everything is constantly changing – nothing is fixed. For some people the changeability of life is a source of anxiety, but in Buddhism we believe that it is useful to become accustomed to change and that strength comes from being adaptable. If we see change as an opportunity, not a threat, then we can think about ways of making the best of a new situation. What any situation is, is to a large extent determined by the way we think about it. But this depends upon developing great flexibility in thinking.

For a dying person, they are about to let go of – or lose – everything that they knew and had in this life. As a Buddhist, we would prefer to think about this as 'letting go', rather than losing. The things of this life were never things that could be kept eternally. A dying person is letting go of their name, their nationality, their friends and possessions. You will notice that in the booklet the first method of preparation suggested by the Tibetan informant is that the dying person should organise their Will and give away all of their possessions to others. Others talk about the importance of organising laundry and shopping. The practical things need to be sorted out so that these are not of concern. Belief in karma means that if the person is able to give away their possessions to others who will use them in a good way, such as to good people or worthwhile charities, that the deceased will continue to benefit from the karma accrued from this action in their future life.

Impermanence means that although the person is losing their particular identity of this life, they will acquire another one in the next life, so in a sense there is some comfort and security in that idea. It is not the case that the person is about to cease to be, merely they are changing the clothes of their identity. As Buddhists we believe that we have been born in all parts of the world in all different races and ethnicities in the past. In the future, we could be anything, we have no way of knowing what, but the future is determined by what we do in the present.

One of the key Buddhist ideas you will always find mentioned is the idea that conventional life is unsatisfactory, that families and possessions and wealth and titles and honour and power do not guarantee happiness, meaning or purpose. The answer here is that life is about not what we can get, but how we can grow and develop in an ongoing way, and most of all, how we can help others. From a Buddhist point of view, the path out of unsatisfactoriness depends upon living ethically, not harming others, and taming the mind. Helping others is very difficult and is easily done badly, but most of all depends upon a compassionate motivation and wisdom. Taming the mind refers to having some awareness when states of anger and fear arise and being able to step back and recognise that these are states of mind that are not intrinsically real.

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Perhaps the principal aim is to create a calm state of mind and to overcome a person's fear. The way that pain is experienced is very often determined by what the pain is believed to mean. If pain is conjoined with fear, then I think the experience of the pain is increased enormously.

I was in Korea two years ago to talk about the booklet at the Sakyadhita International Buddhist Women's Conference. A Korean woman told me about the situation of her brother, who appeared to have terminal cancer. At the same time, it seemed he had a very sad life, first abandoned by his mother and then rejected by his wife. The time of death is very often a truly sad time where all the lost hopes and things that weren't achieved and pain are remembered. A Tibetan lama once said to me that people are much better at remembering pain than enjoyment. At any rate, a depressed state of mind is not a good state of mind for the next life, so I encouraged this woman to remind her brother of all the good things he had done in his life, the children he had raised, the business he had established, and that they at least had had a good relationship. Focus on the positive.

Death is sad and often untimely, but from the Buddhist point of view, there is a continuity and there is a future. If a person has suffered a lot then they can be reassured that all that karma has finished – it's been experienced, it's over.

If you are taking care of a dying Buddhist then please get in touch with one of the organisations that are mentioned in the booklet. Most Buddhists will appreciate a visit by a monk or a nun. A monk or a nun with good discipline is considered to be able to give a blessing and will offer pastoral support. A blessing is something that will lift the spirits of the person substantially. One cultural issue is that very often monks and nuns will not volunteer advice – they have to be asked. So please ask as much as possible. 'What would be good to do? Do you think it would be a good idea to do some chanting? Does he or she have any other needs? Is there something we have forgotten? Is there something that should be changed? What is your advice?' Asking open questions allows them to come up with a level of detail that we can't pre-empt. The person's family may find itself going off to a fish market and buying 100 live eels to release in the Yarra River. Buddhism is a vast science.

I was once asked a series of questions regarding palliative care ethics and I will just summarise the answers that I was given by a Tibetan abbot, Ven. Dungyud Rinpoche.

The first question was whether information regarding prognosis should be openly discussed with the patient/family. The lama said it is better to be truthful. However, he also said that it is good to encourage an atmosphere of hope. The lama is not advocating false hope, but he is counselling against despair.

The next question was about how this information gets handled. Should it be by a family member? The lama advised that information regarding prognosis and medical condition should be given to the sick person by a doctor, not a

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family member. There needs to be some sensitivity and some space for hope. It is really important to give comfort and peace of mind and not to worry a person too much. As already stated, it is important to organise practical matters. I heard that the great ballet dancer, Rudolf Nureyev, was still talking about his next performance in Paris in his last moments. From a Buddhist perspective, that is not very useful. While not negating the possibility of recovery – and Western medical treatment these days, is miraculous – if things are left undone that could have been done that will not help a person's peace of mind. I am thinking of things like reconciliation with a family member or giving someone the key to the locked box in the bank vault or explaining where the jewellery is hidden. If things like that are not done then they could be a real worry to a person.

The third question was whether death and dying seen as appropriate topics for discussion. As already mentioned, our Buddhists from an ethnic Buddhist background will derive great comfort from shrines and the presence of monks and nuns. In terms of how to discuss death and dying, it is possible to engage the monks or nuns in the process of finding a sensitive way to talk about what may be a terminal illness.

The fourth question was whether an individual's perspective would vary from a stated religious perspective, and the answer is certainly. We can't say whether complete disclosure about the illness is the right idea for everyone – it depends on the individual's strength of character and strength of practice. At the same time, it is perhaps useful to also retain an element of genuine uncertainty, even from the medical side, because none of us has a crystal ball and we really don't know what is possible. Buddhists do believe in miracles – particularly Buddhists from an ethnic background – we do believe in the power of blessings and chanting and the creation of a sacred atmosphere. We also believe that the body and the mind are not separate, and the condition of the body is very much contingent on the state of a person's mind. Having said that, the attitude that desperately clings to life at all costs is not the kind of state of mind that will produce a peaceful transition. That requires letting go.

The final question related to determining the quality of life and withdrawing treatment. This is a grey area but on the whole Buddhists view euthanasia and suicide as wrongful killing. The lama said that it is better to die than to suffer too much physically, if a person can't take the suffering. It depends on our motivation. We should have a benevolent mind and a compassionate attitude. The lama did not think that where a person was just kept alive on life support and had no capacity for movement or thinking that it was necessary to keep them alive. While Western medicine is often miraculous, it also presents new situations which were not dealt with in pre-modern societies. Therefore these are questions for which there are not easy answers. We do not have precedents in what happened in India two and a half thousand years ago. Decisions will have to be taken as situations arise, and yes, if it is possible to talk these things through before they happen that will help. The key is the compassionate attitude of the carer.

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I would like to commend the organisers of the seminar today for taking the trouble to invite the representatives of the different faiths and for making available this discussion. There is always a certain mystery in death and I do not think that we can ever dismiss that mystery. But we can certainly find ways of helping others which are more skilful and more optimistic, and maybe we can assist small miracles. There are many values that are shared between Buddhism and other religions and these include faith, hope and love. If these values inform your work then you will certainly assist the dying to make a good transition.