

Death and Dying

Sue Nieuwmeyer

Overview

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Powers of Attorney

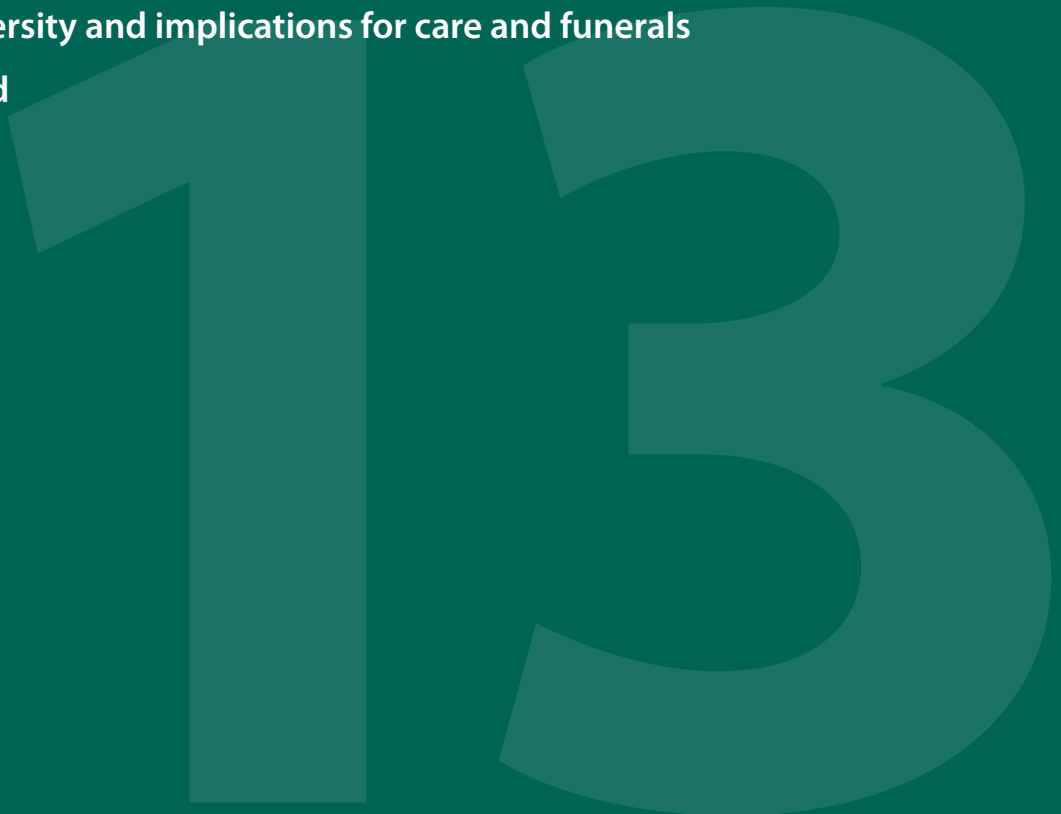
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Overview

The most precious possession any human being has is his spirit – his will to live, his sense of dignity, his personality. We must never lose sight of the person we are treating.

—Dr Paul Brand

Thinking about death and meeting people who are terminally ill can be challenging and even scary to those who are new to palliative care or who are called upon to provide a legal or financial service to patients and their families. This can include administrative staff who assist newly bereaved family members with account queries and other ancillary staff. It also includes lawyers and law students providing legal services.

Our society as a whole does not prepare us for the trauma of losing a loved one or of contemplating our own deaths. There is an expectation that the bereaved should 'be over it' after a few weeks, when the reality is that grieving will continue for many months and sometimes years.

Support by those more experienced in the field of palliative care and training is required to equip newcomers with knowledge and understanding of the needs of patients and family members at this time in their lives. The main supporters of legal practitioners in the palliative care workplace are social workers. Where there is no employed social worker, the support task would fall on the nursing staff.

One lawyer said at debriefing that she was not prepared for the emotional impact of the situation when she went to draw up a Power of Attorney, given by a patient to a family member. She felt that knowledge about the different diseases, especially cancer and HIV/AIDS, would be useful.

When providing a legal service, preparation is important for the current physical and mental state of the patient and the effect on the family of the illness and anticipated loss.

This chapter will discuss the type of legal issues which commonly occur in the palliative care situation, communication with the terminally ill and bereaved family, and the implications of cultural and spiritual diversity with regard to illness and funerals. The importance of thorough debriefing of both palliative care and legal people is addressed. Cross references to other chapters in the manual will be given when appropriate.

Who is 'the dying patient' in Palliative Care?

- The patient who has been treated actively for cancer and has now reached the stage where the extent of the disease has exhausted curative options. The medical practitioner suggests palliative care with the focus on symptom control and keeping the patient comfortable.
- The patient with late stage illness for whom cure is not possible (and in the case of HIV/AIDS, where antiretroviral treatments have failed).
- The patient living with HIV who is currently seriously ill and beginning antiretroviral therapy. If response to treatment is successful, this patient may eventually move into a status of chronic rather than terminal illness and may no longer need palliative care.

Terms you will read in this chapter:

Debriefing: an interview in which a person discusses a task or event after it has happened

Incontinent: unable to control the bladder or bowels

Letters of Executorship: letters authorising a person to carry out the instructions in the deceased's will

Living Will: a document signed while in good health, which specifies the medical treatment to be undertaken when the patient is no longer able to communicate their wishes – usually includes instruction that they are not to be kept alive artificially by life-support systems

Pauper's Burial: burial of a person without any income or relatives – usually undertaken by the municipality

Power of Attorney: the legal authority to act for another person in legal and business matters

Stokvel: an informal savings society in which members contribute regularly and receive payouts in rotation

Taboo: forbidden to be used, mentioned or approached because of social, cultural beliefs

When should legal aspects be addressed in Palliative Care?

The answer to this is: as early in the disease process as possible. It is not advisable to arrange the drawing up of a will in the last days of a patient's life, when the patient does not have the energy to think through his wishes properly and may at times be confused.

The nursing assessment, when the first contact with the patient is made, or early in the caring relationship, should include a question such as: 'Are your affairs in order, do

you have a will?' 'Have you given Power of Attorney to someone?' Where there is a social grant, it is important to ask if the patient has given Power of Attorney to anyone to access the money for him.

These questions should be on the nursing assessment form and ticked off. The replies should be recorded. When assistance is needed, immediate referral to the social worker should be made to access legal assistance as well as social grants.

CASE STUDY

Mr A was a patient in a hospice in-patient unit. He was terminally ill, bedridden and had little energy. His nephew and wife had taken him into their home when it was apparent that he had nowhere else to go. He had been divorced for years and said he had lost contact with his children.

The nephew requested legal assistance so that the patient could draw up a will. Although weak, the patient was mentally lucid. The nephew was present at the bedside with the lawyer during the process of establishing the patient's wishes. The patient had a sum of money in a savings account which he had intended to leave to his children, but now felt he would like to leave to his nephew.

The will was drawn up and duly signed, but the lawyer felt uncomfortable with the conversation which was led by the nephew. The lawyer was also concerned that the will could be contested by the patient's children after his death.

Discussion

The pressure in this situation was that the patient was close to death so there was some urgency when he wanted to make a will. This caused stress to the palliative care staff and to the lawyer.

Should the lawyer have refused to proceed with the will, if he felt uncomfortable with the discussion which took place?

This emphasises the point that, where possible, patients who wish to should be encouraged to make wills earlier on in the disease process. Unfortunately many patients are referred at a late stage of illness. In a case like, this it would be appropriate for the palliative care worker to call the lawyer aside and suggest that he consults the patient and drafts the will without the nephew being present, if the lawyer has not already expressed this to the nephew.

What legal needs may a patient or family member have?

Some common requests for legal assistance by patients and relatives:

- The granting of a General Power of Attorney to another person to manage the person's affairs.
- Power of Attorney is needed so that another person is empowered to collect the patient's social grant.
- The patient wishes to make a will – see chapter on Dying and the Law.
- The patient needs legal protection from other family members who want to evict him from his own house – see case study opposite.
- Guardianship of children – see chapter on the Rights of the Child.
- Advance Directives – see chapter on Ethical Issues.

Legal assistance which might be required after the death of a patient:

- The patient dies early in the month before his social grant has been paid out. The nearest family member wishes to apply for that month's payment to put the money towards funeral costs.
- The brother of the deceased applies for Letters of Executorship and offers the widow an amount of money which she believes is less than she is entitled to in terms of the Will.
- The widow or widower wants the house, which was joint-owned to be put in her/his name. There is no will.
- Minor children are left without guardians – See chapter on the Rights of Children and Young People in Palliative Care.

Problems over house ownership:

CASE STUDY: THE PATIENT COMPLAINED THAT OTHER FAMILY MEMBERS HAD THREATENED TO PUT HIM OUT OF HIS OWN HOUSE

The patient was referred to the hospice social worker, who visited the patient at home. This patient advised the social worker that some of his family members wanted him evicted.

The social worker asked to see the last municipal account and the patient's Identity Document. The account was addressed to the patient and there were no other names on the account.

The social worker asked the patient if he would like her to call round and see all the family together to discuss this matter. The patient was in favour of this.

A family meeting was held and discussion took place about what exactly had been said to the patient about being put out of the house and how this threat had arisen. Family members present were of the opinion that it had been said by one of their number who had been under the influence of alcohol at the time. They said they would not let this happen and that they knew that the house was the property of the patient. The meeting ended amicably and the problem did not recur.

Discussion

If this matter had not been resolved in a satisfactory manner, legal assistance would have been needed.

Powers of Attorney

There are two types:

1. General Power of Attorney (GPA)

- The patient gives another the power to conduct his affairs for practical reasons (illness, disability etc.).
- You can buy a General Power of Attorney form from the CNA or nearest stationery store.
- You may decide to consult a legally qualified person or simply to complete the form yourself.
- The GPA lapses with the death of the patient
- The patient retains overall legal power in any decision-making

2. Special Power of Attorney (SPA)

- Used for specific power rather than general power to conduct affairs of another person
- Banks require an SPA if the financial matters of the account holder are to be handled by another person. Banks have their own forms and will require the following documentation :
 - Identity Document of the account-holder and the recipient of the SPA.
 - Proof of residence: A recent account in the name of the recipient with the current address of the recipient.

Power of Attorney to draw a Social Grant

The Department of Social Development (S.A. Social Security Agency) will issue this to the person who will collect the grant of an ill or disabled client. It is best applied for at the initial application for the grant but may be obtained later as well. Finger prints will be needed.

Communication with the dying patient and family

The following points should be kept in mind:

1. Be prepared for each unique situation

- Both palliative care staff and lawyers or students visiting patients should see that they have basic information about the patient, the illness and the family situation before they set out. They can request a non-confidential summary of the situation from the patient's home care nurse or doctor.
- Be prepared with the usual legal documents/forms required for a dying person and their family.

2. Is an interpreter required?

- The interpreter will preferably be a palliative care staff member or someone the legal person chooses to work with.

3. Is there as much privacy as the patient requires?

- This is difficult to achieve in an open ward or in a small shack with other family members present. The patient is consulted about this. If a patient is mobile, the staff member's car may be used for privacy.

4. Is the patient comfortable?

- Someone in pain will not be able to concentrate on important legal issues or on anything else. It is up to the palliative care professional nurse to help with pain control.

5. Use simple language and check understanding of what is said

- Reflect back the patient's wishes where necessary – to see that both you and the patient are talking about the same thing.

6. Respect cultural and belief systems

- Conversations about death may be taboo for certain patients who see talking about death as 'inviting death in'. For further discussion about culture and beliefs see the section below and refer to the chapter dealing with cultural barriers to access to care.

7. When to refer

- If you are a legal person, you are not expected to answer questions the patient or family ask about his illness or other matters. If you are visiting without a palliative care staff member, tell the patient/family member you will ask the hospice sister to contact them.
- Stick to the legal brief, but show care and compassion.
- If you do not feel comfortable to proceed in terms of legal ethics and boundaries, explain simply to all concerned and withdraw.

How to approach the patient and family

In the palliative care situation, it is the social worker or professional nurse's responsibility to sit down with the lawyer/law student and prepare him/her for the encounter with the patient/family member. The social worker should have the patient's Identity Document in hand or have arranged with the patient that he will bring it in with him.

- Where Power of Attorney is to be given, the Identity Document of the recipient should also be available. Any concerns should be discussed.
- The legal practitioner must be given an outline of the family structure, especially those family members closest to the patient.
- The lawyer prepares him/herself emotionally for the interview.
- The interview with the patient may take place in the community (a very ill or bedfast patient); at the hospice or hospital (in as private a situation as can be arranged).

The appearance of the patient

- Colour may be very pale.
- The patient may be breathless. Listen to him and go at his speed. Allow pauses in the conversation, so that he can recover his breath and have time to think.
- The patient may have rashes, pustules or other disfigurements on his face.
- A patient who is very close to death may not be able to hold a train of thought and may nod off to sleep frequently.
- A patient who has lost the power of speech may be able to write or to use a communication board.
- A very deaf patient may require you to write down questions or comments.
- This may be the patient's first encounter with a legal person and he may feel intimidated. He may be anxious about the importance of what he is about to do in terms of this visit from a lawyer.

It is helpful if the professional person approaches the patient and family showing the following attitudes:

- **Respect** – acknowledging that the patient is the expert on his life.
- **Compassion, caring and commitment** to the needs of the patient.
- **Empathy** – putting oneself in the patient's shoes. Thinking, 'If this were me how would I be feeling? How is this patient probably feeling?'
- **Acceptance** of the patient's looks (he may be disfigured in some way), smell (he may be incontinent) and general

appearance and way of talking.

- **Acceptance** of the patient's language, culture and belief systems.
- **Knowledge of one's own inner thoughts.** The lawyer/law student identifies what he/she is thinking whilst talking with the patient/family member and is able to put these thoughts on one side in order to focus on the patient's needs.
- **A tentative approach** – such as 'Am I understanding you correctly? Are we talking about what you want to talk about?'

There is an invitation to share thoughts and feelings:

- 'What did you want to put in your will?'
- 'I want to be sure I understand you. Are you saying ... ?'

After a period of silence from the patient, the lawyer might ask: 'I wonder what you are thinking about at the moment?'

Starting off

Don't be intimidated by the illness. Address the patient as you would anyone else.

The lawyer introduces himself:

'Good morning My name is I am a lawyer. I understand you would like to draw up an Advance Directive ("Living Will" may be the term some people are familiar with)?'

Sit down, if possible, in a position where the patient can see you easily without turning his/her head too much. The light from a window or other should not be shining in his/her eyes.

When the lawyer wishes to explore exactly what the person means, the following might be said:

- Tell me a little more about that.
- Could you help me understand what you mean?
- If I'm hearing you correctly ...
- Am I right in thinking ... ?
- What has made you think you might need a Living Will?

Ending the conversation

- Summarise what has been decided by the patient and repeat it if necessary.
- Plan to see the patient again as soon as possible for signing of the documents which have been drawn up. Time may be short and terminally ill patients may die at any time.

Debriefing

The lawyer may be faced with an emotional patient, or family members overwhelmed with grief following the death of a loved one. After such an interview, it is important for the lawyer to recognise the emotions which have been transferred from the patient to him/herself. Once identified, he/she realises that these emotions do not belong to him/her and need to be released. This is a vitally important action. Negative emotions (pain, suffering, grief) can be taken up unknowingly from others and stored in the recipient's body to the detriment of the receiver. A sign that this has happened would be when the receiver feels very drained and tired at the end of the day.

This releasing process should be conducted daily by backtracking and remembering who has been seen during the day. Law students and lawyers doing work in palliative care can request time with the social worker, when needed, to help with debriefing.

Other useful practices

- Caring for yourself by eating healthily, exercising and having enough sleep
- Thinking positive thoughts about yourself and rejecting the negative thoughts
- Asking for help when you need it
- Preparing and debriefing properly

Cultural and spiritual diversity and implications for care and funerals

Some understanding of the culture and belief systems of others is helpful, so that people don't talk past each other. (Clues to Culture by Elion and Strieman is recommended for an informative and concise overview of cultural and spiritual diversity in South Africa.) In this chapter we shall outline the practices of the African peoples only.

The African spiritual tradition

- For the African person, belief systems and culture are experienced as being interwoven.
- All of life is seen as inter-connected and all fall under God.
- Those who have gone before, the ancestors or 'living-dead', retain an interest in their families. Since God is a distant divine being, they are the mediators between God and the family. Their function is to see that traditional

- rules and rituals around life and death are adhered to. Where they are not, a warning may be received from the ancestor in the form of a dream or vision. If the family member does not search his spirit to find out what the problem is or consult a Traditional Healer to help him, he may experience an accident or a breakdown in his health.
- There is continuity between life and death, but the emphasis is on life and health. The healthy African person experiences a balance within himself, between himself and the community, and between himself and the spiritual world.
- There is a strong attachment to the soil and a sense of belonging to the place of birth
- People see themselves through their relationships with others (the community) rather than regarding themselves as separate individuals.
- People are able to be members of other religions whilst at the same time observing the rituals of Traditional African Religion.
- Death is feared, and any discussion or preparation for approaching death is often strongly discouraged. There is a fear that by using the words 'death' and 'dying', death may be invited into the room.
- In palliative care, family members may sometimes require a senior member of the family grouping or clan to be present when decisions have to be made regarding the patient.

However, for many families who come from the Eastern Cape or other rural areas in South Africa and now live in urban areas, it is important to be buried in the place where they were born. Sometimes patients feel that the time has come to return to the place of their birth, and they return of their own accord or with family members.

Bereavement

Registering the death

This is normally done by the funeral undertaker.

The funeral

Financial implications

Where tradition is vitally important, African families are prepared to go heavily into debt in order to satisfy the ancestors and the living family by proceeding with the necessary rituals at the place of birth. There are transport costs for those of the family who will attend the funeral; a beast must be slaughtered (a goat for an ordinary family, an ox for a wealthy family); extra cooking pots bought for the food to be cooked.

CASE STUDY

A Xhosa-speaking man was admitted to a hospice in-patient unit in an urban area. He was terminally ill. The patient's son took responsibility for both his parents. The son requested that staff in the unit should not have any discussions about death and dying with his father or mother. This request was respected and no conversations about death or dying took place except with the son. Conversations focused rather on the comfort of the patient. It was explained to the son that his father was close to passing and he was asked if he wished this to happen at home or elsewhere. The son said he wanted his father to continue to receive care in the hospice. When his father died, the son made all the funeral arrangements.

Saving for the funeral

- African families often pay into a 'stokvel' or a burial group. A stokvel is similar to the English word 'co-operative'. People come together and pay in for various purposes, not necessarily for burial, for instance they may do it during the year to have money at Christmas. African people who move from rural areas into towns, often form a burial group with others from the extended family or clan. The members of the group meet once a month and pay in an arranged amount of money. This money is then used to pay for burials for any member of the group. Funerals of members who die are financed out of this fund. If several members of an extended family die within a short space of time, the fund may be insufficient.
- Borrowing money from a micro-lender or a bank. Large amounts of money are needed and it will take many months to repay the amount with interest.
- Other cultures may take out funeral insurance and pay the premium each month.

The wider significance of the funeral

- As well as the ancestors, the community and neighbours have to be satisfied with the way in which this particular family has completed all necessary rituals after the death of a family member.
- If arrangements are not well made, the entire extended family and clan may be ashamed and may suffer emotionally and spiritually as well as socially.
- Other communities in South Africa would also feel that they had lost face in the eyes of friends, church people and the larger community if they provided a cheap funeral and not much in the way of refreshments to honour their family member who had died.
- The funeral can thus be seen as an investment in the future lives of those left behind, even if they struggle financially to repay loans.

Pauper's Burial

When people have died alone at home, on the street or in a Night Shelter and are apparently without relatives or income, a Pauper's Burial is provided by the health district or large municipality.

If the destitute person dies in the provincial hospital or in an ambulance, then the province and not the municipality has liability to meet the cost. The following steps are taken to access a Pauper's Burial:

- The cemetery department of the municipality (health department of a smaller municipality) is contacted.
- A municipal council member or SAPS member determines whether the person was destitute and will complete the necessary forms.
- The body is collected when authorisation is given by the municipality (Cemetery office) to the funeral undertaker who holds the municipal contract.
- The municipality does not pay storage costs if the body has been removed before this process is complete.

Implications for Palliative Care

Sometimes palliative care staff can see that this situation may arise for a particular patient. However, there are concerns and decisions about this type of burial which should not be taken lightly:

- The patient may have been living on the street, but in fact has savings which he has not disclosed.
- He may have a will, which specifies how he wants his remains to be disposed of, and this is not known to others at that time.
- He may have relatives, but has broken off contact and tells staff that he has no family.
- In an African community, others may be prepared to contribute towards a funeral.
- Months later, a member of a traditional family may arrive and require some soil from the place where the person was buried or the ashes scattered, to take back to the place of birth, so that the proper rituals may be carried out for their relative in order to appease the ancestors.

Property grabbing

Colgan reports that some home-based carers she met in Soweto in 2007 spoke of property being grabbed by adult relatives after the funeral; and that sometimes orphaned children are seen as being a potential source of money through social grants. (See the chapter on Dying and the Law and the chapter on the Rights of Children and Young People in Palliative Care).

Talking with the Bereaved

Palliative care includes practical assistance and counselling to bereaved family members. Research has shown that individual and family breakdown can be prevented at this time if support is available to those who need it. Bereaved family members may need legal assistance. Very often the spouse or partner of the person who died will be the one consulting the legal practitioner, in terms of the will.

- An adult son or daughter may be the main beneficiary of the deceased or they may accompany their parent to give support.
- Parents of a deceased adult child may come forward with problems accessing a life policy made out to them.

It is important to remember that grieving people may be 'off-balance' after a death. Judgement and perception may be affected for a while and people say and do things which, a year later, they might regret. The bereaved person is emotionally stressed and is trying to survive; at the same time he or she is called upon to make an extra effort at a time when they feel most vulnerable and exhausted. We know that grieving saps a person's physical and emotional energy.

The lawyer or care giver can help the person to face the reality of the legal and financial situation in a gentle, patient, calm and compassionate way. He/she can explore with the client whether there is another family member who might be able to assist and support them.

Where possible, in practical terms, clients can be advised not to make over-hasty decisions and to give themselves six to twelve months before making major changes.

The following may occur after a loved one has died:

- The grieving client forgets an appointment or gets the time wrong.
- The client cannot locate documents needed or only brings some of the documents. Many telephone calls may be necessary to some clients before all is in order.
- The client bursts into tears and overwhelms the lawyer with sadness and despair.

- The lawyer worries about something he/she may have said which provoked fresh grief from the client.
- The lawyer thinks the person should have got over their grief by this time.

Applying for the social grant after the death of a patient

If the recipient of a social grant or pension dies before the grant has been paid out for that month, the closest family member may apply to the Department of Social Development (SASSA) for that month's pay-out.

Documentation in support of this application is the following:

- Identity Documents of the deceased and the claimant
- Marriage Certificate or proof of relationship
- Death Certificate
- Funeral account

This money will take about three months to come through.

Why is it advisable to obtain several copies of the Death Certificate?

A certified copy of the Death Certificate will be needed in the following instances:

- For pay-out of any insurance policy ceded to the claimant.
- For the cancelling of debts made by the deceased where there is no liability to pay by family members – such as a son or daughter.

Converting the house into the name of the surviving spouse or partner, when it is joint-owned by the deceased and the partner

The following must first be completed:

- If the person died intestate, a letter of authority is required from the Master of the High Court. This is a completed form from the Master's office stating when the patient died and that there was no will.
- The municipal account must be fully paid up.

Application can then be made through the municipal housing office.

Summary

- Legal issues should be addressed as early in the illness process as possible.
- The most common legal requests in palliative care before the death of a patient are for powers of attorney, wills, housing issues, guardianship, advance directives.
- After the death of a patient, legal advice may be required for any disputes about the will, house transfer and children's issues.
- The legal person should be prepared by palliative care staff and have sufficient information before seeing a patient or family member.
- Cultural knowledge of diversity and an attitude of respect is required.
- It is essential that both palliative care and legal people debrief properly after distressing encounters in their work.
- Some understanding of the feelings of the bereaved and the importance of the funeral is helpful knowledge.

The provision of legal advice to patients in palliative care and their families empowers individuals and restores hope when hopelessness has made a bid to be in control of the person's life. It is heartening to know that lawyers, university law departments and law students are willing to be of service at a time when families are in crisis.

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