

New guidance gives nurses clear advice on care surrounding death

Personal care at the end of life and after death

In this article...

- › Why clear, practical guidance on care after death was needed
- › Key points from the guidance on care before, during and after death
- › The importance of privacy and dignity

5 key points

1 Nurses need clear and practical advice on caring for people who have died and supporting their families

2 The new guidance is relevant to all those caring for people who have died

3 The term “care after death” has been introduced to reflect the range of nursing responsibilities involved

4 The term “personal care after death” describes the physical preparation of the body

5 The guidance should help organisations to develop appropriate training to ensure quality of care

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Abstract Henry C, Wilson J (2012) Personal care at the end of life and after death. *Nursing Times*; 108: online issue. New guidance was published earlier this year to provide nurses with clear, practical advice on caring for patients before, during and after death. This article describes how the guidance was compiled and highlights key points for nurses.

Over the past two years, it has become increasingly clear that registered nurses, and those staff who have nursing responsibilities delegated to them, need clear and practical guidance on how best to care for people who have died and support their families (Wilson et al, 2010).

The National End of Life Care Programme and the National Nurse Consultant Group (Palliative Care) (2011) led the writing of *Guidance for Staff Responsible for Care After Death (Last Offices)*, which was endorsed by the Royal College of Nursing and the Royal College of Pathologists. Although the guidance is for nurses, it was written with the cooperation of other health and social care professionals so it is relevant to all those who are responsible for caring for people who have died.

Care after death

The new terminology “care after death” has been introduced to reflect the range of nursing responsibilities involved. These

include the following:

- › Supporting any family and carers present who want to take part in the caring process;
- › Honouring the religious or cultural wishes/requirements of the deceased and their family while ensuring legal obligations are met;
- › Preparing the deceased for transfer to the mortuary or the funeral director’s premises;
- › Ensuring the deceased’s privacy and dignity is maintained;
- › Ensuring the health and safety of everyone who comes into contact with the deceased is protected;
- › Returning the deceased’s personal possessions to the next of kin.

The term “personal care after death” has been introduced to describe the physical preparation of the body.

Pathways of care

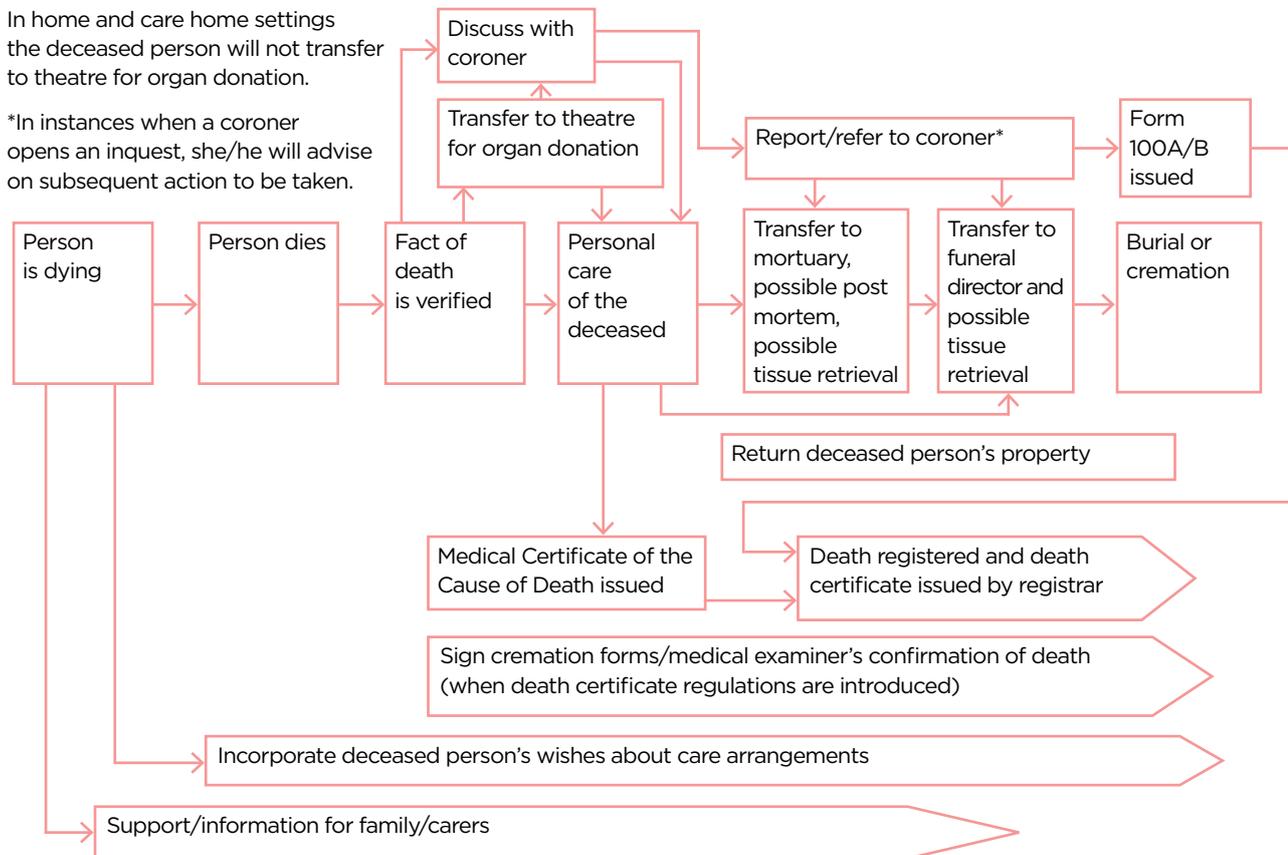
Fig 1 shows the pathways of care for the deceased person. While care after death is the last act of nursing care, it is the first step of a pathway that ultimately leads to burial or cremation. The pathway involves many professional groups including nurses, doctors, porters, mortuary staff, pathologists, coroners, funeral directors and bereavement teams.

The guidance, while helping individual professionals and teams, should also help organisations to develop appropriate training to ensure quality of care.

Drawing up guidance

A consensus methodological approach (Jones and Hunter, 1995) was taken to draw up the guidance, starting with the critical comparison of local guidelines for last offices gathered by the National Nurse

FIG 1. PATHWAYS OF CARE FOR THE DECEASED



Source: National End of Life Care Programme and National Nurse Consultant Group (Palliative Care) (2011)

Consultant Group (Palliative Care). These guidance documents were analysed and 83 common statements identified. They included, for example:

“When the death of a person is expected it is good practice to have identified with the patient, in advance of the death, any wishes for care (spiritual, cultural or practical) they have around the time of death or afterwards.”

The statements were then used as a framework for consultation with 50 national stakeholders, who were asked to comment on whether they agreed or disagreed with them and to provide evidence. Thirty-five organisations responded and their comments were incorporated into the guidance; where there was obvious consensus the guidance was reworded to incorporate advice/evidence.

A national stakeholder event was held to address the initial areas of care, where there was little empirical evidence and varying degrees of consensus. These areas related to:

- » Containing leakage (including the use of sheets and body bags);
- » Identifying the deceased;
- » Preparing the body;

- » Dignity;
- » Cold rooms;
- » Information required from nurses to communicate about the deceased to mortuary staff and funeral directors;
- » Documentation at the time of death;
- » Issues related to care homes.

The guidance was then written to take account of the discussion at the stakeholder meeting and was sent to all stakeholders again for comment before approval was received at national level.

The sections below summarise key points from the guidance.

Care before death

When dying is recognised and expected it is accepted that appropriate care can take place before death. Discussions between medical and nursing teams about a range of different issues can allow unambiguous communication and preparation of the patient who is dying and their family. Such discussions include:

- » Whether to attempt cardiopulmonary resuscitation (which should always involve patients where possible and/or families);

- » Use of the Liverpool Care Pathway (Ellershaw and Wilkinson, 2010) or equivalent;
- » Whether an implantable cardiac defibrillator needs deactivating.

Where possible the dying person's wishes for organ, tissue and body donation are ascertained, and that the local NHS Blood and Transplant specialist organ donation nurses based in acute trusts be involved. Although organ donation can only take place in an acute trust, tissue donation can be facilitated in any care setting.

It can also be helpful, where possible, to ask the dying person where they want to die, who they want to be present at the time of death, and how their cultural/spiritual/individual needs can be met. In communal settings it is helpful to offer patients and their families the option of single-room accommodation if available; however, not everybody will want or be able to have a single room.

Care at the time of death

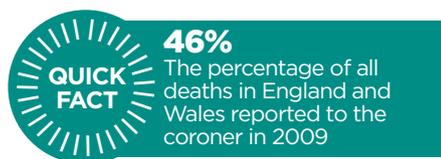
To meet new guidance on death certification processes, which is to be issued by the

Department of Health in 2012, recommendations were included for new nursing practice at the time of death. Although these still include informing the medical practitioner who is primarily responsible for the person's care, they also now involve recording in the written notes details of the death, including:

- » The time;
- » Who was present;
- » The nature of the death;
- » Details of any relevant devices (such as cardiac defibrillators) or treatments (like radioactive procedures).

Where relatives voice concerns about the nature of the death, the registered nurse should note these.

It is essential nurses know which deaths the coroner will want to investigate so they can carry out correct personal care of the deceased, support the viewing, and pre-



pare the family for a potential delay in issuing the Medical Certificate of the Cause of Death as well as the possibility of a post-mortem examination. Forty-six per cent of all deaths in England and Wales were reported to the coroner in 2009, either for forensic examination or to establish the cause of death (Ministry of Justice, 2010). In these cases, legal requirements prevail over normal care and practice decisions.

Those who verify the fact of death are either doctors or nurses who have received further training. Changes have taken place in terms of the responsibilities of those who verify the fact of death to ensure a streamlined pathway of care, enhanced by informed communication. These aim to prevent other professionals who care for the deceased being exposed to unnecessary infection, radiological or implantable device risk.

Personal care after death

Key elements of personal care of the deceased are outlined in Box 1. It is best practice to carry out "personal care after death" within 2-4 hours of death to preserve the deceased's appearance, condition, dignity and ability to donate tissue.

As well as preserving dignity, the aims of personal care after death, include:

- » Allowing the coroner to investigate the death fully if necessary;
- » Preventing leakage of fluids (and hence infection risk);

BOX 1. PERSONAL CARE OF THE BODY

- Family members may wish to be involved in personal care after death. Prepare them sensitively for changes to the body and guide them to minimise risk from manual handling and infection-control issues
- Be aware of manual handling guidelines. It is best practice for two people to be involved, one of whom must be a registered nurse or suitably trained person
- Lay the deceased person on their back, straightening the limbs if possible, and place a pillow under the head
- Close the eyes by applying light pressure for 30 seconds. Use saline-moistened gauze if corneal or eye donation is to take place
- Clean the mouth and clean and replace dentures as soon as possible after death. If dentures cannot be replaced send them with the body in a clearly identified receptacle
- Tidy the hair and arrange into the preferred style, if known
- Shaving too soon after death can cause bruising, so this is done by the funeral director. Explain this to the family if they request shaving. Remember some faith groups prohibit shaving
- Support the jaw with a pillow or rolled up towel underneath, removing before the family view the body
- If the death is **not** being referred to the coroner remove mechanical aids and document disposal of medication
- Contain leakages from the oral cavity or tracheostomy sites by suctioning and

positioning, then cover exuding wounds and unhealed surgical incisions with a clean absorbent dressing and secure with an occlusive dressing

- Pad and pants can be used to absorb any leakage of fluid from the urethra, vagina or rectum
- Intravenous cannulas, drains, indwelling catheters and so on should be capped and left in situ. This helps prevent leakage of body fluids. Mortuary staff will ensure funeral directors can safely remove the lines before the funeral or will remove the lines if a relative is collecting the deceased
- Leave endotracheal tubes in situ without cutting
- Clean and dress the deceased person appropriately. A shroud is used in many acute hospitals
- Remove jewellery (apart from the wedding ring) in the presence of another staff member (unless the family have asked you not to do so) and document this. Provide a signature if any jewellery is removed as procedures are needed to account for this information to onward caregivers
- Ensure the deceased person is clearly identified with a name band on the wrist or ankle. The person responsible for identification is the person who verified the death
- Provided no leakage is expected and there is no infection risk, the body can be wrapped in a sheet and taped lightly.
- If the body continues to leak, place the deceased on absorbent pads in a body bag and advise the mortuary or funeral director

- » Communicating well about the deceased to allow the mortuary/funeral director to continue care of the deceased without undue risk to themselves;
- » Preserving the body in a condition that, with the help of mortuary technicians or funeral directors, will allow families to view and spend time with the deceased at those locations, if they wish.

Some aspects of the guidance differ from current local practice in some areas. For example, see advice on leakage (Box 1).

In many circumstances death takes place in a community setting where intravenous lines are not used in the dying period. In hospital settings where death is

expected it is anticipated that medical interventions will be rationalised and lines removed, as appropriate, ahead of death. When death is sudden or unexpected, lines and endotracheal tubes may be in situ; these will be removed either at post-mortem by mortuary staff (where the lines will help the coroner to investigate the death fully) or by the funeral director (where they will help prevent leakage of body fluids). This means nurses may now be involved in preparing families to view the deceased in a ward setting, with lines in place, and will need to be able to explain that the deceased will be prepared for viewing at the funeral director's premises when all lines will have been removed.

In hospitals, it is now best practice for porters to transfer the body from the ward

to the mortuary within an hour of being asked to do so to help preserve tissues for donation and prevent distress to surrounding patients. The privacy and dignity of the deceased on transfer is paramount.

Box 2 gives advice on care when the death is unexplained or suspicious.

Privacy, dignity and the environment

The guidance notes that while the physical environment – such as single rooms or the viewing room – is important, professional attitudes are also crucial:

“The deceased was once a living person and therefore needs to be cared for with dignity. It is helpful if the surrounding environment conveys this respect. This includes the attitudes and behaviour of staff, particularly as bereaved people can experience high levels of anxiety and/or depression” (National End of Life Care Programme and National Nurse Consultant Group (Palliative Care), 2011).

It also notes that wider aspects of care – such as the journey to the mortuary and the handling of the deceased’s possessions – can have an impact lasting well past the initial hours and days after death. It is good practice for registered nurses to help families find a viewing room alongside the mortuary, if one is to be used, and to ensure mortuary staff know the family is coming.

BOX 2. PERSONAL CARE WHEN THE CORONER IS INVOLVED

- Seek advice from mortuary staff
- Leave all intravenous lines and cannulas in situ and all intravenous infusion connected but clamped
- Do not wash the body or attempt mouth care
- Use universal infection measures to protect people and the scene from contamination
- Leave endotracheal tubes in situ and do not cut them
- Family can only view the body with the permission of the police

Issuing the death certificate

The Medical Certificate of the Cause of Death should normally be issued within one working day so burial or cremation arrangements are not unduly delayed. Organisations should have processes in place for the certificate to be issued on the same day in response to cultural or religious practices (within legal limits).

Conclusion

Caring for those at the end of life and after death is an extremely important

responsibility. Care after death is the final step in the end-of-life care pathway set out in the Department of Health’s (2008) national end-of-life care strategy for England. It is reinforced by two new learning sessions on care after death, which are available through End of Life Care for All. These are available free to many health and social care staff (www.e-lfh.org.uk/projects/e-elca). In addition, nationally available, core training units are being developed in partnership with Skills for Care, to be included in the Health and Social Care diplomas at level 2 and level 3 so all social care staff working in end-of-life care will have access to a care-after-death unit. **NT**

References

- Department of Health (2008) *End of Life Care Strategy – Promoting High Quality Care for All Adults at the End of Life*. tinyurl.com/endoflife-strategy
- Ellershaw J, Wilkinson S (2010) *Care of the Dying: A Pathway to Excellence*. Oxford: Oxford University Press.
- Ministry of Justice (2010) *Statistics on Deaths Reported to the Coroners, England and Wales 2009*. tinyurl.com/deaths-coroner
- Jones J, Hunter D (1995) Consensus methods for medical and health services research. *British Medical Journal*; 311: 7001, 376-380.
- National End of Life Care Programme, National Nurse Consultant Group (Palliative Care) (2011) *Guidance for Staff Responsible for Care After Death (Last Offices)*. tinyurl.com/staff-death
- Wilson J et al (2010) National guidance on last offices would prevent family distress. *Nursing Times*; 106: 27, 8. tinyurl.com/need-guidance

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