

## Caring for the dying, the deceased and the bereaved policy

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<b>CONSULTATION AND DISTRIBUTION RECORD</b>	
<b>Contributing Author /Authors</b>	NHS Lanarkshire Bereavement Care Group
<b>Consultation Process / Stakeholders</b>	<ul style="list-style-type: none"> <li>• Senior NMAHP Leaders</li> <li>• Acute Divisional Management Team</li> <li>• North Health and Social Care Partnership</li> <li>• South Health and Social Care Partnership</li> <li>• Patient Public Focus Groups</li> <li>• Spiritual Care Forum</li> <li>• VASLAN</li> <li>• VANL</li> <li>• SANDS</li> <li>• CRUSE</li> <li>• NHS Lanarkshire Palliative Care Team</li> <li>• Kilbryde Hospice</li> <li>• St Andrews Hospice</li> <li>• Strathcarron Hospice</li> <li>• Maggie's</li> <li>• The Haven</li> <li>• Registrars</li> <li>• Funeral Directors</li> <li>• North Lanarkshire Council</li> <li>• South Lanarkshire Council</li> <li>• Scottish Grief and Bereavement Hub</li> <li>• Scottish Network for Acute Palliative Care</li> </ul>
<b>Distribution</b>	Available to NHS Lanarkshire Staff via NHS Lanarkshire Website

ii)

<b>CHANGE RECORD</b>			
Date	Author	Change	Version No.
29/12/16	Nurse Director, Acute Division		2
May 2018	Risk Department	GDPR statement added into section 3 and updated name of Data Protection Act	2
March 2020	K. Torrance	Extended until December 2020 (COVID-19)	2
December 2021	P Graham	Updates following Consultation (Including review of web links) (December 2021)	3

## 1. **INTRODUCTION**

In February 2011 the Scottish Government issued CEL (2011) Shaping Bereavement Care – A framework for action. The CEL contained guidance to NHS Boards on the implementation of a framework for action for the development and delivery of quality bereavement care services. The guidance was built upon the report “Shaping Bereavement Care” and asked NHS Boards to produce an action plan to meet the recommendations contained within that report.

One of the recommendations in “Shaping Bereavement Care” was that NHS Boards should develop a policy on the care of those who have been bereaved. This policy has been developed to meet that requirement. It also covers the care of the dying and deceased.

## 2. **AIM, PURPOSE AND OUTCOMES**

This policy is intended to ensure the delivery of high quality care to dying and deceased people and to their families and carers. It will provide staff who are caring for them with guidance on the delivery of bereavement care that is responsive to their spiritual, religious and cultural needs.

The policy also acknowledges that staff themselves will be affected by bereavement and points to resources available to support them.

Although the policy largely refers to care in a hospital setting, the principles apply equally when healthcare staff are delivering care in the people’s home or homely setting.

## 3. **SCOPE**

### 3.1 **Who is the Policy intended to Benefit or Affect?**

The policy is intended to benefit:

- the dying and deceased
- families and carers of the dying
- bereaved relatives and carers
- staff delivering care to the dying and deceased and their relatives and carers
- staff and volunteers who have experienced recent personal bereavement

### 3.2 **Who are the Stakeholders?**

NHS Lanarkshire has consulted with the stakeholders listed in section (i) to produce this policy.

“NHS Lanarkshire take care to ensure your personal information is only accessible to authorised people. Our staff have a legal and contractual duty to keep personal health information secure, and confidential. In order to find out more about current data protection legislation and how we process your information, please visit the Data Protection Notice on our website at <https://www.nhslanarkshire.scot.nhs.uk/data-protection-notice/> or ask a member of staff for a copy of our Data Protection Notice.”

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## 4. PRINCIPAL CONTENT

### 4.1 Persons and Carers

#### 4.1.1 Anticipatory Care Planning

People with a long term condition whose general condition is expected to deteriorate should be given the opportunity to express their individual wishes and preferences for their care. This is known as **Anticipatory Care Planning (ACP)**.

The term Anticipatory Care Planning (ACP) fits under the umbrella of Advance Care Planning. The process of anticipatory care planning is based on discussion between an individual and their care provider. This discussion is completely voluntary and takes place in the context of an anticipated deterioration in the person's condition.

The aim of advance care planning is to improve communication and the recording of decisions, which in turn will lead to care being provided according to the needs and preferences of people and carers. This includes recording the person's preferred place of care and their preferred wishes for end of life care. The anticipatory element addresses the clinical aspect of the person's care so that the person or carer is aware of any change in clinical symptoms and knows what to do should the person's condition deteriorate.

ACP is **not legally binding** and the person has the right to change their mind at any time. However, a person can make an **advance statement / directive**. This is a written, witnessed document made when a person is well, setting out how they wish to be treated (or not treated) for a disorder or condition if they were to become unwell and lack capacity to make decisions. An advance statement / directive must be taken into account when those who are responsible for a person's care take decisions about the person's care and treatment. (Not covered by the Mental Health (Care and Treatment) (Scotland) Act 2003), NHS Lanarkshire 2010).

This is an area of development nationally, and resources are available at the below website with guidance and resources on all aspects of ACP to support health and social care professionals throughout the care planning process.

<https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>

NHS Lanarkshire has also developed a **Treatment Escalation Plan (TEP)** which is a communication tool, similar in concept to DNACPR (see below). It is a prompt to staff to consider the patient's prognosis and provide a treatment escalation / limitation plan in the event of an acute medical crisis. In patients who are on an end-of-life trajectory it is designed to make interventions appropriate, given the patient's wishes, to ensure that futile and harmful treatments are avoided and to prompt early use of palliative treatments. The overall aim is avoid bad deaths and facilitate good ones. The Plan also provides for good communication between on-call staff, and has been welcomed as a tool to reduce treatment errors associated with discontinuity of care.

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### 4.1.2 End of Life Care Planning

As someone nears the end of their life, it is vital to optimise the quality of the life they have left. In *Living and Dying Well*, the national palliative care action plan, those providing end of life care are required to follow agreed best practice, based on the most up-to-date evidence of effectiveness. <http://www.gov.scot/Resource/0049/00491388.pdf>

NHS Lanarkshire has developed and tested end of life care documentation (Record of End of Life Care - RELC) to guide and record best practice in the last days and hours of life.

### 4.1.3 Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

Potentially CPR could be initiated on everybody prior to their death. It is therefore fundamental that inappropriate, futile or unwanted attempts at CPR, which may cause persons and families unnecessary distress, are avoided. The DNACPR policy is intended to enable persons' wishes to be followed at the end of life irrespective of their ultimate / final place of care, therefore a national DNACPR policy has been developed for implementation. This needs to be considered alongside Anticipatory Care Plans and Treatment Escalation Plans.

<https://www.nhslanarkshire.scot.nhs.uk/download/do-not-attempt-cardiopulmonary-resuscitation-integrated-adult-policy/>

### 4.1.4 Privacy and dignity

The care offered to people, both dying and deceased, and their carers, must ensure that their privacy and dignity are respected. Staff must display courtesy and sensitivity at all times.

Except in circumstances where infection control requirements make it impractical, people who are dying should be cared for in a single room. Although consideration requires to be given to the space available, other peoples' needs, and infection control issues; families/carers should be given the opportunity to stay with the person for as long as they wish and should be supported in doing so.

Those who have been bereaved will be experiencing a variety of emotions, including shock, sorrow and anger. Staff should ensure that their tone and manner are appropriate at all times. It is important not to appear rushed or impatient.

The bereaved must be offered the support and privacy they need, both prior to an expected death and following their relative's death. This may include:

- Access to a private space where they can make telephone calls, receive information and paperwork and ask questions
- The offer of additional support, such as that of the Spiritual Care team if they are not already present. Wherever possible, a member of the nursing team should be designated to spend time with them
- Ensuring that the person's religious and cultural needs are met. See separate section below
- The offer of tea or coffee
- Written information, including details of support organisations. See separate section below.

### 4.1.5 Communication & Support around the time of death

The key principle here should be that where possible families/carers are prepared for the possible imminence of death. Staff must be honest when providing information relating to a person's general condition or when death has actually occurred. Euphemisms such as 'has taken a turn for the worse' should be avoided. If asked directly if the person has died, staff must say that they have died.

Information about the death of a person must be given in a manner that is easily understood and the services of an interpreter should be considered where appropriate. The NHS Scotland document 'When Someone Has Died' is available in various languages, British Sign Language, and in an audio version and large print version. It can be accessed via the below link:

<https://www.nhsinform.scot/media/1503/when-someone-has-died-2016.pdf>

The national Support Around Death web site also has a range of relevant resources.

<http://www.sad.scot.nhs.uk>

The NHS Inform 'Bereavement Zone' also contains information which can be listened to, read or printed from its' website.

<https://www.nhsinform.scot/care-support-and-rights/death-and-bereavement/>

Palliative Care for People with Learning Disabilities (PCPLD) provides useful resources when communicating and supporting people with Learning disabilities affected by end of life issues, death and bereavement.

<http://www.pcpld.org/links-and-resources/>

Wherever possible a room should be identified where this news can be given in private. News of a death should not normally be given by telephone, however there are circumstances where this may be necessary, for example where the relative lives at a distance. Telephone calls should therefore be made in private and the staff member making the call should try to establish whether the bereaved has understood. They should also try to ascertain if they have someone with them or access to support.



The bereaved should be offered the opportunity to view the deceased and in preparation for this staff should ensure that the environment is made to look as natural as possible whether the death occurs at home or in the hospital setting. The deceased should be laid out in a dignified way, with their hands exposed to ease access should family wish to hold their loved ones hand. The bereaved should be assisted to collect personal effects and paperwork and to raise any questions or concerns that they may have. Arrangements for the above should be made in surroundings that are as private as possible.

In the difficult circumstances surrounding suicide, including supporting those who are bereaved and/or affected by the suicide, staff may find the following a very useful resource: 'Supporting People Bereaved by Suicide – A Good Practice Guide for Organisations who Respond to Suicide.

<http://www.healthscotland.com/uploads/documents/20648-Supporting%20People%20Bereaved%20by%20Suicide-October2019-English.pdf>

### 4.1.6 Completion of Last Offices

The practice of last offices demonstrates respect for the deceased and the bereaved by maintaining privacy and dignity and fulfilling religious and cultural needs. This last act of care is a significant process which is a very difficult time for those who have been bereaved, it can also be emotionally challenging for nurses, and it requires sensitive and skilled communication. Staff undertaking last offices will also have to comply with relevant health and safety requirements.

Once death has been confirmed within a hospital setting, last offices will normally be carried out except in cases where the death has been, or is to be, **reported to the Procurator Fiscal**. In such cases there must be no interference with the body other than to disconnect from any major equipment. Please ensure that all invasive devices such as catheters and cannulae remain in situ.

Section 2.5 of the National Infection Prevention and Control Manual (<https://www.nipcm.hps.scot.nhs.uk/>) provides nursing staff with guidance on related care of the deceased and bereaved. It focuses on the preparation of the body for transfer to the mortuary or undertaker ("laying out"). It includes guidance on the viewing of bodies considered to be a danger of infection to others. In all circumstances, staff must show particular sensitivity when meeting the needs of the bereaved.

#### **4.1.7 Meeting religious and cultural needs**

The dying and deceased and their families/carers must receive care that meets the specific needs of their gender, disability, ethnicity, age, sexual orientation, religion, culture and language.

It is important that people are asked if they have any specific religious, spiritual or cultural needs as early as possible in their care pathway. It may not be possible to establish this if the person is admitted in an emergency situation or is unconscious. In these circumstances guidance should be taken from the next of kin, or any family members or carers present or contactable.

People should be asked if they wish to see a member of the Spiritual Care team or a representative of their faith or belief group. Staff should be aware that whilst this offer may initially be refused, the person may change their mind as their clinical condition changes. The Spiritual Care team will provide contact information for specific faith or belief group representatives if people or their families/carers do not have this information themselves. An on-call NHS Lanarkshire Chaplain is available 24/7 and can be reached through the switchboard of the three acute hospitals.

'A Multi-Faith Resource for Healthcare Staff' is available online and contains guidance on meeting the specific religious and cultural needs of people and their families/carers.

<https://www.nes.scot.nhs.uk/media/ay4je0io/multi-faith-resource-for-healthcare-staff.pdf>

The sanctuaries in the three acute care hospitals are open at all times for those seeking a quiet place for reflection or prayer. Sacred writings and words of comfort and encouragement are available in the sanctuaries.

Where there is a specific religious or cultural need, the nursing or Mortuary staff will facilitate the preparation of the body of the deceased by the family. Where the family requests early release of the body on religious grounds, arrangements should be made with local faith group representatives once all necessary paperwork has been completed. This can be facilitated by the Spiritual Care team.

#### **4.1.8 Mortuary viewing arrangements**

Families/Carers may ask ward staff to visit the deceased in the Mortuary viewing room. The ward staff should inform Mortuary staff who will prepare the body in the viewing room. The ward staff should also ask the family/carer if they wish a member of the Spiritual Care team or another religious representative to accompany them. The Mortuary staff will add or remove religious artefacts from the viewing room as required.

Out with Mortuary office hours, access to the Mortuary can be arranged through the Hospital Cover nursing staff/night managers who will ensure they adhere to the “Mortuary Guidance for Nurse Managers”.



Mortuary guidance  
for nurse managers

### 4.1.9 Care of the deceased’s property

- All property which the person had in his/her possession in hospital must be made available for collection as soon as possible after their death and dealt with in accordance with NHS Lanarkshire policy
- Clothing being returned to the person’s family or carers must be placed carefully either in the deceased’s case or in an appropriate bag (there are purple bags specifically for this purpose in the acute bereavement pack). Any soiled articles must be placed in separate person’s clothing bags and sensitive explanation must be given to the person uplifting the deceased’s belongings
- In instances where the person’s death is sudden or unexpected, the Police will care for all the property
- Any valuables left on the body must be recorded on the deceased’s mortuary documentation and in the person’s nursing record.

### 4.1.10 Hospital and Community Post Mortem Examination

Where medical staff consider that this would be valuable, or where the relative has requested it, medical staff must discuss this promptly with the next of kin, agree the way forward and make any necessary arrangements. NHSL staff must be fully apprised of their responsibilities in terms of processes for informing as and when required to the fiscal and expediting post mortem requests.

#### The Procurator Fiscal

In some cases a death needs to be reported to the Procurator Fiscal. This usually happens if the death has been sudden, unexpected or accidental, or if the death is suspicious or unexplained. The medical staff will contact the Procurator Fiscal, who may decide to investigate the death. Medical staff must explain this to the next of kin and advise that the death certificate cannot be issued until the Procurator Fiscal has reached a decision.

There is an information leaflet available called ‘Post Mortem Examination - Information for Bereaved Relatives’ available from the Crown Office and Procurator Fiscal Service.

<https://www.copfs.gov.uk/images/Documents/Deaths/The%20role%20of%20the%20Procurator%20Fiscal%20in%20the%20investigation%20of%20deaths%20-%20Information%20for%20bereaved%20relatives%20-%20June%202015.pdf>

#### 4.1.11 Provision of the death certificate

In the community setting, where it has been established that a death is to be expected, nursing staff who have been trained in the verification of death are able to carry this out without recourse to medical staff. The link below provides further information on the processes to be followed.

<http://firstport2/staff-support/practice-development-centre/confirmation-of-death-resources/default.aspx>

Nursing staff should sensitively establish with the next of kin whether the deceased is to be buried or cremated in order that the appropriate documentation can be prepared by medical staff.

In some cases the death certificate may not be immediately available to pass on to the next of kin, e.g. where a hospital post mortem has been requested or the death has been reported to the Procurator Fiscal; or where the doctor on-call has not previously been involved in the care of the person. Staff should explain to the next of kin the reason for any delay and update them regularly on progress. It is best practice that the death certificate should be issued by the responsible team and therefore in the out of hours period there may be delays in this process.

[http://www.healthcareimprovementscotland.org/our\\_work/governance\\_and\\_assurance/death\\_certification.aspx](http://www.healthcareimprovementscotland.org/our_work/governance_and_assurance/death_certification.aspx)

<http://firstport2/resources/programmes-projects/death-certification/default.aspx>

When documentation is provided to the next of kin, the member of staff should ask the family/carer whether they have any questions about the care the deceased received. If the member of staff is unable to answer any questions, they should offer to make arrangements for the most appropriate member of staff to meet or speak with them. They should also ensure that the family/carer have received a copy of the bereavement booklet. When documentation is handed over to the next of kin, this should be done in a quiet, private space.

#### 4.1.12 Hospital funeral arrangements

Where a person dies in hospital and there is **no known** next of kin or executor, the nurse in charge must inform the pathology/mortuary department staff who will contact the National Ultimus Haeres Unit.

Where a person dies in hospital and no apparent arrangements for a funeral are being made **by the deceased's next of kin, executor or solicitor**, the nurse in charge should inform the pathology department. They will notify the local council who have a duty under the National Assistance Act 1948, to arrange for burial or cremation where it appears no suitable arrangements are being made. The local council are empowered to seek to be reimbursed from the estate of the deceased.

#### 4.1.13 Provision of verbal and written information

Death and dying are common events in hospital. In 2011, just over half of the deaths occurring in Lanarkshire took place in an acute hospital<sup>1</sup>. Whilst staff may frequently care for people, for families/carers such events are rare for the individual(s) concerned and can be a difficult and distressing time in whatever circumstances. It is important therefore both in the hospital and community setting, that they have immediate access to both verbal and written information and where appropriate the services of an interpreter. This can be important in helping them to understand the grief process and also to provide practical information in regard to the processes that must be followed after the person's death.

If the bereaved are present at the time of death or later attend the ward, they must be given a copy of the bereavement booklet. This covers a wide range of information, including how to register the death, post mortems, organ donation and contact details for voluntary support organisations. Supplies of the booklet are available via HPAC <https://www.hpac.nhs.uk/HPAC//Search> (select Lanarkshire and search for 'Bereavement'). Copies may also be available from the Patient Affairs Managers at each acute hospital site and within community teams.

If the bereaved do not wish to attend the hospital they should be given the contact number for the ward in case they wish to ask questions later.

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<sup>1</sup> Data source: NRS death registrations

#### 4.1.14 Provision of spiritual, emotional and psychological support

Wherever possible, immediate support should be given to the bereaved by a member of the healthcare team who has been caring for the deceased. They should also be available to speak with the bereaved at a later date if requested. The bereaved should be advised of other possible avenues of support, e.g. their GP, the Spiritual Care team or voluntary organisations (details contained in the bereavement booklet) or the "What to do after a death in Scotland booklet"

#### 4.1.15 When death occurs in specific areas

The overriding principles applied earlier in this Policy apply to deaths occurring throughout the hospital, however some local guidance may be available in defined areas e.g. Maternity, Theatres, A&E, Paediatrics, Critical Care areas, which provides specific information for staff. It is important that staff acknowledge that deaths within these clinical specialties can often be sudden and unexpected and support should therefore be gauged to meet the individual needs of the family.

## **4.2 Meeting the Needs of Staff and Volunteers**

### **4.2.1 Training for staff and volunteers**

Training is available to staff and volunteers depending on their level of involvement in caring for the dying, the deceased and the bereaved.

In the case of staff, training and awareness resources are available through the Palliative Care Team and LearnPro. When volunteers are being recruited to areas where there is a greater potential for them to be engaging with the dying and bereaved (e.g. palliative care, cancer care, care of the elderly) the selection process will take their particular skills and needs into account. They and other volunteers who have expressed an interest will have access to the bereavement care module on LearnPro.

### **4.2.2 Provision of spiritual, emotional and psychological support**

As with the dying and bereaved, staff and volunteers have access to the Spiritual Care team for support when one of their own relatives or friends has died. The sanctuaries on each acute site can also provide a space for quiet time/respice.

At times, some people's deaths can also be particularly difficult for staff and volunteers, for example, the death of a long-term patient, a child or a young person, death which has occurred suddenly, or a death reflective of their own personal experiences.

Salus Occupational Health & Safety service and the Spiritual Care Team are available to provide emotional and psychological support to staff, or to direct or refer staff to specialist services, as appropriate. Directly employed staff of NHS Lanarkshire can access Carer and Special Leave policies to support them in times of personal need.

### **4.2.3 Debriefing following critical incidents**

In certain circumstances (e.g. following a major incident or the unsuccessful resuscitation attempts of an infant or child) it may be advisable to carry out a more formal debrief. This should be arranged by the person leading the critical incident review, or by the local manager.

### **4.2.4 Communication with Other Care Providers**

Clinical staff should ensure that, where applicable, community colleagues and those from other agencies who may be providing care, are notified of a person's death to ensure that any care package which may be in place is discontinued. This may include Marie Curie, CrossRoads, Macmillan, Local Authorities etc. Arrangements should also be made to facilitate the uplift/removal of any equipment from the persons' home in a timely manner.

#### 4.2.5 Communication with the Procurator Fiscal

When a bereaved family raises concerns about care with the Procurator Fiscal, arrangements are in place for the Procurator Fiscal to contact the Patient Affairs Managers who will facilitate and co-ordinate the response.

#### 4.2.6 Links with local voluntary support

Many organisations provide support to people at the end of life and during bereavement. Some provide support such as advice, counseling and complementary therapies in their own premises, whilst others bring support to the home. A list of support is available on NHS Lanarkshire's Palliative Care web site and this is regularly updated to ensure the information provided remains current.

[Palliative Care Services](#)

#### 4.2.7 Links with local hospices

Lanarkshire has direct links with three local hospices, namely:

St Andrew's in Airdrie (<http://www.st-andrews-hospice.com>)  
Strathcarron in Denny (<http://www.strathcarronhospice.net>)  
Kilbryde in East Kilbride (<http://www.kilbrydehospice.org.uk>).

In addition to their clinical services, they provide a range of supports, including social / spiritual care, children's support and bereavement counselling. Full details can be found on their web sites.

### 5. **ROLES AND RESPONSIBILITIES**

The Bereavement Care Group is responsible for the development, implementation, monitoring and review of this policy.

### 6. **RESOURCE IMPLICATIONS**

There are no direct additional resource implications identified in the development or implementation of this policy, however it is acknowledged that other related policies such as Carer & Special Leave policies do incur costs to the organisation.

### 7. **COMMUNICATION PLAN**

Once endorsed, this policy will be launched through the following mechanisms:

- Senior Charge Nurse/Midwife forums
- AHP Professional Leads Forum

- Medical Education
  
- Staff Brief
- The Pulse
- Firstport site
- Briefings for Mortuary and Porter Teams
- Communication with partner organisations

**8. QUALITY IMPROVEMENT – MONITORING AND REVIEW**

The monitoring of effective bereavement care may be difficult since this is a sensitive and emotive area in which accurate feedback may not be readily achieved. Formal and informal concerns, compliments, feedback and complaints can be used as a proxy and, to assist in the retrospective review of relevant issues. The Patient Affairs Managers will flag on Datix any complaints that have been received following the death of a person.

The Bereavement Care Group will monitor and review this policy.

**9. EQUALITY AND DIVERSITY IMPACT ASSESSMENT**

This policy meets NHS Lanarkshire’s EQIA



(tick box)

**10. SUMMARY OF FREQUENTLY ASKED QUESTIONS**

N/A

**11. REFERENCES**

1. Shaping Bereavement Care  
[http://www.sehd.scot.nhs.uk/mels/CEL2011\\_09.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2011_09.pdf)
  
2. Living and Dying Well: Building on Progress  
<https://www.gov.scot/publications/living-dying-well-building-progress/documents/>
  
3. A Multi-faith Resource for Healthcare Staff  
<https://www.nes.scot.nhs.uk/media/ay4je0io/multi-faith-resource-for-healthcare-staff.pdf>
  
4. Supporting People Bereaved by Suicide – A Good Practice Guide for Organisations who Respond to Suicide  
<http://www.healthscotland.com/uploads/documents/20648-Supporting%20People%20Bereaved%20by%20Suicide-October2019-English.pdf>