NHS SCOTLAND

THE STATE HOSPITALS BOARD FOR SCOTLAND

DEATH OF A PATIENT/PALLIATIVE AND END OF LIFE CARE (INCLUDING SUDDEN DEATH) POLICY AND PROCEDURE

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	Clinical Effectiveness	
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Accountable Executive Director	Director of Nursing, AHPs and Operations	

The date for review detailed on the front of all State Hospital policies/ procedures/ guidance does not mean that the document becomes invalid from this date. The review date is advisory and the organisation reserves the right to review a policy/ procedure/ guidance at any time due to organisational/legal changes.

Staff are advised to always check that they are using the correct version of any policy/ procedure/ guidance rather than referring to locally held copies.

The most up to date version of all State Hospital policies/ procedures/ guidance can be found on the intranet: http://intranet.tsh.scot.nhs.uk/Policies/Policy%20Docs/Forms/Category%20View.aspx

REVIEW SUMMARY SHEET

No changes required to policy (evidence base checked)	☐

Changes required to policy (evidence base checked)	☒

Summary of changes within policy:

- Policy title and appendix change (recommendation from a Cat 1 review)
- Hyperlinks updated.

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1. PURPOSE

The purpose of the policy is to set out a strategic framework for palliative and end of life care for patients at The State Hospital (TSH) taking into consideration the principles and objectives contained within national guidance:

- NICE Guideline 31 – Care of dying adults in the last days of life
- National Palliative Care Guideline "Care in the last days and hours of life" (2014)
- Shaping Bereavement Care: a framework for action
- Living and Dying Well: a national action plan for palliative and end of life care in Scotland
- The General Data Protection Regulation (GDPR)
- NHS Education for Scotland Palliative and End of Life Care Framework (2016) (education resources) http://www.knowledge.scot.nhs.uk/pceducation.aspx

2. SCOPE

The guideline is intended for all healthcare professionals who might be involved in the care of a patient who is nearing death in the TSH.

The scope of this policy includes:

- Processes for caring for patients with life limiting conditions
- Supporting the patients through anticipatory care planning prior to their death
- Information to support the patients' carers, peers and family following their death.
- Processes to support staff who are caring for / have cared for the dying patient
- Processes required to be undertaken in the event of the death of a State Hospital patient.
- Processes in place to enact Do Not Attempt Cardiopulmonary Resuscitation

3. DEFINITIONS

Palliative Care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO 2018).

End of Life Care

Is that part of palliative care which should follow from the recognition that a person is entering the process of dying, and there is a high likelihood of them dying over the next few hours, days or weeks, whether or not he or she is already in receipt of palliative care. This phase could vary between weeks, days or hours, and with less predictability particularly in the context of Chronic Obstructive Pulmonary Disease (COPD) or other organ failure scenarios in such cases – illness can be unpredictable, and changes can occur suddenly and unexpectedly. End of life care aims to help people live as well as possible and to die with dignity.

Bereavement

Bereavement is the objective situation of having lost someone significant through death.

4. ON DIAGNOSIS OF A LIFE LIMITING CONDITION

On diagnosis, clinical teams should ensure that the Care of a Patient with Life Limiting Conditions document (appendix 1a) is commenced with the patient. The Consultant Psychiatrist, as Responsible Medical Officer, should collect all the relevant information and share this with the Clinical Team who should consider forming a broader care team to support the wider needs of the patient which may include:

- Lead Dietitian

- Practice Nurse and GP
- Lead AHP/OT
- Moving and Handling Co-ordinator
- Infection Control/Nursing Practice Development
- Spiritual and Pastoral Care Team / Volunteers (Via Person Centred Improvement Lead)
- Advocacy

It is expected that those mentioned above will initiate their own processes for managing end of life care. Any referral to the Macmillan Nurse (appendix 1b) will be processed by the Health Centre. It should be noted that the Electronic Patient Record (Vision) will provide external services on a need to know basis, Emergency Care Summary (ECS), Key Information Summary (KIS), and Palliative Care Summary (PCS). The GP and Practice Nurse will ensure this information maintained and accurate.

On diagnosis, Clinical Teams should ensure that all relevant staff are familiar with the appendices to this policy.

If a patient has an ICD (Implantable cardioverter defibrillator) consideration must be given to the device being deactivated. People who are nearing the end of their lives, for example, sometimes feel that this is the right course for them. This decision must be made in consultation with a specialist member of the ICD team, RMO and the physician responsible for the physical health condition of the patient. (See appendix 13)

5. END OF LIFE CARE

The ways in which people die and how long this takes varies widely, mostly because of the underlying diseases responsible but also the person's robustness or frailty, and their social setting. Some people remain mobile and largely self-caring, and can continue to take oral medication and eat and drink up until their death (appendix 12). Others may die suddenly and unexpectedly after a significant trauma or catastrophic medical event. Some people never experience any notable symptoms however people with progressive cardiac, pulmonary or neurological disorders, dementia, some forms of cancer or who have had a stroke may spend several weeks or months in a gradual or intermittent decline. Clinical Teams will manage end of life care based on the individual circumstances of the patient.

Clinical Teams should decide, in conjunction with external clinicians where appropriate, when the End of Life Care Record Initial Assessment (appendix 2) should be enacted. End of Life Care Ongoing Assessment (appendix 3) and End of Life Care Re-assessment (appendix 4) should be initiated as indicated. Typically, the pathway should start during the last few days of life, although it is recognised that this is difficult to estimate.

Clinical Teams in conjunction with relevant external clinicians should decide on the approach to be taken with regards to resuscitation. Where possible this should involve the patient and/or their families as appropriate. A decision not to attempt resuscitation requires the form (appendix 5) and the associated procedure to be adhered to (appendix 13). The decision should be clearly documented in the patient's care plan and communicated with all clinical staff who may come in contact with the patient. All forms must be printed in colour and on white paper.

The RMO, in conjunction with the Associate Medical Director (AMD) and Clinical Team, will give consideration to making contact with the Scottish Government, where it may be appropriate, for a patient at the end stage of life to be cared for out with TSH.

Clinical Teams will liaise closely with family and friends who may wish to visit the patient more frequently in the last stages of illness. The Clinical Team will decide how best to facilitate this and it may be necessary to put special arrangements in place (appendix 14). Where children wish to visit the patient and the patient cannot attend the Family Centre, the visit should be facilitated with the prior involvement of the Child and Adult Protection Forum, Social Work, and Security.

It is important that appropriate respect and procedures are followed in relation to any religious or spiritual beliefs that the deceased may have. Appendix 6 provides general guidance; further advice can be provided by the Person Centred Improvement Lead if required.

6. PREPARING FOR BEREAVEMENT

The aim of bereavement care is "… to benefit the bereaved individual, to help him or her deal with the emotional and practical problems following the loss of a loved one."

The death of a patient will affect the patient's family, other patients, staff and volunteers who may have engaged with the patient.

Training
Two e-learning modules available relating to bereavement are on learnpro (under CPD) to support staff:

1. Bereavement and Loss for NHSScotland
2. CBCS (Cruse Bereavement Care Scotland): 6 – Bereavement following sudden death

Information for Patients, Carers, Volunteers and Staff
Is available via the State Hospitals Intranet or Cruse Scotland to download and distribute.

Bereavement Care for Patients
Clinical Teams will discuss with patients the most appropriate methods of providing bereavement care. In addition to providing 1:1 support when required, additional support should be sought from a range of sources including:

- referral to the Spiritual and Pastoral Care Team
- Increased access / contact with family / friends
- referral to psychologist
- written information leaflets

Bereavement Care for Relatives
Following the death of a patient, Social Work (or others as deemed as appropriate by the clinical team) will liaise with families regarding bereavement care, which may include:

- signposting families to local bereavement services
- information leaflets
- information about independent voluntary/support organisations e.g. Cruse

Bereavement Care for Staff and Volunteers
As per Shaping Bereavement Care (2011), staff will be supported according to individual circumstances. Support can be provided for personal bereavements and also for any difficulty experienced following the death of a patient. Managers should ensure a sensitive approach is adopted according to need. Where a need is identified, staff can self-refer to the Counselling and Psychological Wellbeing Support Services or Occupational Health Services. Line managers can also refer staff to Occupational Health.

Other options to help hospital staff cope with bereavement include:

- informal Clinical Team debrief following the death of a patient
- clinical supervision
- information leaflets
- 1:1 discussion with the line manager

7. PROCEDURES WHEN THE DEATH OF A PATIENT OCCURS

The Hospital requires to notify the police regardless of whether the death of a patient was expected, sudden or unexplained. Any death of a person who was, at the time of death: detained

or liable to be detained under the Mental Health (Care and Treatment) (Scotland) Act 2003 or Part VI of the Criminal Procedure (Scotland) Act 1995; requires reporting to the Procurator Fiscal.

The police will attend the location and investigate the situation. They will determine how to proceed, and will make a report to the Procurator Fiscal who will decide whether a post mortem is required. All death certifications must be completed electronically (all medical staff have personal login details for this); however, if electronic access fails then paper copies of death certificates are located in medical records and can be accessed out of hours via Senior Clinical Cover. Health Records can be contacted for more information about these formal processes. For more information please view http://www.sehd.scot.nhs.uk/cmo/CMO(2009)10.pdf

Roles and responsibilities at this time:

Sudden/ unexpected or expected death during normal working hours (Monday – Friday 0900-1700)	Appendix 7
Sudden/ unexpected or expected out with normal working hours (1700Friday – 0900 Monday and public holidays)	Appendix 8
Sudden/ unexpected or expected out with the State Hospital (at all times)	Appendix 9

TSH understands and makes a commitment to care for a patient after death with the same values as those adopted during life. Appendix 10 – End of Life Care Record Care after Death should be completed by the Nurse in Charge of the ward at this time.

8. REPORTING

In the event of a patient death regardless of location or time, Nurse in Charge will ensure a DATIX is completed promptly with all relevant parties linked to the incident. Those directly involved in the process should complete, sign and date a statement as soon after the event as possible. This may be required for subsequent inquiries e.g. a Fatal Accident Inquiry requested by the Procurator Fiscal.

The doctor i.e. RMO with the most detailed knowledge of the circumstances of the death should report it. The reporting doctor must understand clearly why the death is being reported and must be able to answer any questions about the circumstances of death which the procurator fiscal may ask (Information and Guidance for Medical Practitioners, COPFS 2019). The RMO is responsible for reporting the deaths of any restricted patient to the Mental Welfare Commission. The Mental Welfare Commission require to be formally notified of all deaths in the State Hospital. Notification of Death Form (ND1) (appendix 15) must be used for notifying the Commission, with the RMO ensuring that this is completed and submitted.

Any death of a patient should be investigated through the appropriate review process.

9. PATIENTS' PROPERTY & FINANCES

When a patient dies in the hospital, special arrangements need to be made for the return/disposal of their property and, in some cases, for arranging their funeral.

If the death was expected these discussions should have already taken place between members of the Clinical Team and the patient; however, this is not always possible.

For further information, please refer to Procedures for Dealing with Patients Finances and Property Following their Death (appendix 11).

In all cases money and personal belongings held on the patient's behalf, or in the patient's possession at the time of death, must be retained securely until the person(s) entitled to administer

the estate indicates what should be done with them.

ALL PAPERWORK MUST BE SCANNED ONTO RIO.

10. COMMUNICATION, IMPLEMENTATION, MONITORING AND REVIEW OF POLICY

This policy will be communicated to all stakeholders within The State Hospital via the intranet and through the staff bulletin.

The Advisory Group will be responsible for the implementation policy. All documents are monitored and reviewed on an ongoing basis by the policy author and advisory group as part of working practice.

This policy will be reviewed every three years. Following the practice of instigating a Category 2 Review the document may require to be reviewed at that point.

11. EQUALITY AND DIVERSITY

The State Hospitals Board (the Board) is committed to valuing and supporting equality and diversity, ensuring patients, carers, volunteers and staff are treated with dignity and respect. Policy development incorporates consideration of the needs of all Protected Characteristic groups in relation to inclusivity, accessibility, equity of impact and attention to practice which may unintentionally cause prejudice and / or discrimination.

The Board recognises the need to ensure all stakeholders are supported to understand information about how services are delivered. Based on what is proportionate and reasonable, we can provide information/documents in alternative formats and are happy to discuss individual needs in this respect. If information is required in an alternative format, please contact the Person-Centred Improvement Lead on 01555 842072.

Line Managers are responsible for ensuring that staff can undertake their role, adhering to policies and procedures. Specialist advice is available to managers to ensure that reasonable adjustments are in place to enable staff to understand and comply with policies and procedures. The EQIA considers the Protected Characteristic groups and highlights any potential inequalities in relation to the content of this policy.

Patient pre-admission assessment processes and ongoing review of individual care and treatment plans support a tailored approach to meeting the needs of patients who experience barriers to communication (e.g. Dementia, Autism, Intellectual Disability, sensory impairment). Rapid access to interpretation / translation services enables an inclusive approach to engage patients for whom English is not their first language. Admission processes include assessment of physical disability with access to local services to support implementation of reasonable adjustments. Patients are encouraged to disclose their faith / religion / beliefs, highlighting any adapted practice required to support individual need in this respect. The EQIA considers the Protected Characteristic groups and highlights any potential inequalities in relation to the content of this policy.

Carers / Named Persons are encouraged to highlight any barriers to communication, physical disability or anything else which would prevent them from being meaningfully involved in the patient's care (where the patient has consented) and / or other aspects of the work of the Hospital relevant to their role. The EQIA considers the Protected Characteristic groups and highlights any potential inequalities in relation to the content of this policy".

12. STAKEHOLDERS ENGAGEMENT

Key Stakeholders	Consulted (Y/N)
Patients	Y
Staff	Y
TSH Board	Y
Carers	Y
Volunteers	Y

13. REFERENCES

- Information and Guidance for Medical Practitioners, Crown Office and Procurator Fiscal Service 2015
- NICE Guideline 31 – Care of dying adults in the last days of life
- National Palliative Care Guideline “Care in the last days and hours of life” (2014)
- Shaping Bereavement Care: a framework for action
- Living and Dying Well: a national action plan for palliative and end of life care in Scotland
- The General Data Protection Regulation (GDPR)
- NHS Education for Scotland Palliative and End of Life Care Framework (2016) (education resources) http://www.knowledge.scot.nhs.uk/pceducation.aspx

Care of a Patient with Life Limiting Conditions

Appendix 1a

Patient Name: **CHI:**

When a patient has been diagnosed with life limiting condition regardless of the expected life expectancy the following documentation should be employed. This document will be scanned to the patient's notes in RiO for all members of the clinical team to access.

On diagnosis

Patient information:	**Yes**	**No**	**Variance**	**Date & Time**	**Signature**
Has the patient's RMO spoken to the patient about their understanding of the nature and implication of the diagnosis and treatment informed him of his diagnosis?					
Has a plan of care been discussed with him?					
Has the patients named person/next of kin/family been contacted, explanation of situation been given and appropriate support provided					
An awareness given to the following professions: • Practice Nurse/GP • Lead Dietitian • Occupational Therapy • Moving and Handling Co-ordinator • Infection Control/Nursing Practice Development • Spiritual and Pastoral Care Team (via Person Centred Improvement Lead)					
Form a broader care team to support the wider needs of the patient. Members of this care team should include the professions above.					

Supporting services **Has contact been made with?**	**Yes**	**No**	**Variance**	**Date & Time**	**Signature**
Scottish Gov (restricted patients) to alert of potential increase in suspension of detention requests.					
With the patients consent, specialist service e.g. Macmillan Nurses, district/ community nurses/Advocacy					

Following a change in the patient's presentation the above services should be contacted again to ensure advice/support remains current

Appendix 1b

WE ARE MACMILLAN. CANCER SUPPORT

NHS Lanarkshire

COMMUNITY MACMILLAN SERVICE REFERRAL FORM

Tel. 01698 723278 (North) / 01698 723297 (South) Fax: 01698 723137or 723219

ALL REFERALS MUST BE MADE VIA THE HEALTH CENTRE

Implement the **NHSL Palliative Care Guidelines** before referring to the service. Please complete **as many of the questions as possible** and note that **INCOMPLETE** referrals will result in **delay** in **triage** and **contact** with the patient. All patients should be informed of their diagnosis **PRIOR** to referral to the Macmillan Service.

Referral Date		**Priority**	Urgent ❑ 48hours ❑ 1 week ❑

Patient Details

CHI number	**D.O.B.**	**Age**	**Sex m**

Forename

Surname

Address

Postcode **Tel. No.**

GP Details

GP Name

Practice Address

Tel. No.

Marital Status

Single	❑	Partnered	❑
Married	❑	Divorced	❑
Widowed	❑	Seperated	❑

Ethnic Origin

White	❑	Asian	❑
Black	☒ ❑	Other	❑
Mixed	❑		

Referrers Details

Name

Designation

Location

Tel.

Significant Other Details

Forename **Surname**

Address

Postcode **Tel. No.**

Relationship

Spouse	❑	Child	❑
Partner	❑	Carer	❑
		Other	❑

Names of Other Healthcare Professionals currently involved in Patient's Care

Consultant	**Acute Macmillan Nurse**
District Nurse(s)	**Other**

Has referral been discussed with PATIENT?	Yes ❑	No ❑	Not Applicable ❑
Has PATIENT been informed of Diagnosis?	Yes ❑	No ❑	Not Applicable ❑
Has SIGNIFICANT OTHER been informed of Diagnosis?	Yes ❑	No ❑	Not Applicable ❑
Is Patient able to Travel to Day Care Centre / Outpatient Clinic?	Yes ❑	No ❑	Not Applicable ❑

For office use only

Referral Rec'd Date / / First Contact Date / / Telephone ❑ Visit ❑

First Visit Date / / No Visit Req'd ❑ Visit Refused ❑

Referred on to other service ❑ ______________________ Appropriate ❑ Inappropriate ❑

Diagnosis / Treatment (GP Practices may wish to attach a Patient Encounter/Summary Sheet if available)

(Continue on separate sheet if required)

Past Medical History / Social History (GP Practices may wish to attach a Patient Encounter/Summary Sheet if available)

(Continue on separate sheet if required)

Symptoms (Please use the Support Team Assessment Schedule (STAS) to indicate severity of patient's symptoms)

For advice on how to complete the STAS please contact either 01698 723278/723297 .

N.B. A **STAS score** should be entered in **EACH** of the Symptom boxes.

0 = None
1 = An occasional problem
2 = Moderate distress or disability
3 = Severe distress or disability
4 = Severe & continuous distress or disability (*unable to think of other matters*)
9 = Symptom cannot be assessed

Pain ☐ Constipation ☐ Skin Condition ☐ Dyspnoea ☐

Family Anxiety Dysphagia ☐ Urinary Problems ☐ Diarrhoea ☐

Patient Anxiety Confusion ☐ Lymphoedema ☐ Mobility ☐
Mobile = **0**
Immobile = **4**

Ascites ☐ N/Vomiting ☐ Patient Insight **0** ☐
Full Insight = **0**
No insight = **4**

Family0 Insight ☐
Full Insight = **0**
No insight = **4**

Other ☐

Current Medication: (Where possible please attach a copy of the patient's current medication sheet)

Drug / Dose / Frequency

(Continue on separate sheet if required)

To be returned to Health Centre for processing.

End of Life Care Record
Initial Assessment

Appendix 2

NHS SCOTLAND

Patient Name: **CHI:**

This record will be used to document compliance with Scottish Government guidance, 'Caring for people in the last days and hours of life' (www.scotland.gov.scot.uk/Resource/0046/00466779.pdf) and the National Palliative Care Guidelines, 'Care in the Last Days of Life' (www.palliativecareguidelines.scot.nhs.uk/guidelines/ end-of-life-care/Care-in-the-Last-Days-of-Life.aspx).

This document should:

- Be used to record all assessments/symptom management information
- Be an aid to clinical judgement, not a replacement for it
- Be available for discussion: - within the clinical team
  - and with the person concerned and/or their family

In implementing this Record of End of Life Care you should be aware that:

- People may have made their wishes clear in an Anticipatory Care Plan

Clinical Team Decision - this must involve at least two members of the clinical team

I .... (person completing form) **have undertaken an assessment and excluded potentially reversible causes of deterioration** (e.g. sepsis, acute kidney injury, opioid toxicity, hypercalcaemia of malignancy)

Some of the following may be present, supporting the prediction of a short prognosis (circle as appropriate)

Bed bound   Semi-comatose   Only able to take sips of water   no longer able to take tablets

Following this assessment a Clinical Team decision has been made to use the 'Record of End of Life Care'

I .... (person completing form) **have discussed this decision and sought the approval of the Senior Clinician responsible for the patient's care:**

Dr/Mr/Ms .... on: **Date: .... /............. /........Time: ....** :

Signature of Senior Clinician: ....Date: .... /............... /..............**Time:**.......... : ....

'Record of End of Life Care' document commenced: Date:.............. /.............. /.............. **Time:**.......... : ......

Name: (PRINT)   Signature

Discontinuation of End of Life Care Record

When the 'Record of Endo of Life Care' was discontinued: Date & Time

Reasons why the End of Life Care Plan was discontinued:

Change in prognosis shared with the patient   **Yes ☐** **No ☐**

Change in prognosis shared with the their family/next of kin/named person   **Yes ☐** **No ☐**

Comments

Diagnosis & Baseline Information

MAIN DIAGNOSIS

Co-morbidity

At the time of the assessment is the patient:

Conscious	In pain	**Yes** ☐ **No** ☐	Able to swallow	**Yes** ☐ **No** ☐
Semi-conscious	Agitated	**Yes** ☐ **No** ☐	Continent (bladder)	**Yes** ☐ **No** ☐
Unconscious	Nauseated	**Yes** ☐ **No** ☐	Catheterised	**Yes** ☐ **No** ☐
	Vomiting	**Yes** ☐ **No** ☐	Continent (bowels)	**Yes** ☐ **No** ☐
	Dyspnoeic	**Yes** ☐ **No** ☐	Constipated	**Yes** ☐ **No** ☐
Experiencing respiratory tract secretions		**Yes** ☐ **No** ☐	Confused	**Yes** ☐ **No** ☐
Experiencing other symptoms (e.g. oedema, itch)		**Yes** ☐ **No** ☐		

Communication

Goal 1.1: The patient is able to take a full and active part in communication. **Yes** ☐ **No** ☐

Consider: hearing, vision, speech, first language, learning disabilities, dementia (consider use of assessment tools), other neurological conditions and confusion

Current barriers communication ……………………………………………………………………………………………

Does the patient have:-

An advance care plan? **Yes** ☐ **No** ☐ **don't know** ☐

An advance decision to refuse treatment (ADRT)? **Yes** ☐ **No** ☐ **don't know** ☐

Does the patient have the capacity to make their own decisions on their own treatment at this moment in time? **Yes** ☐ **No** ☐

Ensure involvement of the Attorney/Guardian, if there is one and patient lacks capacity

Comment:

Goal 1.2: Where is the patients preferred place of care?

Home ☐ **Hospice** ☐ **Hospital** ☐ **Other** ☐ Please state

Goal 1.3: The named person/next of kin/family is able to take a full and active part in communication

Yes ☐ **No** ☐

Consider: Hearing, vision, speech, first language, learning disabilities, dementia , other neurological conditions and confusion

Current Barriers to communication

Goal 1.4: The patient is aware that they are dying/their condition is deteriorating? Yes ☐ **No** ☐

Comments:

Goal 1.5: The named person/next of kin/family is aware that the patient is dying **Yes** ☐ **No** ☐

Comments:

Goal 1.6 The Clinical Team have reviewed the contact information **Yes** ☐ **No** ☐

Contact name & relationship to the patient:

When to contact: At any time ☐ Not at night-time ☐ Telephone Number

Named person/next of kin - this may be different from above N/A ☐ **Power of Attorney (if applicable)** **N/A** ☐

Name Name:

Contact details: Contact details:

Facilities

Goal 2.1: A full explanation of the service/visiting times available to the named person/next of kin/family **Yes** ☐ **No** ☐

Comments

Goal 2:2 The named person/next of kin/family are aware of how to contact the team providing care: **Yes** ☐ **No** ☐

Comments

Spirituality

Goal 3.1: The patient is given the opportunity to discuss what is important to them at this time, e.g. their wishes, concerns, thoughts and feelings, faith, beliefs, values. **Yes** ☐ **No** ☐ **Un/semi-conscious** ☐

Consider music, art, poetry, reading, photographs, or something that has been important to the belief system or the well-being of the patient.

Patient may be anxious for self or others.

Consider and document any specific religious and cultural needs

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Did the patient take the opportunity to discuss the above? **Yes** ☐ **No** ☐ **Un/semi conscious** ☐
Religious tradition identified? Please specify:

Support of the spiritual care team offered? **Yes** ☐ **No** ☐
If not, why not:

Needs now:

Needs at death

Needs after death

Goal 3.2: The relative or carer is given the opportunity to discuss what is important to them at this time e.g. their wishes, thoughts and feelings, faith, beliefs, values **Yes** ☐ **No**☐

Comments

Did the named person/next of kin/family take the opportunity to discuss the above? **Yes** ☐ **No** ☐
Support of the Spiritual & Pastoral Care Team offered? **Yes** ☐ **No** ☐
If not, why not:

Medication

Goal 4.1: The patient has medication prescribed on a prn basis for all of the following 5 symptoms which may develop in the last hours or days of life

Pain ☐☐**Respiratory tract secretions** ☐ **Nausea /Vomiting** ☐ **Confusion/delirium** ☐
Restlessness/anxiety/Agitation☐☐

If medication is not prescribed, specify why not:

Current Medication assessed and non essentials discontinued **Yes** ☐ **No** ☐

Have these medication decisions been communicated to the patient **Yes** ☐ **No** ☐ ☐**Not appropriate** ☐

If not appropriate, specify why

Current Interventions

Goal 5.1: The patient's need for current interventions has been reviewed by the Clinical Team and the following interventions are in place (Please tick):

	Not Currently	Discontinued	Continued	Commenced
5.1a: Routine blood tests				
5.1b: Intravenous antibiotics				
5.1c: Blood glucose monitoring				
5.1d: Recording of routine vital signs				
5.1e: Oxygen therapy				

5.2: **The patient has a Do Not Attempt Cardiopulmonary Resuscitation Order in place (use national docs and policy)**
Yes ☐ **No** ☐ If not, why not

5.3: **Implantable Cardioverter Defibrillator (ICD) is deactivated** Yes ☐ No ☐ No **ICD in place** ☐
Contact the patient's cardiologist.

Nutrition

Goal 6: Patient's nutritional needs are reviewed by the Clinical Team
The patient should be supported to take food by mouth for as long as tolerated. A reduced need for food is part of the normal dying process

Current oral dietary intake:
Normal diet ☐ Reduced diet ☐ Minimal diet ☐ Unable to take food by mouth ☐

Normal Diet=Similar to what the patient would normally eat at all mealtimes
Reduced Diet- less than what the patient would normally eat but eating something at most mealtimes
Minimal diet- 2/3 spoonfuls of something at some mealtimes

Patient is currently receiving artificial nutrition : Yes ☐ No ☐

If yes, via:

NG ☐ PEG/PEJ ☐ NJ ☐ TPN ☐

Patient need for clinically assisted nutrition has been reviewed and is: Continued ☐ Reduced ☐ Discontinued ☐

The plan for nutritional care has been explained: to the patient (where appropriate), Yes ☐ No ☐ Not applicable ☐
The plan for nutritional care has been explained: to the relative or carer Yes ☐ No ☐

If no please comment:

Hydration

Goal 7: Patient's hydration needs are reviewed by the Clinical Team
The patient should be supported to take fluids by mouth for as long as tolerated. Symptoms of thirst may indicate a dry mouth rather than dehydration. Good mouth care is essential. Patients should be offered water and assisted to drink as frequently as is safe to.

Current oral fluid intake:
Normal fluids ☐ Reduced fluids ☐ Sip occasionally ☐☐Unable to take fluids by mouth ☐☐

Normal Fluids=Similar to what the patient would normally drink
Reduced fluids- less than what the patient would normally drink but drinks something 3-4 times a day

Patient is currently receiving assisted hydration Yes ☐No ☐

If yes, via: IV☐ SC ☐ PEG ☐ NG☐

Patient need for clinical assisted hydration has been reviewed and is:
Continued ☐ Reduced ☐ Increased ☐ Commenced ☐ Route changed ☐ Discontinued ☐
The plan for hydration has been explained: to the patient (where appropriate), Yes ☐ No ☐ Not applicable ☐
The plan for hydration has been explained: to the relative or carer Yes ☐ No ☐

If no please comment

Skin Care
Goal 8: The patient's skin integrity is assessed Yes ☐ No ☐ If not, why not The aim is to prevent pressure ulcers or further deterioration if a pressure ulcer is present. Contact the Health Centre for advice and use a recognised risk assessment tool e.g. Waterlow / Braden to support clinical judgement. The frequency of repositioning should be determined by skin inspection, assessment and the patient's individual needs. Appropriate mattress in place Yes ☐ No ☐ ☐ If no, please comment:

Explanation of the End of Life Care Plan
Goal 9.1: An appropriate level of explanation of the current plan of care is shared with the patient(where possible) Yes ☐ No ☐ Comments:
Goal 9.2: A full explanation of the current plan of care is given to the named person/next of kin/family Yes ☐ No ☐ ☐if not, why not? Name of named person/next of kin/family: Names of healthcare professionals having discussion: Record of End of Life Care Leaflet or equivalent is offered to relative or carer? (available on intranet) Accepted ☐ Declined ☐ *Information to support children is available*
Goal 9.3: The 'Coping with Dying' leaflet or equivalent is offered to the named person/next of kin/family Accepted ☐ Declined ☐ ☐Not appropriate ☐

Patient Name: **CHI:**

Individual care plan – complete following initial assessment	
Goal	**Plan of Care**
Goal 1.1, 1.3, 2.2 & 9.1 Communication with Patient including communication of deteriorating condition/dying and plan of care	
Goal 1.2, 1.4, 2.1 & 9.2,9.3 Communication with named person/next of kin/family including awareness of dying, plan of care, facilities available	
Goal 3.1 Patient discussed what is important to him	
Goal 3.2 Named person/next of kin/family discussed what is important to them	
Goal 4 Current & PRN medicines	
Goal 5.1(a-e), 5.2, 5.3 Current interventions	
Goal 6 Nutritional Needs	
Goal 7 Hydration Needs	
Goal 8 Skin Integrity	

End of Life Care Record- Ongoing Assessment

Appendix 3

NHS SCOTLAND

Patient Name: **CHI:**

Date..................			**DAY...........**				
Undertake a Clinical Team re- assessment & review of the current care plan if:							
Improved conscious level, functional ability, oral intake, mobility, able to self-care	**and / or**	Concern expressed regarding management plan from either the patient, relative or team member	**and / or**	It is **3 days** since the last **full** Clinical Team assessment			
Codes to be recorded at each assessment (assessment) must be carried out at least every 4 hours							
A= Achieved V = Variance (exception reporting)		**4 hourly**					
Record an A or a V not a signature	**Date**						
	Time						
Goal a: The patient does not have pain Verbalised by patient if conscious, pain free on movement. Observe for non-verbal cues. Consider need for positional change. Use a pain assessment tool if appropriate. Consider prn analgesia for incident pain							
Goal b: The patient is not agitated Patient does not display signs of restlessness or distress, exclude reversible causes e.g. retention of urine, opioid toxicity							
Goal c: The patient does not have respiratory tract secretions Consider positional change. Discuss symptoms & plan of care with patient, **named person/next of kin/family** Medication to be given as soon as symptom occur							
Goal d: The patient does not have nausea Verbalised by patient if conscious							
Goal e: The patient is not vomiting							
Goal f: The patient is not breathless Verbalised by patient if conscious, consider positional change. Use of a fan may be helpful Patient Receiving O_2 therapy ❑							
Goal g: The patient does not have urinary problems Use of pads, urinary catheter as required							
Goal h: The patient does not have bowel problems Monitor – constipation / diarrhoea. Monitor skin integrity **Bowels last opened**:.........................							
Goal i: The patient does not have other symptoms Record symptom here... *If no other symptoms present please record N/A*							
Goal j: The patient's comfort and safety regarding the administration of medication is maintained If Continuous subcutaneous infusion (CSCI) in place – monitoring sheet in progress S/C butterfly in place if needed for prn medication **location:**............................. The patient is only receiving medication that is beneficial at this time. *If no medication required please record N/A*							

End of Life Care Record- Ongoing Assessment

Patient Name: CHI:

Ongoing assessment of EoLCR cont'd – DATE............ DAY.........						
Codes to be recorded at each assessment (assessment) must be carried out at least every 4 hours						
A= Achieved V = Variance (exception reporting)	**4hourly**					
Record an A or a V not a signature **Date**						
Time						
Goal k: The patient receives fluids to support his individual needs The patient is supported to take oral fluids / thickened fluids for as long as tolerated. Monitor for signs of aspiration and/or distress. If symptomatically dehydrated and not deemed futile, consider clinically assisted (artificial) hydration if in the patient's best interest. If in place monitor & review rate/volume. Explain the plan of care with the patient and relative or carer.						
Goal k*Additional Support with fluid needs *In cases where the patient has clinically assisted hydration in place e.g. discharged from hospital with this, monitor and review the rate and volume*						
Goal l: The patient's mouth is moist and clean Mouth care tray at the bedside						
Goal m: The patient's skin integrity is maintained Assessment, cleansing, positioning, use of special aids (mattress / bed). The frequency of repositioning should be determined by skin inspection and the patient's individual needs. ***Waterlow** score:…………………*						
***Goal m*Additional Delivery of Skin Care** (if patient requires skin care more frequently than every 4 hours, please record additional time in this line)*	Time:	Time:	Time:	Time:	Time:	Time:
Goal n: The patient's personal hygiene needs are met Skin care, wash, eye care, change of clothing according to individual needs.						
Goal o: The patient receives their care in a physical environment adjusted to support their individual needs Well fitting curtains, screens, clean environment, silence, music, light, dark, pictures, photographs						
Goal p: The patient's psychological well-being is maintained Staff just being at the bedside can be a sign of support and caring. Respectful verbal and non-verbal communication, use of listening skills, information and explanation of care given. Use of touch if appropriate. Spiritual/religious/cultural needs – consider support of the Spiritual and Pastoral Care Team						
Goal q: The well-being of the named person/next of kin/family attending the patient is maintained Just being at the bedside can be a sign of support and caring. Consider spiritual/religious/cultural needs, expressions may be unfamiliar to the healthcare professional but normal for the named person/next of kin/family – support of chaplaincy team may be helpful. Listen and respond to worries/fears. Age appropriate advice and information to support children/adolescents available to parents or carers. Allow the opportunity to reminisce.						
Signature of the person making the assessment						
Signature of the registered nurse per shift						

End of Life Care Record- Ongoing Assessment
Patient Name: CHI:

In the event of assessments not being undertaken, the rationale for this must be recorded below:

Variance analysis sheet for Ongoing Assessment of the End of Life Care Record		
What variance occurred & why? (What was the issue?)	**Action taken (What did you do?)**	**Outcome (Did this solve the issue?)**
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:

Variance analysis sheet for Ongoing Assessment of the End of Life Care Record

End of Life Care Record- Ongoing Assessment
Patient Name: CHI:

What variance occurred & why? (What was the issue?)	Action taken (What did you do?)	Outcome (Did this solve the issue?)
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:
Goal: Name: Signature: Date / Time:	Name: Signature: Date / Time:	Name: Signature: Date / Time:

End of Life Care Record- Reassessment
(72 Hours after starting EoLCR initial Assessment)

Appendix 4

Patient Name: CHI:

Date of Re-assessment		Time of Re-assessment	

Current Clinical Presentation

At the time of the re-assessment is the patient:

Conscious		In pain	**Yes No**		Able to swallow	**Yes No**
Semi-conscious		Agitated	**Yes No**		Continent (bladder)	**Yes No**
Unconscious		Nauseated	**Yes No**		Catheterised	**Yes No**
		Vomiting	**Yes No**		Continent (bowels)	**Yes No**
		Dyspnoeic	**Yes No**		Constipated	**Yes No**
Experiencing respiratory tract secretions			**Yes No**		Confused	**Yes No**
Experiencing other symptoms (e.g. oedema, itch)			**Yes No**			

Communication

Goal 1.1: The patient is able to take a full and active part in communication.
Yes ☐ No ☐ If not, why not?..

Goal 1.2: The named person/next of kin/family is able to take a full and active part in communication
Yes ☐ No ☐ If not, why not? ....

Goal 1.3: The patient is aware that they are dying/their condition is deteriorating? **Yes** ☐ **No** ☐
Comments:

Goal 1.4: The named person/next of kin/family is aware that the patient is dying/condition deteriorating **Yes** ☐ **No** ☐
Comments:

Goal 2: The named person/next of kin/family is aware of how to contact the team providing the care? **Yes** ☐ **No** ☐

Spirituality

Goal 3: The patient and/or named person/next of kin/family is given the opportunity to discuss their ongoing support needs at this time. (refer to Carer Engagement Facilitator) Yes ☐ **No**☐

Comments..
....
....

Did the patient and/or named person/next of kin/family take the opportunity to discuss the above? **Yes** ☐ **No** ☐

Support of the Spiritual & Pastoral Care Team offered? **Yes** ☐ **No** ☐
If not, why not:

Medication

Goal 4: Current medication assessed and decisions communicated to the patient and family **Yes** ☐ **No** ☐
Comments:

Current Interventions

Goal 5: The patient's need for current interventions has been reviewed by the Clinical Team **Yes** ☐ **No** ☐

the following interventions are in place (Please tick):

	Not currently	**Discontinued**	**Continued**	**Commenced**
5.1a: Routine blood tests				
5.1b: Intravenous antibiotics				
5.1c: Blood glucose monitoring				
5.1d: Recording of routine vital signs				
5.1e: Oxygen therapy				

Nutrition

Goal 6: Patients Nutritional needs have been reviewed by the Clinical Team Yes ☐ No ☐

Currently the patient is:
Normal diet ☐ Reduced diet ☐ Minimal diet ☐ No food by mouth ☐

Reduced Diet- less than what the patient would normally eat but eating something at most mealtimes

Minimal diet- 2/3 spoonfuls of something at some mealtimes

Patient is currently receiving assistedl nutrition : Yes ☐No ☐

If yes, via:

NG ☐ PEG/PEJ ☐ NJ ☐ TPN ☐

Patient need for clinical assisted nutrition has been reviewed and is:
Continued ☐ Reduced ☐ Discontinued ☐

Any changes in nutritional care has been explained:
to the patient (where appropriate) Yes ☐ No ☐
to the named person/next of kin/family Yes ☐ No ☐

If not why not
…….……………………….

Hydration

Goal 7: Patient's hydration needs have been reviewed by the Clinical Team Yes ☐ No ☐
Patient is currently taking:
Reduced fluids ☐ Sip occasionally ☐ Unable to take fluids by mouth ☐

Reduced fluids- less than what the patient would normally drink but drinks something 3-4 times a day

Patient is currently receiving assisted hydration: Yes ☐No ☐

If yes, via:

IV ☐ SC ☐ PEG ☐ NGT ☐

Patients ongoing need for clinical assisted hydration has been reviewed and is:
Continued ☐ Reduced ☐ Increased ☐ Discontinued ☐ Commenced ☐ Route changed ☐
Any changes in hydration has been explained:
to the patients (where appropriate) Yes ☐ No ☐
to the relative or carer Yes ☐ No ☐

If not why not:

Skin Care

Goal 8: The patient's skin integrity is re- assessed **Yes** ☐ **No** ☐
Any changes in care required are documented in the MDT notes

Explanation of End of Life Care Plan

Goal 9.1: A full explanation of the current plan of end of life care is shared with the patient (where possible) and the named person/next of kin/family
Patient Yes ☐ No ☐
Named person/next of kin/family Yes ☐ No ☐

If not why not:

Changes to the Care Plan following reassessment

Please note any changes to the Care Plan following reassessment below by reference to Goals above:
(e.g. Goal 5 – discontinue IV hydration)

Name of person undertaking this re-assessment:

Signature: Date: Time:

Where possible this re-assessment should be discussed with the Senior Clinician responsible for the patients care. They should sign this form shortly thereafter.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)

Name:	Previous discussions may be recorded in the Key Information Summary (KIS); *this should always be checked.*
CHI/DoB:	
Address:	
.... Postcode:	

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) are intended. This decision applies *only to CPR treatment*. All other appropriate treatment and care will be given (2222 or 999 calls may still be appropriate when immediate medical help is needed in an unexpected emergency).

Select reason for DNACPR decision: (please choose only A or B). Within Section A or B select the relevant communication or decision-making strategy by ticking the appropriate option

A ☐ **CPR will not be successful and is not a treatment option for this patient**

Explain why: ....

The patient is aware of this decision.

Yes ☐ Conversation date and where documented ....

No ☐ Reason (e.g. lack of capacity, judgement of harm to patient)..

....

The welfare attorney/guardian and/or relevant other is aware of the decision.

Yes ☐ Name(s) ....Date...

No ☐ Reason (e.g. reasonable efforts to contact unsuccessful so far)..

....

The presumption is that the patient, and those close to the patient who lacks capacity, will be aware of the DNACPR decision – see Decision-making Framework for valid exceptions. Where the conversation has not yet happened, the full explanation and a clear plan to revisit this must be documented in the clinical notes.

B ☐ **CPR could be successful but the likely outcome would not be of overall benefit to the patient.** (The patient's informed views and wishes are of paramount importance.) **One of the following boxes must be ticked:**

The patient **has capacity** for the decision

☐ and does not wish CPR to be attempted.

☐ and does not wish to discuss CPR decisions at the moment. Decision has been made by clinical team in discussion with relevant others (name below) where confidentiality allows.

Name(s): ....

Explain: ....

(A clear plan to revisit this must be documented in clinical notes).

The patient **does not have capacity** for this decision

☐ but has a valid advance healthcare directive applicable to the current circumstances.

☐ but has a legally appointed welfare guardian/attorney (Name: ....) who agrees that CPR would not be of overall benefit for the patient.

☐ and no legal welfare guardian/attorney can be identified. Decision has been made by clinical team in discussion with relevant others: (Name(s): ....)
Explain: ....

Document capacity assessment and all discussions clearly in clinical notes.

NAMES OF MULTIDISCIPLINARY TEAM MEMBERS INVOLVED IN THE DECISION			
Healthcare Professional recording this DNACPR decision		**Responsible Senior Clinician** *(Dr or Nurse)*	
Print:		**Print:**	
Sign:	**Date:**	**Sign:**	**Date:**

This original DNACPR Form should follow the patient (e.g. on admission to, discharge from or transfer between hospitals) with the agreement of the patient and/or relevant others where appropriate.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

Review of decision:

☐ Review not needed as decision will remain clinically appropriate until end of life.

☐ Review needed on clinically appropriate basis.

Review Date	Responsible Clinician (print & sign)	Outcome of DNACPR review (circle review decision)		Plan for next review
		still applicable	reversed	
		still applicable	reversed	
		still applicable	reversed	
		still applicable	reversed	

NB. Good practice guidance recommends review of the decision on transfer of clinical responsibility (e.g. hospital to community) ***for all patients***.

Reversal of a DNACPR order should be recorded on the form which should be scored through with a permanent marker **and** the word "reversed" written clearly across both sides of the form which should then be filed in the back of the clinical notes.

Communication with healthcare professionals and social carers – who has been informed of the DNACPR decision?

	Not Applicable	Names	Date informed	By whom
General Practitioner				
Community Nursing Team				
Ward Team				
Care Provider				
Other				

Communication with Ambulance Crew

All other types of supportive care should be given as appropriate as with any other patient where there is a deterioration in clinical condition. If, whilst in transit, the patient's condition suddenly deteriorates such that death occurs or is imminent, please contact:

Name and tel no: .... and take the patient to:

....

Signed: .... Name: .... Date: ....

GP name/address: ....

.... Postcode: …………....……...

Where it has not been possible to have a discussion to allow the DNACPR Form to be at home with the patient (because the conversation would cause harm) it should not be given to the ambulance crew but should be shown to them prior to the journey. The information that the Form is not going home with the patient, and the reason why, **must be communicated to the GP so that the KIS can be updated**.

End of Life Care and Death of a Patient Policy
Cultural and Religious Issues

Appendix 6

NHS SCOTLAND

Respect for the needs of a patient who has died should be observed in relation to faith/ culture. However, advice should be sought from the police prior to touching the body.

N.B. These are guidelines. Individual preferences / family requests should be respected.

Faith	Regarding the body	Post Mortem	Burial / Cremation	Organ Donation
BADHA'I	No special requirements.	Permitted	Burial only	Acceptable
BUDDHIST	Notify Priest. Do not move the body until prayers said. Priest may not attend; prayers may be said from a distance.	Permitted	According to patient / family wishes	Not usually agreed
CHRISTIAN	Some require prayers to be said with the deceased at or soon after death.	Permitted	Either	Acceptable
MORMONS	Special undergarment remains on body for burial. Family clothe body for funeral.	Permitted	Usually burial but cremation allowed	Personal choice
HINDU	Place head to the North, arms at side, face upwards, eyes closed, cover with a white cloth.	Permitted	Cremation but body taken home first	Not acceptable
JEHOVAH'S WITNESS	No special requirements.	Permitted	Either	Personal decision
JEWISH	Orthodox: Contact the family for instructions wherever possible. Avoid touching the body. If necessary to do, it should be by a person of the same sex wearing gloves to avoid personal contact. All: feet toward the doorway, jaw tied, eyes closed, arms straight by sides, fingers straight. Cover with a plain sheet.	Only permitted when required by civil law	Burial only, within 24 hrs. Funeral preparations cannot be made during Shabbat, sundown Friday until nightfall Saturday	No
MUSLIM	Contact the family for instructions wherever possible. Any contact should be by person of the same sex. Turn head to right, face South East (Mecca / Makka). Cover with plain sheet. The family will wish to carry out the rituals. People of the opposite sex other than family should not touch Muslim mourners.	Only permitted when required by civil law	Burial only, within 24hrs.	No
SIKH	Eyes and mouth closed, arms straightened at sides, cover hair, do not trim hair or beard, do not remove any of the five. Refer to ethnic minority handbook in the ward.	Only permitted when required by civil law	Cremation	Not usual but personal choice

Appendix 7

NHS SCOTLAND

Sudden / Unexpected or Expected Death During Normal Working Hours (Monday to Friday 0900-1700)

The Nurse in charge of the Ward will:

- Secure the area, until advised by the police that this safeguarding is not required.
- Inform the Control Room via the emergency number 2222 that there has been a sudden or unexpected death in the ward.
- Ensure that access and egress is controlled, and log who enters and leaves the area, at what time and the purpose of their visit.

When the apparent death is confirmed by a doctor and the police have given permission, the nurse in charge of the ward will then:

- Arrange for a doctor to issue a death certificate
- Inform other patients in the ward of the death.
- Inform the other patients in the ward of the death

The control room operator will:

- Commence a log of the events
- Contact duty SHO, Senior Clinical Cover who **will attend immediately.**
- Inform the duty Security Manager **who will attend immediately.**

The Duty Security Manager will:

- Arrange access and egress for any transport required
- Contact the police and request them to attend.

The Duty SHO will:

- Assume medical charge of the situation, confirming death, and issuing death certificate unless the police determine otherwise.

Senior Clinical Cover will:

- Assume operational management of the situation.
- Advise named person/next of kin/family
- Inform the patient's RMO & Duty RMO
- Inform the patient's Lead Nurse if they are not already on duty in the hub
- Inform the Social Work Team Leader
- Inform the Person Centred Improvement Lead, who will inform the Person Centred Improvement Advisor, Spiritual and Pastoral Care Team and the Patients Advocacy Service Manager.

The Patient's RMO will:

- Write to the Mental Welfare Commission following the death of the patient.
- Inform the Procurator Fiscal following the death of a patient.

The Chief Executive or Deputy will:

- Inform the nominated person at The Scottish Executive in the event of the death of a Restricted Patient.

Once the police arrive at the scene, they will assume control of the situation. They may require the body to be viewed by the police surgeon, and have a photographer attend. They will determine when the body can be released (or removed to a mortuary for further investigation) and the secured area brought back into normal use. The police will require witness statements from those who they determine will assist their investigation.

Any request for viewings by family members will be in consultation with the funeral director.

NHS SCOTLAND

Appendix 8

Sudden / Unexpected or Expected Death Out With Normal Working Hours (1700 Friday – 0900 Monday)

The Nurse in Charge of Ward will:
- Secure the area, until advised by the police that this safeguarding is no longer required.
- Inform the Control Room via the emergency number 2222 that there has been a sudden or unexpected death in the ward.
- Ensure that access and egress is controlled, and log who enters and leaves the area, at what time and the purpose of their visit.

When the apparent death is confirmed by a doctor and the police have given permission
- Arrange for the duty SHO to issue a death certificate
- Advise named person/ relative /next of kin
- Inform the other patients in the ward of the death

The Control Room Operator will:
- Commence a log
- Contact the duty Security Manager or Senior Clinical cover **who will attend**
- Contact the on call SHO **who will attend**
- Inform the duty RMO

The Duty Security Manager will:
- Arrange access and egress for any transport required
- Contact the police and request them to attend, advising that the on call SHO will be attending to confirm death.

Senior Clinical Cover will:
- Assume operational management of the situation.
- Advise named person/next of kin/family
- Inform the Director of Nursing & AHPs who will in turn inform the SMT
- Inform the patient's RMO & Lead Nurse
- Inform the Person Centred Improvement Lead (by email), who will inform the Person Centred Improvement Advisor, Spiritual and Pastoral Care Team and the Patients Advocacy Service Manager.

The On Call SHO will:
- Assume medical charge of the situation, confirm the death, and issue the death certificate, unless the police determine otherwise.

The Patient's RMO will:
- Write to the Mental Welfare Commission following the death of the patient.
- Inform the Procurator Fiscal following the death of a patient.

The Chief Executive or Deputy will:
- Inform the nominated person at The Scottish Executive the next working day in the event of the death of a Restricted Patient.

Once the police arrive at the scene, they will assume control of the situation. They may require the body to be viewed by the police surgeon, and have a photographer attend. They will determine when the body can be released (or removed to a mortuary for further investigation) and the secured area brought back into normal use. The police will require witness statements from those who they determine will assist their investigation.

Any request for viewings by family members will be in consultation with the funeral director

Sudden / Unexpected or Expected Death Out With The State Hospital at all times

Appendix 9

NHS SCOTLAND

The Nurse in charge of the patient will:

- Secure the area, until advised that this is no longer required by the police. Ensure that access and egress is controlled, and log of who enters and leaves the area, at what time and the purpose of their visit
- Inform the control room immediately

When the apparent death is confirmed by a doctor and the police have given permission

- Arrange for a doctor to issue death certificate; after doctor has done so, contact undertaker to arrange removal of body
- Inform named person/ relatives/next of Kin when advised by the Police
- Inform the other patients in the ward of the death

The Control Room Operator will:

- Commence a log of events
- Inform Senior Cover **who will attend**
- Inform duty security manager
- Inform on call Duty RMO & the Patients RMO

The Duty Security Manager will:

- Arrange for any transport required
- Contact the police and requests them to attend

Senior Clinical Cover will:

- Assume operational management of the situation.
- Inform the Director of Nursing and AHPs who will in turn inform the Chief Executive Inform the patient's RMO
- Inform the patient's Lead Nurse (if they are not already on duty in the hub)
- Inform the Spiritual and Pastoral Care Team via the Person Centred Improvement Lead, who will inform the Person Centred Improvement Advisor and the Patients Advocacy Service Manager.
- Inform the Senior Management Team

The Patient's RMO will:

- Write to the Mental Welfare Commission following the death of the patient.
- Inform the Procurator Fiscal following the death of a patient.

The Chief Executive or Deputy will:

- Inform the nominated person at The Scottish Executive the next working day in the event of the death of a Restricted Patient.

Once the police arrive at the scene, they will assume control of the situation. They may require the body to be viewed by the police surgeon, and have a photographer attend. They will determine when the body can be released (or removed to a mortuary for further investigation) and the secured area brought back into normal use. The police will require witness statements from those who they determine will assist their investigation.

End of Life Care Record -Care after Death

Appendix 10

NHS SCOTLAND

Patient Name: CHI:

Record and Communication of Death

Date & Time of Death……………………………………………………………………………….

Persons present at the time of death………………………………………………

If not present, has the named person/ next of kin/family been contacted **Yes** ☐ **No** ☐

Name of person informed……………………… Relationship to patient………………………………

Signature of Healthcare professional recording death………………………………………………………………

Certification of Death

Cause of death…

1 (a)

(b)

(c)

2.

Name of Certifying Doctor:

Name:…………………………………………………………………………… (please print) Signature:……………………………………………

Is the Procurator Fiscal likely to be involved: **Yes** ☐ **No** ☐

Patient Care & Dignity

Goal 10:

The patient is treated with respect and dignity whilst last offices are undertaken **Yes** ☐ **No** ☐

Universal precautions and local policy and procedures including infection risk adhered to **Yes** ☐ **No** ☐

Spiritual, religious, cultural rituals / needs met **Yes** ☐ **No** ☐

The management of ICD's, where appropriate is managed as per appendix 13 **Yes** ☐ **No** ☐

Patient's valuables and belongings managed as per appendix 11 **Yes** ☐ **No** ☐

Completed by …………………………………. Date…………………

Relative or Carer Information

Goal 11: The relative or carer can express an understanding of what they will need to do next and are given relevant written information *Conversation with relative or carer explaining the next steps* **Yes** ☐ **No** ☐

'Bereavement Support Information' leaflet offered **Accepted** ☐ **Declined** ☐

'What to Do After a Death in Scotland' leaflet or equivalent is offered **Accepted** ☐ **Declined** ☐

Information given as to when the death certificate and patient's valuables and belongings will be made available, where appropriate.

Yes ☐ **No** ☐ **Not applicable** ☐

Discuss as appropriate: viewing the body / the need for a post mortem / the need for removal of cardiac devices / the need for a discussion with the procurator fiscal. **Yes** ☐ **No** ☐

Information given to families on child bereavement services where appropriate. **Yes** ☐ **No** ☐

Do you deem the relative/ carer to be exceptionally vulnerable or at risk at this time? **Yes** ☐ **No** ☐

If the answer to this question is yes, inform the Person Centred Involvement Lead as soon as possible. **Yes** ☐ **No** ☐

Signature Date

Organisation Information

Goal 12.1 : The Health Centre is notified of the patient's death **Yes** ☐ **No** ☐

Signature Date.

Goal 12.2 : The patient's death is communicated to appropriate services

Med Secretaries/Mac Nurses/ palliative care team / district nursing team are informed of the death via the Health Centre **Yes** ☐ **No** ☐

The patient's death is entered on Vision by the Health Centre

The patient's death is documented by nursing staff on Rio **Yes** ☐ **No** ☐

Comments:

Completed by Date

Procedures for Dealing with Patients Finances & Property following their Death

NHS SCOTLAND

1. INTRODUCTION

This procedure describes the processes required to be undertaken in the event of the death of a State Hospital patient. The procedure has been developed to provide guidance and instruction to staff on what to do in relation to funeral arrangements, patient's finances and property in the event of a death of a patient.

The procedure has been developed to ensure that consistent processes are followed.

2. SCOPE

When a patient dies in hospital, special arrangements need to be made for the return/disposal of their property and, in some cases, for meeting funeral costs.

The hospital has two lairs - one at Avenue Road, Carstairs Cemetery and one at Springbank Cemetery, Lanark. These are only to be used in exceptional circumstances.

The following outlines:

- the general responsibilities of the hospital with regard to the property of a patient who dies in hospital
- the rules which apply when there is a valid will
- action to be taken where no valid will exists

It also outlines where, in a variety of circumstances, responsibility lies for arranging and paying for funerals.

3. PATIENTS PROPERTY & FINANCES

Money and personal belongings held on the patient's behalf, or in the patient's possession at the time of death, must be kept securely until the person(s) entitled to administer the estate indicates what should be done with them.

Releasing property before confirmation of the estate is provided

If property is released before the "Confirmation of the Estate" has been inspected, difficulty may subsequently be experienced in accounting for it to the legal representative.

However, in some cases property may be released to the person who appears to be bona fide entitled to it without insisting upon the production of legal proof of the title, where the value of the property does not exceed £5,000 and where it is not intended to obtain a "Confirmation of Estate".

More specific guidance follows on the procedures to be followed in cases where there is a will and where there is not.

Disposal of clothing and small value items

It is customary to dispose of personal clothing, which is not claimed by relatives immediately after death, and to dispose of any other belongings of little value, which are not claimed, after a period of one year.

4. PROCEDURES

WHERE THERE IS A WILL AND PATIENT DOES/DOES NOT HAVE ANY NEXT OF KIN

Funeral arrangements

It is the Executor's responsibility to arrange and pay for the funeral of the patient.

In some cases, the hospital may meet the cost of transporting the deceased from the State Hospital to the patient's home area, if it is not deemed possible for the next of kin to meet this additional cost when making local arrangements.

Disposal of property (including cash)

Responsibility for the estate of the deceased patient lies with the Executor named in the last will immediately upon the patient's death. It is possible that the validity of the will may be contested or that the Executor may renounce the appointment before legal proof of the will has been obtained. Because of this, the production of "Confirmation of Estate" document is considered necessary where the value of the property exceeds £5,000.

If the value of property does not exceed £5,000 the property can be released to the person named as the Executor and a "Form of Receipt from Executor named in Confirmation" received. (See form A)

"Confirmation of Estate" is a legal document from the court giving the Executor authority to receive any money or property that belonged to the deceased patient and to administer and distribute it according to law. An application must be lodged with the sheriff court. When applying for confirmation, the Executor must provide a list of all the deceased's property at the time of death. The list is called an inventory and is to include money, houses, land and shares.

Confirmation is possible only if the inventory includes at least one item of money or other property in Scotland.

There are two types of confirmation, for small estates and for large estates. A "small estate" is an estate where the total value of the deceased's money and property is less than £36,000. A "large estate" is an estate where the total value is over £36,000.

Ward Responsibilities:

- The ward will retain all belongings until further advised.

Finance Department Responsibilities:

- Hold details of the Executor and/or Financial Guardian in the Patients Funds system.
- Request list of patient's property from the ward.
- Contact Executor and/or Financial Guardian for them to provide a "Confirmation of Estate" document.
- Upon receipt of "Confirmation of Estate", Finance will issue a cheque for the balance of the patient's funds to the Executor and complete details in "Form of Receipt from Executor named in Confirmation". They will keep the signed Form of Receipt.

Clinical Team responsibilities:

- Finance will contact the ward when "Confirmation of Estate" is received and advise them that patient's property can be given to Executor named in the confirmation.
- The Clinical Team will contact the Executor to arrange for the property to be handed over.
- The "Form of Receipt from Executor named in Confirmation" is to be signed when handing over the patient's property to Executor and returned to Finance.

WHERE THERE IS NO WILL AND PATIENT HAS NO NEXT OF KIN

Funeral arrangements

The following procedure applies to patients who die without surviving relatives.

It is the hospital's responsibility to arrange a basic funeral for the patient. The Crown Office will then reimburse the hospital for the cost of the funeral, provided that the patient has sufficient funds in his estate to cover the cost of the funeral.

Clinical Team Responsibilities:

- The Clinical Team will liaise with the Patient Welfare Officer in Finance with regards to the type of basic funeral required. Finance will then obtain 3 quotes from local undertakers and sent to the Finance Director for authorisation.
- The Clinical Team will be responsible for arranging the basic funeral after the quote has been approved by Finance Director.

Finance Responsibilities:

- The Patient Welfare Officer will contact the Finance Director to obtain approval of quote and inform the Clinical Team of the selected undertaker.
- If the patient has **insufficient** funds to cover the cost of the funeral, Finance will pay the invoice from the Funeral Directors (once authorised by the Finance Director) and reclaim costs from the Crown Office by issuing an invoice addressed for the attention of the QLTR Department, Crown Office, 25 Chambers Street, Edinburgh EH1 1LA, attaching a copy of the invoice from the Funeral Directors.
- If the patient has **sufficient** funds, Finance will pay the invoice from the Funeral Directors (once authorised by the Finance Director) and deduct this amount from the patient private funds

Please note that the same applies if there is no will and there is a next of kin as they may not wish to pay or are unable to afford to pay this ensures that the undertaker is paid promptly.

Disposal of property (including cash)

All property including cash, bank books, insurance policies, watches, jewellery, clothing etc, and all other documents which the patient had in his possession in the hospital should as soon as practicable after his/her death, be collected together, identified as being his belongings and kept in safe custody until disposal in accordance with the advice given below.

If the patient was of Scottish domicile and is not survived by any next of kin, however remote, any estate which belongs to him at the time of death passes to the Crown as ultimus haeres and is dealt with by the QLTR Dept, Crown Office, 25 Chambers Street, Edinburgh EH1 1LA.
If the patient was not of Scottish domicile and is not survived by any known next of kin, the law governing their succession to his estate will vary according to the law of country of domicile.

Such a case should however be reported in the first instance to the Crown Office for investigation.

In both the foregoing instances all property and documents which the patient had in his possession in the hospital should be retained by the hospital until instructions are received from the Crown Office as to their disposal.

Ward Responsibilities:

- The ward will retain all belongings until further advised by Finance.

Finance Responsibilities:

- Finance will ascertain from the Ward, details of all property held.

- Finance will check whether the patient had external bank accounts and if so, inform the bank of the death of the patient.
- Finance will retain cash until instructions are received from the Crown Office.
- Property held and any monies held are to be notified to the Crown Office. These particulars, including the last known address of the patient dying in these circumstances, should be reported promptly to the QLTR Department, Crown Office, 25 Chambers Street, Edinburgh EH1 1LA each case being reported separately.

WHERE THERE IS NO WILL BUT NEXT OF KIN IDENTIFIED

Funeral arrangements

The hospital has a duty to arrange and pay for a basic funeral for patients whose relatives cannot afford to pay for the funeral and do not qualify for social fund funeral payments from the Department for Work & Pensions.

If the relatives are unwilling to arrange and pay for the funeral, then the hospital is responsible for arranging and paying for a basic funeral.

However, the expenses of the funeral can be defrayed by any funds held by the hospital on behalf of the patient.

Clinical Team Responsibilities:
The Clinical Team will ascertain whether the relatives will arrange and pay for the patient's funeral.

- Where the relatives are arranging and paying for the funeral no further action required.

- Where the relatives cannot afford to pay for the funeral or do not qualify for social fund payments, the Clinical Team will liaise with the Patient Welfare Officer in Finance with regards to the type of basic funeral required. Finance will then obtain 3 quotes from local undertakers and sent to the Finance Director for authorisation.
- The Clinical Team will be responsible for arranging the basic funeral after the quote has been approved by Finance Director.

Where the relatives are unwilling to pay for the funeral, the Clinical Team will liaise with the Patient Welfare Officer in Finance with regards to the type of basic funeral required. Finance will then obtain 3 quotes from local undertakers and sent to the Finance Director for authorisation.

Finance Responsibilities:
- Finance will check whether patient had external bank accounts and if so, inform the bank of the death of the patient.
- Finance will pay invoice (after authorisation from Finance Director) to Funeral Director, only where the relatives cannot afford to pay or are unwilling to pay (see above).
- If the patient has sufficient funds in his/her patients funds account, arrangements will be made to reimburse the Exchequer account for expense incurred.

Disposal of property (including cash)

All property including cash, bank books, insurance policies, watches, jewellery, clothing etc, and all other documents which the patient had in his possession in the hospital should as soon as practicable after his death, be collected together, identified as being his belongings and kept in safe custody until disposal in accordance with the advice given below.

Despite the fact that the next of kin are identified, the position in law is that those items of the estate in the possession of the hospital should only be handed over to the Executor or Executors named in the document known as the "Confirmation of the Estate". The Executor may be the next of kin but need not necessarily be so. Where the total amount of the deceased's estate is less

than £36,000 this is deemed to be regarded as a Small Estate and there is provision for the Confirmation document to be obtained by an expedited procedure, but nevertheless a Confirmation should still be obtained. If the total amount of the deceased's estate is more than £36,000 the next of kin should seek legal advice.

A Confirmation of Estate document can be obtained by the Executor or the next of kin from any Sheriff Clerk's Office. There is no fee payable to the Sheriff Clerk if the value of the estate is less than £50,000 other than the cost of the Certificate of Confirmation which is currently £7. A fee is payable only if the value of the estate is more than £50,000 (£50,001 - £250,000 fee is currently £250; exceeding £250,000 fee is £500).

If the next of kin is not the spouse, a Bond of Caution will be required before Confirmation is issued. (This is an insurance against someone applying for Confirmation when they are not entitled to do so or an Executor failing to distribute the estate according to law).

After applying for confirmation at the Sheriff Clerk's Office, the next of kin takes the form to an insurance company to obtain a Bond. The insurance company will charge a fee for this (cost starts from £150 and is dependent on value of the estate).

If the value of the estate is less than £5,000, then the next of kin may not wish to obtain a Certificate of Confirmation due to the cost of obtaining the Bond of Caution.

Ward Responsibilities:

- Ward will retain all belongings until further advised by Finance.

Finance Responsibilities:

- Finance will contact Medical Records to obtain name and address of next of kin.
- Finance will be responsible for informing the next of kin or Executor to obtain a "Confirmation of Estate". The next of kin may decide not to obtain a "Confirmation of Estate" because the value of the estate is too small.
- Where a Confirmation of Estate is received, Finance will check whether the patient has any funds and issue a cheque for the balance of the patients account to the named person on the Confirmation of Estate document.
- Finance will then complete the "Form of Receipt & Indemnity from Next of Kin" as shown at form B or "Form of Receipt from Executor named in Confirmation" as shown at Form A
- Finance will contact the Clinical Team to arrange for the property to be handed over to next of kin or Executor.
- Staff are strongly advised to ensure that all the items handed over are listed on the receipt.
- If there is no Confirmation of Estate document, the hospital should send a Form of Indemnity from Next of Kin shown as Form C.
- Upon receipt of the form, finance will prepare cheque for balance of patient's funds and detail on the form. Form of Receipt and Indemnity from Next of Kin shown as Appendix B2 which will then be sent to the next of kin.
- After the death of the patient, the hospital should not make any payments to anyone out of the estate funds but should when handing over the items of the estate to the Executor or next of kin, provide him/her with known details of any sums owing and the names and addresses of the creditors.

WHERE THERE IS NO WILL AND OTHER BENEFICIARIES HAVE BEEN IDENTIFIED

The same guidance as above applies, except that for "next of kin" read "beneficiaries".

Where there is no Confirmation of Estate document, any signed Receipt should be in the form shown as Appendix C.

REFERENCE INFORMATION

- NHS Circular GEN(1992)33
- NHS Circular GEN(1993)8
- HFMA Patients Monies and Belongings
- Scottish Courts Service – a guide for Executors seeking Confirmation

Form A

THE STATE HOSPITAL

FORM OF RECEIPT FROM EXECUTOR NAMED IN CONFIRMATION

I * ____________________________ of ______________________________________
_______________________________ (address), being an Executor named in the Confirmation of the Estate of the late

____

of (date) _____________ which Confirmation has been exhibited to The State Hospital, acknowledge having received from The State Hospital the following items of property which belonged to the late __________________________________ being all his property in the custody of The State Hospital.

1. Cash to the value of £ ____________________________ (if none insert "NIL")
2. ____
3. ____

Signature of recipient _____________________________
Date ____

Signature of witness ______________________________

Name ____
Designation ____________________________________
Address _______________________________________
____

Signature of witness _____________________________

Name ____
Designation ____________________________________
Address _______________________________________
____

*** PLEASE COMPLETE THIS FORM IN BLOCK LETTERS**

Form B

THE STATE HOSPITAL

FORM OF RECEIPT AND INDEMNITY FROM NEXT OF KIN

I* _________________________ of ____

_____________________________ (address), being __________________________

(relationship) of the late ____________________________________ who died in The State Hospital on ________________ (a) acknowledge that a decision has been taken that no Confirmation of the estate is to be obtained and (b) acknowledge having received from The State Hospital the following items of property which belonged to the late

_________________________________ .

1. Cash to the value of £ ____________________________ (if none insert "NIL)
2. ____
3. ____

I also acknowledge that in receiving the said items I am responsible for relieving The State Hospital of all claims in respect of the said items at the instance of creditors and any other persons having an interest in the estate of the late_____________________, and hereby undertake to relieve The State Hospital of such liability.

Signature of recipient ________________________
Date _____________________________________

Signature of witness _________________________

Name _____________________________________
Designation ________________________________
Address ___________________________________
____

Signature of witness _________________________

Name _____________________________________
Designation ________________________________
Address ___________________________________
____

*** PLEASE COMPLETE THIS FORM IN BLOCK LETTERS**

Form C

THE STATE HOSPITAL

FORM OF INDEMNITY
FROM NEXT OF KIN

I* __________________________ of ____
______________________________ (address), being __________________________
(relationship) of the late ___________________________________ who died in The State Hospital on ________________ acknowledge that a decision has been taken that no Confirmation of the estate is to be obtained and that I am the next of kin and I am entitled to the following items of property held by The State Hospital which belonged to the late
__________________________________ .

1. Cash to the value of £ ____________________________ (if none insert "NIL)
2. ____
3. ____

Signature of next of kin ________________________
Date _____________________________________

Signature of witness _________________________

Name _____________________________________
Designation _______________________________
Address ___________________________________
____

Signature of witness _________________________

Name _____________________________________
Designation _______________________________
Address ___________________________________
____

*** PLEASE COMPLETE THIS FORM IN BLOCK LETTERS**

Form D

THE STATE HOSPITAL

FORM OF RECEIPT AND INDEMNITY FROM BENEFICIARIES

I * ______________________________ of __________________________________
________________________________(address) being a principal beneficiary of the estate of the late ____
who died in The State Hospital on ______________ (a) acknowledge that a decision has been taken that no Confirmation of the estate is to be obtained and (b) acknowledge having received from The State Hospital the following items of property which belonged to the late
_____________________.

1. Cash to the value of £ __________________________ (if none insert "NIL")
2. ____
3. ____

I also acknowledge that in receiving the said items I am responsible for relieving The State Hospital of all claims in respect of the said items at the instance of creditors and any other persons having an interest in the estate of the late ____________________, and hereby undertake to relieve The State Hospital of such liability.

Signature of recipient _______________________
Date ____________________________________

Signature of witness ________________________
Name ____________________________________
Designation _______________________________
Address __________________________________
____

Signature of witness ________________________
Name ____________________________________
Designation _______________________________
Address __________________________________
____

*** PLEASE COMPLETE THIS FORM IN BLOCK LETTERS**

NHS SCOTLAND

Dietary Intake At End Of Life

Food intake at end of life

Anorexia/cachexia syndrome is a complex metabolic process found in many end stage illnesses. This is characterised by the loss or absence of appetite (anorexia) with weight loss and muscle wasting (cachexia). This impacts significantly on quality of life and can cause anxiety and distress for patients, perhaps even more so for carers.

Whilst food plays an important role in our life, choices at the end of life should be based on the patient's wishes (as long as they will no harm (in case swallowing risk for example) and be at a volume the patients can manage.

The clinical team can support a patient by;

- Offering information and practical advice about nutrition, diet and managing anorexia in advanced illness.
- Addressing patient and carer concerns about the importance of providing nourishment.
- Encouraging patients and their carers to focus on enjoying food and the social interaction associated with eating and drinking.
- Explaining that a gradual reduction in oral intake is a natural part of the illness.

A nutritional assessment needs to be holistic and acknowledge the emotional, social, cognitive and biochemical aspects of nutrition and diet. Each assessment should be individualised taking the patient's condition and stage of illness into consideration.

Practical dietary aspects to consider:

- Consider referral to a dietitian if appropriate.
- Previous dietary advice given regarding diabetes and high cholesterol may be relaxed.
- Gently encourage the patient to take what he can manage. Provide small portions, attractively presented, offered frequently through the day.
- Offer soft, easy to swallow foods such as soup, pudding and nutritious drinks. If tolerated increase intake of higher calorie foods such as butter, cream, cheese.
- Try not to talk about food all the time and try to keep the person involved in the social aspects of meals.
- Supplement drinks are not considered appropriate to initiate a prescription or the initiation of enteral feeding, however if these are already in situ and tolerated may continue.

Problems that may exacerbate anorexia:

- Pain
- Breathlessness
- Depression, Anxiety
- Ascites
- Nausea & Vomiting, Heartburn, Gastritis,
- Constipation
- Dysphagia,
- Medications
- Oral problems: such as dry mouth, ill-fitting dentures, ulcers, candidiasis are also common.

Other contributory factors may include:

- Odours: cooking smells, incontinence, fungating lesions and fistulae can contribute to anorexia.
- Delayed gastric emptying (for example due to local disease, autonomic neuropathy) causing early satiety and vomiting of undigested foods that relieve nausea.
- And Fatigue is commonly associated with anorexia/cachexia syndrome

These can be managed on an individual basis to support a dying patient be more comfortable.

Pharmacological management

Drug therapy is of limited benefit but worth considering as may improve quality of life. The potential side effects and risks of medication should be taken into account when prescribing. The Macmillan Specialists will advise on pharmacological management in Palliative and End of Life Care.

Resources

The Macmillan website also has an e-learning module
https://learnzone.org.uk/courses/course.php?id=38

Learning outcomes

- Understand nutrition and its role in cancer development and treatment.
- Understand the nutritional problems experienced by those affected by cancer.
- Consider how nutritional status can impact on treatment, prognosis and quality of life.
- Explore interventions for use in clinical practice to overcome or manage nutritional problems.
- Understand how to identify and advise on nutrition in relation to secondary cancer prevention and the primary prevention of other chronic diseases

Patient Name: **CHI:**

1. INTRODUCTION

This document **MUST** be read in conjunction with the NHS Scotland Do Not Attempt Cardio Pulmonary Resuscitation Integrated Adult Policy (2016).

When people have an advanced, progressive, life-limiting illness, it is very rare for the heart or breathing to suddenly stop unexpectedly. Cardiopulmonary resuscitation (CPR) is rarely successful in re-starting the heart and breathing in patients with advanced, progressive disease. There can also be complications of CPR such as fractured ribs and hypoxic brain damage. Successful CPR (sustainable breathing and circulation) in the State Hospital (TSH) would normally be accompanied by emergency transfer to an acute hospital, either during or immediately following CPR.

Although CPR is unlikely to have a successful outcome for a number of people, there are some for whom it may work and, given the choice, would opt to have CPR attempted should they experience a cardio-respiratory arrest.

2. AIM, PURPOSE AND OUTCOMES

The aims of this document are:

To detail the process of identifying, through medical assessment, those patients who realistically have potential for a medically successful outcome from CPR (sustainable breathing and circulation) in the event of a sudden cardio-respiratory arrest and those for whom CPR will not be successful.

To help set expectations for those patients for whom CPR would not work and clarify their resuscitation status to ensure inappropriate and futile resuscitation attempts are not made. A decision on whether to attempt CPR will not affect any other treatment that a patient is given.

To detail what steps require to be taken by staff following the cardiac arrest of a staff member, a visitor or a patient.

The document does not seek to**:**

Cover every element and scenario relating to resuscitation.

3. SCOPE

The document is intended to benefit all staff, visitors and patients in TSH by improving the communication with both patients in whom CPR has potential to be successful and those for whom it would not work. Those patients who have potential for CPR to be successful will be able to make an informed decision regarding their care. Those patients for whom CPR will not work will have clarity around what to expect in the event of a cardio-respiratory arrest and ensure inappropriate resuscitation is not attempted. This policy applies to all patients in the care of TSH.

This document is specifically about cardiopulmonary resuscitation (CPR), meaning treatment given with the aim of restoring sustainable spontaneous circulation and breathing when both have stopped. It does not indicate an advance decision about any other emergency treatment and/or care, including

procedures that are sometimes loosely referred to as "resuscitation" such as rehydration, blood transfusion, intravenous antibiotics etc.

4. PRINCIPLE CONTENT

4.1 RESPONSIBILITY FOR DECISION-MAKING: PROFESSIONAL

Each patient should be medically assessed, ideally following diagnosis, as per Palliative and End of Life Care Policy and Procedure (CP 49) appendix 1.

The overall responsibility for making an advance decision about CPR rests with the Senior Clinician (doctor or nurse) who has clinical responsibility for the patient during that episode of care. This will usually be the Consultant RMO (in TSH) or the Physical Health Consultant (in general hospitals) but can be the General Practitioner. However, it is also reasonable for other grades of suitably qualified and experienced medical staff to take responsibility for this decision provided that they accept that they have clinical responsibility for the patient during that care episode. The clinical team must be clear about which members are able to take on this responsibility. A decision about CPR should be made in consultation with wider members of the care team who have knowledge of that patient and his condition.

Where a DNACPR decision has been established with certainty the healthcare professional documenting the decision can sign the form (appendix 5) but the decision must be fully discussed and agreed with the responsible Senior Clinician who should then sign the form at the next available opportunity (as per NHS Scotland Do Not Attempt Cardio Pulmonary Resuscitation Integrated Adult Policy (2016).

For guidance on DNACPR decision making see page 6. DNACPR forms must be printed in colour and on white paper.
http://www.healthcareimprovementscotland.org/our_work/patient_experience/palliative_care/dnacpr_indicator/information_for_dnacpr_leads.aspx

It is the responsibility of the clinical team to ensure that all staff who are involved with this patient are made aware of his resuscitation status, this includes Skye Centre staff.

4.2 RESPONSIBILITY FOR DECISION-MAKING: PATIENTS AND THEIR RELATIVES/CARERS

A competent patient can:

Make an advance refusal of CPR even if CPR is deemed to be likely to be medically successful.

- They do not have to give a reason for such refusal.

Accept (consent to) CPR if it is offered as a treatment option.

- In the event of a cardio-respiratory arrest, CPR must only be offered if it is likely to be successful in achieving sustainable life for that patient.

A patient cannot:

Demand CPR if it is clinically judged that it would not be medically successful in achieving sustainable life for that patient.

- Healthcare staff cannot be obliged to carry out interventions that they judge are contraindicated/may be harmful.
- If agreement cannot be reached after sensitive and open discussion, a second opinion should be offered. Obtaining a second opinion is considered good practice but is not legally required if the multidisciplinary team is in agreement.

4.3 GENERAL

Patients for whom it is thought CPR could be successful and who would wish to have CPR should the need arise, should be fully informed of what can be offered at TSH: Basic Life Support (BLS) including, where appropriate, Automated External Defibrillation (AED), while awaiting transfer to an appropriate hospital. The patient's decision must be documented in their electronic patient record (RiO).

The resuscitation status of patients assessed as being unsuitable for CPR attempts will be reassessed fortnightly at the multi-disciplinary team (MDT) meeting or more frequently if deemed appropriate and recorded in the patient's electronic care record. This information should be recorded both in Vision and as an alert in RiO in order for staff to manage the situation appropriately.

Conversations and discussions about resuscitation status should not be held in isolation but should be part of an evolving conversation including a patient's understanding of their current condition and likely clinical course.

When CPR will not be successful there should be a presumption in favour of sensitively informing the patient of a DNACPR decision unless:

I) it is judged that this conversation would cause the patient physical or psychological harm
II) the patient refuses discussion
III) the patient lacks the capacity to engage (in which case information should be shared with any welfare power of attorney or guardian)

If a discussion has occurred, the appropriate section on the DNACPR form (appendix 5) should be completed and details of the conversation recorded in the patient's notes. If it is deemed appropriate to have this discussion, but the timing is not appropriate the full explanation and plan to revisit this must be documented in the patient's electronic care record. This discussion should take place at the earliest opportunity.

NHS Scotland '***Decisions about cardiopulmonary resuscitation – information for patients, their relatives and carers'*** leaflets are available on the intranet for downloading and distribution.

4.4 Journeys to Hospital Appointments (including by Ambulance)

If a patient is travelling to hospital for consultation/treatment, and **no** DNACPR form exists the default position is that they would be resuscitated – unless this is clearly inappropriate (e.g. patient in the very final stages of terminal illness where death is imminent and for whom CPR would clearly not work).

The resuscitation status of individual patients should be communicated prior to commencing the journey.

4.5 What to do in the event of a cardio-respiratory arrest

When no explicit decision has been made about CPR before a cardiopulmonary arrest occurs, and the express wishes of the patient are unknown, it is presumed that staff will initiate CPR.

However, there will be some people for whom attempting CPR is clearly inappropriate; for example, a person in the advanced stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful, but for whom no formal CPR decision has been made and recorded. Also, there will be cases where healthcare professionals discover patients with features of irreversible death – for example, rigor mortis. In such circumstances, any healthcare professional who makes a carefully considered decision not to start CPR should be supported by their senior colleagues, employers and professional bodies. **It is essential to document clearly in the clinical notes a detailed account of the assessment and rationale for the clinical decision not to attempt CPR in this situation, and clinicians must be supported to do this by colleagues and line managers.**

If patient DOES have a DNACPR form:

CPR should **not** be attempted.

In event of sudden cardio-respiratory arrest, keep the patient comfortable and call the on call doctor.

4.6 What to do in the event of an acute deterioration in a patient's medical condition without cardio-respiratory arrest

Emergency medical or surgical treatment for conditions other than complete cardio-respiratory arrest may still be appropriate for patients, including those with a DNACPR order. These eventualities should be part of the discussion when a DNACPR is put in place and the decisions clearly documented in the RiO and Vision.

4.7 Patients with Implantable Cardioverter Defibrillator (ICD)

The purpose of an ICD is to monitor the heart rhythm and respond to arrhythmia.

The ICD has several key functions:

- automatic administration of defibrillation shocks to terminate ventricular fibrillation (VF) or fast ventricular tachycardia (VT)
- anti-bradycardia pacing,often used after a defibrillation shock as the heart returns to normal sinus rhythm
- anti-tachycardia pacing to terminate slower rate VT, and
- cardioversion of VT.

If a patient has an ICD consideration must be given to the device being deactivated. People who are nearing the end of their lives, for example, sometimes feel that this is the right course for them. This decision must be made in consultation with a specialist member of the ICD team, RMO and the physician responsible for the physical health condition of the patient.

The presence of an ICD device can complicate a DNACPR order. In some cases, ICDs have been left active even though a DNR order was in place. This may have been due to an oversight by the clinical staff, or because staff were unfamiliar with the device, or simply because the equipment needed to deactivate or suspend device activity was not immediately available.
In general, maintaining an ICD in active defibrillation mode is inconsistent with an active DNACPR order and is rarely justified.

It is also important to acknowledge that safe deactivation may also be important after death, particularly as these devices must be explanted before a person is cremated. Therefore, the undertaker must be informed prior to removal of the body.

4.8 Resuscitation Procedure

If a staff member, visitor or patient (as deemed appropriate in the sections above) has a cardio-respiratory arrest, Basic Life Support (BLS) should be commenced as per Medical Emergency Policy.

5. REFERENCES

- Do Not Attempt Cardio Pulmonary Resuscitation(DNACPR) Integrated Adult Policy (2016)
- Joint recommendation by the Resuscitation Council (UK), BMA and RCN, 2007
- European Resuscitation Council Guidelines for Resuscitation 2010. Sections 2. Adult basic life support and use of automated external defibrillators. Koster RW, Baubin MA, Caballero A, et al Resuscitation 2010; 81: 1277-92.
- Implantable cardioverter defibrillators in patients who are reaching the end of life (British Heart Foundation 2007)
- ICD Your quick guide (British Heart Foundation 2017)

NHS Scotland DNACPR Policy 2016
Decision-making framework

Is cardiac or respiratory arrest a clear possibility for the patient?

- **NO** → It is not necessary to discuss CPR with the patient unless they express a wish to discuss it.
- **YES** ↓

Is there a realistic chance that CPR could be successful?

- **NO** → If a DNACPR decision is made on clear clinical grounds that CPR would not be successful there should be a presumption in favour of informing the patient of the decision and explaining the reason for it. Subject to appropriate respect for confidentiality those close to the patient should also be informed and offered an explanation. A decision can be made not to inform the patient at that time only if it is judged that the conversation would cause them physical or psychological harm. This must be clearly documented along with a plan to review the patient's ability to engage with that conversation.

  Where the patient lacks capacity and has a welfare attorney or appointed welfare guardian, this representative should be informed of the decision not to attempt CPR and the reasons for it as part of the ongoing discussion about the patient's care.

  Where a patient lacks capacity the decision should be explained to those close to the patient without delay. If this cannot be done immediately the reasons why it was not practicable or appropriate must be documented.

  If the decision is not accepted by the patient, their representative or those close to them, a second opinion should be offered.
- **YES** ↓

Does the patient lack capacity AND have an advance decision specifically refusing CPR OR have a welfare attorney or guardian?

- **YES** → If a patient has made an advance decision refusing CPR, and the criteria for applicability and validity are met, this must be respected.

  If a welfare attorney or guardian has been appointed they must be consulted.
- **NO** ↓

Does the patient lack capacity?

- **YES** → Discussion with those close to the patient must be used to guide a decision in the patient's overall benefit. The question is what the patient would have wanted rather than what the family would want but account must also be taken of their views regarding what they feel would be of benefit for the patient. Those close to the patient must not be burdened with feeling that they are responsible for the decision as this responsibility rests with the senior clinician.
- **NO** ↓

Is the patient willing to discuss his/her wishes regarding CPR?

- **NO** → Respect and document their refusal. Discussion with those close to the patient may be used to guide a decision in the patient's overall benefit, unless confidentiality restrictions prevent this.
- **YES** → **The patient must be involved in deciding whether or not CPR will be attempted in the event of cardiorespiratory arrest.**

Adapted from Decisions Relating to Cardiopulmonary Resuscitation - guidance from the BMA, RC(UK) and the RCN 2016

A DNACPR decision is intended to prevent inappropriate attempts at CPR where it **clearly will not work or would not be wanted by a patient**. An inappropriate CPR attempt can cause significant harm and distress to a patient and their family as a death during, or just after a CPR attempt will be undignified and highly traumatic. A DNACPR decision **does not refer to any treatment other than a CPR attempt when a patient's pulse and breathing have stopped**. Any unexpected acute deterioration must be assessed and managed appropriately for that patient irrespective of a DNACPR decision, and so **a medical emergency/999 call may be appropriate for a patient with a DNACPR form in place**.

Clinical decisions – would CPR realistically work for your patient?

The role of the clinical team is to decide whether CPR would realistically have a medically successful outcome (sustainable breathing and circulation) – if it will not work, do not offer it. Such decisions cannot involve quality of life judgements. It may be helpful to consider whether the patient would be appropriate for care in a Critical Care or Intensive Care setting as this is the likely outcome of a "successful" prolonged CPR attempt. The overall responsibility for the clinical decision about CPR lies with the most senior clinician (doctor or nurse) who has clinical responsibility for the patient during that care period. However, agreement within the multi-disciplinary team and with the patient and their relevant others is the optimal situation.

New

There should be a presumption in favour of sensitively informing patients of a clinical DNACPR decision in the context of their goals of care and possible treatment options unless (i)it is judged that this conversation would cause the patient physical or psychological harm, (ii)the patient refuses discussion, or (iii)the patient lacks capacity to engage. Where harm would be caused this explanation must be documented along with a plan to review the patient's ability to have this conversation.

Patient decisions about whether CPR would be wanted

Where CPR could realistically achieve sustainable life, but the overall benefit for the patient is in question in terms of the length or quality of that life, then the patient's wishes ***must be*** given priority. Where a patient has capacity, clinicians cannot make a DNACPR decision based on overall benefit unless the patient makes it clear that they do not wish to engage in such a decision. It would then be reasonable to ask if there is anyone else who should be consulted.

Where a patient lacks capacity to make a decision about CPR

If a current and valid advance statement or directive exists, this should be respected. Where CPR could realistically achieve sustainable life, any legally appointed welfare attorney or guardian should be approached to be involved in the decision-making process. If no such person has been appointed then the clinical team should make a decision based on a judgement of overall benefit for the patient. Information should be sought from those who know the patient and have a view on the patient's goals, values and previously expressed wishes.

The role of the relatives / relevant others

Where a patient has capacity, their permission must be obtained before any discussion about care issues takes place. Relatives must never be given the impression that their wishes override those of the patient. Where the patient lacks capacity relatives/relevant others can give information about what they feel the patient's wishes and goals of care are, but not such that they feel burdened with this responsibility, unless their status as legally appointed welfare attorney or guardian has been established. ***Subject to confidentiality restrictions those close to the patient who lacks capacity must be informed of any CPR decision without delay unless it would clearly not be practicable or appropriate to do so.***

New

Discharge to home or care home

It is the clinical team's responsibility to ensure that the patient and family are aware of the positive role of the DNACPR form at home in the context of the patient's goals of care. The family should know what to do and who to contact in the event of the patient's death or in the event of a sudden deterioration. Out of hours, the emergency care information such as DNACPR is communicated via the electronic Key Information Summary (KIS) and the GP must be given enough information to update it in time for the patient's discharge. Every effort must be made to make sure that the emergency services are not called inappropriately where a patient's death is expected, but there may be times when a 999 call is required for urgent assessment. If it is not felt appropriate or possible to have the DNACPR form at home with the patient everyone should be aware that paramedics and police may provide a full emergency response if called to attend.

Patient with a DNACPR form being transported by ambulance

Ambulance control must be informed of the existence of the DNACPR form at the time of booking an ambulance, and the crew should take the original form home with the patient, if he/she and their family is aware of it, and when not, they must understand its instruction prior to any transfer in case the patient dies on that journey.

Where no DNACPR decision has been made and a patient has a cardio-pulmonary arrest

The presumption is that staff should attempt CPR in this event, but where this is clearly inappropriate (eg a patient who is in the very final stages of a terminal illness where death is imminent and for whom CPR would clearly not work), it should not be attempted. Any healthcare professional who makes and clearly documents this considered decision must be supported by their colleagues, employers and professional bodies.

The presence or absence of a DNACPR form should not override clinical judgement about what will be of benefit to the patient in an emergency (e.g. choking, anaphylaxis).

Expected death within The State Hospital out of hours

Access for patient relatives in exceptional circumstances

(Between the hours of 2200 & 0630hrs)

Nurse in charge of the patient will:

- Contact SCC and inform them of the potential imminence of the death of the patient
- Request approval from SCC to contact the family
- Following approval they will contact the patients nearest relative and ascertain who will be attending TSH taking a note of their names to give to SCC and control room staff (Advise the visitors that no personal items will be permitted into the hospital and that a locker will be available to safely store, bags, keys etc
- Inform the control room immediately and advise of estimated time of arrival.

The Control Room Operator will:

- Commence a log of events
- Complete out of hours form
- Prepare for the arrival of the visitors – One member of the control room staff will relocate to the reception area and ensure lights, archway machine and tube stiles are ready to be used.
- Ensure carers are searched on entering the hospital; this must be carried out as per policy (**not** with metal detection wand). Two staff will be required to be present as per search policy.
- Ensure patient visitors are processed through the main reception area and not the carer reception.

Senior Clinical Cover will:

- Contact the Duty RMO & Duty Director to request permission to allow patient visitors into TSH out of hours.
- Liaise with the nurse in charge of the ward to ascertain the appropriate time to contact the relatives.
- Ensure that only authorised patient visitors will be permitted into the hospital out of hours.
- Ensure that there is sufficient gender mix within the reception area to carry out searches.
- Be in the reception area for the visitors arriving and transport them to the ward in a hospital vehicle or arrange for a deputy if they are required elsewhere in the hospital.
- Ensure the hospital is secured prior to leaving the reception area (i.e. doors locked, tub stiles turned off).
- Ensure the welfare facilities for the patients visitors have been addressed if they are to be on site for any length of time.
- Inform Duty Security Manager at commencement of their shift.

Other considerations:

- During out of hours, patient visitors will be permitted to access the disabled bathroom facilities within the night station. These should be searched before the visitors arrive and after they have left the ward. If the visitors are to remain on the ward during normal working hours and should other patients be required to use these facilities then the area should be searched prior to them having access. All searches are to be recorded.
- Only **3** visitors will be permitted at any one time and must already be authorised visitors.
- The visitors may still be on site when the other patients are rising in the morning. This can be a very distressing time for family members therefore consideration should be given to them having access to the small TV room which should be locked from the main day area only, this will prevent other patients having access to this room. Access to room 1 and their relative would remain but under supervision of ward based staff throughout.
- Should a relative need to use the telephone during the night they will be offered the use of the wards hands free phone in the small TV room. This will be for exceptional circumstances only and visitors will not be permitted to access the office at any time.
- When the patient has deceased the guidelines contained within the Death of a Patient policy should be adhered to.
- Consideration should be given to the wishes of the family with regards to preferred undertakers and control room staff should be notified of who will be attending to the body in advance of their arrival.

Notification of death form (ND1)

mental welfare commission for scotland

This form is to be used to notify the Mental Welfare Commission of **all** patient deaths in the following categories within one week of awareness. Please send completed forms to mwc.enquiries@nhs.scot

	Please cross
1. The deceased was subject to compulsory treatment under either the Mental Health (Care and Treatment) (Scotland) Act 2003 or Criminal Procedure (Scotland) Act 1995 at the time of death **ALL DEATHS IN THIS CATEGORY MUST ALSO BE REPORTED TO THE PROCURATOR FISCAL** **(Form EF5 – please attach if available)**	
2. The deceased died within one month of cease of detention under the above Acts	
3. The patient died as a result of actual or suspected suicide as an inpatient or within one month of discharge from hospital based care.	
4. There is a significant concern regarding an aspect of the care and treatment prior to the patient's death.	

Part 1. Particulars of the deceased and nearest relative

CHI Number				
Surname				
First name(s)				
Other / Known as				
Date of birth (dd/mm/yyyy)				
Home address				
Postcode:				
Gender (cross)	Male		Female	
General Practitioner (name, address and telephone number)				

Name of nearest relative	
Relationship to the deceased	
Address of nearest relative	
Phone number	

Part 2. Details of reporter / RMO

Reporter full name	
Title	
Contact address	
Contact phone number	
Reporter's email address	
Name of consultant / RMO (if this is not the reporter)	
Consultant contact phone number	
Consultant email address	

Part 3. Details of detention (any detention within one month of death if applicable)

The deceased was subject to detention under the following order (or died within one month)	
Name of order	
Start date of order	
End date of order (if applicable)	
Under the management of (Name of hospital or HSCP etc)	
Name of Mental Health Officer (MHO)	
MHO address	
MHO email address	
MHO phone number	

Part 4. Circumstances of death

Date and time of death	
Place of death (incl address)	
Has a death certificate been issued	Yes / No
Cause of death if certificate issued	
Name of certifying doctor	
If certificate has not been issued please provide the presumed cause of death in general terms if known	
Has a post mortem been planned or carried out?	Yes / No
Is the death the result of an actual suicide?	Yes / No
Is the death the result of a possible or suspected suicide (not confirmed)?	Yes / No
Is the death caused by coronavirus infection?	Confirmed / Suspected / No

Part 5. Clinical details / history

Relevant past medical history	
Relevant past psychiatric history	
Alcohol and illicit drug use history	

Prescribed medication at time of death (note also if 'high-dose' ie above total BNF combined dose limits)		
Summary of main events prior to death (please attach copies of any relevant information including discharge summary etc)		
Was the patient on authorised pass, leave or suspension of detention at the time of death (hospital CTO)?	Yes / No	
Was the patient on unauthorised absence at the time of death (hospital CTO)?	Yes / No	
Have the circumstances of the death been discussed verbally with the nearest relative (face to face/telephone)?	Yes / No	Date of discussion if held:
Has the **nearest relative** expressed any concerns about the circumstances surrounding the death – either verbally or in writing (if yes please specify)?		
Have **you** any concerns about the circumstances surrounding the death (if yes please specify)?		

Part 6. Reporting and investigation

Has the death been reported to the procurator fiscal?	Yes / No	Date:
Is the death subject to internal NHS review through adverse event investigatory	Yes / No	
	Reference number (eg Datix or other)	

procedures (including standard reporting eg Datix)?	Contact name of senior service manager (if known)	
	Address of hospital or Health and Social Care Partnership	
	If no, please provide reason	

Part 7. Declaration

I confirm that the details contained in this form are accurate to the best of my knowledge.

Signature (e-signature):	
Date:	