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Introduction

In December 2008, the Scottish Government launched “Living and Dying Well: a national action plan for palliative and end of life care in Scotland”.

Several elements of the national action plan have been combined to produce the NHS Grampian palliative and supportive care plan. The plan has been constructed in a manner which:

- assists health and social care professionals provide quality palliative care to patients, no matter their diagnosis or location
- promotes advance and anticipatory care planning and the development of individualised care so that practitioners and their teams can work with patients and those close to them to set and achieve common goals
- aids in the completion of the Palliative Care Directed Enhanced Service
- provides a framework that can be used with existing documentation

The key standards for this Palliative and Supportive Care plan are:

1. The patient has an initial assessment of performance and symptom status when it is recognised that they are palliative.
2. The patient’s care plan has been reviewed by a senior clinician and reflects their palliative and supportive needs.
3. A regular review of the patient’s performance, symptom status and care needs is undertaken and recorded.
4. Potentially reversible causes of decline are identified and treated, if appropriate.
5. Irreversible causes of decline are identified, clearly recorded and appropriate comfort measures put in place.

These five standards can then be used to plan and review patient care. The following flow chart summarises the standards:

[Diagram of the flow chart]

Palliative Patient or at risk of dying

Identification of palliative status
Initial assessment using PPS
Care plan established by senior clinician, outlining upper limits of treatment

Ongoing assessment and review of patient and care plan

Irreversible causes of deterioration in condition – patient dying

Review of care
The Standards

**Standard 1:** The patient has an initial assessment of performance and symptom status when it is recognised that they are palliative.

The Supportive & Palliative care Indicators Tool (SPICT) is used to aid in the identification of the palliative patient (page 3).

The Palliative Performance Scale (PPS) is recommended to be used to assess performance status. It is simple, quick to use and reproducible. The PPS tool and guidance notes are shown in section 2 (pages 4 - 6).

**Standard 2:** The patient’s care plan has been reviewed by a senior clinician and reflects their palliative and supportive care needs.

The care plan will reflect the identified physical, psychological, spiritual and social needs. The nursing activity sheet (page 7) can be used to help guide care planning using existing care plans and protocols.

**Standard 3:** A regular review is undertaken and recorded of the patient’s performance and symptom status. The care needs of both patient and carer should be considered.

This standard can be achieved using the PPS, nursing care activity sheet and symptom control checklist, recording any changes. Clinical judgement should guide the timing of discussions with the patient about their understanding of their situation and their care preferences. Further information about advance/anticipatory care planning can be found on page 8. This will enable subsequent completion of electronic information sharing and DNA CPR form.

**Standard 4:** Potentially reversible causes of decline are identified and treated

The symptom management checklist (page 9) can be used to assess patients for symptoms and to help make decisions about appropriate interventions.

**Standard 5:** In situations where there are irreversible causes of decline, these are confirmed, clearly recorded and appropriate comfort measures put in place.

The ‘Symptom Control in the Last Days of Life’ guidance (pages 10 & 11) can be used to guide comfort care. This is available in both the Adult version contained in this paperwork and in a Paediatric version for children and Young people up to the age of 18. The Paediatric version is available to download from the Grampian Palliative Care Intranet.

Once the patient has died, a review of the integrated care plan can be undertaken according to the 5 Standards.

A sample Review Document is outlined on page 12.
## Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is a guide to identifying people at risk of deteriorating and dying.

### Look for two or more general indicators of deteriorating health.
- Performance status poor or deteriorating, with limited reversibility, (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

### Look for any clinical indicators of advanced conditions

#### Cancer
- Functional ability deteriorating due to progressive metastatic cancer.
- Too frail for oncology treatment or treatment is for symptom control.
- Dementia/ frailty
  - Unable to dress, walk or eat without help.
  - Choosing to eat and drink less; difficulty maintaining nutrition.
  - Urinary and faecal incontinence.
  - Fractured femur; multiple falls.
  - Recurrent febrile episodes or infections; aspiration pneumonia.
- Neurological disease
  - Progressive deterioration in physical and/or cognitive function despite optimal therapy.
  - Speech problems with increasing difficulty communicating and/or progressive dysphagia.
  - Recurrent aspiration pneumonia; breathless or respiratory failure.

#### Heart/ vascular disease
- NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
  - breathlessness or chest pain at rest or on minimal exertion.
- Severe, inoperable peripheral vascular disease.

#### Kidney disease
- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure complicating other life limiting conditions or treatments.
- Stopping dialysis.

#### Respiratory disease
- Severe chronic lung disease with:
  - breathlessness at rest or on minimal exertion between exacerbations.
- Needs long term oxygen therapy.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.

#### Liver disease
- Advanced cirrhosis with one or more complications in past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Liver transplant is contraindicated.

### Assess and plan supportive & palliative care
- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).
## Palliative Performance Scale (Ppsv2) and Guidance Notes

*Used with permission © Victoria Hospice Society, BC, Canada 2001 www.victoriahospice.org*

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; evidence of disease</th>
<th>Self-care</th>
<th>Intake</th>
<th>Conscious level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No evidence of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
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<tr>
<td></td>
<td></td>
<td>Some evidence of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with effort</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some evidence of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable Normal job/work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
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<tr>
<td></td>
<td></td>
<td>Significant disease</td>
<td></td>
<td>Reduced</td>
<td></td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
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<tr>
<td></td>
<td></td>
<td>Significant disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50%</td>
<td>Mainly sit/lie</td>
<td>Unable to do any work</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
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<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
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<td></td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in bed</td>
<td>Unable to do most activity</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or drowsy +/- confusion</td>
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<tr>
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<td></td>
<td>Extensive disease</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>30%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Normal or reduced</td>
<td>Full or drowsy +/- confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Minimal to sips</td>
<td>Full or drowsy +/- confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Mouth care only</td>
<td>Drowsy or coma +/- confusion</td>
</tr>
<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td>-</td>
<td>-</td>
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</tbody>
</table>

The Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society and replaces the first PPS published in 1996 [J of Pall Care 9 (4) 26-32]. It cannot be altered or used in any way other than as intended and described here. Programs may use PPSv2 with appropriate recognition. Available in electronic word format by email request to edu.hospice@viha.ca. Correspondence should be sent to Medical Director, Victoria Hospice Society, 1952 Bay Street, Victoria BC, V8R 1J8, Canada.

Instructions for use of PPS

(see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a ‘best fit’ for the patient who is then assigned as the PPS % score.

2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way ‘leftward’ columns (columns to the left of any specific column) are ‘stronger’ determinants and generally take precedence over others.

Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

Example 2: A patient who has become paralysed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40% or 50% since he or she is not ‘total care’.

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level, but one or two which seem better at a higher or lower level. One then needs to make a ‘best fit’ decision. Choosing a ‘half-fit’ value of PPS 45%, for example, is not correct. The combination of clinical judgement and ‘leftward precedence’ is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient’s current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall ‘best fit’ using all five columns.

1. Ambulation

The items ‘mainly sit/lie’, ‘mainly in bed’, and ‘totally bed bound’ are clearly similar. The subtle differences are related to items in the self-care column. For example, ‘totally bed bound’ at PPS 30% is due to either profound weakness or paralysis such that the patient not only can’t get out of bed but is also unable to do any self-care. The difference between ‘sit/lie’ and ‘bed’ is proportionate to the amount of time the patient is able to sit up vs need to lie down.

‘Reduced ambulation’ is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.
2. Activity & extent of disease

‘Some’, ‘significant’ and ‘extensive’ disease refers to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply ‘some’ disease, one or two metastases in the lung or bone would imply ‘significant’ disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcaemia or other major complications would be ‘extensive’ disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, ‘some’ may mean the shift from HIV to AIDS, ‘significant’ implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. ‘Extensive’ refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics etc.

The above extent is also judged in context with the ability to maintain one’s work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. Trying to walk the halls).

3. Self-care

‘Occasional assistance’ means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

‘Considerable assistance’ means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her own teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

‘Mainly assistance’ is an extension of ‘considerable’. Using the above example, the patient now needs help getting up out of bed but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

‘Total care’ means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with ‘normal intake’ referring to the person’s usual eating habits while healthy. ‘Reduced’ means any reduction from that and is highly variable according to the unique individual circumstances. ‘Minimal’ refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious level

‘Full consciousness’ implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. ‘Confusion’ is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible aetiologies. ‘Drowsiness’ implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. ‘Coma’ in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.
Nursing Care Activities

Nursing care Activities related to the PPS Scores
(by Sally Lawton September 2010 Roxburghe House)

- Consider physical, psychological, spiritual and social needs at each level
- Create a rapport that enables the patient/family/carer to express their understanding of their situation and explore concerns
- Consider environmental factors that will enhance care
- Liaise with relevant health/social care agencies as required

**PPS Score >= 70** (promotion of self care)
Supervise care activities that promote wellbeing using existing local care plans

- skin care that minimises skin breakdown
- food, fluid and nutritional intake as appropriate
- continence care that protects the skin
- wound/stoma care that controls exudate and lessens odour
- concordance with prescribed medication
- assessing and monitoring symptoms

**PPS Score 40-60** (assessment, monitoring and review)
Assess, review and assist as required with care activities that maximise wellbeing using existing local care plans

- moving and handling using appropriate equipment
- skin care that minimises skin breakdown
- oral care to promote a healthy mouth
- food, fluid and nutritional intake as appropriate
- continence care that protects the skin
- wound/stoma care that controls exudate and lessens odour
- concordance with prescribed medication
- assessing and monitoring symptoms

**PPS Score 10-30** (High nursing dependency)
Undertake care activities to promote comfort using existing local care plans

- assisting with moving and handling using appropriate equipment
- providing skin care that minimises skin breakdown
- providing oral care that prevents complications associated with a dry mouth
- assisting with food, fluid and nutritional intake as appropriate
- providing continence care that protects the skin
- providing wound/stoma care that controls exudate and lessens odour
- administering prescribed medication
- assessing and monitoring symptoms
Anticipatory and Advance Care planning (ACP)

Advance Care Planning promotes discussion with respect to future clinical, personal and legal aspects of care. It is planning for end of life care while the person has capacity. Anticipatory Care Planning is more commonly applied to situations where it is expected or anticipated that there may be a change in the health or social status of the individual. It should include a management plan that describes actions which could be taken to manage an anticipated problem.

Anticipatory care planning

The elements within an anticipatory care plan should include:

- The person’s understanding about their condition
- Their wishes for treatment and care in the event of a sudden deterioration
- Their preferred place of care
- Likely causes of unplanned hospital admission
- Prescribed medication and equipment
- Current resuscitation status
- Current contents of the Emergency Care Summary

The decision about when and whether it would be appropriate to support someone to initiate an Anticipatory Care Plan depends on clinical judgement regarding the stage of condition, the readiness to engage in the conversation and the potential benefits of having an ACP in place. This is a voluntary process and the decision to have one rests with the individual patient.

An ACP should be developed over time through an evolving conversation between the person, those close to them and the practitioner to result in shared decision making. The care plan should be reviewed and updated to accurately reflect the patient’s condition, changing views and different priorities.

Sharing the ACP

Information gathered from ACP conversations should be documented and shared, with the patient’s consent, with care providers. Ideally, this would be in an electronic format, supplemented by a written copy readily accessible in the patient’s home.
Symptom Management

Symptoms or problems can be related to physical, psychological, spiritual or social factors. Gaining insight into the patient’s understanding of their situation forms an essential part of the assessment process. Guidance for palliation of a range of symptoms is available on the Grampian Palliative Care Intranet. Family/carer’s needs must also be assessed.

When present, symptoms/problems should be:

- Documented in the care notes
  - Addressed in accordance with existing guidelines and/or current care plans.

- Symptoms/problems to consider include:
  - Agitation/restlessness
  - Anorexia
  - Anxiety
  - Breathlessness
  - Constipation
  - Delirium
  - Depression
  - Diarrhoea
  - Excess respiratory secretions
  - Family concerns
  - Fatigue/Weakness
  - Insomnia
  - Nausea
  - Oral problems
  - Other (e.g) hiccups, itch etc.
  - Pain
  - Social issues
  - Spiritual issues
  - Swallowing difficulties
  - Vomiting

In the presence of irreversible, daily, functional decline, indicating that the patient is dying, the following issues should be discussed/considered and resulting decisions recorded in the care record.

- Discussions with the patient/family members regarding prognosis, care plan and understanding.
- A review of medication and where appropriate, cessation of non-essential drugs.
- A review of care interventions and cessation of non-essential interventions.
- A prescription for ‘just in case’ anticipatory subcutaneous medication.
- The completion of a syringe pump prescription (if necessary).

Symptom Control in the Last Days of Life is available on the Intranet in both Adult and Paediatric versions.
**End of Life Care**

**ADULT - Symptom Control in the Last Days of Life**

**Good care of the dying patient requires:**
- Recognition of dying phase
- Reappraisal of care objectives
- Clarification of resuscitation status (DNA-CPR)
- Good communication
- Consideration of place of care
- Multiprofessional care assessing physical, psychological, social & spiritual needs
- Knowledge of appropriate drugs prescribed for pain, nausea, agitation, breathlessness & respiratory tract secretions

**How do I recognise my patient is dying?**
- Daily continuous deterioration
- Profound weakness & drowsiness
- Difficulty taking things by mouth
- Poor concentration
- Disorientation
- Reducing peripheral perfusion with changes in skin colour & temperature
- Breathing pattern may change
- Calculate PPS

**Comfort measures:**

**Review medication** – discontinue drugs that are no longer necessary or relevant to symptom control.

Check patient's/family's understanding of events. **Explain** what is happening and likely prognosis.

Reduce medical interventions to a minimum including blood tests, BM sticks

Prescribe drugs required for symptom control by routes other than oral if unable to swallow. Subcutaneous/rectal routes are useful. Avoid IM or IV routes if possible

Regular oral care/sips of water/ice chips are usually sufficient to maintain comfort

**Skin care** – attention to pressure areas, regular change of position improves comfort

**Bladder & Bowel care** – urinary retention & faecal impaction are common treatable causes of distress at end of life.

Always consider possible sources of distress other than physical pain in someone who repeatedly fails to respond to analgesia. Spiritual/psychological distress may be considerable and may require help from chaplain or equivalent religious advisor. Different religious/cultural beliefs need to be acknowledged and provided for by maintaining good communication.

**Medication:**

- Prescribe a few core drugs in anticipation of terminal phase ‘as required for’ PAIN, AGITATION & RESPIRATORY SECRETIONS (Death rattle). Include an anti-emetic if patient nauseated.

- Administer drugs as **SC (subcutaneous) bolus** OR via a **CSCI (continuous subcutaneous infusion)** over 24 hours via a syringe pump.

- Many patients will only require a few intermittent bolus doses of medication to settle symptoms.

- Review patients’ needs regularly

- Consider setting up CSCI via syringe pump if symptoms are persistent.

**Individual patients may have different symptom control needs.** See over for simple guidance to prescribe for the most common symptoms in last few days of life. Further advice is available via the on call service based in Roxburghe House or via Grampian Palliative Care Intranet (see contact details below)

**Example of Anticipatory prescribing for opioid naïve adult patient**

**PARENTERAL MEDICINE PRESCRIPTIONS - for as Required Medication**

<p>| | | | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>M</td>
<td>3.3.10</td>
<td>Morphine</td>
<td>2.5 mg</td>
</tr>
<tr>
<td>N</td>
<td>3.3.10</td>
<td>Midazolam</td>
<td>2.5 mg</td>
</tr>
<tr>
<td>O</td>
<td>3.3.10</td>
<td>Hyoscine Butylbromide</td>
<td>20 mg</td>
</tr>
<tr>
<td>P</td>
<td>3.3.10</td>
<td>Levomepromazine</td>
<td>6.25 mg</td>
</tr>
</tbody>
</table>

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This guideline reflects good clinical practice. Prescribers should be aware that doses and routes of drugs may be unlicensed

Further advice can be obtained via the Roxburghe House 24 hour advice line by telephoning 01224 557057 or via the Palliative & End of life care section of the clinical Guidance Intranet at: http://newcgi.grampian.scot.nhs.uk/palliative_care/default.aspx
ADULT - Symptom Control in the Last Days of Life

**PAIN**

**OPIOIDS**
- Morphine is the most frequently used strong opioid for parenteral use. Seek advice if using an alternative.
  - Morphine 2.5 - 5mg SC if opioid naive
  - If already using strong opioid use parenteral equivalent of current breakthrough dose

2mg oral morphine = 1mg SC morphine
Breakthrough dose = 24 hour morphine + 6 (i.e. 4 hourly equivalent)

- Never escalate dose automatically
- If pain remains uncontrolled, increase 24-hour opioid dose by adding total of breakthrough doses required in last 24 hours but no more than 30-50% of total 24-hour opioid dose
- Avoid using opioids to sedate
- Renal failure - requires reduced opioid doses
- Multifocal myoclonus - useful indicator of toxicity

**FENTANYL PATCHES**
- Should not be initiated to treat pain in terminal care
- If already in place, continue and change every 72 hours as normal and an appropriate dose of injectable opioid made available for breakthrough pain
- 25 microgram/hour patch = 60 - 90mg

If already using strong opioid use parenteral equivalent parenteral dose of morphine (i.e. 4 hourly equivalent)

**NSAIDS**
- Diclofenac 50 - 150mg/24hours PR may be useful for inflammatory, bone, joint & pressure sore pain

**RESPIRATORY SECRETIONS**
- Drugs will stop the rattle in only approx 50% patients

- Can be mixed with Morphine 120mg/24hrs

- Optimise patient’s position in bed to promote drainage of secretions
- If requires repeated bolus doses consider starting a CSCI of Hyoscine Butylbromide 60 - 120mg/24 hrs – can be mixed with Morphine (i.e. Midazolam).
- Suction may 1 intractable excess secretions
- Drugs will stop the rattle in only approx 50% patients

**AGITATION / RESTLESSNESS**
- Benzodiazepines are useful in terminal restlessness.
  - Exclude correctable causes e.g. pain, full bladder
  - Initially Midazolam 2.5 mg SC bolus as required
  - If requires repeated bolus doses consider starting a CSCI Midazolam 10 - 15mg/24hrs
  - OR rectal Diazepam 5 - 10mg

Acute Confusional State (Delirium) with hallucinations
  - Exclude reversible causes
  - Use major tranquillisers e.g. Haloperidol 2 mg SC
  - Levomepromazine 12.5 mgSC
  - Either can be added to a CSCI

**NAUSEA & VOMITING**
Consider causes of N&V before prescribing.
- Continuous intractable nausea – Haloperidol 1.5mg SC once or twice daily OR 2-5mg/24hrs in CSCI
- Intermittent nausea associated with movement, sight & smell of food - Cyclizine 25 - 50mg SC six to eight hourly OR 100 - 150mg/24hrs in CSCI (always dilute with Water for Injections)
- Nausea associated with bloating, fullness or reflux - Metoclopramide 10 - 20mg SC six to eight hourly – has useful prokinetic GI effect, but is a large volume injection. Consider 40-60mg/24hrs in CSCI
- Potent broad spectrum anti-emetic - Levomepromazine 6.25mg – 12.5mg/24hrs, but can be sedating. Administer as a single daily dose SC or in CSCI

**BREATHLESSNESS**
Assess. Treat any reversible causes of breathlessness.

**Symptomatic Drug Treatment**
- Oxygen is only useful if patient is hypoxic
- Benzodiazepines reduce anxiety & distress.
  - Lorazepam SL 500 micrograms 4 - 6 hourly as required for breathlessness OR
  - Midazolam SC 2.5 mg up to hourly as required
- Opioids reduce respiratory drive & ease sense of breathlessness. Start with low dose and titrate carefully. Can be given up to two hourly as required.
  - If opioid naive - give oral Morphine 2.5 - 5mg.
  - If taking regular opioid - give 50% of 4hourly breakthrough analgesic dose of opioid
- Persistent breathlessness may require a 24 hour CSCI via a syringe pump.
  - Midazolam SC 5 - 20mg + Morphone SC 5 - 10mg if not already using opioid for pain
  - If patient already using strong opioid calculate the equivalent parenteral dose of morphine and add Midazolam 5 - 20mg SC
- Non-drug measures may be helpful
  - Explain what is happening & what can be done
  - Positioning, a fan & cool environment

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This guideline reflects good clinical practice. Prescribers should be aware that doses and routes of drugs may be unlicensed

Updated April 2013
Review of care after death

The questions within this short review document are based on the 5 standards within the NHS Grampian Palliative and Supportive Care Plan. It is hoped that this document will be used by the healthcare team to reflect on the care provided to their palliative patients and to identify possible areas for development and improvement.

| Standard 1 | Was the patient recognised as being palliative or at risk of dying? | Yes | No |
| Standard 2 | Did the patient have an initial palliative assessment of their condition recorded? | Yes | No |
| Standard 3 | Did the patient have a care plan, agreed with the senior clinician that reflected their palliative needs? | Yes | No |
| Standard 4 | Is there a record that regular palliative reviews were undertaken? | Yes | No | NA |
| Standard 5 | Were relevant changes made to the patient’s care plan? | Yes | No | NA |

Was there clear written evidence of discussion about:
- Prognosis
- Treatment
- Understanding
- Who was present at the discussion(s)

| Standard 4 | Were potentially reversible causes of decline identified? | Yes | No | NA |
| Standard 5 | Were these reversible causes treated? | Yes | No | NA |

In the presence of irreversible decline, were changes made to the care plan to promote comfort care?

| Standard 5 | Was an anticipatory prescription issued/written for the last few days of life? | Yes | No | NA |
| Standard 5 | Did the patient have a current DNA CPR form in their notes? | Yes | No | NA |
| Standard 5 | Was an Electronic Summary available to staff in Acute Care? | Yes | No | NA |

Did the patient express a preferred place of care?

If yes, where was this?

Where did the patient die?
- Home
- Nursing Home
- Community Hospital
- Acute Hospital
- other

Suggestions for development/improvement
The publication of this document has been funded by donations to Friends of Roxburghe House Grampian at the request of the family and colleagues of Raymond Kelly.

This publication is also available in large print and on computer disk.
Other formats and languages can be supplied on request.
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This document has been written by Dr David Carroll and Dr Sally Lawton, NHS Grampian
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