Improving access to palliative care for people who have had a stroke and their carers

APPENDICES

Submitted by

Melbourne Health Palliative Care Services

July 2010
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## Appendix 1. Literature review summary

### 1.1 Palliative care and stroke

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<thead>
<tr>
<th>Name</th>
<th>Article title</th>
<th>Year</th>
<th>Country</th>
<th>Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stevens et al.</td>
<td>Palliative care in stroke: a critical review of the literature</td>
<td>2007</td>
<td>UK</td>
<td>A critical review of the international literature found only seven papers that attempted to identify the palliative care needs of patients diagnosed with stroke. Results of the review showed that the preferences of stroke patients and their families in relation to palliative care services are largely unknown. There is a paucity of data in regards to the distinction between provision of palliative care services for patients who die in the acute phase of stroke and for those who die later.</td>
</tr>
<tr>
<td>Le et al.</td>
<td>Palliative care in stroke</td>
<td>2008</td>
<td>Australia</td>
<td>There has been an increasing number of patients referred to the authors Specialist PCS from non-oncology units, including increased referrals from the Stroke Care Unit (SCU). There is little reported on the palliative needs of this group, and the specific role of palliative care in the care of patients with stroke is, at this time, unclear. It is time to explore what care providers role is, and demonstrate the utility of palliative care in stroke patients.</td>
</tr>
<tr>
<td>Rogers A. et al.</td>
<td>Care of the dying stroke patient in the acute setting</td>
<td>2005</td>
<td>UK</td>
<td>Most acute stroke patients, at least in the short term, will be cared for in the acute hospital environment. Planning care for patients who survive their stroke for longer than five days, but who are thought likely to die, requires considerable skill and decisions about their care become more complex. There is an absence of evidence to suggest where these patients might best be cared for and which healthcare professionals are best placed to plan and deliver their care.</td>
</tr>
<tr>
<td>Blacquiere D et al</td>
<td>Evaluating an Organised Palliative Care Approach in Patients with Severe Stroke</td>
<td>2009</td>
<td>Canada</td>
<td>The adoption of an organised approach to palliative care in devastating stroke would be successful in most situations on an acute stroke unit.</td>
</tr>
<tr>
<td>duPreez et al</td>
<td>Predictors of Hospice Utilisation among Acute Stroke Patients who Died within 30 Days</td>
<td>2008</td>
<td>USA</td>
<td>The premise that stroke patients underutilise hospice care in comparison with other high-mortality diagnosis such as cancer does not hold true in the population studied (stroke patients surviving less than 30 days).</td>
</tr>
<tr>
<td>Holloway et al</td>
<td>Palliative Care Consultations in Hospitalised Stroke Patients</td>
<td>2010</td>
<td>USA</td>
<td>Stroke patients referred to their service were more functionally impaired, less likely to have capacity, more likely to die in hospital and have fewer traditional symptom burdens compared to patients with cancer, congestive heart failure and chronic obstruct airways disease.</td>
</tr>
<tr>
<td>Name</td>
<td>Article title</td>
<td>Year</td>
<td>Country</td>
<td>Conclusion</td>
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<td>----------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------</td>
<td>---------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Creutzfeld C</td>
<td>Palliative Care and the Acute Stroke Patient</td>
<td>2009</td>
<td>USA</td>
<td>Palliative care should be part of the comprehensive plan of stroke. The sudden and unpredictable nature of stroke makes it difficult to accurately predict the course of stroke. The likelihood and extent of recovery needs to be continually reassessed, communicated and recommedicated.</td>
</tr>
<tr>
<td>Payne S et al</td>
<td>Palliative care in acute stroke (Stroke Association Ref TSA 2005/02) Final Report</td>
<td>UK</td>
<td></td>
<td>Acute stroke patients have a high prevalence of needs after stroke which may be met by the integration of principles of palliative care into mainstream stroke practice. More needs to be known about the experiences of families who have witnessed the death of a patient with stroke.</td>
</tr>
<tr>
<td>McIlfatrick</td>
<td>Assessing palliative care needs: views of patients, informal carers and healthcare professionals</td>
<td>2006</td>
<td>UK</td>
<td>All participants considered that there was inequality between palliative care service provision for patients with cancer and non-cancer diseases. Discussed informal patients and caregivers main needs, with social support and financial assistance coming up as some of the main needs. Lack of long term planning-projects that appeared to work well subsequently discontinued owing to lack of money. Concluded that all patients, regardless of diagnosis should be able to access palliative care appropriate to their individual needs.</td>
</tr>
<tr>
<td>Mazzocato C et al</td>
<td>The last days of dying stroke patients referred to a palliative care consult team in an acute hospital</td>
<td>2010</td>
<td>Switzerland</td>
<td>There is a high prevalence of symptoms in dying stroke patients, and these symptoms can be underestimated because of communication difficulties by the patient.</td>
</tr>
<tr>
<td>Addington-Hall et al</td>
<td>Symptom Control, Communication With Health Professionals, and Hospital Care of Stroke Patients in the Last Year of Life as Reported by Surviving Family, Friends, and Officials.</td>
<td>1995</td>
<td>UK</td>
<td>Improvements in symptom control and psychosocial support for patients who die from stroke are needed, as is better communication between health professionals and their families. Education of doctors and nurses working with stroke patients in the principles of palliative care may help to ensure that all dying stroke patients receive high-quality care.</td>
</tr>
<tr>
<td>Neatherlin et al.</td>
<td>End-of-Life Care Concepts in Journal of Neuroscience Nursing</td>
<td>2006</td>
<td>USA</td>
<td>Evaluation of concepts relating to EOL care addressed in Journal of Neuroscience Nursing (JNN) during a 10 year period (1993-2002). Described all neurological conditions, not just stroke. Reluctance of nurses to discuss dying with patients and families reflected in publications. If EOL issues were discussed, more emphasis was placed on coping mechanisms rather than management of physical symptoms. Neuroscience nurses frequently deal with conditions where patients are dying. They need to understand how to care properly for EOL care and incorporate best practice for EOL care.</td>
</tr>
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</table>
### Integrated care pathways

<table>
<thead>
<tr>
<th>Name</th>
<th>Article title</th>
<th>Year</th>
<th>Country</th>
<th>Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campbell et al</td>
<td>Integrated Care Pathways</td>
<td>1998</td>
<td>UK</td>
<td>Description of ICPs and how they can be used in clinical practice.</td>
</tr>
<tr>
<td>Allen D, et al</td>
<td>Systemic review of the effectiveness of integrated care pathways: what works, for whom, in what circumstance</td>
<td>2009</td>
<td>UK</td>
<td>ICPs are most effective in contexts where patient care trajectories are predictable. Their value in settings in which recovery pathways are more variable is less clear. ICPs are most effective in bringing about behavioural changes where there are deficiencies in services; their value in contexts where interprofessional working is well established is less certain.</td>
</tr>
<tr>
<td>Kwan et al</td>
<td>In-hospital care pathways for stroke</td>
<td>2005</td>
<td>UK</td>
<td>No significant difference between care pathway and control groups in terms of death or discharge destination. Patients managed with a care pathway were more dependent at discharge, less likely to have a UTI, less likely to be readmitted to hospital and more likely to have a CTB. Quality of documentation significantly more comprehensively in the care pathway group. Insufficient high-quality evidence to support the implementation of care pathways for acute stroke.</td>
</tr>
<tr>
<td>Allen D, et al</td>
<td>How has the impact of ‘care pathway technologies’ on service integration in stroke care been measured and what is the strength of the evidence to support their effectiveness in this respect?</td>
<td>2008</td>
<td>UK</td>
<td>Some evidence that ICPs may support some elements of service integration in the context of stroke care. Seems to be a result of their ability to support the timely implementation of clinical interventions and the mobilisation of resources around the patient without incurring longer lengths of stay. Appear most successful in the acute stroke care setting where patient care trajectories are predictable. Unclear how documented practice reflects actual care. Suggest that use of ICPs be restricted to use in those areas of the care pathway which can be standardised and predictable.</td>
</tr>
<tr>
<td>Ellershaw et al</td>
<td>Care of the dying; setting standards for Symptom Control in the Last 48 Hours of Life</td>
<td>2001</td>
<td>UK</td>
<td>Palliative care for too long has espoused the delivery of best practice to the dying patient without this care being measurable. The ICP for the dying patient is a method of measuring symptom control in the dying patient and providing demonstrable standards, which are integrated into clinical practice.</td>
</tr>
<tr>
<td>Mirando S et al</td>
<td>Introducing an integrated care pathway for the last days of life</td>
<td>2005</td>
<td>UK</td>
<td>Considerable number of patients with a non cancer diagnosis was cared for via the pathway. 63% of patients cared for on the pathway were not referred to the palliative care team.</td>
</tr>
<tr>
<td>Department of Human Services Victoria</td>
<td>Pathways for care in the last days of life: A review of the current utilisation in Victoria</td>
<td>2009</td>
<td>Australia</td>
<td>Report on the Victorian health services utilising pathways of care in the last days of life and the types of pathways being utilised. Conclusion of the report was that the introduction of care pathways into the acute general setting had a significant impact, in particular in areas of non malignant palliative care where access to specialist palliative care was limited.</td>
</tr>
</tbody>
</table>
### Name | Article title | Year | Country | Conclusion
--- | --- | --- | --- | ---
Veerbeek et al | The effect of the Liverpool Care Pathway for the dying: a multi-centre study | 2008 | Holland | Conclude the LCP contributes to the quality of documentation and symptom management (used in oncology setting only).

Jack C. et al | Towards a good death: the impact of the care of the dying pathway in an acute stroke unit | 2004 | UK | Use of the LCP showed a marked improvement in the documentation of patient care in six of the seven key areas assessed. Authors write that the LCP is transferable to the care of patients with stroke and goes a long way to addressing the needs recognised in the National Service Framework. Needs further work in larger sample group to support conclusion.

Ellershaw et al | Care of the dying; setting standards for Symptom Control in the Last 48 Hours of Life | 2001 | UK | Palliative care for too long has espoused the delivery of best practice to the dying patient without this care being measurable. The ICP for the dying patient is a method of measuring symptom control in the dying patient and providing demonstrable standards, which are integrated into clinical practice.

Murphy D et al | The Liverpool Care Pathway for the rapid discharge home of the dying patient | 2004 | UK | LCP rapid discharge pathway provides a structured and coordinated process to enable a dying patient to go home to die. Crucial that specialist palliative care services take a lead in the use of this pathway. Facilitates choice at the end of life helping to fulfil patient / family wishes.

### 1.2 Carer needs and interventions for patients discharged home

<table>
<thead>
<tr>
<th>Name</th>
<th>Country</th>
<th>Year</th>
<th>Study design</th>
<th>Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Payne et al</td>
<td>UK</td>
<td>2009</td>
<td>Qualitative study</td>
<td>Sufficient evidence from the reviewed studies could not be identified to confirm the efficacy of interventions on caregivers on stroke patients but counselling programs appear to have the most positive outcome.</td>
</tr>
<tr>
<td>Visser-Meily et al</td>
<td>Netherlands</td>
<td>2004</td>
<td>Critical Review</td>
<td>More longitudinal research and user involvement is required to aid development of interventions and more experimental and quasi experimental research to evaluate them</td>
</tr>
<tr>
<td>Grande et al</td>
<td>UK</td>
<td>2009</td>
<td>Review of current state of carer research</td>
<td>Evidence of carers needs in cancer and palliative care consistently call for the development and evaluation of targeted interventions. Ethically, the time is overdue to apply this data and to build on what has begun in the development of accessible and acceptable interventions</td>
</tr>
<tr>
<td>Bee et al</td>
<td>UK</td>
<td>2008</td>
<td>Systematic review</td>
<td>Evidence of carers needs in cancer and palliative care consistently call for the development and evaluation of targeted interventions. Ethically, the time is overdue to apply this data and to build on what has begun in the development of accessible and acceptable interventions</td>
</tr>
<tr>
<td>Harding et al</td>
<td>UK</td>
<td>2003</td>
<td>Systematic Literature review</td>
<td>Evidence of carers needs in cancer and palliative care consistently call for the development and evaluation of targeted interventions. Ethically, the time is overdue to apply this data and to build on what has begun in the development of accessible and acceptable interventions</td>
</tr>
<tr>
<td>Name</td>
<td>Country</td>
<td>Year</td>
<td>Study design</td>
<td>Conclusion</td>
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<tr>
<td>---------------</td>
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</tr>
<tr>
<td>Brereton et al</td>
<td>UK</td>
<td>2007</td>
<td>Systematic review</td>
<td>Benefits were reported for all interventions, although trials were generally of low quality, preventing firm conclusions being drawn.</td>
</tr>
<tr>
<td>Bauer et al</td>
<td>Australia</td>
<td>2009</td>
<td>Literature review</td>
<td>Current evidence indicates that hospital discharge planning for frail older people can be improved if interventions address family inclusion and education, communication between health care workers and family, interdisciplinary communication and ongoing support after discharge.</td>
</tr>
<tr>
<td>Hudson et al</td>
<td>Australia</td>
<td>2004</td>
<td>Review</td>
<td>Resources that focus on supportive information for caregivers appear to be less than adequate. In addition, approaches to providing supportive services need to be enhanced.</td>
</tr>
<tr>
<td>McIlfatrick</td>
<td>UK</td>
<td>2006</td>
<td>Qualitative study</td>
<td>All patients, regardless of diagnosis, should be able to access palliative care appropriate to their individual needs. Integrated approach is essential.</td>
</tr>
<tr>
<td>McMillan</td>
<td>USA</td>
<td>2005</td>
<td>Review</td>
<td>Limited evidence regarding interventions with very few caregiver intervention studies found which included patients near end of life, and all of these focussed on caregivers of patients with cancer.</td>
</tr>
<tr>
<td>Smith et al</td>
<td>UK</td>
<td>2008</td>
<td>Cochrane Review</td>
<td>The best way to provide information is still not clear; however the results of the review suggest that strategies which actively involve patients and carers and include planned follow up should be used in routine practice.</td>
</tr>
<tr>
<td>Johnson et al</td>
<td>Australia</td>
<td>2003</td>
<td>Cochrane Review</td>
<td>Recommend the use of both verbal and written health information when communicating about care issues with patients and/or significant others on discharge from hospital to home</td>
</tr>
<tr>
<td>Kalra et al</td>
<td>UK</td>
<td>2004</td>
<td>Single blind Randomised Controlled Trial</td>
<td>There may be benefit to using a structured program of activities under professional supervision during inpatient rehabilitation, to empower consenting informal care givers in their future role by teaching them appropriate skills.</td>
</tr>
<tr>
<td>Mistiaen et al</td>
<td>Netherlands</td>
<td>2006</td>
<td>Cochrane Review</td>
<td>Could not conclude that telephone follow up is an effective intervention nor is there conclusive evidence to exclude telephone follow up from discharge planning activities.</td>
</tr>
</tbody>
</table>
Appendix 2.  Acute Ischaemic Stroke Pathway

<table>
<thead>
<tr>
<th>THE ROYAL MELBOURNE HOSPITAL</th>
<th>PATIENT IDENTIFICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>WARD</td>
<td></td>
</tr>
<tr>
<td>DIAGNOSIS</td>
<td></td>
</tr>
<tr>
<td>PROCEDURE/INVESTIGATION</td>
<td></td>
</tr>
<tr>
<td>CHART NO.</td>
<td>REFERRAL(S).</td>
</tr>
<tr>
<td>DISCHARGE PLAN</td>
<td></td>
</tr>
<tr>
<td>PLANNED CARE/OUTCOME</td>
<td>INITIAL</td>
</tr>
<tr>
<td>DATE</td>
<td>AM</td>
</tr>
<tr>
<td>COMMMENTS/VARIANCE</td>
<td>State Time</td>
</tr>
<tr>
<td>IN BOL</td>
<td></td>
</tr>
</tbody>
</table>

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Improving access to palliative care for people who have had a stroke and their carers – Appendices
<table>
<thead>
<tr>
<th>Post no.</th>
<th>PLANNED CARE/OUTCOME</th>
<th>INITIAL</th>
<th>COMMENTS/VARIANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>AM</td>
<td>State Time</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>PM</td>
<td></td>
</tr>
</tbody>
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Initial & Sign: D E N

Initial & Sign Date: D = 0700 – 1530 E = 1530 – 2200 N = 2130 – 0730
Appendix 3. Description of modified Rankin Score and Oxfordshire classification

**Modified Rankin Score**

The modified Rankin Score measures functional outcome after stroke. The official definitions of each category are shown in bold. The italicised text provides guidance that may reduce interobserver variability, without requiring a structured interview. Note that only symptoms arising since the stroke should be considered. Walking aids or other necessary mechanical devices are disregarded provided that the patient can use these without external assistance.

If two options appear, equally valid and if further questions are considered unlikely to clarify the correct choice, then the more severe category should be selected.

0. No symptoms at all
The patient should be unaware of any new limitation or symptom caused by the stroke, however minor.

1. No significant disability despite symptoms; able to carry out all usual duties and activities
The patient has some symptoms as a result of the stroke, whether physical or cognitive - for example affecting speech, reading or writing; or physical movement; or sensation; or vision; or swallowing; or mood – but can continue to take part in all previous work, social and leisure activities. The crucial question to distinguish grade 1 from grade 2 (below) may be “is there anything that you can no longer do that you used to do until you had the stroke?” As a guide an activity that was undertaken more frequently than monthly could be regarded as a ‘usual activity’.

2. Slight disability; unable to carry out all previous activities but able to look after own affairs without assistance
The patient will be unable to undertake some activity that was possible before the stroke (eg driving a car, dancing, reading or working) but is still able to look after him/herself without help from others on a day to day basis. Thus, the patient can manage dressing, moving around, feeding, toileting preparing simple meals, shopping and travelling locally without needing assistance from anyone else. Supervision is not necessary. This grade assumes that the patient could be left alone at home for periods of a week or more without concern.

3. Moderate disability; requiring some help, but able to walk without assistance
At this grade, the patient is independently mobile (using a walking frame if necessary) and can manage dressing, toileting, feeding etc but needs help from someone else for more complex tasks. For example, someone else may need to undertake shopping, cooking or cleaning and will need to visit the patient more often than weekly to ensure that these activities are completed. The assistance can be advisory rather than physical; for example, a patient who needs supervision or encouragement to cope with financial affairs would be in this grade.

4. Moderately severe disability; unable to walk without assistance, and unable to attend to own bodily needs without assistance
The patient requires someone else to help with some daily tasks, whether walking, dressing, toileting or eating. This patient will be visited at least once and usually twice or more times...
daily, or must live in proximity to a carer. To distinguish grade 4 from grade 5 (below) consider whether the patient can regularly be left alone for moderate periods during the day.

5. Severe disability; bedridden, incontinent, and requiring constant nursing care and attention
Someone else will always need to be available during the day and at times during the night, though not necessarily a trained nurse.

Wilson JTL, Hareendran A, Grant M, Baird T, Schulz UGR, Muir KW, Bone I. Improving the assessment of outcomes in stroke: use of a structured interview to assign grades on the modified Rankin scale. Stroke 2002; 33:2243-2246

**Oxfordshire Community Stroke Project (OCSP) classification**

The OCSP is a clinically-based classification that links the clinical signs at the bedside to likely pathogenesis and prognosis. It is simple, and does not require results of tests. There are four categories:

1. **TACS/TAC1** = total anterior circulation syndrome/infarct:
   - Pathogenesis: distal ICA or proximal MCA occlusion → infarction/haemorrhage involving deep brain tissue and cortical brain tissue.
   - Clinically: patient has all 3 features: (1) hemiparesis (reflecting damage to deep white matter, ie. internal capsule); (2) higher cortical dysfunction – aphasia/neglect (reflecting damage to the cortex), and (3) hemianopia (reflecting damage to the deep white matter carrying fibres to the temporal or occipital cortex).

2. **PACS/PACI** = partial anterior circulation syndrome/infarct:
   - Pathogenesis: more limited damage, from occlusion of a MCA branch, with often spared deep white matter.
   - Clinically: isolated aphasia, or hand weakness, or just hemiparesis. *(Tip: If all 3 features to make a TACS are not present, then the diagnosis is a PACS)*

3. **POCS/POCI** = posterior circulation syndrome/infarct:
   - Pathogenesis: brain stem infarction that could be caused by vertebrobasilar atheroma, cardioembolism or small vessel disease.
   - Clinically, usually straightforward: brainstem signs such as vertigo, ataxia, dysarthria, dysphagia, lower cranial nerve palsies and/or quadriplegia.

4. **LACS/LACI** = lacunar syndrome/infarct
   - Pathogenesis: lipohyalinosis resulting in ‘small vessel disease’ – producing a small deep infarct.
   - Clinically: classic lacunar syndromes

The table overleaf shows why OCSP classification is useful.
### Oxfordshire Community Stroke Classification

<table>
<thead>
<tr>
<th></th>
<th>TACS</th>
<th>PACS</th>
<th>LACS</th>
<th>POCS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cause</strong></td>
<td>Occlusion of ICA</td>
<td>Cartoid stenosis</td>
<td>Small vessel disease</td>
<td>In-situ atheroma of vertebro-basilar vessels</td>
</tr>
<tr>
<td></td>
<td>Cardiac embolus</td>
<td>Cardiac embolus</td>
<td></td>
<td>Aortic arch atheroma</td>
</tr>
<tr>
<td></td>
<td>Aortic arch atheroma</td>
<td>Aortic arch atheroma</td>
<td></td>
<td>→ Cardiac embolus</td>
</tr>
<tr>
<td><strong>Recurrences</strong></td>
<td>Low</td>
<td>High in first 3 months</td>
<td>Steady over 12 months</td>
<td>High in first 3 months</td>
</tr>
<tr>
<td><strong>Dead</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1 year)</td>
<td>60%</td>
<td>15%</td>
<td>10%</td>
<td>20%</td>
</tr>
<tr>
<td><strong>Dependent</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>35%</td>
<td>30%</td>
<td>30%</td>
<td>20%</td>
</tr>
<tr>
<td><strong>Independent</strong></td>
<td>5%</td>
<td>55%</td>
<td>60%</td>
<td>60%</td>
</tr>
</tbody>
</table>
Appendix 4. Audit tool for clinical record audit

# Palliative Care Stroke Care Pathway Audit

Royal Melbourne Hospital

<table>
<thead>
<tr>
<th>Initials</th>
<th>DOB</th>
<th>Gender</th>
<th>UR number</th>
<th>Date of admission</th>
<th>Date of stroke</th>
<th>Date documented PC</th>
<th>Date of PC referral</th>
<th>Date of death</th>
<th>Hours on pathway</th>
<th>Data seen</th>
</tr>
</thead>
</table>

**Initial assessment:**

1. **Documentation of current medication**
   - Yes
   - No
   - Date

2. **PRN subcutaneous medication written up:**
   - 2.1 Analgesic for pain
   - Yes
   - No
   - 2.2 Sedative for agitation
   - Yes
   - No
   - 2.3 Anti-cholinergic for RTS
   - Yes
   - No
   - 2.4 Anti-emetic for nausea
   - Yes
   - No
   - 2.5 Antialiytic opioid for dyspnoea
   - Yes
   - No
   - 2.6 Aperient for constipation
   - Yes
   - No
   - 2.7 Benzodiazepine for seizure activity
   - Yes
   - No

3. **Comfort medications ordered and readily available as per IP12 Syringe driver in situ**
   - Yes
   - No
   - 3.1 Were there any delays in getting medications
   - Yes
   - No

4. **Were the following interventions discontinued:**
   - 4.1 Blood tests
     - discontinued Yes
     - No
   - 4.2 Antibiotics
     - discontinued Yes
     - No
     - N/A
   - 4.3 I.V. lines
     - discontinued Yes
     - No
   - 4.4 I.V's (fluid/medication)
     - discontinued Yes
     - No
   - 4.5 Vital signs
     - discontinued Yes
     - No
   - 4.6 Limitations of medical treatment documented
     - Yes
     - No
     - Date
   - 4.7 Not for met calls documented
     - Yes
     - No
     - Date

5. **Continue routine nursing interventions:**
   - 5.1 Routine turning regime documented
     - Yes
     - No
   - 5.2 Appropriate assessment of skin integrity documented
     - Yes
     - No
   - 5.3 Mouth care and eye care as needed documented
     - Yes
     - No

6. **Primary language documented**
   - Yes
   - No

7. **Ability to communicate in English assessed as adequate**
   - Patient
     - Yes
     - No
     - Comatose
   - Family/other
     - Yes
     - No

8. **Religious/spiritual needs assessed**
   - Yes
   - No

9. **Identify how family are to be informed of patients impending death**
   - Yes
   - No

10. **Family discussion re palliative approach to care documented**
    - Yes
    - No

11. **Multidisciplinary team aware of patient's condition**
    - Yes
    - No
## Section 2 Patient problem/ focus

<table>
<thead>
<tr>
<th>Symptom</th>
<th>All shifts</th>
<th>Most shifts</th>
<th>Some shifts</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agitation assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RTS assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N&amp;V assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyspnoea assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Micturition assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility/ pressure care assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psych insight (patient) assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psych insight (family) assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious and Spiritual support assessed and documented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 3 Care after death

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>GP informed of patients death</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>11</td>
<td>Procedure for laying out followed according to hospital policy</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>Procedure following death discussed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Family given other information on hospital procedures</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>14</td>
<td>Hospital policy followed for patient's valuables and belongings</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>15</td>
<td>Necessary documentation given and advice given to appropriate person</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>16</td>
<td>Bereavement leaflet given</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
### Appendix 5. Inter-rater reliability for clinical record audit

<table>
<thead>
<tr>
<th>Section of Audit</th>
<th>Audit question</th>
<th>Inter-rater consistency (no. of patient histories)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Initials</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Date of admission</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Date documented palliative care</td>
<td>90% (10)</td>
</tr>
<tr>
<td></td>
<td>Date of death</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Date of birth</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>UR Number</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Date of stroke</td>
<td>80% (8)</td>
</tr>
<tr>
<td></td>
<td>Date of palliative care referral</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Date seen by palliative care</td>
<td>100% (10)</td>
</tr>
<tr>
<td><strong>Medications</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Documentation of current medication</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>Have non essential medications been discontinued</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td><strong>PRN subcutaneous medication written up:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Analgesic for pain</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>Sedative for agitation</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>Anticholinergic for RTS</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>Anti-emetic for nausea</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Antiolytic /opioid for dyspnoea</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>Aperient for constipation</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Benzodiazepine for seizure activity</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>Syringe driver in situ</td>
<td>100% (10)</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Were the following interventions discontinued:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blood tests</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Antibiotics</td>
<td>80% (8)</td>
</tr>
<tr>
<td></td>
<td>I.V. lines</td>
<td>90% (9)</td>
</tr>
<tr>
<td></td>
<td>I.V’s (fluid/medication)</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Vital signs</td>
<td>90% (9)</td>
</tr>
<tr>
<td><strong>Limitations of treatment</strong></td>
<td>Limitations of medical treatment documented</td>
<td>100% (10)</td>
</tr>
<tr>
<td></td>
<td>Not for met calls documented</td>
<td>100% (10)</td>
</tr>
<tr>
<td><strong>Communication of interventions</strong></td>
<td>Appropriate assessment of skin integrit...</td>
<td>80% (8)</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td>Primary language documented</td>
<td>100% (10)</td>
</tr>
<tr>
<td><strong>Religious/Spiritual needs</strong></td>
<td>Religious/spiritual needs assessed</td>
<td>80% (8)</td>
</tr>
<tr>
<td>Section of Audit</td>
<td>Audit question</td>
<td>Inter-rater consistency (no. of patient histories)</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>Communication with family</td>
<td>Identify how family are to be informed of patients impending death</td>
<td>90% (9)</td>
</tr>
<tr>
<td>Communication with family</td>
<td>Family discussion re palliative approach to care documented</td>
<td>100% (10)</td>
</tr>
<tr>
<td>Communication with multidisciplinary team</td>
<td>Multidisciplinary team aware of patient's condition</td>
<td>90% (9)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Pain</td>
<td>22.2% (2)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Agitation</td>
<td>22.2% (2)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Respiratory tract secretions</td>
<td>33.3% (3)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Nausea and vomiting</td>
<td>77.8% (7)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Dyspnoea</td>
<td>77.8% (7)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Constipation</td>
<td>88.9% (8)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Micturition</td>
<td>88.9% (8)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Medication</td>
<td>66.7% (6)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Psychosocial/spiritual needs (patient)</td>
<td>100% (9)</td>
</tr>
<tr>
<td>Assessment and documentation of symptoms</td>
<td>Psychosocial/spiritual needs (family)</td>
<td>66.7% (6)</td>
</tr>
<tr>
<td>Care after death</td>
<td>GP informed of patients death</td>
<td>11.1% (1)</td>
</tr>
<tr>
<td>Care after death</td>
<td>Procedure for laying out followed according to hospital policy</td>
<td>100% (9)</td>
</tr>
<tr>
<td>Care after death</td>
<td>Procedure following death discussed</td>
<td>100% (9)</td>
</tr>
<tr>
<td>Care after death</td>
<td>Family given other information on hospital procedures</td>
<td>100% (9)</td>
</tr>
<tr>
<td>Care after death</td>
<td>Hospital policy followed for patient's valuables and belongings</td>
<td>88.9% (8)</td>
</tr>
<tr>
<td>Care after death</td>
<td>Bereavement leaflet given</td>
<td>100% (9)</td>
</tr>
</tbody>
</table>

Demographics

High inter-rater reliability was evident within the demographic information with minor variations occurring in the date of documented palliative care (10%) and date of stroke (20%). The discrepancy in the date of documented palliative care may be secondary to auditor error or misinterpretation of the documentation regarding when the patient was indicated as palliative care. The date of stroke variation is likely due to uncertainty or variation in the interpretation from the documentation about the date of the actual event of stroke as compared to date of admission.

Medications

The medication section also demonstrated high inter-rater reliability with one variation in the auditor responses evident in 6 questions (as per Error! Reference source not found.). The discrepancy in responses for documentation of current medications may have been due to auditor error or varied interpretation of whether the documentation was adequate to state that current medications had been documented.
Improving access to palliative care for people who have had a stroke and their carers – Appendices

Interventions
Discrepancies in the auditor responses for the questions pertaining to the write up of PRN subcutaneous medications for various symptoms was secondary to limited knowledge of one auditor in relation to recognition of the role of medications for specific symptoms.

The audit responses relating to the discontinuation of blood tests and IV (fluid / medication) were consistent between both auditors demonstrating high inter-rater reliability.

Two patient histories audited received different responses in regard to the cessation of antibiotics. However, on review, this appears secondary to lack of auditor knowledge in recognising antibiotic names on the drug chart.

One inconsistent response occurred in regard to the cessation of vital sign monitoring. On review of the history, it appeared that due to the complexity of the documentation (secondary to patient dying in ICU) it was difficult for the auditors to determine if all vital signs had been ceased. Further definition of the actual signs to audit may increase inter rater reliability.

In regard to the discontinuation of I.V lines, one patient history obtained an inconsistent response secondary to an auditor not recognising a PICC line as an IV line.

Limitations of treatment
Consistent responses were obtained across all patient histories by both auditors for documentation of ‘limitations of medical treatment’ and ‘not for met calls’. A very high inter-rater reliability is therefore inferred.

Communication of interventions
Inconsistent responses were obtained for the documentation of assessment of skin integrity in two patient histories. The varied auditor interpretation of nursing notes and the level of completion of the pressure care/skin integrity form may have contributed to the inconsistent response. However, high inter-rater reliability was demonstrated at 80% consistency.

Language
Consistent responses were obtained for all patient histories inferring a very high inter-rater reliability.

Religious/Spiritual needs
The auditor responses for the religious/spiritual needs section demonstrated and 80% consistency indicating a high inter-rater reliability. The two histories with varying auditor responses were secondary to two missed documented entries; one from pastoral care and the other regarding spiritual needs documented in the Emergency Department.

Communication with family
Whilst high inter-rater reliability was demonstrated in ‘identifying how family are to be informed of patients impending death’, one variation in auditor responses may have been secondary to the definition of the question as one auditor marked no due to absence of documentation whilst the other auditor marked yes as family present remained throughout.

Communication within multidisciplinary team
Complete consistency of auditor responses was obtained for the ‘documentation of family discussion regarding the palliative approach to care’ and therefore indicated very high inter-rater reliability.
A high level of inter-rater reliability was evident with only one variation between auditor responses.

**Assessment and documentation of symptoms**

For the purpose of this section, one history was excluded from analysis of inter rater reliability secondary to the absence of relevant documentation to audit. This was due to the patient dying soon after the palliative approach was documented and prior to any nursing notes being entered. Therefore, the percentage has been calculated on the remaining nine (9) histories audited.

Whilst three sections (constipation, micturition, and psychosocial/spiritual needs – patient) demonstrated high inter-rater reliability over 80%, several other sections indicated lower levels of consistency between auditor responses.

Such discrepancies are likely a result of varied interpretation of whether the nursing documentation directly related to the symptom in question. Inter-rater reliability could be improved by providing further detailed definition about what constitutes reference to a specific symptom. The difficulties of auditing free text format documentation, as opposed to check box or yes/no answers should be noted as a potential factor in varied auditor responses.

**Care after death**

For the purpose of this section, one history was excluded from analysis of inter rater reliability secondary to the absence of relevant documentation to audit. This was due to the patient being discharged home prior to death. Therefore, the percentage has been calculated on the remaining nine (9) histories audited.

High inter-rater reliability was demonstrated in most sections relating to care after death.

A discrepancy between auditor responses relating to the ‘following of hospital policy for patient’s valuable and belongings’ may have been secondary to auditor error or varied interpretation of documentation.

Low inter-rater reliability was evident in whether the GP was informed of the patient’s death. Revision of the histories indicates that auditors had varying interpretation of what constituted a positive response to this question. Whilst one auditor based the response upon staff documentation of communication to GP the other auditor provided a positive response if a discharge summary was completed (as these are routinely sent to the GP). Further definition regarding the criteria for completion of this action may assist with increasing consistency of auditor responses.
Appendix 6. Clinician survey (local)

**Palliative Care Stroke Project – Clinician Survey**

This survey is being conducted as part of the Palliative Care Stroke Project, which aims to improve palliative care for people who have had a stroke and also improve carer support. The project is a joint initiative of the Palliative Care Service and Stroke Care Unit at the Royal Melbourne Hospital, and is funded by the Department of Health.

This survey aims to help the project team gain an understanding of current practice and needs in relation to the care of palliative stroke patients, and thus guide development and implementation of a care pathway and protocol for these patients. All clinical staff at The Royal Melbourne Hospital involved in the care of stroke patients are being asked to complete the survey. Further input will also be sought via focus groups.

Please complete the survey online or download a pdf. The completed survey may be returned to Gillian McCarthy in the Palliative Care Unit (fax: 9342 4928). Any queries or comments concerning the project can be directed to: [Gillian.mccarthy@mh.org.au](mailto:Gillian.mccarthy@mh.org.au) This survey has been approved by the Melbourne Health Human Research Directorate. The survey is anonymous.

---

**Clinical department**

1. In which department(s) do you currently work? (tick one or more)
   - [ ] Stroke Unit
   - [ ] Palliative Care Unit
   - [ ] General Medical Unit
   - [ ] Other (please specify):  

**Clinician background, training and experience**

The following questions will help us to gain an understanding of the nature of the clinical team providing care to stroke patients.

2. What is your professional background?
   - [ ] Nursing
   - [ ] Occupational Therapy
   - [ ] Medical
   - [ ] Physiotherapy
   - [ ] Speech Therapy
   - [ ] Other (please specify): 

3. In what year did you complete your basic training? 

4. Have you undertaken post graduate training (e.g. short course, diploma, graduate diploma, masters, advanced registrar training, fellowship, doctorate) in:
   - [ ] Neurology / stroke  
     - Yes  
     - No
   - Please describe:

   [ ] Palliative care  
     - Yes  
     - No
   - Please describe:
5. Is your current position (tick one)
   - [ ] Permanent
   - [ ] Bank
   - [ ] Agency

6. Is your current position (tick one)
   - [ ] Full time
   - [ ] Part time

7. How long have you worked at the Royal Melbourne Hospital? _____ Years _____ Months

8. Using the following table please describe your experience in providing care to patients with *stroke* (including acute, rehabilitation and/or palliative care)

<table>
<thead>
<tr>
<th>Description of position held involving care for stroke patients and type of ward</th>
<th>Type of facility</th>
<th>Location of position (Metro/Regional/Rural)</th>
<th>Duration of position (Months and/or years)</th>
</tr>
</thead>
</table>
| Examples: 
  - Nurse in neurological ward 
  - Physiotherapist | Public hospital Rehabilitation facility | Metropolitan Regional | 4.5 years 3 years |

9. Using the following table please describe your experience in providing *palliative care* (including for stroke and other conditions). Note the experience may overlap with that described in the previous question.

<table>
<thead>
<tr>
<th>Description of position held involving palliative care and type of ward</th>
<th>Type of facility</th>
<th>Location of position (Metro/Regional/Rural)</th>
<th>Duration of position (Months and/or years)</th>
</tr>
</thead>
</table>
| Examples: 
  - Nurse in neurological ward 
  - Nurse | Public hospital Hospice | Metropolitan Rural | 4.5 years 2 years |
Priorities for palliative care for stroke patients

The following questions will help us understand the issues relating to palliative care for stroke patients and the opportunities for improvement. These issues will be further discussed in the focus group(s).

10. Do you have previous experience in utilising a palliative care pathway (i.e. a tool used to guide, organise and integrate care delivered for patients requiring palliative care)?
   □ Yes □ No

   If YES, please describe briefly

   ________________________________________________________________

   What were your impressions of the pathway?

   ________________________________________________________________

11. Please indicate your level of agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally the palliative needs of stroke patients are well met within our unit/department</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There is an opportunity to improve integration between the stroke and palliative care services</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Implementation of a palliative care pathway for stroke would be beneficial in terms of supporting consistent patient care</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Implementation of a palliative care pathway for stroke would be beneficial in terms of improving efficiency</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Implementation of an additional rapid discharge pathway would be beneficial in improving the efficiency of discharge for palliative stroke patients</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>The potential benefits of a palliative care pathway for stroke are not clear</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>A palliative care pathway for stroke will add further administrative burden without obvious clinical benefit</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I feel I would benefit from further training in palliative care and end of life issues</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Implementation of a palliative care pathway would provide an opportunity to improve communication with carers regarding end of life issues</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Skills in palliative care / end of life issues are generally gained on-the-job</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
12. Please briefly describe any factors (enablers) that currently facilitate the timely and appropriate introduction of palliative care to stroke patients within your department.

________________________________________________________________________

________________________________________________________________________

13. Please briefly describe any factors (barriers) that impact on timely and appropriate care of palliative stroke patients within your department.

________________________________________________________________________

________________________________________________________________________

14. Please briefly describe any factors (barriers) that impact on timely and appropriate discharge of palliative stroke patients from your department (when patient and/or family have indicated this preference).

________________________________________________________________________

________________________________________________________________________

15. What benefits would you expect or wish to gain through the implementation of a care pathway for the palliative care of stroke patients.

________________________________________________________________________

________________________________________________________________________

16. Are there any further issues relating to palliative care for stroke patients that you feel might be addressed by this project? Please describe briefly.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

17. Would you be interested in attending a 90 minute focus group to explore further the issues raised in this survey?

☐ Yes ☐ No

If YES, please indicate which date would be more suitable:

☐ Wednesday 9th December 2009  ☐ Wednesday 13th January 2010

Thank you for your time
Appendix 7. Clinician survey (Statewide)

Palliative Care Stroke Project – Clinician Survey

This survey is being conducted as part of the Palliative Care Stroke Project, which aims to improve palliative care for people who have had a stroke and also improve carer support. The project is a joint initiative of the Palliative Care Service and Stroke Care Unit at the Royal Melbourne Hospital, and is funded by the Department of Health.

The survey aims to help the project team gain an understanding of current practice and needs in relation to the care of palliative stroke patients in Victoria, and thus guide development and implementation of a care pathway and protocol for these patients. A care pathway will be piloted at the Royal Melbourne for potential roll-out to other services. Clinicians involved in the Victorian Stroke Clinical Network are being asked to provide input to the project by completing this survey.

Please complete the survey online or download a pdf. The completed survey may be returned to Gillian McCarthy Gillian.mccarthy@mh.org.au, fax (03) 9342 4928.

Any queries or comments concerning the project can be directed to Gillian.mccarthy@mh.org.au. This survey has been approved by the Melbourne Health Human Research Directorate. The survey is anonymous in terms of individual completion but it would be helpful for us to know the service where you work.

Name of service:

Service demographics – current employment

Please tick the options that best describe the service in which you work:

1. Location:
   - [ ] Metropolitan
   - [ ] Regional
   - [ ] Rural

2. Number of beds:
   - [ ] < 20
   - [ ] 20 - 100
   - [ ] 101 - 300
   - [ ] > 300

3. Service type:
   - [ ] Acute hospital
   - [ ] Sub-acute service
   - [ ] Aged care service
   - [ ] Community based service
   - [ ] Other (please specify):

4. Which ward / department are you currently employed in?
   - [ ] Stroke specific
   - [ ] General medicine
   - [ ] Neurology
   - [ ] Emergency department
   - [ ] Palliative care
   - [ ] Other (please specify):
Clinician background, training and experience

The following questions will help us to gain an understanding of the nature of the clinical teams managing stroke patients.

5. What is your professional background?
   - Nursing
   - Occupational Therapy
   - Medical
   - Physiotherapy
   - Speech Therapy
   - Other (please specify): __________________________

6. In what year did you complete your basic training? ________________

7. Have you undertaken post graduate training (e.g. short course, diploma, graduate diploma, masters, advanced registrar training, fellowship, doctorate) in:
   - Neurology / stroke
     - Yes
     - No
   Please describe:
   ____________________________________________

   - Palliative care
     - Yes
     - No
   Please describe:
   ____________________________________________

   - Other that may be relevant to stroke or palliative care
     - Yes
     - No
   Please describe:
   ____________________________________________

8. Is your current position (tick one)
   - Permanent
   - Bank
   - Agency

9. Is your current position (tick one)
   - Full time
   - Part time

10. How long have you worked at your current position? _____ Years _____ Months

11. In your current position would you care for stroke patients:
   - Routinely (most days)
   - Often (at least weekly)
   - Occasionally (once or twice / month)
   - Rarely / never
   Please describe:
   ____________________________________________
   ____________________________________________
12. Using the following table please describe your experience in providing stroke and palliative care (including acute, rehabilitation aged care and/or palliative care)

<table>
<thead>
<tr>
<th>Description of position held and type of ward</th>
<th>Type of facility</th>
<th>Location of position (Metro / Regional / Rural)</th>
<th>Duration of position (Months and/or years)</th>
<th>Does this position involve: Stroke care</th>
<th>Palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examples:</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>• Nurse in neurological ward</td>
<td>Public hospital</td>
<td>Metropolitan Regional</td>
<td>4.5 years</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>• Physiotherapist</td>
<td>Rehabilitation facility</td>
<td>Regional</td>
<td>3 years</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Priorities for palliative care for stroke patients

The following questions will help us understand the issues relating to palliative care for stroke patients and the opportunities for improvement.

13. Does your service **currently utilise** care pathways in the following practice areas (i.e. tools used to guide, organise and integrate patient care):

For **acute management of stroke**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not applicable / Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>If <strong>YES</strong>, please describe briefly:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For **general palliative care**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not applicable / Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>If <strong>YES</strong>, please describe briefly:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For **stroke specific palliative care**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not applicable / Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>If <strong>YES</strong>, please describe briefly:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. Do you have previous experience in utilising a palliative care pathway for stroke (i.e. a tool used to guide, organise and integrate care delivered for patients requiring palliative care)?
   ☐ Yes  ☐ No
   If YES, please describe briefly

What were your impressions of the pathway?

15. Does your service routinely assess palliative care needs of stroke patients on admission to Emergency Department?
   ☐ Yes  ☐ No  ☐ Don’t know  ☐ Not applicable

16. Does your service routinely assess palliative care needs of stroke patients on admission to the stroke unit (or equivalent)?
   ☐ Yes  ☐ No  ☐ Don’t know  ☐ Not applicable

17. Please indicate your level of agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally the palliative needs of stroke patients are well met within our service</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>There is an opportunity to improve integration between the stroke and palliative care aspects of our service</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Implementation of a palliative care pathway for stroke would be beneficial in terms of supporting consistent care of stroke patients</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Implementation of a palliative care pathway for stroke would be beneficial in terms of improving efficiency within our service</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Implementation of an additional rapid discharge pathway would be beneficial in improving the efficiency of discharge for palliative stroke patients</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The potential benefits of a palliative care pathway for stroke are not clear</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A palliative care pathway for stroke will add further administrative burden without obvious clinical benefit</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Improving access to palliative care for people who have had a stroke and their carers – Appendices

18. Please briefly describe any factors (enablers) that currently facilitate the timely and appropriate introduction of palliative care to stroke patients within your service.

_____________________________________________________

_____________________________________________________

_____________________________________________________

19. Please briefly describe any factors (barriers) that impact on timely and appropriate care of palliative stroke patients within your service.

_____________________________________________________

_____________________________________________________

_____________________________________________________

20. Please briefly describe any factors (barriers) that impact on timely and appropriate discharge of palliative stroke patients from your department (when patient and/or family have indicated this preference).

_____________________________________________________

_____________________________________________________

_____________________________________________________

21. What benefits would you expect or wish to gain through the implementation of a care pathway for the palliative care of stroke patients.

_____________________________________________________

_____________________________________________________

_____________________________________________________
22. Are there any further issues relating to palliative care for stroke patients that you feel might be addressed by this project? Please describe briefly.

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

Thank you for your time
## Appendix 8. Key informant interviews

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Visited</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Melbourne Citymission                                   | 27-28/01/09      | - Two days were spent with staff from Melbourne Citymission.  
- The first day was spent with a staff member on the road observing what is involved in the daily rounds.  
- The second day was spent with staff taking referrals and observing how they are processed and prioritised. Priority is given to those imminently dying and visits can be arranged the next day if required.  
- Melbourne Citymission offers interdisciplinary community care to palliative patients living at home or in residential care facilities. The service offers advice on symptom and pain management, education of clients and carers, advice around resources available and access to pastoral care and bereavement support. Volunteers are available, although they are not permitted to carry out direct patient care. The service offers 7 days a week cover, with limited services over weekends and public holidays. Clients and carers have access to after hours support and can ring for advice or support at any time. RDNS case manage approximately 20% of MCM clients who require more direct nursing care in regard to wound care, diabetes management etc. MCM offers allied health involvement if required.  
- According to Melbourne Citymission records no stroke palliative patients were referred to their service in 2008. |
| Sunshine Palliative Care Unit and Broadmeadows PCU      | 29/01/2009       | - Referral processes and access issues were discussed with the Nurse Unit Managers of both the Sunshine Palliative Care Unit (PCU) and Broadmeadows PCU.  
- Some stroke palliative patients were admitted from acute hospitals to both units for imminent end-of-life care. The exact figures regarding the number of palliative stroke patient admissions were not available, however anecdotaly it was felt there were only a few palliative stroke patients admitted to either unit over the past year.  
- Both units would accept palliative stroke patients if appropriate. A triage system is in place regarding access to beds, and at times there is a waiting list for bed access in both services. |
| Melbourne Health Occupational Therapist (Rebecca Nicks and Rochelle Barnard) | 19/3/2009        | - Discussed the project and how Allied Health, in particular Occupational Therapy, could be involved.  
- It was discussed that issues surrounding equipment hire and discharge planning would be valuable for OT input and advice.  
- Advised to discuss these issues further with the managers’ from the Allied Health Department. |
<p>| Allied Health Allied Health Managers (Genevieve Juj, Jenifer Robinson) | 30/3/2009        | - Discussed the project and need for Allied Health, in particular Occupational Therapy, with involvement planned to commence around August 2009. The workforce imperatives and logistics of employing Allied Health personnel were discussed and support was gained to go ahead with this. |</p>
<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Visited</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Meeting with RMH Royal District Nursing Service liaison (Sue McClellan) | 22/4/2009 | • The project and the care able to be offered by RDNS upon patient discharge discussed.  
• The service providing at home care depends on the geographical location of the patient. RDNS offer a 24 hour service, and can visit regularly to attend to direct patient care needs. Waiting lists are in place, however patients can be prioritised. |
| Eastern Health Dr Sonia Fullerton | 28/5/2009 | • Eastern Health conducted a pilot of the Liverpool Care Pathway (LCP) in the stroke ward of Box Hill Hospital in 2008.  
• Education of staff prior to and during the pilot period and the processes of implementation were discussed at this meeting.  
• No patients were discharged home for end of life care during the pilot period. Four patients commenced on the pathway were taken off as they had an improvement in their condition and were deemed no longer suitable to continue on the pathway.  
• A pre and post implementation audit was conducted which showed improvement in documentation in most areas. It was stressed that to implement the LCP in this ward situation frequent education for all staff was required, and regular support offered to staff. Comments by staff after the pilot phase included that it gave them clearer guidelines and an increased confidence in dealing with end of life issues.  
• Eastern Health are applying for funding for a clinical nurse consultant to act as “lead nurse” to assist in implementing the pathway over the service, and it is felt that the introduction of the LCP will be self sustaining after the introductory period. |
| DHS Stroke Clinical Network (Adele Mollo and Sonia Denishenko) | 7/10/2009 | • Discussed the project to date. Suggestion to send the clinician survey to all members of the Victorian Stroke Clinical Network (VSCN) discussed and thought appropriate to gain an understanding of the needs of palliative stroke patients cared for in other institutions and settings (i.e. regional, rural, acute, sub-acute, aged care, community based).  
• Adele and Sonia felt there should be a question about the definition and understanding of palliative care concepts.  
• Suggestion that survey should go out on survey monkey accepted in order to make distribution and collation of the survey easier. |
| Melbourne Health Palliative Care Unit Occupational Therapist (Louise Meikle) | 21/10/2009 | • Discussed access to equipment. Small/standard item equipment is kept in stock and can be obtained from store room (Patient Appliance Centre) on Ground floor RMH whereas external providers are used for larger items such as hospital beds and pressure mattresses. Larger items can be ordered directly from external provider by Senior Clinician OT’s (or require approval from senior clinician)  
• Informed that Care Plus can do a Saturday delivery of hospital beds (and Pressure mattresses). Care Plus can also usually deliver within 4 hours of order. Life Healthcare are another external provider used for hospital beds and pressure mattresses |
Improving access to palliative care for people who have had a stroke and their carers – Appendices

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Visited</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Melbourne Health Stroke Unit Occupational Therapist (Kerry Orbons) | 28/10/2009 | - Suggestion was made that it is beneficial for the OT to inform the community palliative care services about where the equipment is from (usually via a phone call) to assist with smooth return of equipment after patient passes away  
- Informed that home visits are not essential when ordering a hospital bed (i.e. for space/placement) however, home visits are helpful for education to carer/family regarding caring for patient at home  
- Clinical Nurse Consultants complete the referral (via ISOFT) to the community Palliative Care services  
- Discussion regarding benefits of OT involvement in providing education to carers regarding quality of life aspects as well as equipment provision |
| Educators 4 South (Monique Poulter and Chris Nicholson) | 16/11/2009 | - Discussed the current OT role with stroke patients – stroke patients receive a blanket referral to OT. However, stroke patients who are assessed as palliative by medical team are not regularly seen by OT and currently a low priority as most pass away in hospital  
- Informed there are no current resources for quality of life aspects (i.e. relaxation techniques, environment)  
- Currently there are very limited resources for equipment brochures There are existing brochures for Carer Support Agencies  
- Informed of an existing generic RMH Carers Training Checklist which is used for high level care discharges which could have some relevant sections to guiding carer training for a palliative/stroke discharge  
- Informed that Clinical Nurse Consultant does the referral to the community palliative care service |
| Victorian Stroke Clinical Network Facilitators | 17/11/2009 | - Project discussed and issues other regions have in regard to palliative stroke patients discussed with the group.  
- The Clinical Pathway was presented and discussed. Most of the group were familiar with the concept of the LCP, and felt that it would be useful to have a care pathway for palliative stroke patients.  
- Issues raised by the group included access to specialist palliative care in their region and implementation of a palliative approach and how it differed depending on consultants understanding and use of specialist palliative care. |
<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Visited</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Educator Palliative Care Unit (Kassandra Russell)    | 17/11/2009   | • Discussed staff survey and distribution method, focus group and observational audit.  
• Discussed care pathway and implementation process. Education sessions will be available when pathway pilot commenced. The survey will be distributed to staff on 6SE.                                                                                         |
| Melbourne Health Palliative Care Unit Social Worker (Carissa Wild) | 18/11/2009   | • Discussion regarding difficulty in predicting length of time before death as this affects services/supports patient is referred to. If patient lives longer than anticipated, this can lead to a re-presentation as there is usually a delay in accessing required services in the community (if not referred directly from acute)  
• Recommendation that the population who are appropriate to use the pathway are very clearly defined.  
• Discussion regarding the role of Social Worker (SW) which involves completing an initial assessment based around information gathering and providing emotional support. Further SW input (when discharge has become the plan) around establishing who the main carer(s) will be and providing carer support (managing work/finances). SW works closely with OT to ensure all discharge requirements in place  
• Clinical Nurse Consultant completes the referral and all handover/liason with community palliative care agency  
• Informed that there is no formal written information provided to carers whilst on the ward. However there is a brochure regarding bereavement which is potentially given to families after the patient has passed away  
• Suggestion that areas which relate to quality of life are not as crucial as basic care education and training for patients who have a very short prognosis  
• Issue raised that when families (especially in some cases the proposed carer/close family) are in crisis, intake of verbal information can be limited  
• Discussed the need to ensure community palliative care services can contact/visit patient almost immediately after discharge to provide a continuum of support. It was also recommended that carers/family would benefit from access to 24/7 support. |
| OT Australia                                          | 24/11/2009   | • Phone call to Cheryl at OT Australia who reports the association do not have any resources relating to carer education or clinical interventions for stroke/palliative patients  
• Informed that information/resources at OT Australia pertaining to Stroke and Palliative patients are currently limited to discussion boards and special interest groups which are member only access. |
| Carers Victoria                                       | 24/11/2009   | • Phone call to Carers Victoria who reported they have a few resources for carers which may be relevant and will forward a copy to RMH.                                                                                                                                               |
Appendix 9. Pre-trial pathway questionnaire

Assessment of use of the Stroke Palliative Approach Pathway

Thank you for trialling the Stroke Palliative Care Pathway. Please answer the following questions regarding the use of the pathway.

1. How long (minutes) did it take to complete Section1 (initial assessment)?
_______________________________________________________________________

2. Are there any aspects of the pathway that are not clear in terms of how they are to be completed or what information is required? YES NO
Please describe briefly:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

3. Are there any aspects of the pathway that were not relevant for this patient?
If yes, please describe briefly: YES NO
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

4. Are there any areas not included in the pathway that you feel should have been included for this patient? YES NO
If yes, please describe briefly:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

5. Did the sections of the pathway flow well for ease of use? YES NO
If not, please describe briefly:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

6. Was it clear to you how to use the descriptors ‘A’ Achieved and ‘V’ Variance when using the pathway? YES NO
If not please describe why:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Continued overleaf......
7. What did you like most about using the pathway?
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

8. What did you like least about using the pathway?
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

9. Overall, and on a scale of 1 to 5 (1 being easy and 5 very difficult) how did you find using the pathway (please circle)?
   1  2  3  4  5

10. Do you have any further comments about the use of the pathway including any suggestions for improvement?
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Thanks for your time.

Any queries please phone Gillian 0419811298 or page 20580
Appendix 10. Final pathway

Stroke Palliative Approach Pathway
Royal Melbourne Hospital

Objective
This pathway has been developed to guide the multidisciplinary care of stroke patients in the last hours or days of life. It addresses the clinical and personal needs of the patient, as well as the needs of carers and is in line with current evidence and best practice in the areas of stroke and palliative care. The aims of palliative care are to:

- Affirm life and regard death as a normal process
- Neither hasten nor postpone death
- Provide relief from pain and other distressing symptoms
- Integrate the physical, psychological and spiritual aspects of care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help patients’ families cope during the patients’ illness and their own bereavement
- Uphold the right of every person to receive good end of life care

This Pathway is intended as a guide and does not replace clinical judgement. All decision making and changes in care, made in the best interests of the patient and family or carers, need to be assessed and reviewed regularly by the multidisciplinary team and communicated clearly to the patient where appropriate and to the family or carer. The pathway recognises that dying can be a complex and uncertain process. There may be times when a person lives longer than expected, or dies sooner than anticipated.

Pathway criteria
This pathway supports an appropriate care approach for stroke patients, implemented once the multidisciplinary stroke team has considered the clinical situation and the wishes of the patient and family / carer, and agrees that:

- There is an anticipation of imminent death OR an expectation of poor prognostic outcome OR the patient is in a semi-comatose or comatose state and not expected to improve, as a result of severe stroke and/or other concurrent co-morbidities.

Using the care pathway

- Undertake an initial assessment and commence appropriate palliative approaches according to Section 1 as soon as possible after a palliative approach has been documented by the medical team in the patient medical record.
- Provide ongoing care and monitoring according to the clinical domains identified in Section 2.
- Each goal should be marked as ‘A’ (Achieved) or ‘V’ (Variance). If a goal is not achieved this should not be viewed as a negative; it reflects that individual care, assessment and clinical needs of each patient and the needs of the family and carer are being regularly assessed and met.
- If a Variance ‘V’ is recorded, document the reason for the variance in the patient’s medical record.
- The appropriateness of interventions should be assessed for each individual patient. Treatment protocols for pain, terminal restlessness and agitation, respiratory tract secretions, nausea and vomiting and dyspnoea are included at the end of this pathway documentation.

Also note:

- The Stroke Palliative Approach Pathway should remain in the medical record.
- This pathway replaces the Nursing Care Plan
Section 1. Initial assessment and initiation of palliative approach
The nurse caring for the patient should complete this section as soon as medical staff have documented in the patient medical record that a palliative approach is to be adopted

**Diagnosis**
- Stroke diagnosis
- Other significant diagnoses
- Presenting symptoms
- Date referred to palliative care service via ISOT
- Date pathway commenced

**Goal 1: Non-essential medications are discontinued and medication is prescribed for common symptoms which may arise**
- Current medications assessed and non-essential medication discontinued
- Parenteral route of medication delivery prescribed for those not able to swallow oral medication
- Syringe driver commenced if required and appropriate equipment available
- PRN comfort medication written up on IP12 for the following (see protocols at the back of care pathway for guidance)
  - Respiratory tract secretions
  - Agitation
  - Seizure activity
  - Pain
  - Nausea and vomiting
  - Constipation
- Comfort medications readily available or ordered from pharmacy

**Goal 2: The patient’s need for current interventions has been reviewed by the multidisciplinary team**
- Interventions reviewed:
  - Antibiotics
  - Vital signs
  - Blood tests (inc. blood sugar monitoring)
  - Limitation of medical treatment form completed including information regarding not for MELT call (IP4)
  - Possibility of a reportable death to the coroner identified and per Melbourne Health Policy 1.4.38

**Goal 3: The patient’s skin integrity is assessed**
- Assessment of skin integrity as per Melbourne Health Pressure Ulcer Prevention Assessment and Planning Form (IP/OP 8G)

**Goal 4: The provision of nutrition is reviewed by the multidisciplinary team**
- Oral food and fluid for comfort / patient enjoyment, at safest consistency
  - Educate family and carers that a reduced need for food is a natural part of the dying process

**Goal 5: The patient is able to take a full and active part in communication**
- Record primary language
- Interpreter required
- Patient has an advance care plan
- Patient has a Medical Power of Attorney
- Organ / tissue donation discussed with patient / family if appropriate
- Patient has expressed wish for organ / tissue donation

**Goal 6: The family / carer is able to take a full and active part in communication**
- Record primary language
- Interpreter required

**Goal 7: The patient has been able to express their religious / spiritual needs**
- Pastoral care contacted

**Goal 8: The family / carer has been able to express their religious / spiritual needs**
- Consider if the family or carer has any specific religious or spiritual needs that need to be addressed

**Goal 9: Family / carer understand that the goals of care are now palliative**
- Identify how family / NOK are to be informed of patient’s imminent death
- Primary contact
- Secondary contact
- Family / NOK given hospital information (e.g. car parking, visiting times, any other relevant information, ward clerks aware that family may be staying after visiting hours, valuables taken home)

**Goal 10: Multidisciplinary team is aware that the patient is now for a palliative approach to care**
- Multidisciplinary team notified by group page (neurology team # 7590) of commencement of palliative approach

If you have charted a Variance please complete reason for variance in the patient medical record

Health Professional
Name
Signature
Designation
Date
### Section 2. Ongoing care and assessment

<table>
<thead>
<tr>
<th>Goal</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal 12: The patient does not have pain</strong></td>
<td>- Patient does not verbalise or show any signs of pain. Observe for non-verbal clues. If in pain consider position change and / or analgesia.</td>
</tr>
<tr>
<td><strong>Goal 13: The patient is not agitated</strong></td>
<td>- Patient does not show any signs of delirium, terminal anguish, restlessness / thrashing, plucking, twitching. Exclude retention of urine or constipation as cause. If agitated consider need for positional change.</td>
</tr>
<tr>
<td><strong>Goal 14: The patient does not have excessive respiratory tract secretions</strong></td>
<td>- Confirm that IV fluids are discontinued. Anticholinergic given as required. Discuss symptoms with family / carer and offer reassurance. Consider need for positional change.</td>
</tr>
<tr>
<td><strong>Goal 15: The patient is not breathless</strong></td>
<td>- Anxiolytic / opioid given as required. Consider need for positional change.</td>
</tr>
<tr>
<td><strong>Goal 16: The patient does not have nausea</strong></td>
<td>- Confirm enteral feeding is discontinued. Give anti-emetic as required.</td>
</tr>
<tr>
<td><strong>Goal 17: The patient does not have bowel problems</strong></td>
<td>- Chart bowel actions daily. Give aperients as required.</td>
</tr>
<tr>
<td><strong>Goal 18: The patient does not have urinary problems</strong></td>
<td>- Initiate urinary catheter only if patient is in retention. Provide pads if incontinent.</td>
</tr>
<tr>
<td><strong>Goal 19: The patient’s comfort and safety regarding medication is maintained</strong></td>
<td>- Medications are given as per IP12 (If medication not required please record as N/A). If syringe driver is in progress check at least 4 hourly and record on IP12 E</td>
</tr>
<tr>
<td><strong>Goal 20: The patient’s personal hygiene needs are met</strong></td>
<td>- Patient is clean and comfortable. Relatives are included in care of patient if appropriate.</td>
</tr>
<tr>
<td><strong>Goal 21: The patient’s mouth is moist and clean</strong></td>
<td>- Regular mouth care is attended to. If appropriate educate family in regard to mouth care.</td>
</tr>
<tr>
<td><strong>Goal 22: The patient’s skin integrity remains intact</strong></td>
<td>- Assess skin integrity as per MHPUHMP (IP/OP 86). Consider need for pressure relieving air mattress.</td>
</tr>
<tr>
<td><strong>Goal 23: The patient does not have other symptoms (e.g. oedema, itch)</strong></td>
<td>- Patient is aware of situation and informed of procedures as appropriate. Touch and verbal communication continued as appropriate.</td>
</tr>
<tr>
<td><strong>Goal 24: The patient’s psychosocial / spiritual needs are met</strong></td>
<td>- Family / carer understand death is imminent, goals of care are palliative. Family / carer are aware of the patient’s imminent death and that they recognise measures are being taken to maintain comfort. Discuss patient symptoms as required. Offer pastoral care and social work support. Ensure physical needs of those attending the patient are accommodated. Ensure awareness of ward facilities, visiting hours etc. Provide family with information brochures as required.</td>
</tr>
<tr>
<td><strong>Goal 25: The family / carer’s psychological / spiritual needs are met</strong></td>
<td>- If decision is made to die at home commence ‘Discharge Home Pathway’.</td>
</tr>
</tbody>
</table>

### Shift

<table>
<thead>
<tr>
<th>Shift</th>
<th>Date</th>
<th>Name (print)</th>
<th>Full signature</th>
<th>Designation</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
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</tr>
</tbody>
</table>
Section 1a. To be completed by the Specialist Palliative Care Team after patient review

Goal 11. Location of dying has been discussed with the family / carer

<table>
<thead>
<tr>
<th>Planned location of dying</th>
<th>Achieved</th>
<th>Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing end of life care at home for your family member's brochure provided to carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If decision made to discharge patient home</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section 3. To be commenced when it is decided that patient is going home to die

Objective

This section has been developed to guide the multidisciplinary care of stroke patients who are palliative and who are to be discharged home to die.

- It should be followed when the patient or family / carer have elected for the patient to die at home.
- It should not be commenced unless the multidisciplinary team have agreed that the patient is dying, and the team, patient and family / carers support the patient going home to die.

This is a multidisciplinary plan of care. Each discipline should initial after the intervention has been attended to and record their full details in the name register at the end of the section.

Discharge home pathway commenced – Date ______________ Time ______________ Proposed date of discharge ______________

Goal 27: Non-essential medications are discontinued and post discharge medications are prescribed for common symptoms which may arise

<table>
<thead>
<tr>
<th>Current medications assessed and non essential medication discontinued</th>
<th>Achieved</th>
<th>Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenteral route of medication delivery prescribed (for those not able to swallow oral medication)</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>Syringe driven commenced if appropriate Date commenced</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>PRN subcutaneous comfort medications written up and prescribed as take home medication ensuring adequate supply until review by GP (see sheets at the back of care path for guidance) Date commenced</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>Respiratory tract secretions Agitation Seizure activity Pain</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>Nausea and vomiting Breathlessness Constipation</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>Comfort medications ordered and dispensed or pharmacy script provided</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>Pharmacy alerted to discharge and need for rapid supply of discharge medication</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
<tr>
<td>If patient is on a syringe driver ensure it is refilled just prior to discharge</td>
<td>Achieved</td>
<td>Variance</td>
</tr>
</tbody>
</table>

Goal 28: Interventions required for discharge to the community have been completed

- Referral made to Community Palliative Care via Scitti tool
- Community Palliative Care alerted to patient discharge and need for early assessment
- Post Acute Care referral completed for community services
- Equipment requirements assessed and ordered by the Occupational Therapist
- Equipment delivered to discharge residence and in place ready for use
- Community nursing service informed of the source of all equipment items loaned to patient
- Care / Family are provided with a summary outlining source and relevant contacts for equipment
- Care / Family Training Checklist completed and Family / Carer have received training in all relevant areas of care

Goal 29: The family / carer understand and are prepared for patient to be discharged home for end of life care and are aware death is imminent

- Family / other aware of planned discharge date / time
- Name of primary carer
- Relationship
- Tel no.
- Discharge address
- Family / carer aware of how community nursing services will contact them
- Family / Carer informed of ward contact number for assistance prior to Community Palliative Care visit

Goal 30: Relevant correspondence compiled ready for patient discharge and in accordance with Melbourne Health policy

- Patient's GP is aware and supportive of discharge home
- Written discharge plan / summary completed and provided to family / carer prior to discharge
- Copy of discharge plan / summary sent to GP and relevant community services
- Copy of discharge plan filed in patients medical record
- Family / carer provided with information regarding referrals and appointments which have been organised

Goal 31: Transport is arranged in preparation for patient discharge

- Ambulance booked for transport
- Ambulance staff alerted that patient is Not for Resuscitation and provided with a copy of the Limitations of Treatment form

If you have charted "Variance" against any goal so far, please complete variance in patient history

<table>
<thead>
<tr>
<th>Shift</th>
<th>Date</th>
<th>Name (print)</th>
<th>Full signature</th>
<th>Designation</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 4. Verification of death:

<table>
<thead>
<tr>
<th>Date of death</th>
<th>Time of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relative or carer present at time of death</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>If not present has a relative or carer been notified</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
</tr>
<tr>
<td>Is this likely to be a coroner’s case</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

### Care after death

**Goal 32: Procedure for laying out followed according to Melbourne Health Procedure (Procedure 1.4)**

- Family consulted about specific religious / cultural / spiritual needs
- All jewellery should be removed from the body and lodged with security. Clothing/valuables belonging to the patient can be collected from the security officer. The nurse in charge, following proof of identification, may issue personal effects from the ward and this should be noted in the Medical Record (Melbourne Health Policy 1.6.5.7).
- In Coronal inquiries all therapeutic, surgical and resuscitative equipment either inserted or attached to the body must remain in situ

**Goal 33: Family or carer are aware of the procedures following death and are provided with appropriate information**

- Bereaved family / visitors allowed privacy to view the body
- Next-of-kin advised to contact a funeral director of their choice
- Property packed for collection
- Medical certificate provided for family members if appropriate
- Family given information about procedures following death; coroners, post mortem, organ donation as required
- Information booklet “When someone dies” and information leaflet on bereavement and local support services given to family

**Goal 34: The primary health team and GP are contacted regarding patient’s death**

Melbourne Health protocol followed regarding the recording of patient’s death (Melbourne Health Procedure 1.4.5)

If you have charted a Variance please complete the reason for variance in the patient medical record

<table>
<thead>
<tr>
<th>Health Professional</th>
<th>Name</th>
<th>Signature</th>
<th>Designation</th>
<th>Date</th>
</tr>
</thead>
</table>
1. **Pain treatment protocol**

![Flowchart of pain treatment protocol]

**Supporting information**
- To convert from other opioids contact the Palliative Care Team for further advice as needed.
- If symptoms persist contact the Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay in responding to a symptom if it occurs.
2. **Nausea and vomiting treatment protocol**

**Assess nausea and vomiting**

- **Nausea/vomiting present**
  1. Metoclopramide 10mg s/c bolus injection 4 hourly prn
  2. After 24 hours review symptom. If two or more prn doses given, then consider medical review and use of a syringe driver
  3. Metoclopramide 40-60mg s/c via syringe driver over 24 hours

- **Nausea/vomiting absent**
  1. Metoclopramide 10mg s/c 4 hourly prn

**Supportive information**
- If symptoms persist contact the Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay in responding to a symptom if it occurs.

3. **Respiratory tract secretions treatment protocol**

**Assess respiratory tract secretions**

- **Present**
  1. Hyoscine Hydrobromide 0.4mg s/c bolus injection. Consider syringe driver 1.2mg over 24 hours
  2. Continue to give prn dosage accordingly
  3. Increase total 24 hour dose to 2.4mg after 24 hours if symptoms persist

- **Absent**
  1. Hyoscine Hydrobromide 0.4mg s/c prn

**Supportive information**
- If symptoms persist contact the Palliative Care Team.
- Glycopyrronium 0.4mg s/c prn may be used as an alternative.
- Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay responding to a symptom if it occurs.
4. **Dyspnoea treatment protocol**

![Diagram of dyspnoea treatment protocol]

**Assess dyspnoea**

- **Dyspnoea present**
  - Is patient already taking oral morphine for breathlessness?
  - **YES**
    - Convert to s/c morphine and give 4 hourly or via a syringe driver – for further advice and support liaise with the Palliative Care Team
  - **NO**
    - 1. Morphine 2.5mg – 5mg s/c prn
    - 2. After 24 hrs review medication, if three of more doses required prn then consider a syringe driver at 5-10 mg/24 hrs over 24 hrs

**Supportive information**
- If the patient is breathless and anxious consider midazolam stat 2.5mg s/c prn.
- If symptoms persist contact the Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay responding to a symptom if it occurs.

5. **Terminal restlessness and agitation treatment protocol**

![Diagram of terminal restlessness and agitation treatment protocol]

**Assess restlessness and agitation**

- **Restlessness/agitation present**
  - 1. Midazolam 2.5 – 5 mg s/c prn
  - 2. After 24 hours review medication. If three or more doses required or ineffective within 24 hours, then consider medical review and syringe driver
  - 3. Midazolam via syringe driver 5-10 mgs over 24/24

- **Restlessness/agitation absent**
  - 1. Midazolam 2.5 - 5 mgs s/c prn
  - 2. If three of more doses required prn, consider the use of a syringe driver over 24 hrs

**Supportive information**
- If symptoms persist contact the Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay responding to a symptom if it occurs.
## Appendix 11. Carer training checklist

### CARER TRAINING CHECKLIST

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Education &amp; Demonstration</th>
<th>Carer Trial of Care 1</th>
<th>Carer Trial of Care 2 (further training not required if carer is competent)</th>
<th>Carer Trial of Care 3 (further training not required if carer is competent)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Date</td>
<td>Staff member/denomination</td>
<td>Date</td>
<td>Staff member</td>
</tr>
<tr>
<td>Wounds</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifying and caring for wounds and pressure areas</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Safe manual handling techniques and back care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rolling on to side in the bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using slide sheets to move in the bed or reposition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting out of bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving to/from chair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobilising with a gait aid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using a standing or mobile hoist to get out of bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using a standing or mobile hoist to get out of a chair</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

*Please document carer progress and outcomes of training in the patient's current progress notes.
<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Education &amp; Demonstration</th>
<th>Care Trial of Care 1</th>
<th>Care Trial of Care 2</th>
<th>Care Trial of Care 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toileting</td>
<td></td>
<td>Date</td>
<td>Staff member</td>
<td>Further trial?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes/No</td>
</tr>
<tr>
<td></td>
<td>Crossing (x) out activities not applicable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Using a bottle/pan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Managing catheters/</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>changing bags</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Changing incontinence pads</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Giving a sponge wash in bed</td>
<td></td>
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<tr>
<td></td>
<td>Assisting with showering</td>
<td></td>
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<tr>
<td></td>
<td>using a shower chair/</td>
<td></td>
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<tr>
<td></td>
<td>commode</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Assisting with undressing</td>
<td></td>
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<tr>
<td></td>
<td>/dressing</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Understanding peg feeding</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Preparing required</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>dietary meals</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Assisting with feeding</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Managing/administering</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>daily medications</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Managing diabetes and</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>associated medications</td>
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<tr>
<td></td>
<td>Using a nebuliser and/or</td>
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<tr>
<td></td>
<td>oxygen</td>
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<tr>
<td></td>
<td>Discussing communication</td>
<td></td>
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<tr>
<td></td>
<td>problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Managing difficult</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>behaviors</td>
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</tr>
</tbody>
</table>
Appendix 12. Equipment hire agreement for palliative care patients

Royal Melbourne Hospital Occupational Therapy
Equipment hire agreement for Palliative Care

The following equipment has been provided on loan from the Royal Melbourne Hospital Patient Appliance Centre [Ph: 9342 7578]:

_____________________________________________________________________
_____________________________________________________________________

The following equipment has been provided on loan from an external supplier:
☐ Care plus living solutions [Ph: 1300 85 45 15]
☐ Life health Care [Ph: (03) 9384 1846]
☐ Other ____________________ [Ph: ____________________]

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

The equipment is on loan for a period of 30 days free of charge from ___/___/___ to ___/___/___, after which the patient is responsible for ongoing hire costs. After 30 days, your Community Palliative Care Service (ticked below) may be able to assist with equipment funding. Please contact them before 30 days to discuss.

<table>
<thead>
<tr>
<th>Region</th>
<th>Palliative care service</th>
<th>Contact number</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>City and north</td>
<td>(03) 9486 2666</td>
</tr>
<tr>
<td>☐</td>
<td>West</td>
<td>(03) 9364 9777</td>
</tr>
<tr>
<td>☐</td>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

If the equipment is no longer required, please contact the relevant provider.

If in doubt about what to do, please contact your Occupational Therapist (OT) on (03) 9342 7440.

OT name: ___________________________ Date: ___________________________

cc. Patient/family member, Royal Melbourne Hospital Medical file Community Palliative care team, Equipment hire company
Appendix 13. Palliative care after stroke – Information for families and carers (brochure)
What is palliative care and what is involved?

Palliative care is the term used to describe the physical, psychological, emotional and spiritual support provided to people who have a progressive, life threatening or life-ending illness, such as severe stroke. It also includes the care provided to family and carers during this difficult time.

For the patient, palliative care aims to ensure comfort, quality of life and dignity during the dying process. The sort of care provided depends on the individual patient, however, it will usually involve:

- ceasing active medical treatments such as medications, diagnostic tests, invasive procedures and artificial feeding
- introducing supportive care to make the patient more comfortable, both physically and emotionally

For families and carers, palliative care involves providing emotional support, information and practical guidance.

Who provides palliative care?

The Stroke Care team provides expert care for patients who have had a stroke, including providing palliative care when needed. The team will talk to family members / carers about the patient’s needs and help make decisions about their care. If, after discussion with the family, it is decided that a palliative approach is best, the Stroke Care team will make changes to treatment. This may also involve referral to the Palliative Care Service.

The Palliative Care Service is a team of health professionals, who coordinate the medical, nursing and other services required by each patient. The Palliative Care team will work closely with staff in the Stroke Unit to assess your family member’s needs and to develop a suitable plan of care.

They will talk to you about changes to the patient’s treatment and options for ongoing care; and help you access support services such as pastoral care and social work.

If you are aware of any special requests which you would like considered throughout this time, please discuss them with the team caring for your relative. These may be cultural, spiritual or other aspects you feel would be important to your family member.
What changes can I expect and what can I do to help?

Some of the common symptoms that may occur during the last few days of life following a stroke are described below. These may not be experienced by every person, and they may not occur in any particular order.

Pain
The person may experience some pain, either as a result of their stroke or because of another health problem. It may be difficult for them to tell staff they are in pain, however they will be closely observed, and medication will be given to make sure they are as comfortable as possible.

Secretions
Coughing and swallowing reflexes are often affected by a stroke, leading to saliva and mucus collecting in the back of the person’s throat. This causes gurgling, bubbling or other noise. This noise can be distressing to others, but rarely causes distress to the person. Medication can be given to reduce these secretions. Changes of position in bed can also help.

Intravenous fluids and nasogastric feeding are usually stopped as the extra fluid is no longer required and can put added stress on the body, leading to a build up of fluid and increased respiratory or airway secretions.

Breathing
Breathing patterns may change. Sometimes the person’s breathing may be rapid, and at other times there may be long pauses between breaths. Breathing may also be shallow or noisy. This is not painful or distressing for the person. Medication can be provided to ease breathing difficulties.

Sleep and alertness
The person may be drowsy and difficult to wake. It is common for people who have had severe strokes to have changes in their level of alertness from day to day and throughout the day. Occasionally people can become restless and agitated. Medication can be given to reduce this symptom.

Appetite and thirst
It is common and normal for a person’s appetite and thirst to be reduced during the dying process. Sips of water, ice chips or a moist mouth swab can be beneficial during this time. Please discuss with the medical team before giving other food or fluid.

Nausea and vomiting
The person may have some nausea and vomiting as a result of their stroke. This will be managed with medication.

Temperature
The person’s temperature may fluctuate during this period. They may alternate between being cold to touch and hot and clammy, and their skin may become blotchy and discoloured. This is a normal part of dying and is due to slowing of the blood circulation. Light bed clothes are best at this time. If necessary a fan can be used.

Incontinence
As a person drinks less fluid, the amount of urine they produce will decrease and their urine may become stronger and darker in colour. As a result of their severe stroke, the person may also become incontinent (lose control of their bladder or bowels). This can be managed by providing incontinence pads and protective sheets.
Can my relative go home to die?

You may have wondered or been asked by hospital staff if it is possible for the patient to go home.

Providing end of life care for your relative at home in a non-clinical and familiar environment can be very rewarding for some people. Other people feel that the hospital is the most suitable place for their relative to die given the round the clock nursing care and ready access to other support and assistance.

Should you prefer to take your family member home it is important to discuss this as soon as possible with hospital staff to allow time to arrange for appropriate equipment and services at home. There are some occasions where it is not practical for a patient to be discharged home.

What about organ donation?

You may be asked by staff caring for your relative to consider organ or tissue donation.

This involves giving your consent to allow specific organs or tissues to be retrieved from the deceased person so that they may be given for transplant to a person whose life it may improve. In some cases the deceased person may have left instructions to proceed with organ or tissue donation, and you will be asked to support this instruction with your consent.

In other cases staff will ask you to make this decision on behalf of the deceased person, discussing with you all aspects of the process and how respect for the deceased is maintained at all times. We encourage you to ask as many questions as you need to allow you to make an informed decision.

Whatever you decide, staff will provide you with as much information as you need, as well as support in the form of specially trained counsellors. There will also be time to allow family, friends or special people to visit with the deceased person.

Additional Information is available from:
Victorian Organ Donation Service; Life Gift
Ph: (03) 9349 4762 or 1300 133 050 (Free call)
www.organdonor.com.au
Contact details
The Royal Melbourne Hospital

The Specialist Palliative Care Service at The Royal Melbourne Hospital is available between 8am and 4.30pm Monday to Friday.

Contact may be made via one of the Palliative Care Clinical Nurse Consultants:

- **James Watt**
  9342 7000 – ask for pager 27067

- **Marian Allison**
  9342 7000 – ask for pager 20305

The **Stroke Clinical Nurse Consultant** at The Royal Melbourne Hospital is available between 8am and 4.30pm Monday to Friday.

- **Louise Weir**
  9342 7000 – ask for pager 2425

Questions?
If you have any questions or concerns, write them down so that you can remember to discuss them with the healthcare team

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Issued: March 2010
Authorised by: Approved by Director Palliative Care Services, The Royal Melbourne Hospital
Appendix 14. Providing end of life care at home for your family member – Information for families and carers (brochure)
Planning for end of life care at home

Providing end of life care for your family member at home can be a very fulfilling role, allowing your loved one to die at home in a familiar and comfortable setting. However, it can also be physically and emotionally demanding, so it is important to plan carefully and involve other family members/friends as you will need their support.

Listed opposite are the steps involved in planning to take your loved one home. The hospital staff will guide you through this process, and more detailed information is provided later in this brochure. Please raise any questions or concerns with the staff to make sure you and your family feel comfortable and confident to provide care for your family member.

Please also be aware that things can arise unexpectedly which may mean discharge home is not recommended. Our staff will keep you informed of any changes.

---

1 Providing end of life care at home for your family member

---

Planning for end of life care at home

☑ Discussions with the family
Once you have told hospital staff that you would like to take your family member home, they will arrange a meeting with relevant family members to talk about the plan for discharge. This is a good time to ask any questions or raise any concerns you may have.

☑ Ongoing support
Whilst your family member is in hospital, ongoing emotional support and information about practical matters (such as finances and work) will be available.

☑ Equipment
Equipment which may assist you with caring for your family member will be organised by the occupational therapist. They will discuss the set up of your home and teach you how to use the equipment. The equipment will be delivered to your home before your family member is discharged home.

☑ Learning how to care for your family member
Before you take your family member home, the occupational therapist and nursing staff will teach you about how to care for them, including bathing and hygiene and rolling them in bed.

☑ Access to community services
A referral to a Community Palliative Care service will be arranged by the Palliative Nurse Consultant to make sure you have ongoing support at home.

Practical services, such as help with home cleaning, which may assist with caring for your family member at home will be also arranged by hospital staff.

☑ Transport
When all equipment and services have been organised, a time for your family member to go home will be confirmed and an ambulance will be booked to provide transport for your family member.
What assistance is available after my family member has come home?

Specialist staff from a Community Palliative Care Service will visit after your family member has been discharged home. They will be available to answer any questions you may have and will:
- Help manage pain and other symptoms
- Assist with medication management
- Provide you with any instruction you need about caring for your loved one
- Arrange additional care needed
- Provide emotional and spiritual support to your loved one and the family
- Provide support in coping with bereavement and grief

Following the initial visit, the Community Palliative Service will also give you a 24 hour contact phone number to make sure you can get advice and support when you need it. It is a good idea to record this number in the back of this brochure.

The hospital staff will also discuss with you any practical services which may be available while you are caring for your family member at home. This may include help with personal hygiene for your loved one as well as cleaning or in home respite.

Practical information to help you care for your family member at home

☑ Moving the person in bed
The nurses and occupational therapist will show you how to roll your family member on to their side in bed. This will help when you are bathing or dressing your family member in bed. Changing their position in bed is also important for keeping them comfortable.

☑ Equipment to help provide practical care
The equipment you will need will depend on your individual situation. However, common pieces of equipment include an electric hospital bed and a pressure relieving mattress. An electric bed can be raised or lowered with an adjustable head rest to make sure your family member is comfortable and to make it easier for you to care for them. A pressure relieving mattress also provides comfort and helps prevent pressure areas developing.

☑ Hygiene and bathing
General hygiene is an important part of caring for your loved one and keeping them comfortable. The hospital staff will teach you about this before you take your family member home. Some important things to remember include:
- making sure your family member is wearing fresh clean night clothes
- making sure their continence pads are changed as required
- that their mouth is kept clean and moist
Improving access to palliative care for people who have had a stroke and their carers – Appendices

- **Dressing**
  Dressing your family member can be quite a difficult task as this will need to be done in bed and they may not be able to provide any assistance with movement. It is best to use loose fitting clothing or nightwear. Hospital staff will teach you the best approach to dressing.

- **Pain**
  Before your family member is discharged home, the medical staff will organise medications for pain relief. If your family member appears to be in pain at home, contact your general practitioner or Community Palliative Care Service.

- **Mouth care**
  As your family member is unlikely to be drinking fluids, their mouth may become dry. To keep them comfortable, it is important to make sure their mouth (including lips and tongue) is clean and moist. This can be done by applying swabs soaked in water every 1 to 2 hours. Vaseline/lip balm should not be applied if your relative is using oxygen at home as this can result in burns.

- **Bladder and bowel care**
  The nursing staff will give you information about pads and absorbent sheets for the bed.

The Community Palliative Care Service will be able to provide further information and support in each of these areas when they visit you at home.

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### Creating a calm and comfortable environment

A calm and comfortable environment can be beneficial for both you and your family member. This might include:
- Placing photos or favourite items in the room to make it more familiar
- Maintaining a comfortable temperature in the room
- Keeping items you might need close at hand, such as mouth swabs and face washers
- Quietly playing your family member’s favourite music

![Image of hands]

### Caring for the carer

It is very important to make sure that you, as a carer, are well supported and have time to rest.
- Consider rotating the care role between a few family members or friends to give yourself a rest
- Consider any offers of assistance (such as meals or shopping) from family or friends
- Keep all contact phone numbers in a convenient location to ensure they are easily available should you need assistance or support
- Discuss convenient visiting times with family and friends if you are feeling overwhelmed by visitors

Providing end of life care at home for your family member
How will I know that death has occurred?

Many people are very concerned about what will occur when their family member passes away; however, the actual moment of death is usually very peaceful.

When your family member dies, you may notice some of the following:
- Their chest will stop moving
- An absence of breathing or pulse/heartbeat
- They cannot be roused
- Blinking will stop however, their eyes and mouth may remain open
- Their skin may appear pale and feel cool to touch
- They may pass some urine or faeces

What do I do when my family member has died at home?

After your family member has died, there is no need to do anything immediately.

- Their body can remain at home for a few hours however, it is a good idea to remove all heat sources from within the room (i.e. electric blankets, hot water bottles, heaters).
- You may prefer to sit with your loved one or contact family members/friends who you would like to be present or allow them to come and say their goodbyes.
- You will then need to contact the GP and/or Community Palliative Care Service to inform them of the death of your family member as a doctor will need to visit to sign a medical certificate of death.
- You do not have to bathe your family member (unless you would prefer to) however, it is important to straighten out their limbs and replace any dentures.
- It is advisable not to shave your family member after death as this requires a special process and can be discussed with your funeral director.
- Refer to a will or speak with other family members to determine any end of life preferences that your family member may have indicated (i.e. regarding burial or cremation).
- Following a visit from the doctor you can contact a funeral director who will arrange to collect the body.

For more information refer to the brochure What to do when someone dies, which is available through the Palliative Care Service.
Returning equipment

After your family member has passed away, the equipment which was provided to assist with their care can be returned. Some families prefer the removal of the equipment to occur promptly whilst others prefer to deal with this task after the funeral.

To organise pick up of the equipment, you can contact the equipment provider directly or contact your Community Palliative Care nurse and discuss your preferred arrangements.

Questions?
If you have any questions or concerns, write them down so that you can remember to discuss them with the healthcare team.

Contact details
The Royal Melbourne Hospital

Palliative Care Nurse Consultant: __________________________
Phone: __________________________

Occupational Therapist: __________________________
Phone: __________________________

Social Worker: __________________________
Phone: __________________________

Ward (to speak with Nurse in Charge): __________________________
Phone: __________________________

Other: __________________________

Community Referrals / Services
________________________________________
________________________________________
________________________________________
________________________________________
________________________________________

Providing end of life care at home for your family member
Appendix 15. What to do when someone dies – Information for families, friends and carers (brochure)
Introduction

The management and staff of the Royal Melbourne Hospital wish to express our sincere condolences to you at this time.

Our staff will do their best to support you to carry out what is appropriate to your needs, recognising there are many different cultural, spiritual and traditional beliefs and practices associated with death. This booklet provides information that you may find useful, including:

- Answers to some of the questions that you and your family may ask
- Information about how you might expect to feel and how you can help other members of your family, including children
- Details of support services in the community, which may be able to assist you in the weeks and months ahead
- A list of practical issues you may need to attend to

Please inform our staff as soon as possible if you have any particular needs, including any cultural or spiritual needs, or any traditional customs that you would like assistance in arranging.

What to do when someone dies - Information for families, friends and carers 2
Important contacts

Interpreters
If you have English language difficulties or if English is not your first language we can arrange for an interpreter to assist you. Please ask staff to arrange for a professional interpreter, by asking directly or showing your Interpreter Card.

Telephone Interpreter Service (TIS) Ph 131 450

This service is free of charge for all the Government funded organisations marked with the following symbol:

Palliative Care

The Palliative Care Service at the Royal Melbourne Hospital is a team of health professionals who coordinate the medical, nursing and other services required by patients who are dying. They also provide emotional support, reassurance and practical guidance to families. The Palliative Care Service work closely with allied health professionals. Staff are available to answer your questions and to offer information and support during this time.

Our clinical nurse consultants can be contacted from Monday to Friday, 8am – 4.30pm. Contact the hospital (03) 9342 7000 and ask for the Palliative Care Nurse Consultant.

Pastoral care

Pastoral Care staff at the Royal Melbourne Hospital are available to assist with any spiritual needs you may have, whatever your culture or religious denomination. Please ask a staff member if you would like to contact Pastoral Care and this will be arranged.

A special quiet room (sacred space) is available for family and friends to use if needed. This room is located on the ground floor of the main building of the Royal Melbourne Hospital, on the right hand side as you head towards the Royal Women’s Hospital. It is sign posted, but please ask staff to direct you if you are unsure of how to get there.

Financial support

Funeral arrangements can be expensive and some people are entitled to financial support through Centrelink.

To check if you are entitled to any assistance contact the Centrelink office in your area. Further information can be obtained from the Centrelink website www.centrelink.gov.au. See also page 10.

More useful contacts

More useful contacts, including counselling and bereavement services, are included on page 22.
What happens next? Some frequently asked questions

Can visiting or viewing be arranged?
Viewing your loved one who has died or sitting with them while they are still in their hospital bed can be arranged. Please discuss your needs with staff and let them know if you are waiting for additional family members to arrive.

Viewing the body is a very individual decision. For some people, seeing the deceased person is an important part of their grieving process as it enables them to understand the person is no longer alive. Others would prefer not to.

Viewings can also be arranged through the funeral director. This can give family or friends who were not able to be at the hospital at the time of death, or soon after, an opportunity to say their final goodbyes. It is important to remember a cost may be associated with this request.

A viewing can also be very important if the deceased person is to be transferred interstate or overseas for burial, cremation or internment.

How long will the deceased person stay in hospital?
The deceased person will remain at the hospital until you have arranged a funeral director and given them permission for transfer to occur to the funeral home or other arranged location.

If an autopsy is to be carried out there may be a delay in releasing the body to the funeral director. Another cause for delay can be the involvement of the State Coroner. For further details on autopsies and the State Coroner see page 15.
**How do I go about making funeral arrangements?**

There are number of things to consider when making funeral arrangements:

- **Pre-paid funerals:** Check if the deceased person has left any paperwork indicating they have pre-paid their funeral arrangements, including burial or cremation or internment decisions, with a particular company.

- **Which funeral director?** The Royal Melbourne Hospital does not recommend particular funeral directors, preferring you to discuss this decision with your family or friends. Consult your local telephone directory for a listing of funeral directors. Most offer 24 hour service every day of the year.

- **Options:** It is a good idea to meet with your chosen funeral director to discuss your choice of: burial, internment or cremation of the deceased person. The type of funeral and specific rituals can also be discussed at this time.

In some circumstances, families may wish to have the deceased person buried, cremated or interred in a different town, interstate or overseas. This should be discussed with the funeral director as soon as possible.

- **Costs and financial support:** Costs and services vary between funeral directors and we recommend you talk with, and compare, a few different companies before making any final decision to ensure your needs will be met. The funeral director should provide a written quote.

Some people are entitled to financial support through Centrelink for funeral arrangements (refer page 10).

- **Certificates and paperwork:** The funeral director will arrange for the deceased to be removed from the place of death, and they will provide certificates for the burial or cremation service. They will also collect all information required for registering a death and send it to the relevant authorities. A copy of the Death Certificate for the next of kin is also usually arranged by the funeral director, and this may take several weeks.

- **Other legal obligations:** The only legal requirement is to make arrangements for the burial, internment or cremation of the deceased person's body through a recognised cemetery or crematorium. There is no legal requirement for a service or ritual of any kind.
Other practical issues

There are a number of practical issues which may arise in the days and weeks following a person’s death. You may wish to ask another person to help you organise these things, or carry them out on your behalf. Some people find attending to these practical tasks is often helpful. It is important to do what you feel is right for you. Do not be afraid to ask others for assistance as many people like to feel useful at this time, but do not know how to help.

Wills

A Will is a legal document that states how the deceased person’s belongings are to be distributed after their death. It may take into account:

- The likely value of their estate
- Special funeral arrangements
- Prepaid cemetery plots
- Beneficiaries and special gifts
- Organ donation
- Appointing an Executor

It is important to locate the deceased person’s Will as soon as possible to ensure that any final instructions they may have are carried out.

For legal advice about Wills and final instructions contact any of the following:

- The Victorian State Trustees
  Ph: (03) 9667 6444
  www.statetrustees.com.au
- The Victorian Legal Aid Commission
  Ph: (03) 9269 0234 or 1800 677 402 (country callers)
  www.legalaid.vic.gov.au

- A private solicitor of your choice (refer to the local telephone directory for a list)

Probate

The Probate Office is part of the Supreme Court, which officially recognises an Executor, the person authorised to finalise an estate. If there is no Will, the Probate Office will appoint an Executor (usually the next of kin) for the estate. The Probate Office will give you guidelines identifying the tasks that need to be completed. A solicitor or Trustee Company may be nominated to assist with the responsibilities of being an ‘Executor’.

The Probate Office
Ph: (03) 9603 9296

Financial support

Funeral arrangements can be expensive and some people are entitled to financial support through Centrelink.

To check if you are entitled to any assistance contact the Centrelink office in your area. Further information can be obtained from the Centrelink website www.centrelink.gov.au.

Bereavement Assistance is a ‘not for profit’ funeral director run as an ethical charity. It can provide the actual funeral service: cremation or burial, including chapel service with an experienced funeral celebrant if required. They can provide a dignified, low-cost funeral service for those on social security or for people with no family or friends.

Payment is based on pension status and estate.

92 Atherton Road
Oakleigh VIC 3166
Ph: (03) 9564 7778    Fax: (03) 9564 7775
Email: info@bereavementassistance.org.au
Who to notify – checklist

When someone dies, a number of people and organisations need to be told. The list below offers a guide to some of the people or organisations who may need to be contacted.

<table>
<thead>
<tr>
<th>Person or organisation to be contacted</th>
<th>Contact person, phone number and address (if needed)</th>
<th>Details of person who died (e.g. account no., Medicare no.)</th>
<th>Notified of death (Yes / No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members, relatives and friends</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Executor of the Will</td>
<td></td>
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<tr>
<td>Solicitor</td>
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<tr>
<td>Australian Taxation Office</td>
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<tr>
<td>Doctor, dentist and any other health practitioners involved in the deceased person's life</td>
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<tr>
<td>Banks, credit unions</td>
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<tr>
<td>Centrelink</td>
<td>13 23 00 <a href="http://www.centrelink.gov.au">www.centrelink.gov.au</a></td>
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<tr>
<td>Clubs (e.g. the Returned and Services League)</td>
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</tbody>
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Who to notify – checklist (continued)

<table>
<thead>
<tr>
<th>Person or organisation to be contacted</th>
<th>Contact person, phone number and address (if needed)</th>
<th>Details of person who died (e.g. account no., Medicare no.)</th>
<th>Notified of death (Yes / No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department of Veterans Affairs</td>
<td>13 32 54</td>
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<tr>
<td>Australian Electoral Commission</td>
<td>13 23 26</td>
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<tr>
<td>Employers</td>
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<tr>
<td>Health benefits fund</td>
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<tr>
<td>Insurance companies</td>
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<tr>
<td>Landlord, tenants</td>
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<tr>
<td>Local council</td>
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<tr>
<td>Medicare</td>
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<tr>
<td>Local post office</td>
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<tr>
<td>Preferred funeral director</td>
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<tr>
<td>Superannuation company</td>
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<td></td>
<td></td>
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<tr>
<td>Utilities (e.g. gas, electricity and phone companies)</td>
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<tr>
<td>Vehicle registration and licensing authorities</td>
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</table>
Organ or tissue donation

You may be asked by staff to consider organ or tissue donation.

This involves giving your consent to allow specific organs or tissues to be removed from the deceased person and given for transplant to a person whose life it may improve. In some cases the deceased person may have left instructions to proceed with organ or tissue donation, and you will be asked to support this instruction with your consent.

In other cases staff will ask you to make this decision on behalf of the deceased person. They will provide information and discuss all aspects of the process, encouraging you to ask as many questions as you need to. Support is also available from specially trained counsellors. Importantly, there is time for family, friends or special people to visit the deceased person.

Additional information is available from DonateLife Victoria
Ph: (03) 8317 7400   Free call: 1300 133 050
Email: donatelife@arcbs.redcross.org.au
www.donatelife.gov.au

DonateLife Victoria is part of a national network of organ and tissue donation agencies.

Post mortem examination (autopsy)

Post mortem (after death) examinations or autopsies are conducted to help understand the cause of a person’s death.

There are two different types of autopsies:
• Non coronial autopsies which occur at the hospital
• Coronial autopsies, which are part of the State Coroner’s review process

The Coroner becomes involved when a person:
• Dies unexpectedly or is involved in an accident, injury or dies in an unnatural way
• Was in the custody of police prior to death
• Died unexpectedly during a medical procedure
• A doctor was unable to sign a death certificate giving the cause of death
• The identity of the person is not known

A person who dies as a result of asbestosis will always be referred to the Coroner.

Non coronial autopsy

An autopsy cannot be conducted by the hospital without the consent of the ‘senior available next of kin.’ Before you give permission, Royal Melbourne staff will discuss what is going to happen and why it is helpful. They will also give you an opportunity to ask any questions.

Staff will also check documentation to see if the deceased person has provided any objections to autopsy.
It is very important at this time that you let staff know any special cultural customs that may be related to handling of the deceased person’s body.

Where next of kin are not available, permission for autopsy may also be given by the Designated Officer (an appropriate Royal Melbourne Hospital staff member).

In some cases the deceased person may have requested an autopsy for themselves. This will be carried out provided the request is confirmed in writing by two witnesses who were present at the time the person made the request.

Once the post mortem examination is complete, the funeral director will be able to transfer the deceased into their care.

Involvement of the Victorian State Coroner

Usually a review by the Coroner involves a phone call between the hospital staff and the Coroner. Occasionally, the deceased person will need to be transferred from the hospital directly to the Coroner’s Court for a more detailed review.

An autopsy or pathology tests may need to be carried out. You must inform Royal Melbourne staff if you do not want an autopsy to be carried out on the deceased person. Staff can then advise the Coroner of your wishes and this can be taken into account.

Depending on the circumstances of death, specialist reports from experts, such as police, doctors, fire brigade etc, and statements from witnesses may also need to be gathered. Only a small number of deaths involve an inquest (court hearing), where all the evidence and reports are reviewed. Most investigations involve people who have died of natural causes.

A Royal Melbourne Hospital doctor will discuss any decisions or outcomes with the family. Family members may also consult the Coroner’s Office directly if they would like to discuss any issues further.

Coroner’s Service Centre
Ph: 1300 309 519
www.coronerscourt.vic.gov.au

TIS – Translating and Interpreter Telephone Service: Ph: 13 14 50 Telephone this service if you need an interpreter to speak to the hospital or Coroner. This service is free of charge for all Government funded organisations marked with the following symbol.

The Coroner’s Court has a list of support services for individuals or families involved in this process.

Delay in funeral arrangements

Transfer of the body of the deceased person to the funeral director may be delayed longer than 24 hours if the Coroner is involved. This does not usually take longer than 48 hours, and the funeral director can transfer the deceased person directly from the Coroner’s Office on your behalf.

Please ask Royal Melbourne Hospital staff to advise the Coroner if you require funeral arrangements to take place within a certain time frame for specific reasons.
Understanding and coping with grief

Grief is the response that we have when we have experienced a significant loss. It is a natural response to a loss, and each person’s experience is unique and highly personal. This section explains how you might feel and respond, and provides practical advice to help you through the grieving process. More information may be found in the resources listed on page 24.

Feelings
The feelings you experience when someone close to you dies may include guilt, loneliness, sadness, anger, shock and fatigue. You may also feel a sense of relief and acceptance, especially if the deceased person had been ill for a long time, or the relationship with that person had been difficult.

Thoughts
Your thoughts may include preoccupation with the loved one and a sense of the presence of the person. You may also experience confusion, including an increasing search for answers to life questions or rejection of previously formed spiritual beliefs.

Physical reactions
Common physical reactions to grief can include a change in appetite, fatigue and lack of energy. A ‘hollow stomach’ or butterflies and dry mouth are also common.

Behaviours
Your behaviour is also likely to be affected by grief. Crying is a common reaction. You might also be more sensitive or overactive; you might avoid or seek things that remind you of the loved one; your sleeping patterns may change; and you may withdraw from social situations.

It is important to remember that there is no right or wrong way to feel or express grief. Expressions vary from one culture, tradition or spirituality to another. Individuals from the same family or group can also feel and express their grief differently to those around them. It is important to respect each other’s way of grieving.

Helpful strategies
Grief is like an unknown journey that you cannot control or plan for, and it will be an individual process for everyone. Be patient with your grief process as it takes different amounts of time for each individual. For some people the grief never goes away but does become more bearable over time. As the intensity diminishes, it will become easier to focus on special positive memories. Overleaf are a few practical suggestions to help get you through the difficult times.
Privately and personally

You may like to keep your thoughts and feelings to yourself:
- Try not to make big decisions too soon
- Create a memorial – do or make something to honour the person who has died
- Continue the relationship with the person who has died by talking to them, looking at photos, visiting special places
- Develop your own rituals – light a candle, listen to special music, make a special place to think about the person
- Exercise – do something with your pent up energy such as walking, swimming or gardening

With other people

Sharing your thoughts and feelings with other people can reduce the sense of isolation and feelings of loneliness that come with grief:
- Allow people to help you – you will be able to help someone else at another time
- Talk to a trusted person about your feelings
- Don’t feel you have to grieve all the time – try some things you enjoy when you feel up to it

It is important to remember that what is helpful to you may not be the same for others around you. Even the people close to you may not be able to respond to your feelings, perhaps saying unhelpful things or not saying anything at all. If possible, try to tell the people around you what you need them to do.

Getting professional help

If your grief does feel overwhelming there are professional counsellors available to help and support you through this time, so don’t be afraid to ask for help. See the list of support services provided on page 22.

Supporting children and helping them to understand death

Depending on their age, children express their grief differently to adults. This can include asking lots of questions about the deceased person:
- Where are they?
- What is happening to them?
- When will they be coming home?
- Where are they going?

If children have not experienced anyone dying or have not had the experience of an animal dying, such as a pet cat or dog, they may want to know what being dead means. It is very important for adults to answer children’s questions as honestly as possible and to be age appropriate. If you or other adults do not feel comfortable answering these questions please ask the hospital staff, funeral director or a counsellor to help you with this.

Answers that are vague or indicate the deceased person has gone away or passed away only confuse and sometimes distress children more. Not knowing where someone is can make it harder for children to trust that other adults who may be absent will return as promised. Sometimes children feel frightened that these adults may also leave them. If a child thinks somebody has just gone away, they may think they have done something wrong if there has always been contact and there is no contact now.

Involving children in a viewing

Involvement of children in a viewing of the deceased person should be encouraged where appropriate to your specific traditions. Sometimes children like to place special items in the coffin or casket with the deceased person, and if they cannot do this themselves, items can be given to the funeral directors to arrange for them.
Involving children in the funeral service
Where appropriate to your specific traditions, involving children in any form of service, ritual or time of remembering gives them an opportunity to feel part of what is happening. Depending on their age, they can be given an opportunity to share a story or draw a picture that shows something important to them about the deceased person. Even the simple task of giving out a service leaflet or some kind of memento can be enough to involve them.

The most important part of any participation is having an adult present who will answer honestly and age appropriately the questions children ask. This adult needs to explain to them what is happening and why, and what is the meaning of the different things people are doing.

Support agencies offering further information about supporting children through the grief process are listed on page 22.

Supporting children
Helping children to grieve and express their feelings varies from one culture, tradition and family to another. Where appropriate to your specific traditions, try to support children to share their thoughts and feelings and participate in any events that remember or honour the person who has died.

Useful contacts
Listed below are the contact details of some of the organisations in the community who support people after someone has died.

**Australian Centre for Grief and Bereavement**
Bereavement and Counselling Support Service and Kids Grieve Too
Ground Floor, McCulloch House
Monash Medical Centre
246 Clayton Road
Clayton VIC 3168
Ph: (03) 9265 2111 (Monday – Friday)
Email: counselling@grief.org.au
Web: www.grief.org.au

**24 hour Telephone Support**
Griefline (noon to 3 am)
Ph (03) 9596 7799

Lifeline
Ph 13 11 14

Suicide Helpline
Ph 1300 651 251

Mensline
Ph 1300 789 978

Kids Help Line
Ph 1800 551 800
Other organisations

NALAG (Vic)
National Association for Loss and Grief
NALAG can provide the contact details of counsellors in your local area
Ph: (03) 9650 3000
www.nalagvic.org.au

Solace – Support Group for Bereaved Partners
Solace provides grief support for those grieving over the death of their partner
Ph (03) 5331 4730

The Compassionate Friends – Bereaved Parents Centre
For parents who have suffered the death of a son or daughter at any age, from any cause
Ph: (03) 9888 4944 or 1300 641 091 (Free call)
www.compassionatefriendsvictoria.org.au

Western Region Community Health Centres
Provide free or low cost counselling. Community Centres include:
Banyule Community Health (Ph: (03) 9450 2000)
Darebin Community Health Service (Ph: (03) 8470 1111)
Dianella Community Health Service (Ph: (03) 8345 5678)
Djerriwarrh Health Service (Ph: (03) 8746 1100)
Doutta Galla Community Health Service (Ph: (03) 9377 7100)
ISIS Primary Care Ltd (Ph: (03) 9296 1200)
Merri Community Health Service (Ph: (03) 9387 6711)
Sunbury Community Health Centre (Ph: (03) 9744 4455)
Western Region Health Centre Ltd (Ph: (03) 8398 4100)

Palliative care organisations, psychologists, social workers and counsellors
Refer to your local telephone directory or discuss with hospital staff.

Useful resources

The resources listed are a guide only and we encourage you to speak to Royal Melbourne Hospital Staff for recommendations about any new materials that may be available.

Reading materials can also be found through your local library.

Additional resources are also available from the following organisations:

Australian Centre for Grief and Bereavement
Ph: (03) 9265 2111 (Monday – Friday)
Email: counselling@grief.org.au
www.grief.org.au

Open Leaves Books
A specialist bookshop which can provide resources on grief and loss
Ph: (03) 9347 2355
www.openleaves.com.au

Books to read with children
There are many different children’s books, which can be helpful when supporting children through the death of someone they know or love. The following could be read with a child.

Badger’s parting gift
Susan Verley (1992)

Beginnings and endings with lifetimes in between
Bryan Mellonie and Robert Ingpen (2005)

Gentle willow: A story for children about dying
Joyce C. Mills (1993)
Grandma's shoes
Libby Hathorn and Caroline Magerl (1994)

Grandpa
Lilith Norman and Noela Young (1998)

The grief book: Strategies for young people

General reading list

A to Z, Reflections on loss and grief
Linda Espie, Australia (2003)

Grief and remembering: 25 Australians tell it like it is
Allan Kelleher, Australia (2001)

Lessons of loss: A guide to coping
Robert A Neimeyer, USA (2001)

Now that the funeral is over: Understanding the effects of grief
D. Zagdanski, Australia (1997)

Stuck for words: What to say to someone who is grieving
D. Zagdanski, Australia (1994)
Appendix 16. Training PowerPoint

Palliative Care Stroke Project
Pathway Training and Information Session

Aim of palliative stroke project information session
- To provide staff caring for palliative stroke patients with the knowledge and skills to implement the Stroke Palliative Approach Pathway (SPAP)
  - Knowledge and understanding of the palliative stroke project
  - Knowledge and understanding of the Stroke Palliative Approach Pathway (SPAP) and how it is to be used, including discharge criteria

Session Outline
- Review the principles of palliative care
- What is the palliative stroke project
- Care pathways and why we are utilising them
- How to utilise the Stroke Palliative Approach Pathway
- Possibility of discharge home and how this will be raised with carers / families
- Process of discharge
- Resources developed to support use of the SPAP
- Further education to be provided

Principles of palliative care
- Affirm life and regard death as a normal process
- Neither hasten nor postpone death
- Provide relief from pain and other distressing symptoms
- Integrate the physical, psychological and spiritual aspects of care
- Offer a support system to help patients live as actively as possible till death
- Offer a support system to help patients' families cope during the patients' illness and their own bereavement
- Uphold the right of every person to receive good end of life care

Palliative Stroke Project
- 18 month pilot project funded through the DHS (January 2009 – June 2010)
- Supporting recommendation nine of the Stroke Care Strategy for Victoria
  - Appropriate and culturally sensitive palliative care should be provided and communication with carers / family members undertaken in accordance with existing national guidelines and Strengthening palliative care – policy for health and community care providers 2004-09

Palliative Stroke Project
- WHY
  - Growing interest in the role of palliative care in non-malignant disease
  - Despite the high mortality and morbidity level in stroke, evidence to guide palliative care in this area is lacking
  - Limited information available on the needs of carers, especially in regard to possibility of discharge home
Care Pathways

- Map out a patient’s journey
  - ‘the right people, doing the right things, in the right order, at the right time, in the right place, with the right outcome’

Care Pathways

- Main aims:
  - Help improve clinical outcomes
  - Support the introduction of evidence-based medicine and use of clinical guidelines
  - Improve multidisciplinary communications and care planning
  - Decrease unwanted practice variations
  - Improve clinician – patient communication and patient satisfaction
  - Help ensure quality of care and provide a means of continuous quality improvement

Care Pathways

- Benefits:
  - Reduce variations in care from case to case (and consultant to consultant) in the same department
  - Facilitate the introduction of local protocols based on research evidence into clinical practice
  - Encourage multidisciplinary communication and care planning
  - Enable new staff to learn quickly the key interventions for specific conditions and to appreciate likely variations
  - Embed clinical audit into daily practice

Development of Stroke Palliative Approach Care Pathway (SPAP)

- Based on the Liverpool Care Pathway (LCP) adapted for local use
- Goal of pathway:
  - Meet the needs of patients and their carers by providing timely assessment, education and access to palliative care services as required.

Stroke Palliative Approach Care Pathway

- Introduction
  - Sets out the objective, criteria and use of the pathway
- Section 1
  - Initial assessment and initiation of the palliative approach
- Section 2
  - Ongoing care and assessment
- Section 3
  - Discharge home
- Section 4
  - Verification of death
Utilisation of the SPAP

- When to commence the pathway
- How to utilise the pathway
- Who completes each section

Resources developed

- Staff brochure
- Carer brochures
  - Family and carer information
  - Discharge home information
  - “When somebody dies” information

Resources developed

- Where they will be kept
  - 4 South and 6 South East
- Who will give resources out

Why examine the process of discharge for Palliative Stroke patients?

- Population which has not been greatly examined from a discharge process perspective
- To facilitate a smooth and efficient discharge for palliative stroke patients whose families would like to take their relative home to die
- To guide staff in the process of discharging palliative stroke patients home (via the pathway)
- The aim is not to persuade or ask families to care for their family member at home but rather attempt to fulfil the families wishes should they want to take their relative home

Resources to Support the Discharge of Palliative Stroke Patients

- ‘Providing End of Life Care for your Family Member at Home’ brochure
- Carer Training Checklist
- Stroke Palliative Approach Pathway - Section 3

Considerations for the Discharge of a Palliative Stroke patient

- The exact process will vary for each individual patient
- A discussion must occur between Specialist Palliative Care Medical staff and the patient’s family/carer to determine proposed location of dying (and documented in Section 1a of the pathway)
- If the proposed location of dying is at home, this can only be confirmed following all relevant Allied Health assessments (i.e. OT assessment of home environment)
- Different to a standard discharge home
  - High Care needs (i.e. training, support)
  - Family emotional/grief
  - Short time frame to organise discharge
  - Anticipate only short period (i.e. days) at home prior to death
Potential Process and Multidisciplinary Involvement in a Palliative Stroke Discharge

1. Family identify wish to take patient home to die during discussion with Medical staff and Palliative Nurse Consultant (Documented in patient's file).
2. Palliative Nurse Consultant completes referral and liaison with Community Palliative Care Service and initiates needed Allied Health referrals.
3. Occupational Therapist establishes home environment information, determines care training requirements (to be included on Care Training Checklist) and organises required equipment.
4. Ward nursing staff and OT complete care training as per care training checklist.

Potential Process and Multidisciplinary Involvement in a Palliative Stroke Discharge (cont)

1. Social Work provides emotional support for family and organises any required community services (outside the scope of the Community Palliative Care Service).
2. Medical Staff provides post-discharge instructions, discusses preferences of care with family and completes required discharge correspondence.
3. Referrals and services organised. Equipment delivered and ready for use at patient’s home.
5. Patient is discharged home via ambulance.

Further education

- Palliative stroke management
- Family communication
- Discharge information
## Appendix 17. Training evaluation form

**Palliative Care in Stroke**  
**TRAINING EVALUATION**

We would greatly appreciate your feedback on today’s session. Your comments will be confidential and will be valuable in planning future sessions.

Please indicate your response to the following statements by ticking the appropriate box.

<table>
<thead>
<tr>
<th>Relevance of training content</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The program content was relevant to the needs of my role/function at work</td>
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</tbody>
</table>

Comments:

<table>
<thead>
<tr>
<th>Activities and materials</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. The structure of the training was logical and easy to follow</td>
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<td></td>
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<tr>
<td>3. The training materials (e.g. manual, handouts) were well presented and useful</td>
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<tr>
<td>4. There was a good balance between theoretical content and application to cases</td>
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</table>

Comments:

<table>
<thead>
<tr>
<th>About the trainer</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. The personal style and language of the trainer was appropriate</td>
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<tr>
<td>6. The level of expertise of the trainer was appropriate</td>
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Comments:

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Improving access to palliative care for people who have had a stroke and their carers – Appendices
Perceived training outcomes

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<thead>
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<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>This training program improved my understanding of the palliative approach to patient care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8.</td>
<td>As a result of this training I feel confident in using the Palliative Approach in Stroke Pathway</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9.</td>
<td>As a result of this training I feel more confident in my role in supporting palliative care of stroke patients</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10.</td>
<td>This training program improved my understanding of the role of the Palliative Care Service</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11.</td>
<td>As a result of this training I feel more confident in communicating with families and carers about the palliative approach</td>
<td>☐</td>
<td>☐</td>
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</tr>
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Comments:

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

12. Please note if there are any areas where you would benefits from further guidance/ training (tick any that are appropriate):

☐ Palliative care – general principles

☐ Palliative care – clinical considerations in stroke

☐ Communicating with family members/carers about end of life issues

☐ Discharge process for end of life at home

☐ Other (please specify):

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

Thank you for your assistance
Appendix 18. Palliative care after stroke – Information for staff (brochure)
What is palliative care?

Palliative care encompasses the coordinated medical, nursing and allied services for people who have a progressive, life-threatening and/or life-ending illness. It aims to improve the quality of life of patients and their families, through early identification, assessment and management of pain and other symptoms, and to provide psychosocial and spiritual support.

At the Royal Melbourne Hospital, palliative care advice and services are available through the Palliative Care Service.

The Principles of Palliative Care

- Affirm life and regard death as a normal process
- Neither hasten nor postpone death
- Provide relief from pain and other distressing symptoms
- Integrate the physical, psychological and spiritual aspects of care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help patients’ families cope during the patients’ illness and their own bereavement
- Uphold the right of every person to receive good end of life care

About the Palliative Care Service

The Palliative Care Service at the Royal Melbourne Hospital consists of specialist palliative care consultants and specialist clinical nurse consultants. They work closely with allied health professionals in the hospital, including occupational therapy, pastoral care and social work. The Palliative Care Service offers both a consultative based service as well as an in-patient service.

The Palliative Care Service assists in managing patients’ symptoms and supporting family and staff in the care of the patient in the palliative stage.

The Service provides specialist advice in a range of areas related to patient and carer support including:

- symptom assessment and management (including pain management, nausea, shortness of breath and restlessness)
- recognition and management of the dying/terminal phase and supporting staff in this process
- patient prognosis and rate of illness progression
- input into decision-making regarding cessation or non-commencement of treatment
- issues related to fluid and food management, modification or cessation
- issues related to medication rationalisation/cessation
- advance care planning and power of medical attorney appointment
Accessing the Palliative Care Service

**When can a patient be referred to the Palliative Care Service?**

A patient can be referred to the Palliative Care Service if they have a progressive, life threatening or life-ending illness, such as severe stroke, and their condition has progressed beyond the stage where curative treatment is effective and cure is attainable. Patients on the Stroke Care Unit can be referred to the Palliative Care Service after discussion with medical staff and the family.

**How do I refer a patient to the Palliative Care Service?**

After discussion with the Stroke Care team and family, a referral for consultation should be made via i-soft. Patients will be seen within 24-hours of referral (Monday-Friday). Urgent referrals should be made by contacting the consulting staff via pager (see back page of this brochure for details).

**What happens after a palliative care referral?**

The Palliative Care Service can act as a consultative service, with the patient remaining under the care of the Stroke Care Unit, or patient care can be transferred to the Palliative Care team. The decision to transfer care to the Palliative Care Service will be made on a case by case basis by the medical staff of both units. If patient care is transferred to the Palliative Care team, depending on bed availability, the patient may be transferred to the Palliative Care Unit on 6 South East.

**The Stroke Palliative Care Pathway**

There has been a growing interest in the role of palliative care in patients dying of non-malignant disease, including stroke, and recognition of the need to guide such service provision in the clinical setting. As part of a Department of Health funded project, the Palliative Care Service has developed a clinical pathway to support consistent access to appropriate palliative care services for stroke patients and their families/carers. Implementation of the pathway is supported by clinician training and carer resources.

**What is the Stroke Palliative Care Pathway?**

The Stroke Palliative Approach Care Pathway (SPAP) is a structured, multidisciplinary care plan which details essential steps in the care of palliative stroke patients. It provides guidance on key aspects of care including:

- discontinuation of non-essential medications
- discontinuation of active treatment interventions
- anticipatory prescribing of comfort medications
- general comfort measures
- various psychosocial and spiritual needs, including information for carers

The SPAP maps out a patients journey and ensures that “the right people, do the right things, in the right order, at the right time, in the right place, with the right outcome”.

---

Palliative care after stroke - information for clinical staff
The pathway is divided into four sections, corresponding with the phases of patient management:
- Initial assessment and initiation of the palliative approach
- Ongoing care and assessment
- Discharge home
- Verification of death

It also includes protocols for comfort measures such as pain management.

**When can I start a patient on the Stroke Palliative Approach Pathway (SPAP)?**

Once the medical team has documented in the patient medical record that a palliative approach to care is to be commenced, and it has been discussed with the family, the patient can commence on the SPAP. A patient **MUST NOT** commence on the pathway prior to a palliative approach being discussed and documented by medical staff in the medical record.

**Criteria for commencing the SPAP**

The multidisciplinary stroke team has considered the clinical situation and the wishes of the patient and family/carer, and agrees that, as a result of severe stroke and/or other concurrent co-morbidities:
- there is an anticipation of imminent death **OR**
- an expectation of poor prognostic outcome **OR**
- the patient is in a semi-comatose or comatose state and not expected to improve.

**Frequently Asked Questions**

**What information is available for carers?**

The Palliative Care Service has produced a number of useful information resources for carers to help them understand the palliative approach and what to expect, as well as what to do after a person dies. These resources are available on the Ward and through the Palliative Care Service and include:
- **Palliative care after stroke**
- **Providing end of life care for your family member at home**
- **What to do when someone dies**
How do I discuss end of life issues with family members?

Due to the often sudden nature of stroke, discussing end of life issues with family members can be difficult. It is important to approach families with empathy and ensure that they feel respected and understood.

Consider asking the family what they have been told by other health care professionals and what other information they have sourced (e.g., Internet). Be willing to initiate and engage in conversations about what may happen in the future, and also be aware of cultural differences in information preferences and attitudes to discussing prognosis and dying.

The Stroke and Palliative Care teams are available to assist you if required (see contact details on the back of this brochure).

What do I do if the family wants to take the person home?

If family members ask about taking the person home, staff should contact the Palliative Care team to discuss this. The Palliative Care team will review the home situation and provide advice regarding the possibility of discharge home. If it is decided that the patient will be discharged home, the patient will be commenced on Section 3 of the SPAP – Discharge Home.

Information about home discharge is included in the brochure Providing end of life care for your family member at home, which is available through the Palliative Care Service.

References
2. Strengthening Palliative Care: a policy for health and community providers 2004-09
3. Stroke Care Strategy Victoria, Department of Human Services 2009

Information about the palliative approach, including how family members can assist is included in the brochure Palliative care after stroke – information for families and carers, which is available through the Palliative Care Service.
Contact details
The Royal Melbourne Hospital

The Specialist Palliative Care Service at The Royal Melbourne Hospital is available between 8am and 4.30pm Monday to Friday.

Contact may be made via one of the Palliative Care Clinical Nurse Consultants:

James Watt
9342 7000 – ask for pager 27067

Marian Allison
9342 7000 – ask for pager 20305

The Stroke Clinical Nurse Consultant at The Royal Melbourne Hospital is available between 8am and 4.30pm Monday to Friday.

Louise Weir
9342 7000 – ask for pager 2425
Appendix 19. Palliative Care in Stroke Documentation review / Follow up Clinician

Palliative Care in Stroke

Documentation review / Follow-up Clinician

This data collection seeks to:

- Review the degree and quality of completion of the pathway
- Document clinicians’ experience with use of the pathway
- Identify any issues arising from use of the pathway, including issues relevant to the client, carer or staff member
- Identify benefits of using the pathway, including benefits for the client, carer or staff member.

The review involves:

1. A review of the pathway documentation and clinical notes
2. A brief interview with the staff member(s) involved

Please attach to this review:

- A de-identified copy of the completed pathway

Audit completed by: _____________________________________________________________
1. Documentation review

Date of documentation review: ________________________________

1.1 Overview of episode:

Unit (SCU/PCU other): __________________________________________

Date admitted: ________________________________

Diagnosis: ________________________________________________

Date referred to PCU (if applicable): ________________________________

Date commenced on palliative care pathway: ________________________________

Number of days on pathway: ________________________________

Discharge date (if applicable): ________________________________

Additional notes to describe episode:

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

1.2 Completion of pathway

For each section of the pathway, rate the degree and quality of completion and comment as appropriate:

Section 1 (Assessment)

Degree of completion

☐ Not completed  ☐ Partially completed  ☐ Fully completed

Quality of completion

☐ Poorly completed  ☐ Moderately well completed  ☐ Completed as intended

Specific section/aspects not well completed (describe)

________________________________________________________________
________________________________________________________________
________________________________________________________________
Section 2 (Ongoing care and assessment)

Degree of completion
☐ Not completed ☐ Partially completed ☐ Fully completed

Quality of completion
☐ Poorly completed ☐ Moderately well completed ☐ Completed as intended

Specific section/aspects not well completed (describe)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Section 3 (Discharge) – complete if appropriate ☐ Not appropriate

Degree of completion
☐ Not completed ☐ Partially completed ☐ Fully completed

Quality of completion
☐ Poorly completed ☐ Moderately well completed ☐ Completed as intended

Specific section/aspects not well completed (describe)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Section 4 (verification of death)

Degree of completion
☐ Not completed ☐ Partially completed ☐ Fully completed

Quality of completion
☐ Poorly completed ☐ Moderately well completed ☐ Completed as intended

Specific section/aspects not well completed (describe)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
1.3 **Supporting clinical notes**

Where variances (i.e. goals not achieved) explained in the clinical notes:

- [ ] In all or most instance
- [ ] In some instances
- [ ] Not at all

Please comment:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

________________________________________________________________________
2. Clinician feedback

Date of clinician interview: ______________________

The following questions are to be explored with relevant clinician(s) involved in using the pathway, as soon as possible after use for an individual patient.

2.1 Professional background:

☐ Nursing  ☐ Occupational Therapy
☐ Medical  ☐ Physiotherapy
☐ Speech Therapy  ☐ Other (please specify): ___________________________

2.2 Did you previously complete a survey regarding the pathway?  ☐ Yes  ☐ No

2.3 Did you attend training regarding the pathway?  ☐ Yes  ☐ No

2.4 How many times have you used the pathway prior to using it for this patient?_____

Your experience with this patient:

2.5 Do you think using the pathway changed the process of care compared to previously? Please describe?

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<thead>
<tr>
<th>No, Disagree</th>
<th>Unsure</th>
<th>Yes, Agree</th>
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2.6 Do you think use of the pathway facilitated communication between clinicians in the unit and the palliative care team? Please describe

<table>
<thead>
<tr>
<th>No, Disagree</th>
<th>Unsure</th>
<th>Yes, Agree</th>
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</table>
2.7 Do you think use of the pathway improved efficiency in delivery of care? Please describe.

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<tr>
<th>No, Disagree</th>
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<th>Yes, Agree</th>
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2.8 Was there anything about using the pathway that you were unclear about? Please describe.

<table>
<thead>
<tr>
<th>No, Disagree</th>
<th>Unsure</th>
<th>Yes, Agree</th>
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2.9 Overall did using the pathway for this particular patient provide any clinical benefit? Please describe.

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<thead>
<tr>
<th>No, Disagree</th>
<th>Unsure</th>
<th>Yes, Agree</th>
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2.10 Did using the pathway for this patient simply add to the administrative burden without providing clinical benefit? Please explain.

<table>
<thead>
<tr>
<th>No, Disagree</th>
<th>Unsure</th>
<th>Yes, Agree</th>
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2.11 Did using the pathway for this patient improve the communication with carers? Please explain.

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<thead>
<tr>
<th>No, Disagree</th>
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<th>Yes, Agree</th>
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2.12 Which information resources did you (or other staff) provide to the carers/family of this patient?

☐ Providing end of life care at home for family members
☐ Palliative Care after Stroke – information for families and carers
☐ What to do if someone dies

2.13 As a result of using the pathway for this particular patient, would you suggest any changes to the pathway, processes or training for clinical staff? Please describe.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix 20. Case Studies

Case 1a and 1b
Mrs J, an 85 year old woman previously living independently at home with her ill partner, was admitted to the RMH on the 11/3/2010 with a right sided intraparenchymal haemorrhage. A palliative approach to care was discussed with her family shortly after admission by the treating medical team from the SCU, and Mrs J was commenced on the SPAP that evening. By the 13/3/2010 Mrs J’s condition had stabilised, and it was felt by the SCU team that she was not imminently dying, and the SPAP was consequently ceased. Mrs J was transferred to a GEM unit on the 19/3/2010.

In reviewing use of the SPAP Section 1 was fully completed with all details recorded as intended. Section 2 was partially completed, with five out of six shifts completed. All areas completed were completed as intended. Section 3 (discharge) was not completed, and Section 4 was not completed as the pathway was discontinued.

The clinician follow up tool had not been completed at this time, so detailed information regarding use of the SPAP was not obtained. On questioning one staff member on use of the SPAP they said that they had found it useful, however concerns were raised regarding commencing the pathway and then ceasing it.

Mrs J was subsequently readmitted to the RMH on the 7/4/2010 with a left frontal intracerebral haemorrhage. She was documented for a palliative approach to care on the 9/4/2010 and was commenced on the SPAP later that evening. Mrs J was on the pathway for 18 shifts, and died on the 18/4/2010.

On review of the SPAP Section 1 was fully completed and completed as intended. Section 2 was partially completed, with 14 out of 18 shifts completed. Section 3 was not completed, but it was not appropriate to discuss discharge home as the patient’s partner was very ill at the time and discharge home impractical. Section 4 was not completed. Variances were explained in the clinical notes in most instances. Mrs J was transferred from the SCU to the PCU on the 12/4/2010.

Four nursing staff members were interviewed regarding use of the SPAP. All but one had previously attended one of the training sessions regarding use of the SPAP, with one having utilised the pathway previously. All interviewees felt that the SPAP was easy to follow and was relevant to patient care. The person completing Section 1 felt that it did take a long time to complete (approximately 20 minutes), however they felt that as they used it more this time should decrease. Section 2 felt logical and user friendly, however staff commented that it does take time to read all the prompts the first time. It was commented that it would be expected to become easier once they were more familiar with use. The “Palliative care after stroke” booklet was provided to the family with positive feedback.

Case 2
Mrs F, an 87 year old female previously living independently at home by herself, was admitted on 11/4/2010 with a left MCA infarct (TACI). She was referred to the PCS on the morning of the 12/4/2010 and commenced SPAP at 1250 hrs 12/4/2010. Mrs F was on the SPAP for 5 shifts and died on the 13/4/2010 at 2330 after transfer to the PCU on 13/4/2010 at 1930 hrs.

Section 1 was fully completed with all sections completed as intended. Section 2 was partially completed and the areas completed were moderately well completed. Mrs F was on the SPAP for 5 shifts, with 3 shifts completed. The AM and PM shifts on the 13/4/2010 were not completed; this was after the patient was transferred from the SCU to the PCU. Section 3
was not completed, but it would have been inappropriate as Mrs F lived by herself and her only close family was her elderly sister. Section 4 was not completed.

Two staff members were interviewed regarding use of the SPAP for this patient. Neither had previously completed a survey regarding use of the SPAP, or utilised the SPAP on previous patients. Both had attended a training session regarding use of the SPAP. Both respondents felt the SPAP was useful and set out the goals of care clearly. The prompt regarding pastoral care was highlighted as a positive by one respondent. One respondent felt that the pathway added to the administrative burden; however this was not without benefit. Although it did take longer to complete than the previous NCP, it was felt that the time was not wasted. Neither staff member was aware if the families had been provided with the booklets.

Case 3

Mr G, an 84 year old male previously living in a nursing home, was admitted on 23/4/2010 with right fronto-parietal ICH. He was commenced on the SPAP on the 27/4/2010 at 0930 and referred to the PCS that day. Mr G was on the SPAP for 4 shifts and died on 29/4/2010 on the AM shift.

Section 1 of the pathway was partially completed, with no mention of an advance care plan and no NOK documented. Section 2 was partially completed, with 3 shifts completed thoroughly; however the shift Mr G died was not completed. Section 3 was not completed as Mr G was from a nursing home and was not appropriate for discharge back there. Section 4 was not completed after death. Variations noted were completed correctly in the medical record.

Two staff members were interviewed regarding use of the SPAP. One had previously completed a survey, and both had attended training in use of the pathway. One respondent, a senior member of the nursing team, did not feel that the SPAP changed her practice, but did feel that it was extremely useful for more junior staff or staff not familiar with the care of palliative patients. She felt that Section 1 did add to the administrative burden without clear clinical benefits, as the information contained was generally filled out in the patient notes. The other respondent felt the pathway was logical to use, was comprehensive and was good in creating a culture around care of the dying and as new staff come in it will be the accepted culture. Both responded that further education and ongoing training in palliative care is vital. Both were unsure whether booklets had been provided to family members.

Case 4

Mrs S, an 85 year old woman previously living at home with her daughter, was admitted on 16/4/2010 with a right MCA infarct. She was reviewed by the PCS on 19/4/2010 and was commenced on the SPAP on the 20/4/2010 on the AM shift. Mrs S was on the SPAP for 12 shifts, with 5 shifts completed on the SCU prior to transfer to the PCS. The SPAP was misplaced on transfer to the PCU and could not be located at that time, although was found later in the patients history when recalled for review. Mrs S died on the PCU at 0700 hrs 24/4/2010.

Section 1 of the SPAP was partially completed. No information was entered into the diagnosis section and goals 4, 7 and 8 were not completed. Goal 9 was not fully completed as the family contact name had not been included. Section 2 was well completed for the five shifts the patient was on the SCU. Due to the form being misplaced it was not completed whilst the patient was in the PCU. In section 1a it was documented that the location of dying was to be hospital. Section 3 was not completed as the patient died in hospital and section 4 was not completed.
Two staff members were interviewed regarding feedback on use of the pathway. One had previously completed a survey and attended training and one had neither completed a survey nor training. Both staff members had previously utilised the SPAP with other patients. One staff member commented that the SPAP helped in communicating with families, and prompted them to think of things they may not have thought of before. It allowed staff to put a plan in process and contribute to an “attitude change” on the ward. One staff member did comment that use of the SPAP would not have been as clear without the education sessions. Staff stated the SPAP helped in highlighting the importance of communication with families, and ensuring that the spiritual / religious needs of family members have been acknowledged. It was commented that frequent updates regarding the pathway would be useful.

**Case 5**

Mrs M, a 72 year old female previously living at home with her son was admitted on the 8/5/2010 following a left MCA infarct (TACI). She was thrombolysed but showed no improvement in condition over the following days. After discussion with her family a palliative approach to care was commenced on the 14/5/2010, a Friday, and she was reviewed by the PCS that afternoon. She was not commenced on the SPAP until the Sunday night duty shift 17/5/2010. Mrs M was on the SPAP for 13 shifts, with 6 shifts completed. Mrs M died on 21/5/2010 at 0545 hrs.

Section 1 of the SPAP was poorly completed, with only goals 1 and 2 completed. Section 2 was well completed for the first two days of use (17/5/2010 and 18/5/2010) but no further days were completed after that point. Section 3 was not completed; however it would not have been practical to discuss taking the patient home to die as the family situation would not have supported this. Section 4 was not completed after death.

No staff members were interviewed regarding this patient at the time the patient was on the pathway.

**Case 6**

Mrs L, a 90 year old female, was admitted with a (R) MCA infarct (TACI) on the 11/5/2010. She was referred to the PCS on the 12/5/2010 and was commenced on the SPAP that day. She was on the SPAP for 20 shifts, and died on the 19/5/2010 at 1050 hrs.

Section 1 of the SPAP was partially completed, with goal 8 not completed. The goals that were completed were completed as intended. Section 2 was partially completed, with 19 of the 20 shifts completed. The shifts that were completed were completed as intended. Section 1a was completed with documentation that the patient would be dying in hospital. Section 3 was not completed as the patient died in hospital. Section 4 was not completed. The variances documented were explained in the clinical notes in all or most instances.

Three staff members were interviewed regarding use of the SPAP. All had previously utilised the SPAP with other patients and had attended training. Staff commented that the pathway was useful in helping staff plan care for the patient and prompt care. One staff member commented that the SPAP was useful in supporting and communicating with families. All staff members questioned stated that the more occasions they used the SPAP the easier and quicker it was, and staff felt confident in using the SPAP.

**Case 7**

Mrs F, a 77 year old female, was admitted to the SCU on the 13/5/2010 following a (R) MCA infarct. She previously lived at home with her elderly partner and required assistance with some aspect of daily living. She was referred to the PCS on the 14/5/2010 and was
commenced on the SPAP that PM. Mrs F was on the SPAP for 20 shifts in total. She was transferred to the PCU on 20/5/2010 at 1230 hrs and died on the 21/5/2010 at 0550 hrs.

Section 1 was partially completed, with the Next of Kin and contact with the multidisciplinary team not completed. All other goals were well completed in this section. Section 2 was partially completed, and the sections completed were moderately well completed. Sixteen shifts were completed out of the 20 shifts. All shifts were completed on the SCU; however the pathway was not continued once the patient was transferred to the PCU. Section 1a, 3 and 4 were not completed. Variances were documented in all or most instances, and were explained in the clinical notes.

Three staff members were interviewed regarding use of the SPAP. One staff member felt that the SPAP changed the process of care in some ways, commenting that they continued to do the “same sort of things”, but the pathway prompted them to think of things they may not have thought of immediately. The SPAP assisted with efficiency of care by setting out goals of care and helped staff to think about things they may not have when caring for a palliative stroke patient. It was felt that filling out the SPAP took about the same time as completing the Nursing Care Plan previously utilised, which is an improvement in time compared to earlier comments regarding utilisation of the SPAP, demonstrating that the more staff used the SPAP the quicker completion would be. Another staff member stated that whilst the physical aspect of care remained the same, the SPAP assisted with communicating with the family. The SPAP highlighted the importance of communicating what you are doing with the carers, and the spiritual / religious prompt was important as a reminder to staff.

**Case 8**

Mr D, an 89 year old man previously living at home with his wife and daughter, was admitted on the 28/5/2010 with a (R) MCA (TACI) stroke. He previously required daily assistance with aspect of daily living. He was referred to the PCS on the 31/5/2010 and was commenced on the SPAP that day. Mr D was on the pathway for 21 shifts and died at 0635 7/6/2010.

Section 1 of the SPAP was partially completed, with goal 4, the provision of nutrition, not filled in. The sections completed were completed as intended. Section 2 was partially completed, with 17 of the 21 shifts the patient was on the SPAP completed, with these shifts completed well. Section 1a was completed with documentation that the patient was to die in hospital. Section 3 was not completed as the patient died in hospital and Section 4 was not completed. The patient had no variances documented.

Two staff members were interviewed regarding use of the SPAP with this patient. Both had attended the training session and had utilised the SPAP previously. Both staff members commented that frequent use of the SPAP made it easier and quicker to use and both felt that it assisted them in planning care for the patient. One staff member commented that they provided the “Palliative care after stroke – Information for families and carers” brochure to the family who were grateful for it.