

**Appendix 5. Carer education and support- useful prompts**

<b>Care information that may assist families to continue care on discharge.</b>	
<p><b>Medication Management</b> <i>Note- it is advisable that written advice is also provided on medication management</i></p>	<p>Provide information on:</p> <ul style="list-style-type: none"> <li>• What the medications are for</li> <li>• When the medications should be given</li> <li>• How the medications should be administered</li> <li>• Any specific plans for symptom management including use of a continuous subcutaneous infusion</li> </ul>
<p><b>Patient comfort</b></p>	<p>Provide information on how to:</p> <ul style="list-style-type: none"> <li>• Deliver simple mouth care</li> <li>• Deliver simple eye care</li> <li>• Deliver simple pressure area care prevention</li> <li>• Move the patient in a safe manner</li> <li>• Change sheets while the patient is in the bed</li> <li>• Attend to the patients hygiene</li> <li>• Manage reduced hydration and dietary needs</li> </ul>
<p><b>What to do if the patient becomes distressed?</b></p>	<p>Provide advice on which healthcare providers should be contacted in the event of the patient becoming symptomatic. Explanation that if the family dial “999” this will usually result in admission of the patient to hospital.</p> <p>Remember to give the contact numbers of the GP and out of hours services (and the Community Palliative Care Team if involved)</p>
<p><b>What to expect as the patient approaches death?</b></p>	<p>Explanation that the person is expected to die following discharge but that this may not happen immediately and there may be an interval of hours or days at home.</p> <p>Discuss the usual changes to expect as death approaches</p> <ul style="list-style-type: none"> <li>• The patient weakens, sleeps more</li> <li>• He/ she has reduced interest in food or fluid</li> <li>• Eventually he/she becomes less responsive and changes in breathing pattern and circulation occur                             <ul style="list-style-type: none"> <li>○ Breathing becomes more shallow and irregular</li> <li>○ Breathing may become more noisy</li> <li>○ The person’s colour changes and he/ she may become cool to touch</li> </ul> </li> <li>• Eventually his/her breathing will stop and pulse will disappear.</li> </ul> <p>Discussion and explanation that cardiopulmonary resuscitation should not be attempted as this is not appropriate.</p>
<p><b>What to expect/do around time of death?</b></p>	<p>Important to reassure death is not usually dramatic and to encourage the family to spend time with the patient, if this is what they want</p> <p>Describe how to recognise death has occurred</p> <p>Contact GP or Out of Hours service as appropriate</p> <p>Contact funeral director</p> <p>+/- Contact spiritual advisor</p> <p>+/- Take battery out of the continuous subcutaneous infusion but <b>do not</b></p>

## National Rapid Discharge Pathway for Patients Who Wish to Die at Home

	<p><b>remove the needle of the</b> continuous subcutaneous infusion</p> <p>Turn off the heating in the room</p>
<b>How to organise the funeral/burial?</b>	<p>Discuss the patient's preferences if possible</p> <p>Involve the appropriate people</p> <p>Choose and contact a funeral director</p> <p>Contact the religious advisor (if indicated)</p> <p>If cremation is chosen, cremation form must be completed before funeral arrangements progress by the responsible doctor.</p>
<b>Support</b>	<p>Provide information on who family can contact if they are worried e.g. GP/ PHN/ Specialist Palliative Care Team /Hospital</p> <p>Advise to try to pace themselves and that it is alright to accept offers of help.</p>