

Care of the Dying Adult

Consultation on draft guideline – deadline for comments 5pm on 09/09/2015 email: CareofDyingAdult@nice.org.uk

| | | | | <p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none"> 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) <p>See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p> |
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| Stakeholder organisation(s) (or your name if you are commenting as an individual): | | | | Catholic Medical Association (UK). |
| Name of commentator (leave blank if you are commenting as an individual): | | | | <p>Dr Philip Howard MA MD MA LLM FRCP.President of the CMA (UK)</p> <p>Contact</p> <p>To contact the Association officers regarding this consultation please contact secretary@catholicmedicalassociation.org.uk or president@catholicmedicalassociation.org.uk</p> |
| Comment number | Document (full version, short version or the appendices) | Page number Or 'general' for comments on the whole document | Line number Or 'general' for comments on the whole document | Comments |
| Example 1 | Full | 16 | 45 | We are concerned that this recommendation may imply that |
| Example 2 | Full | 16 | 45 | Question 1: This recommendation will be a challenging change in practice because |

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| Example 3 | Full | 16 | 45 | Question 2: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact..... |
| 1 | FULL | General | General | <p style="text-align: center;">EXECUTIVE SUMMARY</p> <p>We welcome this opportunity to contribute to the consultation on the draft NICE guidelines on the care of the dying adult and would like to start by summarising our overall position.</p> <ul style="list-style-type: none"> • One of our main concerns is that the guideline focuses upon the belief that the diagnosis of dying can be accurately and safely made. Prognosis is particularly difficult in non malignant conditions such as heart and respiratory failure and dementia. • Palliative care should be based on the patient’s needs rather than the perceived prognosis which is at best a subjective judgment. • Patient management should be holistic and address the medical, psychological and spiritual needs of the patient. • Palliative treatment should be evidence-based wherever possible. Further research is clearly needed and should be compared to best available practice. • The focus of palliative care should be the relief of symptoms and where possible should include the restoration of mental and physical function and psychological and spiritual wellbeing. • Good communication with the patient is fundamental to all clinical practice. • Discussion of the patient’s condition and treatment with relatives should not be a substitute for dealing with the patient directly. Communication with relatives and carers is especially important in the care of the dying. However, this should always be done in a timely manner and with the consent of the patient unless the patient |

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| | | | | <p>lacks capacity.</p> <ul style="list-style-type: none"> • Good palliative care requires good communication and timely intervention. It must start early as the patient’s condition and circumstances become clearer and should not be confined to the few last remaining days of life. • Consent to treatment is necessary in palliative care as in other fields of medicine and should always be sought in a timely fashion where the patient has capacity regarding the diagnosis and treatment of their condition throughout the patient journey and not just in the last few days of life. This is particularly true of palliative care where the needs and wishes of patients should be actively determined before the patient loses capacity as a result of the underlying condition or treatment. • The responsibility for patient care normally rests with the Consultant or General Practitioner. The overall responsibility for palliative care should not rest with unsupervised junior doctors. • Treatment plans should be endorsed by senior medical personnel who should be available for further help and advice as the patient’s condition changes. • There should be regular audit of the care of the dying which takes into account medical treatment, nursing care, spiritual support and the concerns of relatives and carers • Hydration and nutrition should not be withheld or withdrawn with the intention and purpose of bringing about the death of the patient. This is both unethical and unlawful. • There should not be financial incentives and targets for placing patients on an ‘end-of- life’ pathway.. • There should be appropriate funding made available for training of healthcare professionals in palliative care. • It is particularly important that healthcare professionals attend to the spiritual needs of the dying and help to arrange the appropriate pastoral care. |
| 2 | FULL | P 54-85 | | 5. RECOGNISING WHEN A PERSON IS IN THE LAST DAYS OF LIFE |

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| | Appendix E Appendix J | P75 P234 | <p>Assessment of prognosis: paucity of available and reliable data.</p> <p>There are a number of problems inherent in assessing prognosis. The most obvious is the paucity of studies. Of the 7 studies reviewed by the GDG, 4 papers were written by the same two groups of investigators (Chiang et al (2009) and Kao et al (2009) and Loektio et al 2013. The Loekito papers were excluded as they involved laboratory parameters in large numbers of patients (n=47,701 and n = 71,453) admitted as emergencies to hospital. The Matsunuma (2014) paper was regarded as being of low quality and looked at mortality within 14 days. Only the Hui (2014) paper looked specifically at mortality within the last 3 days of life . The Chiang and Kao studies looked at mortality at 1 week.</p> <p>Of 102 full text articles assessed for eligibility only 5 were selected for analysis. (Appendix E. P 75). There were no GRADE scores for any of the studies (Appendix J GRADE scores p 234). The available evidence is therefore limited to studies in selected groups of known cancer patients admitted to palliative care units and undergoing palliative care treatment which may be expected to alter the profile of the prognostic factors under review. The pathophysiology of dying may be very different in different malignant diseases compared to non-malignant conditions. For example respiratory parameters are more likely to be important in those with lung cancer, compared with ascites, jaundice and hypoalbuminaemia in those with gastrointestinal malignancy. None of the studies involved patients with chronic non-malignant conditions such as motor neurone diseases, heart failure or dementia. Nevertheless, the NICE guidelines are recommended for a variety of malignant and non-malignant conditions including dementia.</p> <p>There are now over thirty prognostic scales or screening tools for predicting the risk of death in a variety of settings which depend on laboratory parameters, clinical observations and judgment to varying extents. The best known are perhaps the Karnofsky Performance Score (KPS); Acute Physiology and Chronic Disease Evaluation or ;APACHE scores, Palliative Performance Scale, various Early Warning Scores, Rothman Index and the Palliative Prognostic Index. None of these were specifically evaluated by the GDG group, although the Chiang paper examined the Eastern Cooperative Oncology Group scale. There are also important speciality specific scores such as the Rokall Score for upper gastrointestinal bleeding which are not included in the draft guidelines.</p> <p>Inherent difficulties in the use of prognostic indicators.</p> <p>There are a number of inherent difficulties with the use of prognostic indicators:</p> <p>First, Prognostic tools apply to group statistics and do not take into account inter-individual variability. Generally, the extrapolation of group statistics to individuals introduces a further element of bias and subjectivity.</p> <p>Second, whilst the number of prognostic factors will increase in any individual as death approaches (as shown by the</p> |
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| | | | <p>Hui study), not all patients will develop prognostically significant signs or symptoms. Moreover, patients may die suddenly for example from an unexpected pulmonary embolus.</p> <p>Third, whilst the emphasis in the report has been on attempting to identify those likely to die within 3 days, there will be both false positives – those thought likely to die who would not in fact die within 3 days and false negatives – those who will in fact die but do not have the relevant prognostic signs. If treatment is predicated on prognosis it will be given to those who are falsely thought to be dying and might exclude those who are in fact dying but have not been identified using the prognostic tool.</p> <p>Fourth, there are problems with extrapolation of group statistics to individual cases and a failure to recognise inter-individual variation¹. There was no attempt by the GDG to estimate inter-individual variation and to prospectively evaluate the accuracy of the timing of death.</p> <p>Fifth, there is a need to take into account not only individual variation but also disease trajectories. The value and danger of prognostic tools is they rely on the presence or absence of what are considered to be prognostically relevant factors to predict future outcomes. In practice, knowing the trajectory of different diseases and the changing condition of the patient are important in predicting the likely outcomes for individual patients.</p> <p>Sixth, it is important to separate the natural history of disease from the effects of treatment on disease progression. No attempt was made to estimate the effects of treatment even when the patients were undergoing intensive palliative care treatment. This is particularly true of the effects of opiates and sedation on respiratory parameters, consciousness and oral intake.</p> <p>Seventh, the reliability of any diagnostic tool needs to be evaluated prospectively for different healthcare professionals in different settings. For example are nurses more or less reliable than doctors, or generalists more accurate than specialists?</p> <p>There is very little evidence about the accuracy of predicting death in the last 3 days of life which was the focus of the GDG review and only the Hui (2014) study specifically examined mortality within this time frame.</p> <p>Basing treatment upon need and not prognosis.</p> |
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¹ See for example, Brabrand M, Folkestad L, Clausen NG, et al. Risk scoring systems for adults admitted to the emergency department: a systematic review. Scand J Trauma Resusc Emerg Med 2010;18:1–8.

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| | | | <p>One of our greatest worries is that the guideline still focuses upon the belief that the diagnosis of dying can be accurately and safely made. It is very clear that this is difficult with evidence that the diagnosis of dying is especially difficult in dementia, heart failure and respiratory failure. The guideline therefore unquestioningly replicates one of the key failings of the Liverpool Care Pathway and suggests to clinicians that they can accurately and reliably make a diagnosis that someone is dying.</p> <p>The GDG might wish to amend the content of this section and we would suggest the following text: <i>Clinicians must therefore be aware that if a possible or likely death is predicted, then the care that is provided must be based both upon the palliation of symptoms and provision of appropriate care. Medical treatment and personal care should be based on a careful clinical assessment and tailored to the individual needs of the patient.. Treatment is not indicated simply because someone is thought likely to die n the next few days</i></p> <p>The guidance in this section should flow from the overarching principle that treatment should be based upon need and not prognosis. Palliative care should be based upon the relief of symptoms and the needs of the individual patient and not merely on the premise that the clinician thinks someone is dying.</p> <p>We advise that the GDG should state clearly that the diagnosis of dying is inaccurate. The safest course in terms of patient outcome and the available evidence is that palliative care should be based upon need and not prognosis</p> |
| 3 | FULL | P 86-108 | <p style="text-align: center;">6. COMMUNICATION.</p> <p>The GDG found no studies “that elicited experiences or perceptions of the dying person” p87 line16. There was one study “which interviewed bereaved careers and healthcare professionals about people that that died in acute hospital settings, about the general care they received including communication of prognosis.” P87. L20-22. However the GDG reports that this had “very poorly reported methodology” and that “the context of the quotes and themes was hard to ascertain.”</p> <p>Nevertheless, the GDD acknowledges that “much of the distress and controversy surrounding the Liverpool Care Pathway could have been prevented by sensitive and timely communication between clinicians, relatives and other</p> |

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|--|-------------|---------------|--|--------------------------|-------------|---------------|---|-------------|--------------|--|-------------|--------------|---|-------------|--------------|---|-------------|--------------|--|------------|---------------|--------------------------|-------------|---------------|--|-------------|--------------|---|-------------|--------------|--|-------------|--------------|--|-------------|--------------|
| | | | <p>carers. The More Care Less Pathway report highlighted this as a “non-negotiable aspect of best practice in end of life care.”</p> <p>Despite the paucity of studies on communication, there is no doubt from the last Audit of the Liverpool Care Pathway (NADH 20010/11) showed that the degree of communication about the Liverpool Care Pathway was poor as shown below.</p> <p style="text-align: center;">NATIONAL AUDIT ON LCP 2010/11 NCDAH R3 TABLES COMMUNICATION WITH PATIENT.</p> <table> <tr> <td>Patients in audit</td> <td style="text-align: right;">7058</td> <td style="text-align: right;">(100%)</td> </tr> <tr> <td>Patients deemed able to take a full and active part in communication</td> <td style="text-align: right;">2725</td> <td style="text-align: right;">(39%)</td> </tr> <tr> <td>Patients aware that they were dying</td> <td style="text-align: right;">1548</td> <td style="text-align: right;">(22%)</td> </tr> <tr> <td>Patients given the opportunity to discuss what was important to them</td> <td style="text-align: right;">1303</td> <td style="text-align: right;">(18%)</td> </tr> <tr> <td>Patients given a full explanation of the LCP</td> <td style="text-align: right;">1249</td> <td style="text-align: right;">(18%)</td> </tr> <tr> <td>Patients who took the opportunity to discuss what was important to them</td> <td style="text-align: right;">389</td> <td style="text-align: right;">(5.5%)</td> </tr> </table> <p style="text-align: center;">COMMUNICATION WITH RELATIVES/CARERS</p> <table> <tr> <td>Patients in audit</td> <td style="text-align: right;">7058</td> <td style="text-align: right;">(100%)</td> </tr> <tr> <td>Relatives/carers aware that they were dying</td> <td style="text-align: right;">5586</td> <td style="text-align: right;">(79%)</td> </tr> <tr> <td>Relatives/carers given a full explanation of the LCP</td> <td style="text-align: right;">4737</td> <td style="text-align: right;">(67%)</td> </tr> <tr> <td>Relatives/carers given the opportunity to discuss what was important to the</td> <td style="text-align: right;">4189</td> <td style="text-align: right;">(59%)</td> </tr> <tr> <td>Relatives/carers who took the opportunity to discuss what was important to them</td> <td style="text-align: right;">1889</td> <td style="text-align: right;">(27%)</td> </tr> </table> <p>The LCP appeared to be implemented without the consent of the patient or the knowledge or agreement of relatives in a significant proportion of patients. A large proportion of patients were either deemed to be ‘unconscious’ at the instigation of the LCP (45%) or were otherwise unable, or not given the opportunity, to give their consent. As many as one in 5 patients on the LCP have dementia either as their main diagnosis (4%) or as a significant co-morbidity (16%). The GDG makes a number of recommendations (recommendations 6 to 21 inclusive) regarding communication and shared decision-making.</p> | Patients in audit | 7058 | (100%) | Patients deemed able to take a full and active part in communication | 2725 | (39%) | Patients aware that they were dying | 1548 | (22%) | Patients given the opportunity to discuss what was important to them | 1303 | (18%) | Patients given a full explanation of the LCP | 1249 | (18%) | Patients who took the opportunity to discuss what was important to them | 389 | (5.5%) | Patients in audit | 7058 | (100%) | Relatives/carers aware that they were dying | 5586 | (79%) | Relatives/carers given a full explanation of the LCP | 4737 | (67%) | Relatives/carers given the opportunity to discuss what was important to the | 4189 | (59%) | Relatives/carers who took the opportunity to discuss what was important to them | 1889 | (27%) |
| Patients in audit | 7058 | (100%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| Patients given a full explanation of the LCP | 1249 | (18%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Patients who took the opportunity to discuss what was important to them | 389 | (5.5%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| | | | | <p>We agree that communication is key to good palliative care and commend the recommendation of the Neuberger Review: “Respectful treatment of the dying patient and the carers requires time to be taken over the difficult tasks of providing information, including the difficult task of delivering the news that the person is dying, understanding the person’s needs and capacity to assimilate bad news and providing the opportunity to reflect on that information and to ask questions. This should be a non-negotiable aspect of best practice in end of life care. (More Care Less Pathway. 2013)”</p> |
| 4 | FULL | P111-134 | | <p style="text-align: center;">7. SHARED DECISION MAKING AND CONSENT</p> <p>“I would add that we should not “give up” on any patient, terminal or not terminal. It is the one who is beyond medical help who needs as much if not more care than the one who can look forward to another discharge.” Dr Elizabeth Kubler-Ross.</p> <p>“How people die lives on in the memory of those who live on.” Dame Cicely Saunders</p> <p>The guidance makes only a brief reference to the involvement of family and friends in decision making. The GDG needs to highlight the importance of discussion with the mentally competent patient and with family and those important to the patient when they lack capacity to make decisions for themselves. It cannot be assumed that clinicians may make decisions on behalf of mentally incapacitated patients. Therefore it is important to mention in the recommendations the importance of enquiring whether the mentally incapacitated patient has appointed a donee of Lasting Power of Attorney (or Welfare Attorney in Scotland) to make decisions on their behalf. The Neuberger Review recommended an independent advocate for those without relatives who lacked capacity.</p> <p>The Neuberger review stated “<i>For each patient on an end of life care plan that has no means of expressing preferences and no representation by a relative or carer, views on their care should be represented by an independent</i></p> |

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| | | | | <p><i>advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This applies to people of whatever age who lack capacity</i>.²</p> <p>We would suggest that this recommendation concerning an independent advocate is added to the guidance.</p> <p>Patient management should be holistic and should address the medical, psychological and spiritual needs of the patient.</p> <p>Consent to treatment is especially important in palliative care as in other fields of medicine and should always be sought in a timely fashion where the patient has capacity. As in any other field of medicine, consent should be sought from patients for the diagnosis and treatment of their condition throughout the patient journey and not confined to the last few days of life. This is particularly true of palliative care where the needs and wishes of patients should be actively determined before the patient loses capacity as a result of the underlying condition or treatment.</p> <p>Decisions about palliative care must be made or supervised by senior clinicians who should be available for further help and advice as the patient's condition changes. It must be clear to the medical team and relative who is the named responsible consultant. The Neuberger Review recommended that "A named consultant or GP, respectively, should take overall responsibility for the care of patients who are dying in hospital or the community"³. Neuberger also recommended "the name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed"⁴.</p> <p>There should be regular audit of the care of the dying which takes into account medical treatment, nursing care, spiritual support and the concerns of relatives and carers. We also agree with the Neuberger Review that "The National Institute for Health Research fund should fund research into the experience of dying. Research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience"⁵.</p> |
| 5 | Short | 5 | 1.2 | |

² Neuberger Review "More Care Less Pathway, 2013) Recommendation 32.

³ Neuberger Review "More Care Less Pathway, 2013) Recommendation 26

⁴ Neuberger Review "More Care Less Pathway, 2013) Recommendation 27.

⁵ Neuberger Review "More Care Less Pathway, 2013) Recommendation 5.

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| | Guideline | | | <p>Communication</p> <p>We recognise that poor communication was one of the major problems with the implementation of the LCP in practice. Indeed, the Neuberger Review noted that “preventable problems of communication between clinicians and carers accounted for a substantial part of the unhappiness reported to us. Relatives and carers felt that they had been “railroaded” into agreeing to put the patient on a one-way escalator. We feel strongly that if acute hospitals are to deal with dying patients – and they will – whether or not they are using the LCP – they need to treat patients, their relatives and carers with more respect”.</p> <p>We therefore agree with the GDG in stressing the importance of discussing the care of the dying patient with the family and chosen next of kin unless it is clear that the patient does not wish them to be involved. It is also important for doctors to act in the best interests of any patients who lack the mental capacity to make decisions for themselves.</p> <p>We agree with the GDG that families and the chosen next of kin should normally be fully consulted and closely involved in the decision making process. In particular we agree with the GDG that it is important to involve those that the person considers important to them so that they can be present when making decisions about their care (recommendation 6); to consider with the dying person and those important to them their stated preferences about their care (recommendation 10) and whether the dying person or those important to them have any cultural, religious, social or spiritual preferences that should be considered (recommendation 14).</p> <p>The GDG should also make it clear in the guidance that it is important to make positive enquires as to whether the patient has appointed an attorney who may have the legal powers to make decisions for the patient (i.e. donee of Lasting Power of Attorney or Welfare Attorney in Scotland).</p> |
| 6 | Short Guideline | P8 | 1.3.9 | <p>Spiritual and holistic care</p> <p>In our experience, families will usually want to see that people die in a way that is compatible with their life-long faith. For example, many will have specific hopes that sacraments, prayers or other rituals will be offered as they are dying. The spiritual care of the dying person is crucial and we recommend the updated NHS Chaplaincy Guidelines (2015) published by NHS England.</p> <p>We therefore recommend that the GDG adds a section on Spiritual and Holistic care to its summary document and that there should be a reference to the NHS Chaplaincy Guidelines, “Promoting Excellence in Pastoral” (March 2015),</p> |

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| | | | | <p>The GDG should therefore considering add a section on spiritual care and we would suggest</p> <p>“Spiritual care should be offered to all who are dying. Friends, relatives and those who are important to them should also be involved wherever possible. Clinicians should therefore refer those who have a faith and who it is thought would want spiritual care to the relevant priest, pastor or minister of religion. The guidance of the Chaplaincy service, who have special expertise in issues relating to the pastoral care of the dying, should be sought at an early stage. We recommend the NHS Chaplaincy Guidelines (2015) for further help and assistance in this important aspect of care and compassion for the dying.”</p> |
| 7 | FULL | P 137-154 P152 P154 | | <p style="text-align: center;">8. PROVISION OF HYDRATION AND NUTRITION.</p> <p>The GDG questioned the overall validity of the evidence available due to the risk of bias in the study design in all papers and the imprecision of a large proportion of the outcome measurements. They noted that the randomised clinical trials (RCTs) were terminated early due to recruitment or financial problems and were therefore underpowered. (p152). We also agree “that a trial of assisted hydration should more readily be started when there is uncertainty that a person is dying and might recover but is currently unable to take oral fluids. This would be important to prevent death from dehydration in a potentially reversible condition. (p 154).</p> <p>The third Cochrane review on the provision of hydration by Good and colleagues was repeated in 2014.⁶ Six studies were indentified including three RCTs (222 participants) and three prospective controlled trials (360 participants). The authors concluded that the small number of studies and heterogeneity of the data meant that a quantitative analysis of the data was not possible. However, qualitatively one study showed that sedation and myoclonus scores improved in the intervention group and another study showed that dehydration was greater in the non-hydration group. However, some symptoms related to fluid retention e.g. pleural effusions, peripheral oedema and ascites worsened with hydration. The other four studies did not show significant differences in outcomes between the two groups. The authors concluded that “the studies published do not show a significant benefit in the use of medically assisted hydration in palliative care patients; however, there are insufficient good-quality studies to inform definitive recommendations for practice with regard to the use of medically assisted hydration in palliative care patients”.</p> <p>The studies are difficult to interpret because of their heterogeneity, short duration and reporting of data. In particular,</p> |

⁶ Good P, Cavenagh J, Mather M, Ravenscroft P. Medically assisted hydration for adult palliative care patients. *Cochrane Database of Systematic Reviews* 2008, Issue 2.

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| | | P151 | <p>the amount of oral intake and details of fluid balance were often missing. For example, in the latest study by Burera (2013) the oral intake in the two groups was simply not documented which is a significant omission in a study to examine dehydration.</p> <p>The GDG group were broadly in agreement with the Cochrane Reviews. They noted that “the experience of the GDG was that there is benefit in some circumstances, such as in the case of managing thirst or managing delirium caused by dehydration, this was not captured by the evidence” (p. 151). The GDG also noted that patients “may develop symptoms of dehydration including dry mouth, thirst, confusion and agitation, particularly if there are associated conditions such as hypocalcaemia and opioid toxicity due to impaired renal clearance. This can cause considerable distress to the patient and those important to them particularly if hydration is not adequately assessed and managed.” (p152). The issue of increased midazolam toxicity due to accumulation of the drugs and its active metabolite in those who are dehydrated or oliguric has also been recently recognised.⁷ The GDG recognise the importance of opioid toxicity due to impaired renal function.⁸ Morphine and its metabolite (morphine 6 glucuronide which is also pharmacologically active) accumulate in the body, especially if the patient is becoming dehydrated (as the active metabolite is excreted in the kidneys).</p> <p>The GDG concluded that the management of hydration in the dying person should always be individualised and be provided wherever possible by oral means.</p> |
| | | P154 | <p>We disagree with the view regarding the use of laboratory tests, that “there was not always additional benefit to performing these tests in the last days of life. They agreed that the principle should be that these tests not be routinely undertaken as hydration status could be assessed clinically” (p. 154). The GDG does state that if laboratory test results are present then they may guide decisions around assisted hydration but no recommendation was made as this was considered to be outside the remit of this guideline. We feel that a proper assessment of hydration is important which may require both a clinical and laboratory assessment. Many sick elderly patients will not complain of thirst even when dehydrated. Indeed, symptoms of dehydration may include confusion, agitation and delirium which are well recognised in healthy individuals who become dehydrated. Laboratory tests may indicate dehydration and deteriorating renal</p> |

⁷ Quail M A. Continuous infusions of midazolam and interrupted hydration – like insulin infusions without glucose? The international journal of clinical Practice. Int J Clin Pract, April 2014, 68, 4, 410–412

⁸ Ibid. P 152.

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| | | | | function and also alert the clinician to the increased susceptibility of dehydrated patients to the effects of opiates and sedatives. |
| 8 | FULL | P155-222 P158-160 P164-175 | | <p style="text-align: center;">9. PHARMACOLOGICAL INTERVENTIONS</p> <p>(i) Pain.</p> <p>The use of opiates for pain is well established and supported by several Cochrane reviews. The guidelines emphasise that “the management of pain in the last days of life should follow principles of pain management used at other times.”⁹. Indeed, the GDG chose “not to make any specific recommendations about pain management in different patient groups and suggested the clinician should follow the normal prescribing practices present any other time of life.”¹⁰</p> <p>We would agree that pain management strategies should follow the principles of pain management used at other times. However, we would also point out that there are a variety of specialised pain relief strategies which tend not to be emphasised but which are evidence based e.g. nerve block techniques.</p> <p>But note that doses may need to be lower in non cancer situations such as renal failure, dementia, frailty and old age. See our comment no 9 .</p> <p>(ii) <u>Breathlessness</u></p> <p>Opiates are widely used for breathlessness.. However, it is of interest that there was a Cochrane review by Jennings and colleagues in 2001 on the use of opiates for the palliation of breathlessness in terminal illness which was</p> |

⁹ Ibid. Recommendation 33. P. 160

¹⁰ Ibid. P. 163.

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| | | | <p>withdrawn in July 2012. Therefore, whilst opiates are still used in breathless patients, further evidence on this subject is awaited with interest.</p> <p>A Cochrane review in 2010 by Simon and colleagues¹¹ tried to determine whether benzodiazepines relieve breathlessness. They identified circumstances including 200 participants with advanced cancer and COPD. They concluded that "There is no evidence for a beneficial effect of benzodiazepines for the relief of breathlessness in patients with advanced cancer and COPD. There is a slight but non-significant trend towards a beneficial effect but the overall effect size is small. Benzodiazepines caused more drowsiness as an adverse effect compared to placebo, but less compared to morphine." The review supported "the use of benzodiazepines only if other first-line treatments, such as opioids and non-drug treatments, have failed". They noted conflicting results in the comparison of midazolam to morphine based on two studies within the same research group (Navigante et al 2006).</p> <p>There is still an urgent need for more studies to find better ways to relieve this burdensome symptom in patients with advanced diseases. The studies comparing the use of oxygen versus room air and with the use of morphine or hydromorphone were regarded as of 'very low' quality.</p> <p><i>The GDG examined 3 studies for breathlessness. The two examining the effects of oxygen and opiates were regarded as being of 'very low' quality. In the third study, the GDG considered that there was moderate and low quality evidence to suggest that a combination of morphine and midazolam was beneficial compared to the use of either intervention alone. This effect was more apparent at 24 rather than 48 hours. This view was not shared by the Cochrane Reviews. There was no evidence concerning survival outcomes in any of these studies.</i></p> <p><i>The paucity of information on the management of breathlessness is striking and in identifying 3 studies for analysis the GDG had examined 144 articles on pharmacological interventions. Simon et al had excluded 74 out of 79 reviews for the Cochrane Review.</i></p> <p><i>The GDG was therefore right to consider non-pharmacological management of breathlessness and to try and identify and treat reversible causes of breathlessness e.g. pulmonary oedema. Whilst not recommending the routine use of oxygen for breathlessness in the absence of hypoxaemia, the GDG did recommend consideration of an opioid,</i></p> |
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¹¹ Simon ST, Higginson IJ, Booth S, Harding R, Bausewein C. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. Cochrane Database of Systematic Reviews 2010, Issue 1. Art. No.: CD007354. DOI: 10.1002/14651858.CD007354.pub2

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| | | P176-185 | <p><i>benzodiazepine or combination of the two even though there was no UK marketing authorisation for this indication whilst recognising that monitoring “would minimise the risks of clinical harm in using these medications.”</i></p> <p><i>We are concerned that NICE has not been more cautious in recommending drugs for unlicensed indications in the absence of a sound evidence base. The hallmark of good prescribing is a sound evidence base. In the absence of such evidence we would suggest NICE should be more cautious in its recommendations.</i></p> <p>(iii) Nausea and vomiting</p> <p>The GDG notes that “there is no evidence- based guidance on best practice in the pharmacological management of nausea and vomiting in the last few days of life and current practice has been extrapolated from our knowledge of treating these symptoms at other stages of illness in different diseases.” (p 176, lines 17-19) Nevertheless, the GDG reviewed 3 randomised controlled trials which examined the effects of octreotide and hyoscine butylbromide. The clinical evidence showed that octreotide was more clinically effective than hyoscine butylbromide in 1 study and less clinically effective in another. Two of the studies were small and the third had a high attrition rate. Not surprisingly, the GDG noted that there “was currently wide national variability in the management of nausea and vomiting in the last days of life. They were particularly surprised that a recent national audit of care for the dying adults in hospitals found that cyclizine was the most commonly prescribed antiemetic given. In the GDG’s opinion this drug had lower efficacy compared with others, was often poorly tolerated by people at the end of life, is incompatible with many other drugs in a syringe driver and is frequently associated with site reactions if administered subcutaneously. No evidence was identified for cyclizine and no recommendations were make” (p 183).</p> <p>Perkins and Dorman concluded in their Cochrane review that “There is not enough evidence to be able to recommend haloperidol for the treatment of nausea and vomiting in adult patients suffering from incurable progressive medical conditions”.</p> <p>In the Cochrane Reviews, there was no clear evidence of benefit for levopromazine,¹² haloperidol,¹³ or droperidol.¹⁴</p> <p>There is a lack of good quality evidence for the use of anti-emetics and antipsychotics for nausea and vomiting. We</p> |
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¹² Darvill E, Dorman S, Perkins P. Levomepromazine for nausea and vomiting in palliative care. *Cochrane Database of Systematic Reviews* 2013, Issue 4. Art. No.: CD009420. DOI: 10.1002/14651858.CD009420.pub2

¹³ Perkins P, Dorman S. Haloperidol for the treatment of nausea and vomiting in palliative care patients. *Cochrane Database* 2009.

¹⁴ Dorman S, Perkins P. Droperidol for treatment of nausea and vomiting in palliative care patients. *Cochrane Database of Systematic Reviews*. 2010.

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| | | P186-191 | <p>would emphasise that good practice in prescribing should be evidence-based wherever possible. We agree that non-pharmacological methods of treating nausea and vomiting should be considered (but not only in the last few days of life). There should be a search for reversible causes and drug toxicity and the use of nasogastric suction considered for bowel obstruction.</p> <p style="text-align: center;">(iv) Agitation and anxiety</p> <p>A trial of a benzodiazepine (Recommendation 45) and an antipsychotic (Recommendation 46) is suggested. Despite the widespread advocacy of benzodiazepines and antipsychotics such as haloperidol and levomepromazine in the Liverpool Care Pathway, this is not evidence based and the review by Candy et al (2012) concluded:</p> <p><i>“There remains insufficient evidence to draw a conclusion about the effectiveness of drug therapy for symptoms of anxiety in adult palliative care patients. To date no studies have been found that meet the inclusion criteria for this review. Prospective controlled clinical trials are required in order to establish the benefits and harms of drug therapy for the treatment of anxiety in palliative care”¹⁵.</i></p> <p><i>Hirst and Sloan concluded their review (in 2002) by stating: “Despite a comprehensive search no evidence from randomised controlled trials was identified. It was not possible to draw any conclusions regarding the use of benzodiazepines in palliative care”¹⁶.</i></p> <p>We agree that possible sources of anxiety and agitation should be sought e.g. metabolic disturbance and psychological causes (Recommendation 45). The evidence base for the use of benzodiazepines and antipsychotics is poor.</p> <p style="text-align: center;">(v) Respiratory tract secretions.</p> |
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¹⁵ Candy B, Jackson KC, Jones I, Tookman A, King M. Drug therapy for symptoms associated with anxiety in adult palliative care patients. Cochrane Database of Systematic Reviews. 2012.

¹⁶ Hirst A, Sloan R. Benzodiazepines and related drugs for insomnia in palliative care. Cochrane Database of Systematic Reviews 2002, Issue 4. Art. No.: CD003346. DOI: 10.1002/14651858.CD003346

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| | | P192 | | <p>Antisercretory drugs such as glycopyrronium and hyoscine are used for respiratory secretions.</p> <p>Approximately half of those relatives and friends who witness it, as well as hospital staff, find the noise of 'death rattle' distressing. Dr Bee Wee and Hillier (2008) concluded: <i>“In our original Cochrane review, we concluded that there was no evidence to show that an intervention, be it pharmacological or non-pharmacological, was superior to placebo in the treatment of noisy breathing. This conclusion has not changed”¹⁷.</i></p> <p>Despite the absence of evidence for their efficacy, it is recommended (recommendation 51, p 17, lines 4-11) that atropine, glycopyrronium and hysoscine are considered even though they have no marketing authorisation for this indication.</p> <p>We agree that (as per recommendation 50, p 17, lines 1-3) non-pharmacological measures should be considered to manage pharyngeal secretions and that medication should be stopped if it is not helpful or causing side effects. However, the guidelines do not specifically mention suctioning, positioning and physiotherapy.</p> |
| | | P17 | | |
| 9 | Short guidance | Pp27-33 | Tables 1-6 | <p>The doses recommended appear to be relevant to cancer care. We think that risks of oversedation and over treatment are likely to be higher in those with dementia, severe frailty, low body mass, renal failure, dehydration and other non cancer conditions.</p> <p>Morphine requires additional caution in renal impairment. We suggest that the doses of medication in supporting</p> |

¹⁷ Wee B, Hillier R. Interventions for noisy breathing in patients near to death. Cochrane Database of Systematic Reviews 2008, Issue 1. Art. No.: CD005177. DOI: 10.1002/14651858.CD005177.pub2

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| | | | | <p>documentation for the LCP were too high. Those with dementia may be very sensitive to morphine . . Pace, Treloar and Scott¹⁸ recommended starting with 2.5mg of morphine when pain was uncontrolled, and not the 2.5-5mg recommended by these guidelines</p> <p>Table 5 helpfully mentions reduced doses in older and frail people,</p> <p>We think that the GDG might consider adding cautions relating to illnesses such as renal failure and dementia, as well as age, frailty and low body mass to all tables in the Short Guidance.</p> |
| 10 | Short Guideline | 10 | 1.5 | <p>We recognise that pharmacological interventions may be necessary for the alleviation of distressing symptoms. However, prescribing should be evidence based as a matter of good clinical practice wherever possible. As the GDG and Cochrane reviews demonstrate, the evidence base for many of the pharmacological interventions currently in use is often lacking with the exception of the use of opiates for pain control. Nevertheless, opiates, benzodiazepines and hyoscine can cause sedation . In those who contacted us about the use of these medicines, it is clear that there is a real concern that having started them, relatives and friends see their loved ones become comatose and die. For those who are dying the last few days with their love ones are very precious. Loss of conscious awareness can deny patients the opportunity to be with friends and family as when they are dying. We recall the words of Dame Cicely Saunders that “You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.”</p> <p>The GDG should consider adding the following statement: “Deprivation of consciousness “While it is often essential that medication is given as part of appropriate symptom alleviation, care must be taken to avoid unnecessarily use of drugs which cause patients to be deprived of their conscious awareness as they die. Balancing the control of symptoms with avoiding over-sedation should be a clear priority. Patients should die peacefully but also be allowed to live well until they die with those who are dear to them”.</p> |
| 11 | FULL | P223 | | 10.Anticipatory Prescribing |

¹⁸ Pace V, treloar A, Scott S. (2012), *Dementia, from advanced disease to bereavement*. Oxford Specialist Handbook, Oxford University Press.

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| | | | | <p>We are seriously concerned at the prospect of anticipatory prescribing, which would appear to allow the introduction of pre-prescribed medication by insufficiently senior staff for what others might regard as inadequate reasons. It appears to presuppose that the senior person in charge of the case may not be available for a relatively long period of time. As you, yourselves, express it (Long Draft, p 223, l 32ff) the danger is of “injudicious administration and prescription of medication by inexperienced staff, possibly unfamiliar with the person” however careful the original prescriber have been.</p> <p>Anticipatory prescribing must not be allowed to substitute for proper ongoing assessment and care for the patient. We do not accept that anticipatory prescribing should be ‘as early as possible’ but rather should be limited to the period of 24 or 48 hours before the likely need, and then only when there is expected to be a serious and significant delay in obtaining the medication (for example in general practice over a weekend when chemists may be shut).</p> |
| 12 | Equality Impact assessment | | | <p>We are concerned about several issues missing from the Equality Impact Assessment which can affect clinical practice</p> <p>Vulnerable people and people with cognitive impairment</p> <p>We commend the GDG for having carefully thought through issues around dementia. But other groups such as those with learning disabilities, very frail patients and those with other forms of cognitive impairment are also vulnerable. We think Equality Impact Assessment needs to be enlarged to include specific reference to these groups and to state how the risks are to be mitigated. Once again, this requires strong clinical leadership to ensure the needs of these patients are met appropriately and sensitively.</p> <p>Patients with no family members or advocates</p> <p>Those with no family members, attorneys or advocates are at greatest risk as they die. The guidelines recommendation of the anticipatory use of potent sedatives before symptoms merit their use means that those who are weak, alone or frail may well be at increased risk of poor care, over sedation and death by dehydration as was seen so often with the LCP. The guidance needs to consider how to safeguard against this, so that people can be comfortable but also prepare appropriately for death, whilst not being unduly deprived of consciousness.</p> <p>Senior second opinion in cases with doubt</p> <p>When families fear or question a prognosis of imminent death or are concerned about poor care a senior second opinion can be very helpful.</p> |

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| | | | | <p>Mental Capacity Act There needs to be clear reference to where the Mental Capacity Act applies and must be considered by clinicians. This should include guidance about seeking second opinions and assuring that treatment decisions are taken at an adequately senior level . The GDG should also make it clear that it is important to make positive enquires as to whether the patient has appointed an attorney who may have the legal powers to make decisions for the patient .</p> |
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