<table>
<thead>
<tr>
<th>Identifier</th>
<th>Question</th>
<th>Why is there uncertainty?</th>
<th>Rank of question in PSP</th>
<th>Original uncertainty</th>
<th>References to reliable up-to-date systematic reviews</th>
<th>Systematic reviews in preparation</th>
<th>Systematic reviews that need updating or extending</th>
<th>Ongoing controlled trials</th>
<th>Which outcomes?</th>
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<tr>
<td>421073</td>
<td>Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?</td>
<td>Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects</td>
<td>5</td>
<td>This uncertainty was identified from six professionals and two bereaved carers questions. This is an indicative uncertainty and the following submissions were merged to form this one: The palliative care team allocated to [patient's name] came from the local hospice. They were very good and part of the process works well. However they were qualified nurses, and well suited to the situation. Will there be a gold standard recommendation to guide hospital staff in the final days or hours of a person's life? Could I as a healthcare assistant be trained to give injections to a family member as they approach the end of their lives? Is there a range of therapies available for patients?</td>
<td>Chan RJ, Webster J. End-of-life care pathways for improving outcomes in caring for the dying. Cochrane Database of Systematic Reviews 2013, Issue 11. Art. No.: CD008006. DOI: 10.1002/14651858.CD008006.pub3.</td>
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<td>Patient Satisfaction; health related quality of life; health related costs.</td>
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<td>421074</td>
<td>Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?</td>
<td>Existing relevant systematic reviews are not up-to-date</td>
<td>25</td>
<td>This uncertainty was identified from five professionals and one bereaved carer's questions. This is an indicative uncertainty and the following submissions were merged to form this one: Can we not have a self refer system to run alongside health care professional referrals? Signpost at diagnosis. Can we make it mandatory to provide a range of care choices for those at the end of their life in the same way that we mandate 2 week cancer waits and 18 week operation dates? Could contact and support from the hospice team begin at the beginning of a stage 4 diagnosis regardless of how long the end of life phase might be to build relationships and stay focused?</td>
<td>Haun MW, Estab S, Piñero G, Frederich HC, Thomas M, Hartmann M. Early palliative care for improving quality of life and survival time in adults with advanced cancer (Protocol). Cochrane Database of Systematic Reviews 2014, Issue 5. Art. No.: CD011129. DOI: 10.1002/14651858.CD011129.</td>
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<td>Health-related quality of life; good death.</td>
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<td>Are some palliative care approaches better than others (e.g. holistic support, co-ordinated care, nurse-led care, early intervention) and for whom?</td>
<td>No relevant systematic reviews identified. This uncertainty was identified from one bereaved carer and four professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: Should end of life care be more nurse lead? What need to be done to enhance Health Promoting Palliative Care? Could a reasonable timescale be set for a palliative emergency home visit to be carried out in rapid response visit to provide essential pain relief? Does early intervention from specialist palliative care improve symptom burden and quality of life? What evidence is there to demonstrate benefit/value of care, support and treatment in palliative care? Particularly the impact of support and resulting benefits due to the interdependence between physical, emotional and psychological well-being?</td>
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<td>Do people at the end of life who receive support from volunteers, carers, family or friends, have better end of life experiences than those who do not?</td>
<td>This uncertainty was identified from two professionals' and two members of the public's question. This is an indicative uncertainty and the following submissions were merged to form this one: How can we involve volunteers in more meaningful ways to enhance and enrich the lives of patients and their families at end of life.</td>
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<td>Do people who are dying and their carers and families fare better if domestic support with shopping, washing-up, laundry, etc, is provided?</td>
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| 21077 | Existing relevant systematic reviews are not up-to-date  
This uncertainty was identified from two carer’s and a bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one:  
- How can we reduce anxiety about practical issues such as finance, housing and transport?  
- What services i.e. Domestic care to assist with school runs etc can be sorted and maintained.  
The effects of the National Quality Improvement Program Palliative Care http://www.trialregister.nl/trialreg/admin/rctvieww.asp?TC=4085  
The National Quality Improvement Program Palliative Care http://www.trialregister.nl/trialreg/admin/rctvieww.asp?TC=4085  
Health related quality of life, good death.  |

<table>
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<th>Page</th>
<th>Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?</th>
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</table>
| 21078 | Existing relevant systematic reviews are not up-to-date  
This uncertainty was identified from two carers’ and two patients’ questions. This is an indicative uncertainty and the following submissions were merged to form this one:  
- What is best treatment for lung cancer that has spread to bone in leg? Not enough known about end of life with brain tumour patients.  
- What can I know, that can help me cope? Could contact and support from the hospice team begin at the beginning of a stage 4 diagnosis regardless of how long the end of life phase might be to build relationships and lay fears?  
Randomized Study of Early Palliative Care Integrated With Standard Oncology Care Versus Standard Oncology Care Alone in Patients With Incurable Lung or Non-Colorectal Gastrointestinal Malignancies NCT02349412. Feasibility of an Interdisciplinary Palliative Care Planning Intervention in Pancreatic Cancer NCT02307539. Impact of Early Palliative Care on Quality of Life and Survival of Patients With Non-small-cell Metastatic Lung Cancer in Northern France NCT02308865.  
Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms.  |
Does earlier palliative intervention for patients with Chronic Obstructive Pulmonary Disease (COPD) improve quality of life? When is the right time to intervene to improve understanding of prognosis, exercise tolerance, overall progression and access to pulmonary rehabilitation?

Existent relevant systematic reviews are not up-to-date. This uncertainty was identified from one bereaved carer’s and seven professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: Not all COPD patients have access to pulmonary rehabilitation despite NICE guidelines, and there is potential to improve their understanding, exercise tolerance and overall progression if targeted at the right time. Dad didn’t have cancer but suffered as much as mum did when she died of cancer. We didn’t get the same support though. Nothing seemed certain or sure. How can we improve access to specialist palliative care units for those suffering from non-malignant, life limiting conditions such as COPD etc?


Can Early Introduction of Specialized Palliative Care Limit Intensive Care, Emergency and Hospital Admissions in Patients With Severe and Very Severe COPD? A Randomized Study NCT02223780

Identification of Patients with COPD with a Poor Prognosis and Implementation of Proactive Palliative Care - PROLONG

http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4037

Patient Satisfaction, health-related quality of life, health-related cost; timing of introduction of palliative care; quality of care

Does practical advice for concerns about housing, finance and transport, etc., reduce anxiety for patients on palliative and end of life care, their carers and families and increase their wellbeing?

Existent relevant systematic reviews are not up-to-date. This uncertainty was identified from a patient’s, two carer’s and a bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: Breaks away and distractions along with any financial support were welcome, as my wife had to take time off work to care for her and that was unpaid. Where can one turn to for impartial advice on ‘smaller’ financial matters - e.g. advantages/disadvantages of informing banks, building societies, credit cards, life insurance, etc. of one’s illness - when, how etc. What are one’s obligations, when is it irrelevant, when is it up to the individual?


The effects of the National Quality Improvement Program Palliative Care

http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4085

Health-related quality of life, good death
### 421081
**Does respite for people caring for a family member or friend who is dying benefit the patient’s care and the quality of life for both the patient and carer? What is the best way to provide respite?**

Existing relevant systematic reviews are not up-to-date. This uncertainty was identified from nine professionals’, a carer’s and a patient’s question. This is an indicative uncertainty and the following submissions were merged to form this one: Planned respite care can be essential in supporting families etc - how easy is it to get this? And to what extent does frequent respite support for families alleviate these problems? This could benefit from much better understanding, especially with lifespans of life-limited children increasing, as the strain on families can encompass much or all of the sibling’s childhood. The extent to which they do, or need to, access mental health services could. How can we provide equitable access to respite care for all? And to what extent does frequent respite support for families alleviate these problems??


### 421082
**How are steroids best used in palliative care (dose, duration, etc) for patients with different conditions, including those with brain tumours?**

No relevant systematic reviews identified. This uncertainty identified from a sawed off carer and two professionals’ question. This is an indicative uncertainty and the following submissions were merged to form this one. I think the best strategies for using steroids during the course of an illness - particularly intracranial or metastatic brain tumours is worthy of some research - how best to balance short term or ongoing benefits against medium term harms. Steroids- studies looking at efficacy and harms, best doses and duration for steroid use for different indications- brain tumours, breathlessness, pain etc. Should steroids really be part of the first line regime considering their long list of side effects? For instance wakefulness - from the patient point of view, sleep is respite when feeling nauseous, and being kept awake by steroids prolongs the torture. Domperidone and ondansetron plus steroids seem to be standard. Is steroid really necessary?

- A phase III multi-centre randomised controlled trial to assess whether optimal supportive care alone (including dexamethasone) is as effective as optimal supportive care (including dexamethasone) plus whole brain radiotherapy in the treatment of patients with inoperable brain metastases from non-small cell lung cancer ISRCTN13826061. Change in symptoms; change in management of symptoms.
<table>
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<th>Page Dimensions: 829.7x607.2</th>
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| 421083 How can access to palliative care services be improved for everyone regardless of where they are in the UK? Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified from one bereaved caregiver's, one member of the public, three caregiver's and eight professional's questions. This is an indicative uncertainty and the following submissions were merged to form this one: How do you get through the system? Why is there inadequate access to therapy services when their aim is to improve or at least maximise quality of life? Can we not have a self-referral system to run alongside health care professional referrals? Evaluation of an initial assessment palliative care clinic for new clients referred to palliative care by retrospective case note audit http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=361983. The effectiveness of the National Quality Improvement Program Palliative Care on the number of patients that die at the preferred place, the patients' and family's experienced control regarding end-of-life care, the patients' and family's experienced coordination of end-of-life care, the patients' and family's experienced concomitant care with their needs, preferences and values, and the number of patients and families that receive care for their needs in the physical, psychosocial, and spiritual domains http://www.trialregister.nl/trialregister/administratio n.aspx?TC=41935. A Randomized Control Trial for Advance Care Planning and Symptom Management for patients identified in the emergency department and followed up at home http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=366429. A Randomised Control Trial for Advanced Care Planning plus Symptom Management and Support for patients with advanced progressive life-threatening health conditions who present to the Emergency Department at Prince of Wales Hospital http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=366429. Patient Satisfaction; health related quality of life; health related cost; benefits of advanced care planning.


| 421085 How can carers and families of people receiving palliative and end-of-life care be encouraged to seek support for themselves at the right time? No relevant systematic reviews identified. This Uncertainty identified from a bereaved caregiver's and a professional's question: This is an indicative uncertainty and the following submissions were merged to form this one: How can we better support families of patients dying from non-malignant disease? ADD Men are more reluctant to seek medical help than women - what is being done to counter this dangerous head-in-the-sand attitude? How do you encourage carers to seek extra support at the appropriate time - (neither too early nor too late...)? Health related quality of life, good death.
How can distress that is not related to pain be best assessed and managed in palliative patients with Dementia, Parkinson’s disease and other diseases that affect communication?

This uncertainty was identified from two professionals questions. This is an indicative uncertainty and the following submissions were merged to form this one: What sort of help works best - control of pain and other symptoms, ensuring no restlessness or distress? How are people with communication difficulties supported to ensure that they can still communicate with their family, friends and carers when they can no longer speak (e.g. people who have MND, people with brain tumour, head and neck cancer). Terminal agitation is a term that has little meaning. Hyperactive delirium at the end of life is a more accurate description. The difference is important since the former is traditionally treated with midazolam while the latter sets in train an assessment and management of the cause and, if drugs are needed, non-sedative haloperidol becomes first choice. An evaluation of end of life hyperactive delirium is long overdue.


How can palliative and end of life care patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?

This uncertainty was identified from one bereaved carer’s and one volunteer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: How can we learn to discuss openly end of life the preparation for it? Were you offered any advice/support in how to inform your family/friends/colleagues about your impending death? Why do some physicians insist on telling the patient his/her prognosis when the patient doesn’t wish to be told? Why does the physician then go against the patient’s wishes and try to tell family members who also don’t want to know because they are respecting the patient’s wish?


Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms.
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<th>Question</th>
<th>Relevant up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects</th>
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<tr>
<td>How can palliative and end of life care patients, carers and families</td>
<td>This uncertainty was identified from one carer, a bereaved carer and two professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: How can we better support families of patients dying from non-malignant disease? Is it possible to provide increased care resources in the community to support patient (and their family) in the terminal phase of their life upon diagnosis? Can retrospective research be carried out on looking at how long before death patients (especially those who have chosen to die at home) receive any end of life care (including help with taking medicines) a service district nurse only provide for those in palliative care? How can palliative care information be made more accessible to people whose first language is not English? has this really been improved? How can palliative care information and services be made more accessible to people whose first language is not English? How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?</td>
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How can the risk of intense and long-lasting grief be best assessed and treated? Can this be prevented through early bereavement support?

No relevant systematic reviews identified

This uncertainty was identified from two professionals and four bereaved carers' questions. This is an indicative uncertainty and the following submissions were merged to form this one: 1. I know now that there is support for the bereaved, should this not be given soon after death occurs? Professionals seem to know how long before the end - this information would help prepare family if some indication is given to them. I know now that there is a support for the bereaved, should this not be given soon after death occurs? Professionals seem to know how long before the end - this information would help prepare family if some indication was given to them. What does good bereavement care look like? What's the best way to risk assess for complicated grief reactions much earlier in the patient's disease trajectory?


Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support.

How is incontinence best managed?

No relevant systematic reviews identified

This uncertainty was identified from four professionals, two carers, one patient and one bereaved carers' questions. This is an indicative uncertainty and the following submissions were merged to form this one: 1. Is it essential that all back pain: physical, emotional, social/ economic and spiritual? Professionals are not interested in empowering people and traditional spiritual and community support has not been replaced by guides and helpers. Would religion be taken into account would they be treated with utmost respect? There seems to be little clarity about what spiritual support needs are needed in people who are approaching the end of life (including those with neurological diseases). Parkinson’s disease, Dementia and Neurone Disease (MND), cancer diseases such as Motor Neurone Disease (MND), Parkinson’s disease, Dementia and heart failure?

Meetable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

This uncertainty was identified from one patient's, one member's, two volunteers', four carers', four bereaved carers' and nine professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: 1. What criteria should trigger discussions about end of life support and care for people with cardiac disease and their families eg. end stage cardiac failure/repeated near-fatal arrhythmic events? Is specialist palliative care needed for those with long term conditions such as Parkinson's disease, multiple sclerosis, COPD, heart failure etc? What is the best way of managing this in MND is specialist palliative care needed for patients in particular with end stage heart failure, and renal failure? Are patients with long term conditions eg Parkinson being recognised as being in their last year of life and offered specialist palliative care services appropriately?


How can we best determine a person’s palliative care needs, particularly for patients with non cancer diseases such as Motor Neurone Disease (MND), Parkinson’s disease, Dementia and heart failure?

Meetable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

This uncertainty was identified from one patient, one volunteer’s, one member’s, two volunteers', four carers', four bereaved carers’ and nine professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: 1. Are patients with long term conditions eg Parkinson being recognised as being in their last year of life and offered specialist palliative care services appropriately?


How can we best determine a person’s palliative care needs, particularly for patients with non cancer diseases such as Motor Neurone Disease (MND), Parkinson’s disease, Dementia and heart failure?

Meetable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

This uncertainty was identified from one carer’s, one member’s, two volunteers’, four carers’, four bereaved carers’ and nine professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: 1. Are patients with long term conditions eg Parkinson being recognised as being in their last year of life and offered specialist palliative care services appropriately?


### 42096
**Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition) for people on palliative and end of life care?**

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<th>Objective</th>
<th>Evidence</th>
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<tr>
<td>Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.</td>
<td>This uncertainty identified by two professionals, two carers and six bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: What is the role of hydration and sedation at the end of life? Further research regarding artificial hydration/nutrition at the end of life (especially the last few weeks) is important in order to guide clinical practice where possible.</td>
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### 42097
**Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?**

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<td>Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.</td>
<td>This uncertainty was identified from a professional’s, and carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: What is the role of hydration and sedation at the end of life? Further research regarding artificial hydration/nutrition at the end of life (especially the last few weeks) is important in order to guide clinical practice where possible. The practice of maintaining hydration/nutrition seems variable and inconsistent across patients/hospitals. How can the withdrawal of these be done in a sensitive and consensual way for person, family and medical/care staff?</td>
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*Change in symptoms; change in management of symptoms.*
Is there evidence that some volunteer services that provide support for palliative and end of life care patients, carers and families reduce the need for paid trained staff?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified from one professional’s, one lay person’s and one researcher’s question. This is an indicative uncertainty and the following submissions were merged to form this one: How can we involve volunteers in more meaningful ways to enhance and enrich the lives of patients and their families at end of life? I currently attend a day care hospice as I have had bladder and bowel cancer along with COPD. I would like to volunteer for some palliative care/help and have helped many other less fortunate patients. Impact of reduced funding on staffing levels/quality of service of volunteers to replace paid roles.


Health related cost

Much palliative and end of life care is provided by charities. What are the benefits and risks of this and is it sustainable and efficient?

No relevant systematic reviews identified

This uncertainty was identified from one bereaved carer’s question. This uncertainty was identified from one professional’s, one lay person’s and one researcher’s question. This is an indicative uncertainty and the following submissions were merged to form this one: There is a severe lack of continuity, no weekend care from GP or MacMillian Nurses and why does end of life treatment have to be given by charity. We have NHS which let’s down those that need help in their final stage of illness. Why is there no support from the media that knows the patient?

The effects of the National Quality Improvement Program Palliative Care http://www.trialregister.nl/trialreg/admin/trialview.asp?TC=4085

Patient Satisfaction; health related quality of life; health related cost; adverse effects; quality of care

Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?

No relevant systematic reviews identified

This uncertainty was identified from two professionals and 5 bereaved carer’s questions. This uncertainty was identified from one volunteer’s, one professional’s and one bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: Whilst there were services put in place as soon as my husband was told he was dying there was no consideration of support or counselling after his death. Having saved the NHS considerable sums personally nursing him at home in the last six months of his life, my own health would have benefited at least from referral to counselling and a GP review. I know now that there is support for the bereaved, should this not be given soon after death occurs? What does good bereavement care look like? We had plenty of help during palliative care but had nothing afterwards would have been nice to have had some support after husband died.

Malawi’s and staff’s experience of the moment of death in the Intensive Care unit of a tertiary referral hospital http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903

Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support.

Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?

No relevant systematic reviews identified

This uncertainty was identified from one volunteer’s, one professional’s and one bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: Why do I have to repeat my information can patients not carry their own chart as maternity patient do why is there no joined up thinking? There appears to be a lack of understanding of MND when admitted to a hospital ward despite “Patient Passports” being carried by the patient. I think we all need to be more comfortable in talking about this phase of living/ dying. Continuity of care is essential but not easy to achieve. Good communication (patient held records) and named key comp personnel increase confidence- and managing death at home requires confidence all round.

Malawi’s and staff’s experience of the moment of death in the Intensive Care unit of a tertiary referral hospital http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903

Patient Satisfaction; health related quality of life; health related cost;
42102 What are the best ways of managing constipation, including when caused by medication, such as opioids?

Reliable, up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.

This uncertainty was identified from a bereaved carer's and a professional's question. This is an indicative uncertainty and the following submissions were merged to form this one: What is the best treatment for opioid-induced constipation?

Candy B, Jones L, Goodman ML, Drake R, Tookman A. Laxatives or methylcellulose for the management of constipation in palliative care patients. Cochrane Database of Systematic Reviews 2011, Issue 1. Art. No.: CD003448. DOI: 10.1002/14651858.CD003448.pub3

42103 What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?

No relevant systematic reviews identified.

This uncertainty was identified by two professional's question. This is an indicative uncertainty and the following submissions were merged to form this one: What are the advantages and disadvantages (physical, social, psychological) of blood transfusion towards end of life - balancing benefit with, for example, risk of increased bleeding. Benefits of increased hydration; the potential for medical 'kit' acting as barrier to form this one: How can evaluate the pros & cons of life-prolonging interventions (e.g. tracheostomies, PEGs) that may nevertheless negatively impact one's quality of life? How do you deal with any pressure from others on these questions? Further research regarding artificial hydration/nutrition at the end of life is important in order to guide clinical practice where possible. How does nutritional status influence survival and death in cancer patients?


42104 What are the benefits and limitations (physical, social, psychological) of providing artificial hydration and nutrition for example, a drip to patients at the end of life, including those with bowel obstruction? When should this be done?

Reliable, up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.

This uncertainty was identified from a patient, two carers', two bereaved carer's and three professional's question. This is an indicative uncertainty and the following submissions were merged to form this one: What is the best treatment for opioid-induced constipation?

Candy B, Jones L, Goodman ML, Drake R, Tookman A. Laxatives or methylcellulose for the management of constipation in palliative care patients. Cochrane Database of Systematic Reviews 2011, Issue 1. Art. No.: CD003448. DOI: 10.1002/14651858.CD003448.pub3


Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.

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ID=JPRN-JapicCTI-111510
What are the benefits and limitations of chemotherapy and radiotherapy for patients approaching the end of their lives? How can health care professionals best communicate this?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.

This uncertainty was identified from three professionals, a patient and a bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: Question why continue with Chemotherapy when it’s not working and affects quality of life so much. RCT on benefit of whole brain radiotherapy in metastatic melanoma, not non small cell lung cancer, not breast cancer.


Change in symptons: change in management of symptoms. Adverse effects or complications

What are the benefits for patients, carers and families of day hospitals and day therapies such as complementary therapies, rehabilitation and physical exercise for palliative and end of life care? Do they help people stay more independent? When are the best times to refer palliative patients to these services and who benefits most?

No relevant systematic reviews identified

This uncertainty was identified from two carers, one bereaved carer, one patient, one member of the public eight professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: Why don’t people who present to the Emergency Department at the Prince of Wales Hospital with advanced progressive recurrent cancer opt for palliative care? Do they help people stay more independent and to live until they die? Why is there inadequate access to therapy services when their aim is to improve or at least maximise quality of life? Why is this not considered essential for all people not just those who can afford to pay privately? Why can’t we have more day therapy support? I would like more research on the benefits of this and how these services can be made more available to a wide range of people with advanced illnesses.


A randomised controlled trial to evaluate a complex rehabilitaive intervention for patients with advanced progressive recurrent cancer. ISRCTN22485853

Patient Satisfaction: health related quality of life; health related cost; change in symptoms; change in management of symptoms.

What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients’ preferences for palliative and end of life care? Who should implement this and when?

No relevant systematic reviews identified

This uncertainty was identified from two carers, one bereaved carer and two professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: Are outcomes better for relatives with advance care planning for patients? Does the timing of ACP have a differential impact on how and where a person is supported in the last weeks of life? Can ACP improve costs at the end of life (I think the evidence on improving patient satisfaction is already quite compelling)?


Patient Satisfaction: health related quality of life; health related cost; change in symptoms or change in management of symptoms.
| 421108 | What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible? | No relevant systematic reviews identified | This uncertainty was identified from one bereaved carer and three professional questions. This is an indicative uncertainty and the following submissions were merged to form this one: I think every nursing home/hospice should have a member of staff able to dedicate themselves to emotional support of close family and friends - a little company, the opportunity to talk, while visiting a loved one. Should there be specific training for ward nurses in bereavement counselling? Working in a hospice we offer bereavement support pre and post death and offer follow ups via GPs and Community Palliative Care Nurses. Is there bereavement training or online counselling skills available for staff members. For dealing with family members | Relative's and staff's experience of the moment of death in the Intensive Care unit of a tertiary referral hospital. [http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903](http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903) | Family/care satisfaction, quality of life, health related cost; timing of introducing bereavement support. |
| 421109 | What are the benefits of alternative therapies (such as homeopathy) or complementary therapies (such as acupuncture) for palliative care patients? How and where are these best provided? | No relevant systematic reviews identified | This uncertainty was identified from one member of the public, two professionals and two bereaved carers. This is an indicative uncertainty and the following submissions were merged to form this one: Do you provide library trolley services/ability to record music/make scrapbooks/last family trips away - Is there anyone you could approach who does? How can acupuncture reduce unpleasant symptoms? What is the effectiveness of acupuncture for pain control? How can acupuncture reduce anxiety for patients and carers? How can acupuncture reduce important symptoms and side effects such as dry mouth and tiredness is there possibilities of funds for alternative therapy eg massage and aromatherapy for patients in their home, not just in hospice, and training for generic therapists to be more skilled for palliative. Complementary and spiritual healing do no harm why are they not embraced by mainstream medicine. There is evidence to support the benefit of other therapies patients | [Lian WL, Pan QX, Zhou DH, Zhang ZJ. Effectiveness of acupuncture for palliative care in cancer patients: a systematic review. Chinese Journal of Integrative Medicine.2014;20(2):136?147 PMID:24338183](http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903) [Shin ES, Lee SH, Seo HY, Park YH, Nguyen TT. Aromatherapy and massage for symptom relief in patients with cancer (Protocol). Cochrane Database of Systematic Reviews 2012, Issue 6. Art. No.: CD009873. DOI: 10.1002/14651858.CD009873) [Music therapy to relieve pain and depressive symptoms for community-dwelling frail older adults: study protocol for a randomised controlled trial](http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903) [A randomised controlled trial to evaluate a complex rehabilitative intervention for patients with advanced progressive recurrent cancer ISRCTN22458583](http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903) [A Feasibility Study in Acupuncture for Symptom Management in Palliative Care. NCT00302185](http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903) | Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms. |
| 421110 | What are the benefits of bereavement support, including preventing depression and other illness? | No relevant systematic reviews identified | This uncertainty was identified from two professionals and six bereaved carers. This is an indicative uncertainty and the following submissions were merged to form this one: Sadly when someone dies, not only is there a huge hole where their loved one was, but also an immediate void from all the health and social care professionals involved, understandably, but maybe there needs to be mechanism whereby they are not left to their own devices (unless they want to of course) sometimes creating mental health issues, which is not helpful to anyone. I also think continued support for carers after bereavement is essential as this could possibly prevent depression and illness and increased burden on the health care system at a later stage. Why aren't families asked to attend support groups or given information about help with their bereavement? we had plenty of practical help but not enough emotional support, help was offered by the doctor but no talking therapy. | Relative's and staff's experience of the moment of death in the Intensive Care unit of a tertiary referral hospital. [http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903](http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=336903) | Family/care satisfaction, quality of life, health related cost; timing of introducing bereavement support. |
What are the benefits of increasing the numbers of palliative clinical nurses/nurse specialists in hospitals, GPs, nursing homes and other settings?

No relevant systematic reviews identified. This uncertainty was identified from two professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: Is it possible to have a Specialist Palliative nurse in all nursing homes? Can we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t, I’d like to know how funding decisions are made. Could we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t. I’d like to know how funding decisions are made. Could we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t. I’d like to know how funding decisions are made. Could we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t. I’d like to know how funding decisions are made. Could we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t. I’d like to know how funding decisions are made. Could we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t. I’d like to know how funding decisions are made. Could we have a unified national system for recording preferences for care at the end of life and bolster community nursing to improve community care? Again I worry about inequality. Some areas are able to offer a lot of support at this time whereas others don’t. I’d like to know how funding decisions are made.

Patient Satisfaction; health related quality of life; health related cost; quality of care

What are the benefits of occupational, beauty, diversion therapies (such as mindfulness, meditation, art, dance and gardening) for palliative care patients? How and where are these best provided?

No relevant systematic reviews identified. This uncertainty was identified from one professional, one volunteer, one bereaved carer and carers questions. This is an indicative uncertainty and the following submissions were merged to form this one: How many patients are being referred to Occupational Therapy as a standard part of care to ensure that their needs are picked up early and that they are aware of what OT can offer? Arts therapies are being used by patients and carers at the end of life; systematic investigation of their potential benefits would be useful. Teaching mind over matter. Use of alternative therapies – beauty and health.

Music therapy to relieve pain and depressive symptoms for community-dwelling frail older adults: study protocol for a randomised controlled trial


A randomised controlled trial to evaluate a complex rehabilitative intervention for patients with advanced progressive recurrent cancer ISRCTN22485853

A Feasibility Study in Acupuncture for Symptom Management in Palliative Care. NCT00302185


PMID: 24338183


Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms.
What are the benefits of setting up universal training courses for volunteers, carers, families and complementary therapists who have regular contact with palliative care patients?

Existing relevant systematic reviews are not up-to-date

This uncertainty identified from three professionals, one volunteer, two bereaved carers and one researcher’s question. This is an indicative uncertainty and the following submissions were merged to form this one: How can we involve volunteers in more meaningful ways to enhance and enrich the lives of patients and their families at end of life. Ability for carers to have some training to recognise the end of life signs. Supporting the patient to die at home is a priority, yet there is no practical support for the carer to ensure this is successful. By this I mean instruction on how to provide basic nursing care intravenously to volunteers or District Nurses. Why? Why are carers not given help in recognising the patient of deterioration in long term health conditions? Particularly in the last stages of life, can we teach carers to give subcutaneous breakthrough doses of drugs at home? (did this from an [hospice location] and it worked very well).


Supporting family carers of palliative patients at home: the carer support needs assessment intervention. NCTID0226135

Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

This uncertainty identified from a carer, five bereaved carers, two patients, three professionals and three members of the public. This is an indicative uncertainty and the following submissions were merged to form this one: That care homes have more knowledge of how to cope with the ever changing condition. Why do older people nearing the end of their life get discharged from hospital to rehabilitation centres, care homes or carers at home when all they really need is Hospice care at home 24 hours. Care and support needs to be in one department to manage all the care, equipment and support patient and families will need.

The effect of different models of facilitation when implementing the Gold Standards Framework in Care Homes (GSFCH): a cluster randomised control trial ISRCTN76029577

Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?

No relevant systematic reviews identified

This uncertainty was identified from two bereaved carers and one member of the publics questions. This is an indicative uncertainty and the following submissions were merged to form this one: Why is there so little time to talk to the person in a comfortable, discrete situation? Can those near the end of life be given a space of their own - not shared with other patients - so that they and their loved ones have the opportunity of time together without a sense of being invaded/invaded? Can you visit any time you wish?

Patient Satisfaction; health related quality of life, health related cost.

What are the benefits, and best ways, of providing palliative care in the patient’s home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

This uncertainty was identified from two professionals, one carer and one member of the publics questions. This is an indicative uncertainty and the following submissions were merged to form this one: Do you think it’s important that the patient stays in their own home as long as possible & what support & care would we have with the increasing numbers of frail older people coming into Acute care needing 24hr support, how will we support their preferred place of care/death when it is home without 24hr community care? "Support - more support whilst in community social service input"? Currently the burden of care falls squarely on family members. When will free nursing care be available at home, preventing admittance to nursing homes or hospital, to those who are palliative?


Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.
What are the best approaches to giving medicines, such as morphine, in a patient’s home, for example using different cannulas such as BD-saf-T-intimaTM in palliative and end of life care? What are the pros and cons of training carers, families and non-palliative professionals, such as healthcare assistants, to give these medicines?

**Pros and cons of training carers, families and non-palliative professionals:**

- **Pros:**
  - Increased patient comfort and quality of life.
  - Improved autonomy.
  - Reduced hospital admissions.

- **Cons:**
  - Increased risk of medication errors.
  - Psychological burden on carers.
  - Cost implications.

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.

This uncertainty was identified from one carer’s and three professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: What role does being able to have controlled medicines administered at home make to the quality of the last days/weeks/months? Why are social and health care assistants not getting trained to administer medications in the patients homes? This is the biggest frustration to staff as we feel we are not providing the service patients and their carers are expecting from us. Why do we still give stat doses in the last days of life into a person’s skin? It seems so cruel. In this day and age of technology. Haven’t they suffered enough. Night after night I go to patients with a syringe driver in, not enough drugs to increase the whole driver so I have to give sublet injections sometimes it a night. Sat T Intima was supposed to stop this but we never see Sat T intimas on the community where I work in [location] can we teach carers to give subcutaneous breakthrough doses of drugs at home? (did this from an [hospice location] and it worked very well)

**Clustered, Randomized, Controlled Trial of the Home Care Nurse Carer Support Needs Assessment Practice Tool With Family Caregivers of Palliative Patients at Home**

NCT02261935  Improving quality of life for south Tyrolean palliative patients in home care: a randomised controlled trial of home-based palliative care ISRCTN10224372

**Gomes B, Calanzani N, Currao F, McClone P, Higginson IJ.**


What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease, such as motor neurone disease (MND), dementia, brain tumour (including glioblastoma) or head and neck cancer?

**Existing relevant systematic reviews are not up-to-date**

Ranked 11th in the PeolcPSP prioritisation. This uncertainty was identified from two patients, a bereaved carer and volunteer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: Whilst thinking she’d had a stroke mum was taking aspirin. Once the diagnosis of a brain tumour came in, she was put on other steroids. But her condition had improved (a little) on aspirin, in retrospect the aspirin was doing some good. Use aspirin used widely for brain tumours? They are obviously designed to make your final days,weeks,months as comfortable as possible. A relevant question might be why is there no specific research into drugs which might help to ease the pain but can also incorporate some type of protection against side effects Palliative care for people with dementia particularly better assessment techniques to find out if they are in pain or discomfort so that this can be treated[?]

**Concordance of Pain Detection in Patients by Doloplus? and Algoplus? Behavioural Scales NCT02174744**

A randomised control trial for Advanced Care Planning plus Symptom Management and Support for patients with advanced progressive life-threatening health conditions who present to the Emergency Department at Prince of Wales Hospital http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=366429

What are the best approaches to support carers and families of people at the end of life where there are substance and/or alcohol addiction and/or domestic violence issues?

**No relevant systematic reviews identified**

This uncertainty was identified from one professional’s question. This is an indicative uncertainty and the following submissions were merged to form this one: How to support families with MND, palliative care and domestic violence, palliative care and alcohol abuse.

**Clustered, Randomized, Controlled Trial of the PACSLAC-D in older adults with dementia in nursing homes - N/A**


A relevant question might be why is there no specific research into drugs which might help to ease the pain but can also incorporate some type of protection against side effects Palliative care for people with dementia particularly better assessment techniques to find out if they are in pain or discomfort so that this can be treated[?]

**Investigation of the feasibility of the PACSLAC-D in older adults with dementia in nursing homes - N/A**


**Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.**

**Change in symptoms; change in management of symptoms;**

**Health related quality of life; good death.**
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<tr>
<th>ID</th>
<th>Question</th>
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<td>42118</td>
<td>What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual progresses into consideration for palliative and end of life care?</td>
<td>This uncertainty was identified from one bereaved carer's and five professional's questions. This is an indicative uncertainty and the following sub-questions were merged to form this one: Will there be a gold standard recommendation to guide hospital staff in the final days or hours of a patient's life? Will the organisation of care for people in acute wards who are rapidly approaching the end of their life, what forms of service organisation work best to maximise quality of care - e.g. palliative care keyworkers, equivalent of midwives, palliative care teams, working as advisors, palliative care experts working hand in hand, etc. How could oncology be changed to align with a more person centered approach using joint decision making?</td>
<td>Chan RJ, Webster J. End-of-life care pathways for improving outcomes in care at the end of life. Cochrane Database of Systematic Reviews 2013, issue 11. Art. No.: CD003566. DOI: 10.1002/14651858.CD003566. PubMed: 24134353 INSPIRE study: Investigating Social and Practical Support at the End of Life. EPRICH194002594 Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium. NCT02260059 A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. Patient Satisfaction; health related quality of life; health related cost; timing of access to care and support; good death.</td>
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<td>42119</td>
<td>What are the best models of palliative care for people who have learning difficulties?</td>
<td>This uncertainty was identified from two professional's and a member of the public question. This is an indicative uncertainty and the following sub-questions were merged to form this one: There is a need for expertise in the area of palliative care for people with intellectual disabilities and at the end of life. Government Policy in Ireland advocates 'normalisation' and 'deinstitutionalisation' for people with intellectual disabilities. This policy may not be in the best interest of those with intellectual disabilities who need palliative care or who are at the end of their lives. There is a need for expertise in the area of palliative care for people with intellectual disabilities and who are rapidly approaching the end of their life. My concern is really about vulnerable populations - for example people with learning disabilities, complex mental health issues who are not well served by palliative care services - even when have illnesses that are the typical remit for such services - eg cancer!</td>
<td>Chan RJ, Webster J. End-of-life care pathways for improving outcomes in care at the end of life. Cochrane Database of Systematic Reviews 2013, issue 11. Art. No.: CD003566. DOI: 10.1002/14651858.CD003566. PubMed: 24134353 INSPIRE study: Investigating Social and Practical Support at the End of Life. EPRICH194002594 Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium. NCT02260059 A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. Patient Satisfaction; health related quality of life; health related cost; timing of access to care and support; good death.</td>
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<td>42120</td>
<td>What are the best models of palliative care for people who have mental health issues?</td>
<td>This uncertainty was identified from two professional's and a member of the public question. This is an indicative uncertainty and the following sub-questions were merged to form this one: My concern is really about vulnerable populations - for example people with learning disabilities, complex mental health issues who are not well served by palliative care services - even when have illnesses that are the typical remit for such services - eg cancer!</td>
<td>Chan RJ, Webster J. End-of-life care pathways for improving outcomes in care at the end of life. Cochrane Database of Systematic Reviews 2013, issue 11. Art. No.: CD003566. DOI: 10.1002/14651858.CD003566. PubMed: 24134353 INSPIRE study: Investigating Social and Practical Support at the End of Life. EPRICH194002594 Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium. NCT02260059 A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. Patient Satisfaction; health related quality of life; health related cost; timing of access to care and support; good death.</td>
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<td>42121</td>
<td>What are the best models of palliative care in an acute setting, such as a hospital?</td>
<td>This uncertainty was identified from two carer's, two bereaved carer's and two professional's question. This is an indicative uncertainty and the following sub-questions were merged to form this one: If there were specialist palliative care paramedics working in conjunction with hospices would this provide reassurance and immediate access care and support? Is it possible to have more palliative clinical nurse specialist in acute hospital to assist in the care support and treatment of patient and families who will also assist in the feedback of information to other professionals involved in the care?</td>
<td>Chan RJ, Webster J. End-of-life care pathways for improving outcomes in care at the end of life. Cochrane Database of Systematic Reviews 2013, issue 11. Art. No.: CD003566. DOI: 10.1002/14651858.CD003566. PubMed: 24134353 INSPIRE study: Investigating Social and Practical Support at the End of Life. EPRICH194002594 Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium. NCT02260059 A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer. <a href="http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523">http://www.ctri.in/Clinicaltrials/pmaindet2.php?trialid=7523</a>. Patient Satisfaction; health related quality of life; health related cost; timing of access to care and support; good death.</td>
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What are the best treatments for fluid retention in patients approaching the end of life?

No relevant systematic reviews identified

This uncertainty identified from a bereaved carer’s and a professional’s question. This is an indicative uncertainty and the following submissions were merged to form this one: How to balance providing fluids to those who are dying who cannot swallow safely or easily. Use of subcutaneous/IV fluids in the last days of life. What treatment is available for end-stage patients with significant oedema?


What are the best treatments for nausea and vomiting, including for people with bowel obstruction and those having palliative chemotherapy?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.

This uncertainty was identified from two bereaved carer’s and a carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one: what is the best antiemetic for nausea and vomiting with specific causes. Out of hours emergency care, e.g. for sudden onset of infections, is provided by my local specialist cancer hospital, followed by a triage phone call, and then a decision as to whether I should come into hospital. But how do I deal with things such as nausea, tooth problems and debilitating pain, which can strike at any time (but typically do strike at weekends/public holidays)? Does dopamine help with cachexia/nausea?


What are the best ways and times to meet the emotional support needs of palliative and end of life care patients, carers and families, including one-on-one peer support, support groups and professional counselling?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified from one volunteer, one patient, two members of the public, nine carers, ten bereaved carers' and ten professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: Why no psychological support and counselling so poorly available? Both for patients, carers families? Could carers be given direct access to mental health support?


Clustered, Randomized, Controlled Trial of the Home Care Nurse Carer Support Needs Assessment Practice Tool With Family Caregivers of Palliative Patients at Home NCT02261935

What are the best ways for healthcare professionals to tell patients, carers and families that a patient’s illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?

No relevant systematic reviews identified

This uncertainty was identified from one bereaved carer and two professionals’ question. This is an indicative uncertainty and the following submissions were merged to form this one: Why can't doctors and clinicians be more honest and clear in their explanations about end of life and prognosis? Why are the patients, carers and families not told about what to expect during the last couple of days/hours before passing? More information about the extreme side of end of a life should be available to help plan better. What is the policy about being honest with carers? My mum was quite stubborn and did not really want anyone else involved, how would you talk to her?


Health System Intervention to Improve Communication About End-of-Life Care for Vulnerable Patients NCT01933789  Dignity Talk: a Novel Palliative Care Intervention for Patients and Their Families NCT01883375


Patient Satisfaction; health related quality of life; health related cost; quality of support; psycho-social wellbeing
This uncertainty was identified from seven professional’s and a patient’s question. This is an indicator uncertainty and the following submissions were merged to form this one: Is there a direct correlation between nutritional status and progression of MND? What is being researched about wasting, anorexia and cachexia? What level of nutritional support should be provided to those with cancer cachexia?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

A prospective cohort study exploring the impact of offering telephone support to palliative patients and their family caregivers to enhance the community-based palliative care service ACTRN12613001317774

What are the best ways of providing palliative care outside of ‘working hours’ to avoid crises and help people at the end of life with advanced dementia, Parkinson’s disease and other diseases that affect cognition and communication?

What are the best ways of providing palliative care outside of ‘working hours’ to avoid crises and help patients to stay at home as long as possible?

What are the best ways of providing palliative care outside of ‘working hours’ to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?

What are the best ways of providing palliative care outside of ‘working hours’ to avoid crises and help people at the end of life with advanced dementia, Parkinson’s disease and other diseases that affect cognition and communication?
What are the best ways to begin to deliver palliative care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD)), heart failure, motor neuron disease (MND), AIDS, multiple sclerosis, Crohn's disease and stroke?  
No relevant systematic reviews identified

421131  
What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?  
No relevant systematic reviews identified

421132  
What are the best ways to ensure that people with Motor Neurone Disease (MND) receive essential palliative end of life care transition to palliative care and what should a "just in case kit" be considered?  
No relevant systematic reviews identified

421130  
What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD)), heart failure, motor neuron disease (MND), AIDS, multiple sclerosis, Crohn's disease and stroke?  
No relevant systematic reviews identified
421133 What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology for palliative and end of life care?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.

This uncertainty was identified from one member of the public, one bereaved carer's and four carers' questions. This is an indicative uncertainty and the following submissions were merged to form this one: There was always a problem when [patients name] went into hospital. Several times she was rushed into hospital with breathing problems, and the performance of the emergency services was exemplary. However, when the hospital was ready to discharge [patients name], getting the care plan re-established was a nightmare and considerably prolonged her stay. How could IT systems be synchronized between providers to optimize care? In the community, GPs and the wider team have meetings to discuss patients on palliative care registers - there is no clear national guidance regarding this. Does this system produce outcomes and benefits? What model works best? How often should these meetings happen?

Patient Satisfaction; health related quality of life; health related cost.

421134 What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?

No relevant systematic reviews identified

This uncertainty was identified from six bereaved carers, six professionals and two carers questions. This is an indicative uncertainty and the following submissions were merged to form this one: Are there any painkillers that can make a person more comfortable but not make them so drowsy? What is best / common practice with pain management? The questions that need an answer are mostly about how pain will be relieved and how it can be achieved.


Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms; counselling and advice; GP visits; 24-hour support; for patients, carers and families; patient Satisfaction; health related quality of life; health related cost.

421135 What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?

No relevant systematic reviews identified

This uncertainty was identified from one member of the public, two patients, five professionals and seven bereaved carers questions. This is an indicative uncertainty and the following submissions were merged to form this one: Who is responsible for coordinating all the different types of care NHS/hospice/ community/social services/therapy occupational/speech and language services? In my experience there is little coordination which leads to delays for patient and carer and vital delays in response and treatment. My experience of caring for a terminally ill husband was that the health and care services worked well but I was concerned about the number of health professionals that could be involved eg OT in hospital and community, physio in hospital and from hospice. All excellent but one point of call would be so helpful - can we organise care so that there is a key worker to help people through this maze? Is it possible to have palliative clinical nurse specialists in GP surgeries to co-ordinate the care support and treatment of palliative patients?

Patient Satisfaction; health related quality of life; health related cost; good death.
What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?

No relevant systematic reviews identified

This uncertainty was identified from two professionals’ and a member of the public question. This is an indicative uncertainty and the following submissions were merged to form this one: We currently have no way of measuring if we are having any impact on a patient’s quality of life following input from a physiotherapist, or medical input to manage breathlessness. How can we better support patients with respiratory problems, especially breathlessness in palliative care, including patients with COPD and pulmonary fibrosis? What is the best treatment for breathlessness in patients with life-limiting conditions? How can we better support patients with respiratory problems, especially breathlessness in palliative care, including patients with COPD and pulmonary fibrosis? We currently have no way of measuring if we are having any impact on a patient’s quality of life following input from a physiotherapist, or medical input to manage breathlessness. It would also be beneficial to know if we were able to see patients like this slightly earlier in the disease process, whether we could improve their quality of life for longer.


Effectiveness of the “Calming Hand” and the hand held fan for the relief of refractory breathlessness from exercise in palliative patients and the self-efficacy of the interventions in a “ritual for care” plan for the patient and carer: A feasibility study using a 2x2 factorial randomised controlled trial design (IRCTN40230190).

What are the best ways to manage drooling and excessive salivation in patients with diseases such as Motor Neurone Disease (MND) who are approaching the end of their life?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects

This uncertainty was identified from two professionals’ and a carer’s and two bereaved carer’s questions. This is an indicative uncertainty and the following submissions were merged to form this one: What is the best way to manage symptoms in advanced neurological disease: hypersalivation/drooling - spasms. What could I have done to have made my dad more comfortable when suction for his excess saliva wasn’t working and it was the saliva that was causing problems? My father’s biggest question would be how to control his saliva and drooling?? This is a huge problem for him at the moment? Himself and his MND nurse are trying different medications and it is all trial and error!


Assessment of the efficacy and the influence on swallowing function of transdermal scopolamine for ALS patients’ drooling. http://apps.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-UMIN000011494

Study of the Safety and Efficacy of Tropicamide Thin Films to Reduce Hypersalivation in Parkinson’s Patients. NCT01844648


Assessment of the efficacy and the influence on swallowing function of transdermal scopolamine for ALS patients’ drooling. http://apps.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-UMIN000011494

Study of the Safety and Efficacy of Tropicamide Thin Films to Reduce Hypersalivation in Parkinson’s Patients. NCT01844648

Health-related quality of life, good death, Change in symptoms, or change in management of symptoms, adverse effects or complications
| What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life? | Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified from three professionals', a carer's and three bereaved carer's questions. This is an indicative uncertainty and the following submissions were merged to form this one: Why do we not have effective treatment for the management of respiratory secretions? What could I have done to have made my dad more comfortable when suction for his excess saliva wasn’t working and it was the saliva that was causing problems? My father’s biggest question would be how to control his saliva and drooling? This is a huge problem for him at the moment? Himself and his MND nurse are trying different medications and it is all trial and error!! | Lokker ME, van Zuylen L, van der Rijt CC, van der Heide A. Prevalence, impact, and treatment of death rattle: a systematic review. Journal of Pain and Symptom Management. 2014;47(1):105-112. PMID: 23790419 | Lokker ME, van Zuylen L, van der Rijt CC, van der Heide A. Prevalence, impact, and treatment of death rattle: a systematic review. Journal of Pain and Symptom Management. 2014;47(1):105-112. PMID: 23790419 |

Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications.
What are the best ways to prevent blood clots, deep vein thrombosis and pulmonary embolism for patients at the end of life? What is the role of low molecular weight heparin (LMWH)?

Existing relevant systematic reviews are not up-to-date. This uncertainty was identified from a bereaved carer and three professionals' question. This is an indicative uncertainty and the following submissions were merged to form this one: Please can more to be done about preventing blood clots. My dad had cancer but we were told he died of a pulmonary embolism. Why are we doing so much research to cure cancer if you die from something different.


What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?

Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified from three professionals’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: Anxiety is a problem on its own but also decreases ability to cope with pain. How does counselling and psychotherapy help? Which kind of counselling is most effective for people in end of life care? Should counselling be available to all patients or those who cross a clinical threshold of measured distress? What’s the best way to evaluate effectiveness/efficacy of intervention (especially psychological spiritual care). Is there a way to get emotional support? My father sank into depression as the treatment for his cancer stopped working. He was particularly difficult to live with, but there didn’t seem to be any support for dealing with his depression, or maybe we didn’t know where to turn to. The depression was as difficult to cope with (for all of us) as the cancer was.


Change in symptoms; change in management of symptoms.
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<thead>
<tr>
<th>Question</th>
<th>Relevant up-to-date systematic reviews</th>
<th>No relevant systematic reviews identified</th>
<th>No relevant systematic reviews identified</th>
<th>Relevant up-to-date systematic reviews</th>
<th>No relevant systematic reviews identified</th>
<th>Relevant up-to-date systematic reviews</th>
<th>Supporting references</th>
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<tr>
<td>What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.</td>
<td>This uncertainty was identified from a patient, four professionals, and two bereaved carer’s question. This is an indicative uncertainty and the following submissions were merged to form this one. And to what extent does frequent respite support for families alleviate these problems? This could benefit from much better understanding, especially with lifespan of life-limited children increasing, as the strain on families can encompass much or all of the sibling’s childhood. The extent to which they do, or need to, access mental health services could point towards the preventative value and value-for-money of regular lifelong respite. It is difficult to know what advice is given to families with young teenagers who have a parent that is terminally ill and the young patient’s needs support from an outside source. I know the advice my late husband and I were given by a professional. I’m curious to know what advice is given these days. Why can children who have lost a parent only receive 5 sessions with a bereavement counsellor?</td>
<td>No relevant systematic reviews identified</td>
<td>No relevant systematic reviews identified</td>
<td>Relevant up-to-date systematic reviews</td>
<td>No relevant systematic reviews identified</td>
<td>Relevant up-to-date systematic reviews</td>
<td>Rousner R, Kraus J, Feghali A. A meta-analysis of interventions for bereaved children and adolescents. Death Studies. 2010;34(2):99-136. 2 <a href="http://www.tandfonline.com/doi/abs/10.1080/07481180903492422#.VSE-XFzF__E">http://www.tandfonline.com/doi/abs/10.1080/07481180903492422#.VSE-XFzF__E</a> McDaid C, Trowman R, Golder S, et al. Interventions for people bereaved through suicide: systematic review. Br J Psychiatry 2009;193:438–443 <a href="http://bjp.rcpsych.org/content/193/6/438.Perkins">http://bjp.rcpsych.org/content/193/6/438.Perkins</a> P, Dorman S. Haloperidol for the treatment of nausea and vomiting in palliative care patients. Cochrane Database of Systematic Reviews 2009, Issue 2. Art. No.: CD006271. DOI: 10.1002/14651858.CD006271.pub2.</td>
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<td>What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple?</td>
<td>This uncertainty was identified from a professional’s question. This is an indicative uncertainty and the following submissions were merged to form this one. Why is pineapple perceived to be so useful for mouth dryness? Does it actually work?</td>
<td>No relevant systematic reviews identified</td>
<td>No relevant systematic reviews identified</td>
<td>Relevant up-to-date systematic reviews</td>
<td>No relevant systematic reviews identified</td>
<td>Relevant up-to-date systematic reviews</td>
<td>Change in symptoms; change in management of symptoms.</td>
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<td>What are the core palliative care services that should be provided no matter what the patients’ diagnosis is?</td>
<td>This uncertainty was identified from several professionals’ question. This is an indicative uncertainty and the following submissions were merged to form this one. How does counseling and psychotherapy help? Which kind of counseling is most effective for people in end of life care? Should counseling be available to all patients or those who cross a clinical threshold of measured distress? What’s the best way to evaluate effectiveness of intervention (especially psychological spiritual care)? Those who are rapidly approaching end of life but fall outside the Specialist Palliative Care services fail to get the holistic assessment and management associated with these services - when people in this situation find themselves in an acute hospital setting how can we improve and ensure appropriate and of life attention - HPC Teams are not staffed to meet these core needs what is the best model of care for specialist palliative care for those with long term conditions such as Parkinson’s disease, multiple sclerosis, COPD, heart failure etc…</td>
<td>No relevant systematic reviews identified</td>
<td>No relevant systematic reviews identified</td>
<td>Relevant up-to-date systematic reviews</td>
<td>No relevant systematic reviews identified</td>
<td>Relevant up-to-date systematic reviews</td>
<td>Patient Satisfaction; health related quality of life; health related cost.</td>
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<td>Question</td>
<td>Relevant Reviews</td>
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<td>What are the pros and cons of receiving palliative care in different environments, including at home, in a hospice, hospital or care home? Are there certain people and conditions that each are best for?</td>
<td>Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.</td>
<td>This uncertainty was identified from two members of the public, six bereaved carers and seven professionals questions. This is an indicative uncertainty and the following submissions were merged to form this one: Why is it thought appropriate or acceptable for people to die in noisy shared wards in hospitals? Why do older people nearing the end of their life get discharged from hospital to rehabilitation centres, care homes or care at home when all they really need is hospice care at home 24 hours. Care and Support need to be in one department to manage all the care, equipment &amp; support patient and families will need. Why is the option of a move to a hospice bed presented in such a guarded way rather than as a real and positive option which in some cases may provide a much improved and more clearly focused quality of care? What is it, for example, about hospice care that they value? If we know this, we could perhaps recreate what they want in other settings.</td>
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<td>Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium NCT02289995. Improving quality of life for south Tyrolean palliative patients in home care: a randomized controlled trial of home-based palliative care ISRCTN10224372.</td>
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<td>Change in symptoms, change in management of symptoms, patient satisfaction, health related quality of life, health related cost.</td>
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<td>What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?</td>
<td>No relevant systematic reviews identified.</td>
<td>This uncertainty was identified by three carer's and one bereaved carer's question. This is an indicative uncertainty and the following submissions were merged to form this one: Does morphine always change the patient's character? Recently she has been prescribed MST for a wedge fracture. At the moment is decreasing MST but this feels very unsupported as no real advice on possible withdrawal side effects.</td>
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<td>Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications.</td>
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<td>What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?</td>
<td>Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects.</td>
<td>This uncertainty was identified by three carer's, two professionals and ten bereaved carer's question. This is an indicative uncertainty and the following submissions were merged to form this one: How to diagnose dying-are there any biomedical markers which may prevent the subjectivity of the process. Were you offered any advice/support in how to inform your family/friends/colleagues about your impending death. Quality of life is important, companionship and friends with an understanding of their personal type of disease &amp; likely progression. If they are able to understand an explanation of their drug regimes and reasons for each, with possible side effects.</td>
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<td>Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications.</td>
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What information and training do carers and families need to provide the best care for their loved one who is dying? Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified from one carer’s, one volunteer’s, four professionals’ and one bereaved carer’s questions. This is an indicative uncertainty and the following submissions were merged to form this one: If I had more idea of what it involved and more support during the process I suspect I could have avoided the resulting problems for me I knew she was dying but I did not know how it would happen. Had I known in advance I would have been able to help more. I’m sure of it. The families and carers need to be taken through the whole process. I have found that palliative care patients and families are not given enough information Ability for carers to have some training to recognise the end of life signs

Carers’ and families’ needs in palliative care: a systematic literature review. Journal of Medical Internet Research. 2014;16(2):e72 DOI: 10.2196/jmir.3195 pubs: CD009500

Medical nutrition for adult palliative care patients. Cochrane Database of Systematic Reviews 2011, Issue 12. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2


What is the best diet for palliative care patients? For example can maintaining a healthy weight and eating fatty or protein-rich foods have an impact on their disease progression? Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects. This uncertainty was identified by a member of the public, two professionals’ and four carers’ questions. This is an indicative uncertainty and the following submissions were merged to form this one: How does nutritional status influence survival and death in cancer patients? What is a healthy diet in the various stages in the last few years of life? Are care homes given guidance about this? Is there advice and support with community dwelling adults living with advanced life-limiting illness in Luxembourg, Ireland? (SRGCTN/54020924) The effectiveness of the National Quality Improvement Program Palliative Care on the number of patients that die at the preferred place, the patient’s and family’s experienced coordination of end-of-life care, the patient’s and family’s experienced control regarding end-of-life care, the patients? and family’s experienced conduction care with their needs, preferences and values, and the number of patients and families that receive care for their needs in the physical, psychosocial, and spiritual domains - N. A. http://www.isrctn.org.au/ TrialRegistration/TriReview.aspx?ACTRN=12613000733774 For family carers of hospitalised palliative care patients, does a Structured Family Meeting shortly after admission to palliative care, compared to standard care only, improve psychological distress? Patient Satisfaction; health related quality of life; health related cost; good death; information needs

Effectiveness of ehealth interventions and information needs in palliative care: a systematic literature review. Journal of Medical Internet Research. 2014;16(2):e72 DOI: 10.2196/jmir.3195 pubs: CD009500

Exploratory delayed intervention randomised controlled trial to investigate the feasibility, acceptability and potential effectiveness of a volunteer-led model of social and practical support with community dwelling adults living with advanced life-limiting illness in Luxembourg, Ireland. (SRGCTN/54020924) The effectiveness of the National Quality Improvement Program Palliative Care on the number of patients that die at the preferred place, the patient’s and family’s experienced coordination of end-of-life care, the patient’s and family’s experienced control regarding end-of-life care, the patients? and family’s experienced coordination care with their needs, preferences and values, and the number of patients and families that receive care for their needs in the physical, psychosocial, and spiritual domains - N. A. http://www.isrctn.org.au/ TrialRegistration/TriReview.aspx?ACTRN=12613000733774 For family carers of hospitalised palliative care patients, does a Structured Family Meeting shortly after admission to palliative care, compared to standard care only, improve psychological distress? Patient Satisfaction; health related quality of life; health related cost; good death; information needs

Medically assisted nutrition for adult palliative care patients. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2

42150 What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?

Existing relevant systematic reviews are not up-to-date.

This uncertainty was identified from a patient and two professional's question. This is an indicative uncertainty and the following submissions were merged to form this one: What support is there for younger patients with early body dementia in the latter stages at the moment its hard to find support especially in Scotland? What care is there available for elderly dementia people who need constant supervision but are not violent who do not want to go into an institution or even a day centre but want to stay in their own home. End of life care for those with dementia and their carers is fraught with difficulty. Why does getting cancer mean that continuing healthcare funding applies yet dementia does not qualify?


Promoting Informed Decision Making and Effective Communication Through Advance Care Planning for People With Dementia and Their Family Caregivers NCT02070874. Cluster-randomised controlled trial of facilitated case conferencing versus usual care for improving end-of-life outcomes in aged care residents with advanced dementia and their families http://www.anzctr.org.au/TrialRegistration Trial Registration.aspx?ACTRN=12612001164884. The effect of different models of facilitation when implementing the gold Standards Framework in Care Homes (GSFFCH): a cluster randomised control trial ISRCTN76028577

Health related quality of life, good death, change in symptoms or change in management of symptoms, adverse effects or complications

42151 When is it appropriate to receive palliative care and end of life care virtually (such as via Skype or video phone call)? What are the benefits and potential harms for patients, carers and families?

No relevant systematic reviews identified

This uncertainty was identified from one carer, one bereaved carer and one member of the public's question. This is an indicative uncertainty and the following submissions were merged to form this one: Technology is wonderful, but does not replace human contact. This contact and communication is acually vital for the well being of a patient. Perhaps re-visiting the whole concept of human care? How might digital technologies be used to best effect for maximum health and social care outcomes for patients and their loved ones at the end of life? Why is it not standard that there is one expert professional in charge of a patient's palliative care that can make rapid, informed decisions and delegate work to other professionals?

Assessment of Patient Satisfaction in Palliative Care When They Return Home After Hospitalization in Palliative Care NCT02207152. Palliative Care Symptom Management in Rural Communities NCT02070874. Optimization of complex palliative care at home by means of expert consultation via telemedicine – FRONTDA http://www.trialregister.nl/trialregister/administratior.aspx?TCID=2617 End of Life Treatment Preferences of Latino Medicare Beneficiaries With Cancer NCT01389830

Patient Satisfaction; health related quality of life; health related cost; adverse effects; optimal methods of communication

42152 When is the best time to introduce bereavement support, and for how long for palliative and end of life care patients? Should it be offered before the death of a loved one? How can this support be catered to individual needs, including access to 24-hour support?

No relevant systematic reviews identified

This uncertainty was identified from one patient, two carers, four professionals and seven bereaved cases questions. This is an indicative uncertainty and the following submissions were merged to form this one: Pre-Bereavement support should be offered as a matter of course BEFORE the death of the person to assist carers/family to begin to come to terms with this, as the journey of the family and patients of a journey of loss. Bereavement counselling/support should continue after the death of the person. I know now that there is support for the bereaved, should this not be given sooner after death occurs? What are the impact and implications of having 24 hour support for those who are just bereaved? A few years ago I was GP I would carry out bereavement visits - this has gone now with conflicting time pressures and QOF (quality and outcomes framework) - how can the resource be made available to improve bereavement care again?


Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support
<table>
<thead>
<tr>
<th>ID</th>
<th>Question</th>
<th>Systematic Review</th>
<th>DOI</th>
<th>Other Information</th>
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<tbody>
<tr>
<td>42153</td>
<td>When should palliative and end of life care patients be (deeply) sedated? What are the benefits and limitations of sedation and what are the best ways of consulting patients, carers and families?</td>
<td>Reliable up-to-date systematic reviews revealed important continuing uncertainties about treatment effects.</td>
<td>10.1002/14651858.CD0010206.pub2</td>
<td>Bruijnzeels SM, Rietjens JA, Seymour JR, Anguelov L, van der Heide A. The experiences of relatives with the practice of palliative sedation: a systematic review. Journal of Pain and Symptom Management 2012;44(3):431-45 PMID: 22658470</td>
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<tr>
<td>42154</td>
<td>Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial for managing agitation at the end of life and which are best in terms of side-effects? Do these drugs have an effect on other symptoms?</td>
<td>Reliable up-to-date systematic reviews revealed important continuing uncertainties about treatment effects.</td>
<td>10.1002/14651858.CD0010206.pub2</td>
<td>Candy B, Jackson KC, Jones L, Leurent B, Tookman A, King M. Drug therapy for delirium in terminally ill adult patients. Cochrane Database of Systematic Reviews 2012, Issue 11. Art. No.: CD004770. DOI: 10.1002/14651858.CD004770.pub2</td>
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<tr>
<td>42155</td>
<td>Who should be part of the palliative and end of life care team (such as chaplains, occupational therapists, GPs, etc)?</td>
<td>No relevant systematic reviews identified.</td>
<td>10.1002/14651858.CD0010206.pub2</td>
<td>Improving Palliative and End-of-Life Care in Nursing Homes NCT01990742</td>
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