Palliative and end of life care PSP									
Identifier	**Question**	**Why is there uncertainty?**	**Rank of question in PSP**	**Original uncertainty**	**References to reliable up-to-date systematic reviews**	**Systematic reviews in preparation**	**Systematic reviews that need updating or extending**	**Ongoing controlled trials**	**Which outcomes?**
421073	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**5**	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 [patients 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 health care assistant be trained to give injections to a family member as they approach the end of their lives Is there possiblities 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 palliaitive patients Nurses are increasingly uncomfortable at not having skills or time to offer a more holistic approach. In particular they know they are to help with spiritual care but are not given training in this aspect. In hospice care this training should be mandatory for all staff in contact with patients Why is education /training in caring for the patient in the last days and hours not a mandatory session for all staff with a refresher every two years?	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.				Patient Satisfaction; health related quality of life; health related cost.
421074	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?	Existing relevant systematic reviews are not up-to-date	**25**	This uncertainty was identified from five professional's and a carer's, and four 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 referral 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 alay fears?		Haun MW, Estel S, R?cker G, Friederich 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.			Health related quality of life, good death

421075	Are some palliative care approaches better than others (e.g. holistic support, co-ordinated care, nurse-led care, early intervention) and for whom?	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 ie 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?		Haun MW, Estel S, R?cker G, Friederich 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.		A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer http://www.ctri.nic.in/Clinicaltrials/pmaindet2.php?trialid=7523 Palliative care and satisfaction of family members of patients with incurable cancer http://www.irct.ir/searchresult.php?keyword=&id=5866&number=16&prt=4195&total=10&m=1 The Role of Early Systematic Best Palliative Care Versus on Request Palliative Care Consultation During Standard Oncologic Treatment for Patients With Advanced Gastric or Pancreatic Cancers: a Randomized, Controlled, Multicenter Trial NCT01996540	Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms
421076	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from two professional's and two memberss of the public 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.	Candy B, France R, Low J, Simpson E. Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. International Journal of Nursing Studies. 2015 Mar;52(3):756-68. doi: 10.1016/j.ijnurstu.2014.08.007 PMID: 25205665				Patient satisfaction, health related quality of life, good death

421077	Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?	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: It is esential that all needs are met: physical, emotional, social/economic and spiritual, not only the first of these. -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.			Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2 Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, Smith LN, Langhorne P. Non-pharmacological interventions for caregivers of stroke survivors. Cochrane Database of Systematic Reviews 2011, Issue 10. Art. No.: CD008179. DOI: 10.1002/14651858.CD008179.pub2.	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
421078	Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?	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 to expect is so expansive and different for everyone suffering. 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 alay fears?			Huisman M, van den Bosch MA, Wijlemans JW, van Vulpen M, van der Linden YM, Verkooijen HM. Effectiveness of reirradiation for painful bone metastases: a systematic review and meta?analysis. International Journal of Radiation Oncology, Biology, Physics.2012;84(1):8?14 PMID: 22300568	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

421079	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?	Existing 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 spec pall care units for those suffernig from non malignant , life limiting conditions such as COPD etc?			Puhan MA, Gimeno-Santos E, Scharplatz M, Troosters T, Walters EH, Steurer J. Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. Cochrane Database of Systematic Reviews 2011, Issue 10. Art. No.: CD005305. DOI: 10.1002/14651858.CD005305.pub3 Nonoyama M, Brooks D, Lacasse Y, Guyatt GH, Goldstein R. Oxygen therapy during exercise training in chronic obstructive pulmonary disease. Cochrane Database of Systematic Reviews 2007, Issue 2. Art. No.: CD005372. DOI: 10.1002/14651858.CD005372.pub2.	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
421080	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?	Existing 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 was 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?			Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2 Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, Smith LN, Langhorne P. Non-pharmacological interventions for caregivers of stroke survivors. Cochrane Database of Systematic Reviews 2011, Issue 10. Art. No.: CD008179. DOI: 10.1002/14651858.CD008179.pub2.	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, epecially 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 coudl. How can we provide equitable access to respite care for all?? And to what extent does frequent respite support for families alleviate these problems??			Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2 Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, Smith LN, Langhorne P. Non-pharmacological interventions for caregivers of stroke survivors. Cochrane Database of Systematic Reviews 2011, Issue 10. Art. No.: CD008179. DOI: 10.1002/14651858.CD008179.pub2.	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
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 identiified from a bereaved carer and two professional's 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 intinsic 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 wakefullness - 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.

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	**1**	This uncertainty was identified from one bereaved carer's, one member of the public, three carers' and eight professionals' 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 concordant 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/trialreg/admin/rctview.asp?TC=4085 A Randomised 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
421084	How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from one bereaved carer's and one volunter's question. This is an indicative uncertainty and the following submissions were merged to form this one: Were you offered any advice/support in how to inform your family/friends/colleagues about your impending death How can we learn to discuss openly end of life the preparation for it?	Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta?analysis. Journal of the American Medical Directors Association.2014;15(7):477?489 PMID: 24598477		Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC, Vollenweider D, Bass EB, Aslakson RA. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. Journal of General Internal Medicine. 2013;28(4):570?577 PMID: 23099799	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 Improving communication and quality of life (QOL) at the end of life: A randomised controlled trial of a multifocal communication intervention for patients with advanced incurable cancer, carers and doctors. http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12610000724077	Patient Satisfaction; health related quality of life; health related cost; optimal methods of communication
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 identifed from a bereved carer'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

421086	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?	No relevant systematic reviews identified	**15**	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.			Lonergan E, Luxenberg J, Colford JM, Birks J. Haloperidol for agitation in dementia. Cochrane Database of Systematic Reviews 2002, Issue 2. Art. No.: CD002852. DOI: 10.1002/14651858.CD002852. Rueda JR, Sol? I, Pascual A, Subirana Casacuberta M. Non-invasive interventions for improving well-being and quality of life in patients with lung cancer. Cochrane Database of Systematic Reviews 2011, Issue 9. Art. No.: CD004282. DOI: 10.1002/14651858.CD004282.pub3.	Effects of a behavioral intervention for agitation of people with dementia http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4815	Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms.
421088	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		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?	Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta?analysis. Journal of the American Medical Directors Association.2014;15(7):477?489 PMID: 24598477		Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC, Vollenweider D, Bass EB, Aslakson RA. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. Journal of General Internal Medicine. 2013;28(4):570?577 PMID: 23099799	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 Improving communication and quality of life (QOL) at the end of life: A randomised controlled trial of a multifocal communication intervention for patients with advanced incurable cancer, carers and doctors. http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12610000724077	Patient Satisfaction; health related quality of life; health related cost.

421089	How can palliative and end of life care patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		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 carer resources in the community to support patient (and their family) in the terminal phase of their life signpost at 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 nurses only provide for those in palliative care)?	Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2.	Haun MW, Estel S, R?cker G, Friederich 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.		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 concordant 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/trialreg/admin/rctview.asp?TC=4085 A Randomised 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	Patient Satisfaction; health related quality of life; health related cost; time it takes to access care services, equipment and statutory welfare benefits from point of need
421090	How can palliative care information and services be made more accessible to people whose first language is not English?	No relevant systematic reviews identified		This uncertainty was identified from one professionals' question This is an indicative uncertainty and the following submissions were merged to form this one: How many services have leaflets available in languages other than English? has this really improved.				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 Improving communication and quality of life (QOL) at the end of life: A randomised controlled trial of a multifocal communication intervention for patients with advanced incurable cancer, carers and doctors. https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=335841	Patient Satisfaction; health related quality of life; health related cost.
421091	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	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**11**	This uncertainty was identified from one member of the publics, one carer's, two volunteers', eight bereaved carers' and four professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: Modern extended families tend not to be local and have pressures of work which leave a vacuum for the very elderly when needing support.			Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2		Patient Satisfaction; health related quality of life; health related cost; optimal methods of communication

421092	How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?	No relevant systematic reviews identified		This uncertainty was identified from two professionals and 4 bereaved carers questions. This is an indicative uncertainty and the following submissions were merged to form this one: 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 was given to them 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 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?				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	Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support.
421093	How can the spiritual support needs of palliative care patients and their carers and families best be met in a way that is appropriate for people of different religions and people who are not religious?	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: It is essential that all needs are met: 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 Care is about				Measuring effects of training primary caregivers by healthcare chaplains in multidisciplinary spiritual care in palliative care in Dutch teaching hospitals. http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4559	Patient Satisfaction; health related quality of life; health related cost
421094	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from one patient's, one member's of the public, two volunteers', four carers', four bereaved carer's and nine professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: 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). 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 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	Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta?analysis. Journal of the American Medical Directors Association.2014;15(7):477?489 PMID: 24598477	Houttekier D, Cohen J, Cools F, Deliens L. Advance care planning for end-of-life care (Protocol). Cochrane Database of Systematic Reviews 2012, Issue 2. Art. No.: CD009618. DOI: 10.1002/14651858.CD009618.	Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and Ageing.2012;41(2):263?269 http://ageing.oxfordjournals.org/content/early/2011/12/07/ageing.afr148.full.pdf	Do case conferences between general practitioners and specialist teams improve outcomes and service utilisation in people with life limiting heart and lung disease compared to usual care? http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=365458 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 The study of Australian general practitioners using a systematic death prediction tool versus clinical intuition on the accuracy of prediction of patient death http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12613000266763 Barriers and facilitator to palliative care of patients with chronic heart failure - PaCa-HF http://www.uniklinik-freiburg.de/aqms/projekte/versorgungsforschung/pacahf.html	Patient Satisfaction; health related quality of life; health related cost; type of care/support needed
421095	How is incontinence best managed in people who are approaching the end of life (including those with Parkinson?s disease)?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from a carer's and two bereaved carer's question. This is an indicative uncertainty and the following submissions were merged to form this one: Why is support with continence problems so limited ? My mother is approaching 91 and has Parkinson's Disease.... We have swallowing, handling and continence issues.	Coggrave M, Norton C, Cody JD. Management of faecal incontinence and constipation in adults with central neurological diseases. Cochrane Database of Systematic Reviews 2014, Issue 1. Art. No.: CD002115. DOI: 10.1002/14651858.CD002115.pub5.				Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost, good death

421096	Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)for people on palliative and end of life care?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty identified by two professional's, two carer's 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.	Raijmakers NJ, van Zuylen L, Costantini M, Caraceni A, Clark J, Lundquist G, Voltz R, Ellershaw JE, van der Heide A, OPCARE9. Artificial nutrition and hydration in the last week of life in cancer patients: a systematic literature review of practices and effects. Annals of Oncology.2011;22(7):1478?1486 PMID: 21199887				Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421097	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**22**	This uncertainty was identified from a professional's, and a 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/caring staff?	Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD006273. DOI: 10.1002/14651858.CD006273.pub3. Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted nutrition for adult palliative care patients. Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD006274. DOI: 10.1002/14651858.CD006274.pub3.				Change in symptoms; change in management of symptoms.

421098	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 paliative care/help where possible I have attended this day care for 4 years now and have helped many other less fotunate patients Impact of reduced funding on staffing levels/ quality of service/ use of volunteers to replace paid roles	Candy B, France R, Low J, Simpson E. Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. International Journal of Nursing Studies. 2015 Mar;52(3):756-68. doi: 10.1016/j.ijnurstu.2014.08.007 PMID: 25205665				Health related cost
421099	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 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 care life treatment have to be given by charity. We have NHS which let's down those that need help in there final stage of illness Why is there no support from the medic team that knows the patient				The effects of the National Quality Improvement Program Palliative Care http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4085	Patient Satisfaction; health related quality of life; health related cost; adverse effects; quality of care
421100	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 carers questions. 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				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	Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support.
421101	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 caring personnel increase confidence- and managing death at home requires confidence all round					Patient Satisfaction; health related quality of life; health related cost.

421102	What are 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 idendified 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 opiod-induced constipation?	Candy B, Jones L, Goodman ML, Drake R, Tookman A. Laxatives or methylnaltrexone 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.			A phase 3, multicenter, randomized, double-blind, placebo-controlled, parallel-group study of naldemedine in cancer patients with opioid-induced constipation, http://apps.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-JapicCTI-132340 A Phase IIb, Randomized, Double-blind, Placebo-controlled, Parallel Group Study of S-297995 for the Treatment of Opioid-induced Constipation (OIC) in Cancer Patients. http://apps.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-JapicCTI-111510	Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.
421103	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 parenteral hydration towards end of life - balancing appropriate hydration with the body's natural ceasing of normal function (also bearing in mind the distress that can be caused when a body cannot cope with increased hydration; the potential for medical 'kit' acting as barrier between patient and loved ones towards end of life etc). 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 blood transfusion in the last months/weeks of life.					Adverse effects or complications, change in symptoms
421104	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 identifed from a patient, two carer's, two bereaved carer's and three professional's question This is an indicative uncertainty and the following submissions were merged 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 know, in advance, whether such interventions may be 'right' for you? What should be the process for deciding this? How do you deal with any pressure from others on these questions? 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. How does nutritional status influence survival and death in cancer patients?	Payne C, Wiffen PJ, Martin S. Interventions for fatigue and weight loss in adults with advanced progressive illness. Cochrane Database of Systematic Reviews 2012, Issue 1. Art. No.: CD008427. DOI: 10.1002/14651858.CD008427.pub2. Nugent B, Lewis S, O'Sullivan JM. Enteral feeding methods for nutritional management in patients with head and neck cancers being treated with radiotherapy and/or chemotherapy. Cochrane Database of Systematic Reviews 2013, Issue 1. Art. No.: CD007904. DOI: 10.1002/14651858.CD007904.pub3. Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD006273. DOI: 10.1002/14651858.CD006273.pub3.		Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. Cochrane Database of Systematic Reviews 2009, Issue 2. Art. No.: CD007209. DOI: 10.1002/14651858.CD007209.pub2. Katzberg HD, Benatar M. Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease. Cochrane Database of Systematic Reviews 2011, Issue 1. Art. No.: CD004030. DOI: 10.1002/14651858.CD004030.pub3		Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

421105	What are the benefits and limitations of chemotherapy and radiotherapy for patients approaching the end of life, including those with brain tumours? 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, met non small cell lung cancer, met breast cancer	Reveiz L, Rueda JR, Cardona AF. Chemotherapy for brain metastases from small cell lung cancer. Cochrane Database of Systematic Reviews 2012, Issue 6. Art. No.: CD007464. DOI: 10.1002/14651858.CD007464.pub2. Stevens R, Macbeth F, Toy E, Coles B, Lester JF. Palliative radiotherapy regimens for patients with thoracic symptoms from non-small cell lung cancer. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD002143. DOI: 10.1002/14651858.CD002143.pub4. Reveiz L, Rueda JR, Cardona AF. Palliative endobronchial brachytherapy for non-small cell lung cancer. Cochrane Database of Systematic Reviews 2012, Issue 12. Art. No.: CD004284. DOI: 10.1002/14651858.CD004284.pub3	Sultana A, Jackson RJ, Cox T, Palmer D, Neoptolemos J, Ghaneh P. Chemotherapy, radiotherapy, chemoradiotherapy and combination therapy in localised and locally advanced pancreatic cancer (Protocol). Cochrane Database of Systematic Reviews 2014, Issue 8. Art. No.: CD011044. DOI: 10.1002/14651858.CD011044.	Best L, Simmonds P, Baughan C, Buchanan R, Davis C, Fentiman I, George S, Gosney M, Northover J, Williams C, Collaboration Colorectal Meta-analysis. Palliative chemotherapy for advanced or metastatic colorectal cancer. Cochrane Database of Systematic Reviews 2000, Issue 1. Art. No.: CD001545. DOI: 10.1002/14651858.CD001545. Bramwell V, Anderson D, Charette M, Sarcoma Disease Site Group. Doxorubicin-based chemotherapy for the palliative treatment of adult patients with locally advanced or metastatic soft tissue sarcoma. Cochrane Database of Systematic Reviews 2003, Issue 3. Art. No.: CD003293. DOI: 10.1002/14651858.CD003293. Sze WM, Shelley M, Held I,	Prognostic and predictive factors for use of palliative chemotherapy in advanced stage esophageal/ gastroesophageal junction cancer. http://www.ctri.nic.in/Clinicaltrials/pmaindet2.php?trialid=8426 NO Concomitant Radiotherapy and Erlotinib in advanced lung cancer ThoRaT-studien Thoracal Radiotherapy and Tarceva? An open randomized multicenter phase II study. http://www.clinicaltrialsregister.eu/ctr-search/search?query=NO+Concomitant+Radiotherapy+and+Erlotinib+in+advanced+lung+cancer+ThoRaT-studien+Thoracal+Radiotherapy+and+Tarceva Patient informed choice between palliative chemotherapy and best supportive care. http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=NTR1113	Change in symptoms; change in management of symptoms.Adverse effects or complications
421106	What are the benefits for patients, carers and families of day hospices 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 carer's, 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 are diagnosed with a palliative condition get offered rehabilitation services to help them stay 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 cant we have more day therapy support? hospice rehab day care centre . I would like more research on the benefits of this and how these services can be made more available toa a wide range of people with advanced illnesses				A randomised controlled trial to evaluate a complex rehabilitative 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.
421107	What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients? preferences for palliatve and end of life care? Who should implement this and when?	No relevant systematic reviews identified	**3**	This uncertainty was identified from two carers', five bereaved carers' 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)?	Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta?analysis. Journal of the American Medical Directors Association.2014;15(7):477?489 PMID: 24598477	Houttekier D, Cohen J, Cools F, Deliens L. Advance care planning for end-of-life care (Protocol). Cochrane Database of Systematic Reviews 2012, Issue 2. Art. No.: CD009618. DOI: 10.1002/14651858.CD009618.		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; change in symptoms or change in symptom management

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 professionals questions. This is an indicative uncertainty and the following submissions were merged to form this one: I think every nursing home/hospice shold 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	Family/carer 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 signpost 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 possiblities 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 palliaitive Complementary and spiritual healing do no harm why are they not embraced my mainstream medicine. There is evidence to support the benefit of other therapies patients		Lian WL, Pan MQ, 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 Shin ES, Lee SH, Seo KH, 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=365752 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	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 questions 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 there 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 arent families asked to attend suport 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	Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support.

421087	What are the benefits of increasing the numbers of palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?	No relevant systematic reviews identified		Ranked 5th in the PeolcPSP 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 inequity. Some areas are able to offer a lot of support at this time wherever the person chooses to be but others don't.I'd like to nknow how funding deciosions are made Could I as a health care assistant be trained to give injections to a family member as they approach the end of their lives. Is there bereavement training or online counselling skills available for staff members For dealing with family members Many hospices provide excellent support for people with motor neuron disease, but there are instances where hospices shy away from taking on MND cases. Is this a resource issue - financial, apparatus or human resource or is it down to a lack of confidence in dealing with less common and/or 'non-cancer' conditions? Identifying the reasons might open up opportunities for educational and training programmes and increase access to timely and effective hospice-based care.					Patient Satisfaction; health related quality of life; health related cost; quality of care
421111	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		Lian WL, Pan MQ, 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 Shin ES, Lee SH, Seo KH, 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=365752 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	Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms

421112	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 professional's, one volunteer, two bereaved carer'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. Ability for carers to have some training to recognise the end of life signs Supporting the patients' wish 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 inbetween visits by carers or District Nurses. Why/ Why are carers not given help in recognising the pattern 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			Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2	Supporting family caregivers of palliative patients at home: the carer support needs assessment intervention NCT02261935	Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421113	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	**18**	This uncertainty idendified from a carer, five bereaved carer's, two patient's, three professional's and three members of the public question 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 reabilation 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
421114	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/intruded? Can you visit any time you wish?					Patient Satisfaction; health related quality of life; health related cost.
421115	What are the benefits, and best ways, of providing 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	**8**	This uncertainty was identified from two professionals, one carers and one members of the public 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 24-hr 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?	Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2.				Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.

421116	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from one carer's and three professional's 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 cares are expecting from us. Why do we still give stat doses in the last days of life into a persons 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 6 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)	Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2.			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 randomized controlled trial of home-based palliative care ISRCTN10224372	Change in symptoms; change in management of symptoms.
421129	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) to us 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.[?]				Investigation of the feasibility of the PACSLAC-D in older adults with dementia in nursing homes - N/A http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4359 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	Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.
421117	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.					Health related quality of life, good death

421118	What are the best care packages for patients, carers, family and staff which combine heath care and social care and take individual prognosis into consideration for palliative and end of life care?	No relevant systematic reviews identified	**24**	This uncertainty was identified from one bereaved carer's and five professionals' questions. This is an indicative uncertainty and the following submissions 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 person's life? Re the organisation of care for people in acute wards who are rapidly approaching the end of their lives: 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 hands on, etc. How could oncology be changed to align with a more person centered approach using joint decision making?	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. Mead EL, Doorenbos AZ, Javid SH, Haozous EA, Alvord LA, Flum DR, Morris AM. Shared decision-making for cancer care among racial and ethnic minorities: a systematic review. American Journal of Public Health. 2013; 103 (12): e15 PMID: 24134353			INSPIRE study: INvestigating Social and PractIcal suppoRts at the End of life ISRCTN18400594 Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium NCT02266069 A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer http://www.ctri.nic.in/Clinicaltrials/pmaindet2.php?trialid=7526 A study to assess the feasibility of introducing early palliative care in ambulatory patients with advanced lung cancer http://www.ctri.nic.in/Clinicaltrials/pmaindet2.php?trialid=7523	Patient Satisfaction; health related quality of life; health related cost; timing of access to care and support; good death
421119	What are the best models of palliative care for people who have learning difficulties?	No relevant systematic reviews identified		This uncertainty was identified from two professional's and a member of the public question. This is an indicative uncertainty and the following submissions 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, compllex 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!					Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.
421120	What are the best models of palliative care for people who have mental health issues?	No relevant systematic reviews identified		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: My concern is really about vulnerable populations - for example people with learning disabilities, compllex 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					Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421121	What are the best models of palliative care in an acute setting, such as a hospital?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**16**	This uncertainty identifed from two carer's, two bereaved carer's and two professional's question. This is an indicative uncertainty and the following submissions were merged to form this one: If there were specalist 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 hospitals 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?					Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

421122	What are the best treatments for fluid retention in patients approaching the end of life?	No relevant systematic reviews identified		This uncertainty idendified 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 sub cutanous/iv fluids in the last days of life What treatment is available for end stage patients with significant oedema?				Intraperitoneal injection of in vitro expanded Gamma Delta T cells together with zoledronate for the treatment of malignant ascites to ovarian cancer ; to evaluate the safety and efficacy. (A Phase 1/2a study); http://apps.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-UMIN000015233 Clinical Study in Treatment of Malignant Ascites of Ovarian Cancer With Intraperitoneal Injection Bevacizumab Combined With Intraperitoneal Hyperthermic Perfusion Chemotherapy. NCT01838538 Effect of additional single or repeated dosage of Kappaproct? to corticosteroid treated patients with brain oedema caused by brain tumour: a multicentre open one-arm non-randomised trial ISRCTN84460768	Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost.
421123	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	**27**	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, first 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/pubic holidays)? Does olanzapine help with cachexia/ nausea?	Storrar J, Hitchens M, Platt T, Dorman S. Droperidol for treatment of nausea and vomiting in palliative care patients. Cochrane Database of Systematic Reviews 2014, Issue 11. Art. No.: CD006938. DOI: 10.1002/14651858.CD006938.pub3. Darvill E, Dorman S, Perkins P. Levomepromazine for nausea and vomiting in palliative care. Cochrane Database of Systematic Reviews 2013, Issue 4. Art. No.: CD009420. DOI: 10.1002/14651858.CD009420.pub2.			Efficacy of Thalidomide in Preventing Chemotherapy-induced Delayed Nausea and Vomiting NCT02203253 Effectiveness of Auricular Acupressure in the Treatment of Chemotherapy Induced Nausea and Vomiting in Ovarian Cancer and Endometrial Cancer http://www.clinicaltrials.in.th/index.php?tp=regtrials&menu=trialsearch&smenu=fulltext&task=search&task2=view1&id=1134 The effects of the Cardamom aroma on the nausea and vomiting induced by chemotherapy http://www.irct.ir/searchresult.php?id=13936&number=1	Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

421124	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 memebers 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 counselling available at these times support services like this appear to be 9-5 for the terminally ill To what extent are 'Mindfulness courses', counselling and other similar therapies effective? If so, what are the main benefits? How can such benefits be maintained on an ongoing basis? Why is psychological support and counselling so poorly available!? Both for patients, carers familys Could carers be given direct access to mental health support?	Parahoo K, McDonough S, McCaughan E, Noyes J, Semple C, Halstead EJ, Neuberger MM, Dahm P. Psychosocial interventions for men with prostate cancer. Cochrane Database of Systematic Reviews 2013, Issue 12. Art. No.: CD008529. DOI: 10.1002/14651858.CD008529.pub3.		Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2.	Clustered, Randomized, Controlled Trial of the Home Care Nurse Carer Support Needs Assessment Practice Tool With Family Caregivers of Palliative Patients at Home NCT02261935	Patient Satisfaction; health related quality of life; health related cost; quality of support; psycho-social wellbeing
421125	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	**12**	This uncertainty was identified from one bereaved carer and two professional's 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?	Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta?analysis. Journal of the American Medical Directors Association.2014;15(7):477?489 PMID: 24598477		Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC, Vollenweider D, Bass EB, Aslakson RA. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. Journal of General Internal Medicine. 2013;28(4):570?577 PMID: 23099799	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 Improving communication and quality of life (QOL) at the end of life: A randomised controlled trial of a multifocal communication intervention for patients with advanced incurable cancer, carers and doctors. http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12610000724077	Health related quality of life; health related cost.

421126	What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or Motor Neurone Disease (MND)?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from a carer's and four professional's question. This is an indicative 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 providing to those with cancer cachexia?	Ruiz Garcia V, L?pez-Briz E, Carbonell Sanchis R, Gonzalvez Perales JL, Bort-Marti S. Megestrol acetate for treatment of anorexia-cachexia syndrome. Cochrane Database of Systematic Reviews 2013, Issue 3. Art. No.: CD004310. DOI: 10.1002/14651858.CD004310.pub3. Reid J, Mills M, Cantwell M, Cardwell CR, Murray LJ, Donnelly M. Thalidomide for managing cancer cachexia. Cochrane Database of Systematic Reviews 2012, Issue 4. Art. No.: CD008664. DOI: 10.1002/14651858.CD008664.pub2. Payne C, Wiffen PJ, Martin S. Interventions for fatigue and weight loss in adults with advanced progressive illness. Cochrane Database of Systematic Reviews 2012, Issue 1. Art. No.: CD008427. DOI: 10.1002/14651858.CD008427.pub2.		Dewey A, Baughan C, Dean TP, Higgins B, Johnson I. Eicosapentaenoic acid (EPA, an omega-3 fatty acid from fish oils) for the treatment of cancer cachexia. Cochrane Database of Systematic Reviews 2007, Issue 1. Art. No.: CD004597. DOI: 10.1002/14651858.CD004597.pub2.	A study to evaluate the efficacy of theracurmin (highly absorbtive curcumin) for cachexia in treatment-resistant cancer patients http://apps.who.int/trialsearch/Trial2.aspx?TrialID=JPRN-UMIN000014335 Study of Ruxolitinib in the Treatment of Cachexia in Patients With Tumor-Associated Chronic Wasting Diseases NCT02072057 Development and evaluation of a psycho-educational intervention for patients with advanced cancer who have cachexia and their lay carers: a randomised controlled trial ISRCTN22427358	Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421127	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**1**	This uncertainty was identified from seven professional's and a bereaved carer's questions. This is an indicative uncertainty and the following submissions were merged to form this one: Access to information, support and help 24/7 is essential, so why isn't this the case? Why are hospice and specialist end of life care service so difficult to access out or normal working hours? Are there any plans to provide 24 hour care in patients own homes to enable them to stay at home as long as possible?				A prospective cohort study exploring the impact of offering telehealth support to palliative patients and their family caregivers to enhance the community based palliative care service ACTRN12613000733774	Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421128	What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**10**	This Uncertainty idendified from two carer's,f ive bereaved carer's, a member of the public, two professionals and a patient's questions This is an indicative uncertainty and the following submissions were merged to form this one: How to tell when someone in the very end stages of dementia is in pain and or distress. How good is pain relief when the person suffering is no longer able to communicate verbally? I realise pain can be subjective, but it would be worth looking to develop better pain tools for those who are unable to communicate (either due to level of conciousness, impact of drugs, or due to the condition such as MND or stroke.	Pieper MJ, van Dalen?Kok AH, Francke AL, van der Steen JT, Scherder EJ, Husebo BS, Achterberg WP. Interventions targeting pain or behaviour in dementia: a systematic review. Ageing Research Reviews.2013;12(4):1042?1055 PMID: 23727161		Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. Cochrane Database of Systematic Reviews 2011, Issue 3. Art. No.: CD007132. DOI: 10.1002/14651858.CD007132.pub2.	Implementation of improved diagnosis and treatment of pain and depression in demented elderly http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=1483 Pain Management and Behavioral Outcomes in Patients With Dementia NCT00012857 Pain Perception in Alzheimer's Disease NCT00192816.	Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

421130	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 neurone disease (MND), AIDs, multiple sclerosis, Crohn's disease and stroke)?	No relevant systematic reviews identified	**6**	This uncertainty was identified from one carer's, one volunteer, two members of the public, two bereaved carers' and fourteen professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: Why is MCNS still overlooked by health care professionals when considering support for families caring for patients who are approaching end of life 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 What is the role of a specialist palliative care serves (if any) when patients have chronic (rather than terminal illness What is the best model of palliative care provision for patients with heart failure?				Do case conferences between general practitioners and specialist teams improve outcomes and service utilisation in people with life limiting heart and lung disease compared to usual care? http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=365458 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 The study of Australian general practitioners using a systematic death prediction tool versus clinical intuition on the accuracy of prediction of patient death http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12613000266763 Barriers and facilitator to palliative care of patients with chronic heart failure - PaCa-HF http://www.uniklinik-freiburg.de/aqms/projekte/versorgungsforschung/pacahf.html	Patient Satisfaction; health related quality of life; health related cost; quality of care
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	**17**	Ranked 17th in the PeolcPSP This uncertainty was identified from two bereaved carers 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 End stage liver and lung cancer in a younger person question. The agitation could not be controlled in the final days, I have spoken to many others where this happened. More information about the extreme side of end of a life should be available to help plan better.	Candy B, Jackson KC, Jones L, Tookman A, King M. Drug therapy for symptoms associated with anxiety in adult palliative care patients. Cochrane Database of Systematic Reviews 2012, Issue 10. Art. No.: CD004596. DOI: 10.1002/14651858.CD004596.pub2. Beller EM, van Driel ML, McGregor L, Truong S, Mitchell G. Palliative pharmacological sedation for terminally ill adults. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD010206. DOI: 10.1002/14651858.CD010206.pub2. 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.		Wee B, Hillier R. Interventions for noisy breathing in patients near to death. Cochrane Database of Systematic Reviews 2008, Issue 1. Art. No.: CD005177. DOI: 10.1002/14651858.CD005177.pub2. Akechi T, Okuyama T, Onishi J, Morita T, Furukawa TA. Psychotherapy for depression among incurable cancer patients. Cochrane Database of Systematic Reviews 2008, Issue 2. Art. No.: CD005537. DOI: 10.1002/14651858.CD005537.pub2.	The Preventative Role of Exogenous Melatonin Administration in Patients With Advanced Cancer Who Are at Risk of Delirium: a Feasibility Study. NCT02200172 Early recognition and optimal treatment of acute confusion in patients with advanced cancer. NCT01539733 The Effect of Cognitive Behavior Intervention on Psychological Distress of Cancer Patients and Their Family Members NCT00279474	Patient Satisfaction; health related quality of life; health related cost; change in symptoms; change in management of symptoms.
421132	What are the best ways to ensure that people with Motor Neurone Disease (MND) receive essential palliative and end of life care transition to palliative care and when should a "just in case kit" be considered?	No relevant systematic reviews identified		This uncertainty was identified from three bereaved carer's and three professionals' questions. This is an indicative uncertainty and the following submissions were merged to form this one: I feel it important to enable people with MND (for example) and other rarer and rapidly progressing conditions to gain access to palliaitive care as early as possible, long before the person is nearing the end of their life People living with MND can deteriorate quickly, so judging when the 'just in case kit' should be considered can be tricky. When is the optimum time and who is the best professional to raise the matter with appropriate clinician? Why is there no fast track system for putting in place support, equipment etc for people with rapidly progressing conditions such as bulbar onset MND?					Patient Satisfaction; health related quality of life; health related cost; timing of introduction of palliative care; quality of care

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	**13**	This uncertainty was identified from one member of the public's, 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	**19**	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 mainly about how pain will be releived and how it can be achieved	Bell RF, Eccleston C, Kalso EA. Ketamine as an adjuvant to opioids for cancer pain. Cochrane Database of Systematic Reviews 2012, Issue 11. Art. No.: CD003351. DOI: 10.1002/14651858.CD003351. pub2. Wiffen PJ, Derry S, Moore RA. Impact of morphine, fentanyl, oxycodone or codeine on patient consciousness, appetite and thirst when used to treat cancer pain. Cochrane Database of Systematic Reviews 2014, Issue 5. Art. No.: CD011056. DOI: 10.1002/14651858.CD011056. pub2. Wiffen PJ, Wee B, Moore RA. Oral morphine for cancer pain. Cochrane Database of Systematic Reviews 2013, Issue 7. Art. No.: CD003868. DOI: 10.1002/14651858.CD003868. pub3.			Switching From Morphine to Oral Methadone Plus Acetaminophen in the Treatment of Cancer Pain: A Randomized, Double-Blind Study NCT00525967 IMPACCT: exploratory study of a community pharmacy pain medicines consultation for patients with cancer pain ISRCTN14670659 Effect of therapeutic touch on pain and anxiety in patients with cancer http://www.irct.ir/searchresult.php?id=4115&number=3	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	**9**	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 distress for patient and carerand vital delays in response and treatment My experience of caring for a terminally husband was overall 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

421136	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	**20**	This uncertainty was identified from two professional's 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 patients 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 for 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 patients quality of life following input from a physiotherapist, or medical input to manage breathlessness. It would also be beneifical 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	Walters JAE, Tan DJ, White CJ, Gibson PG, Wood-Baker R, Walters EH. Systemic corticosteroids for acute exacerbations of chronic obstructive pulmonary disease. Cochrane Database of Systematic Reviews 2014, Issue 9. Art. No.: CD001288. DOI: 10.1002/14651858.CD001288.pub4	Barnes H, McDonald J, Smallwood N, Manser R. Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness (Protocol). Cochrane Database of Systematic Reviews 2014, Issue 3. Art. No.: CD011008. DOI: 10.1002/14651858.CD011008.	Simon ST, Higginson IJ, Booth S, Harding R, Bausewein C. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. Cochrane Database of Systematic Reviews 2010, Issue 1. Art. No.: CD007354. DOI: 10.1002/14651858.CD007354.pub2	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 crisis" plan for the patient and carer: a feasibility study using a 2x2 factorial randomised controlled trial design ISRCTN40230190 .	Change in symptoms; change in management of symptoms.
421137	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 professional's, 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 wasnt 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 trail and error!!	Young CA, Ellis C, Johnson J, Sathasivam S, Pih N. Treatment for sialorrhea (excessive saliva) in people with motor neuron disease/amyotrophic lateral sclerosis. Cochrane Database of Systematic Reviews 2011, Issue 5. Art. No.: CD006981. DOI: 10.1002/14651858.CD006981.pub2. Squires N, Humberstone M, Wills A, Arthur A. The use of botulinum toxin injections to manage drooling in amyotrophic lateral sclerosis/motor neurone disease: a systematic review. Dysphagia.2014;29(4):500?508 http://rd.springer.com/article/10.1007%2Fs00455-014-9535-8			The effect of botulinum toxin on decrease of sialorrhea in patients with neurologic disorder http://www.irct.ir/searchresult.php?keyword=IRCT2013110515289N1&id=15289&number=1&field=a&prt=1&total=1&m=1 Assessment of the efficacy and the influence on swallowing function of transdermal scopolamine for ALS patinets' 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

421138	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 professional's, 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 wasnt 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 trail 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?122 PMID: 23790419		Wee B, Hillier R. Interventions for noisy breathing in patients near to death. Cochrane Database of Systematic Reviews 2008, Issue 1. Art. No.: CD005177. DOI: 10.1002/14651858.CD005177.pub2.		Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421139	What are the best ways to manage the problems associated with difficulty in swallowing, including for patients with Parkinson?s disease, Motor Neurone Disease (MND) and dementia who are at the end of their life?	No relevant systematic reviews identified	**28**	This uncertainty was identified from two professionals' and one carers questions. 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?	Dai Y, Li C, Xie Y, Liu X, Zhang J, Zhou J, Pan X, Yang S. Interventions for dysphagia in oesophageal cancer. Cochrane Database of Systematic Reviews 2014, Issue 10. Art. No.: CD005048. DOI: 10.1002/14651858.CD005048.pub4	Flynn EP, Smith CH, Walsh CD, Walshe M. Modifying the consistency of food and fluids for swallowing difficulties in dementia (Protocol). Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD011077. DOI: 10.1002/14651858.CD011077.	Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. Cochrane Database of Systematic Reviews 2009, Issue 2. Art. No.: CD007209. DOI: 10.1002/14651858.CD007209.pub2. Katzberg HD, Benatar M. Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease. Cochrane Database of Systematic Reviews 2011, Issue 1. Art. No.: CD004030. DOI: 10.1002/14651858.CD004030.pub3	A multicenter, prospective feasibility follow-up study to evaluate a fully covered stent with new antimigration properties for the palliation of malignant dysphagia: HANARO study http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=3313	Patient Satisfaction; health related quality of life; health related cost.

421140	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 professional's 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.			de Castria TB, da Silva EMK, Gois AFT, Riera R. Cisplatin versus carboplatin in combination with third-generation drugs for advanced non-small cell lung cancer. Cochrane Database of Systematic Reviews 2013, Issue 8. Art. No.: CD009256. DOI: 10.1002/14651858.CD009256.pub2. Akl EA, Kahale LA, Sperati F, Neumann I, Labedi N, Terrenato I, Barba M, Sempos EV, Muti P, Cook D, Sch?nemann H. Low molecular weight heparin versus unfractionated heparin for perioperative thromboprophylaxis in patients with cancer. Cochrane Database of Systematic Reviews 2014, Issue 6. Art. No.: CD009447. DOI: 10.1002/14651858.CD009447.pub2 Kakkos SK, Caprini JA,	Anti-Platelet and Statin Therapy to Prevent Cancer-Associated Thrombosis NCT02285738 Randomized, Placebo-controlled, Double-blind Phase II/III Trial of Oral Isoquercetin to Prevent Venous Thromboembolic Events in Cancer Patient NCT02195232	Change in symptoms; change in management of symptoms.
421141	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	**23**	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 counseling be available to all patients or those who cross a clinical threshold of measured distress? What's the best way to evaluate effectiveness/outcomes 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.	Walker J, Sawhney A, Hansen CH, Symeonides S, Martin P, Murrey G, Sharpe M. Treatment of depression in people with lung cancer: a systematic review. Lung Cancer 2013; 79: 46-53 PMID: 23102652			Intervention for treating depression among palliative care patients and their families. http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12610000183088 CanTalk: A trail into the benefits of a talking therapy called CBT for the treatment of depression in adults with advanced cancer. ISRCTN07622709.	Patient Satisfaction; health related quality of life; health related cost;quality of care

421142	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.	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**26**	This uncertainty was identified from a patient's, four professional's 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, epecially 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 coudl point towards the preventative value and value-for-money of regular lifelong respite. I would like to know what advice is given to families with young teenagers who have a parent that is terminally ill and the youngster/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 is advice is given these days. Why can children who have lost a parent only receive 5 sessions with a bereavement councillor?			Rosner R, Kruse J, Hagl M. A meta?analysis of interventions for bereaved children and adolescents. Death Studies.2010;34(2):99?136. 2 http://www.tandfonline.com/doi/abs/10.1080/07481180903492422#.VS-EXfzF__E McDaid C, Trowman R, Golder S, et al. Interventions for people bereaved through suicide: systematic review. Br J Psychiatry 2008;193:438?43 http://bjp.rcpsych.org/content/193/6/438 Perkins 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.		Change in symptoms; change in management of symptoms; Patient Satisfaction; health related quality of life; health related cost, good death
421143	What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple?	No relevant systematic reviews identified		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					Change in symptoms; change in management of symptoms.
421144	What are the core palliative care services that should be provided no matter what the patients' diagnosis is?	No relevant systematic reviews identified	**7**	This uncertainty was identified from several professional's question. This is an indicative uncertainty and the following submissions were merged to form this one: 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/outcomes 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 end 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..					Patient Satisfaction; health related quality of life; health related cost.

421145	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		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 reabilation centres, care homes or carers 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 & 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 focussed 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	Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2. Luckett T, Davidson PM, Lam L, Phillips J, Currow DC, Agar M. Do community specialist palliative care services that provide home nursing increase rates of home death for people with life?limiting illnesses? A systematic review and meta?analysis of comparative studies. Journal of Pain and Symptom Management.2013;45(2):279?297 PMID: 22917710			The effectiveness of the Liverpool Care Pathway Japanese version in improving the quality of end-of-life care for patients with cancer in general ward http://upload.umin.ac.jp/cgi-open-bin/ctr/ctr.cgi?function=brows&action=brows&type=summary&recptno=R000016706&language=E Implementation of the Care Pathway for Primary Palliative Care in Five Research Clusters in Belgium NCT02266069 Improving quality of life for south Tyrolean palliative patients in home care: a randomized controlled trial of home-based palliative care ISRCTN10224372	Change in symptoms; change in management of symptoms; patient satisfaction; health related quality of life; health related cost.
421146	What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?	No relevant systematic reviews identified		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.					Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421147	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects	**21**	This uncertainty was identified by two carer's, two professional's and six 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, companion and friends with an understanding of their personal type of disease & likely progression. If they are able to understand an explanation of their drug regimes and reasons for each, with possible side effects					Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

421148	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	**4**	This uncertainty was identified from one carer's, one volunteer's, four professionals' and six bereaved carers' questions. This is an indicative uncertainty and the following submissions were merged to form this one: If I had 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 talked through the whole process. I have found that palliative pt's and families are not given enough information Ability for carers to have some training to recognise the end of life signs	Capurro D, Ganzinger M, Perez?Lu J, Knaup P. Effectiveness of ehealth interventions and information needs in palliative care: a systematic literature review. Journal of Medical Internet Research.2014;16(3):e72 DOI: 10.2196/jmir.2812	Horey D, Street AF, O'Connor M, Peters L, Lee S. Training and supportive programs for palliative care volunteers in community settings (Protocol). Cochrane Database of Systematic Reviews 2011, Issue 12. Art. No.: CD009500. DOI: 10.1002/14651858. CD009500	Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011, Issue 6. Art. No.: CD007617. DOI: 10.1002/14651858.CD007617.pub2	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 Limerick, Ireland. ISRCTN18400594 The effectivensess 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 concordant 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.trialregister.nl/trialreg/admin/rctview.asp?TC=4085 A prospective cohort study exploring the impact of offering telehealth support to palliative patients and their family caregivers to enhance the community based palliative care service http://www.anzctr.org.au/Trial/Registration/TrialReview.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
421149	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 professional's, a carer for people with disabilities and a bereaved carer's question. 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 on how to maintain a healthy weight that retains mobility as long as possible? Research into effects of fatty foods etc & other healthy eating. Should health care professionals be more proactive in supporting carers to care for their loved ones in the last months/weeks. In particular help in avoiding pressure sores, understanding how to improve nutrition by adding high protein/fat foodstuffs to meals (dried milk powder, cheese etc). Understanding how to look after their loved one in the last hours (using a soft tooth brush to maintain mouth hygiene etc)?	Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted nutrition for adult palliative care patients. Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD006274. DOI: 10.1002/14651858.CD006274.pub3				Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications

421150	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	**14**	This uncertainty was identified from a patient's 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 lewy 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 ?	Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and Ageing.2012;41(2):263?269 PMID: 22156555		Mahendra N, Hopper T, Bayles K A, Azuma T, Cleary S, Kim E. Evidence?based practice recommendations for working with individuals with dementia: Montessori?based interventions. Journal of Medical Speech?Language Pathology.2006;14(1):xv?xxv http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0023274/ Zientz J, Rackley A, Chapman S B, Hopper T, Mahendra N, Kim E S, Cleary S. Evidence?based practice recommendations for dementia: educating caregivers on Alzheimer's disease and training communication strategies. Journal of Medical Speech?Language Pathology.2007;15(1) http://www.asha.org/Me	Promoting Informed Decision Making and Effective Communication Through Advance Care Planning for People With Dementia and Their Family Carers NCT02211287 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/Trial/Registration/TrialReview.aspx?ACTRN=12612001164886 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
421151	When is it appropriate to receive palliative and end of life care virtually (such as via Skype or video-phone calls)? 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 publics questions. 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 'nursing' 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 Cancer When They Return Home After Hospitalization in Palliative Care NCT02207543 Palliative Care Symptom Management in Rural Communities NCT02070874 Optimization of complex palliative care at home by means of expert consultation via telemedicine. - FRONTIDA http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2817 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
421152	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 patien, two carers, four professionals and seven bereaved carers questions. This is an indicative uncertainty and the following submissions were merged to form this one: Pre-Bereavement support shoud 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 id 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 soon after death occurs? What are the impact and implications of having 24 hour support for those who are just bereaved? A few years ago as a 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?				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	Family/carer satisfaction; quality of life; health related cost; timing of introducing bereavement support.

421153	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from two professional's, a carer and a bereaved carer's question. This is an indicative uncertainty and the following submissions were merged to form this one: I would like to see more research that is open and honest on the drugs that are routinely used in the last hours of life to understand their mechanisms, actions and their real effects. What is the role of hydration and sedation at the end of life?	Beller EM, van Driel ML, McGregor L, Truong S, Mitchell G. Palliative pharmacological sedation for terminally ill adults. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD010206. DOI: 10.1002/14651858.CD010206.pub2. Bruinsma SM, Rietjens JA, Seymour JE, Anquinet 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?445 PMID: 22658470				Change in symptoms; change in management of symptoms.Adverse effects or complications. Good death.
421154	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?	Reliable up-to-date systematic reviews have revealed important continuing uncertainties about treatment effects		This uncertainty was identified from two patient's, three professionals, three carer's and one bereaved carer's question. This is an indicative uncertainty and the following submissions were merged to form this one: More information about the extreme side of end of a life should be available to help plan better What is happening when someone develops terminal restlessness - what do we understand about it now and what more can we discover (that will be helpful)? What is the most effective way to use sedation (eg during terminal restlessness) - in order to get the balance right between not giving too much but at the same time giving enough to ease distress.	Beller EM, van Driel ML, McGregor L, Truong S, Mitchell G. Palliative pharmacological sedation for terminally ill adults. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD010206. DOI: 10.1002/14651858.CD010206.pub2. 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.				Health related quality of life, good death, Change in symptoms or change in management of symptoms, adverse effects or complications
421155	Who should be part of the palliative and end of life care team (such as chaplains, occupational therapists, GPs, etc)?	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: Re the organisation of care for people in acute wards who are rapidly approaching the end of their lives: 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 hands on, etc How can Specialist palliative Care teams be expected to deliver adequate care when they do not have essential disciplines e.g social workers, in their ranks?				Improving Palliative and End-of-Life Care in Nursing Homes NCT01990742	Patient Satisfaction; health related quality of life; health related cost; quality of care