Continuity and care co-ordination in palliative and end of life care

Evidence for what works

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Foreword

Palliative care has been [defined by the World Health Organization](#) (WHO) as *"an approach that improves the quality of life of patients and their families who are facing… problems associated with life-threatening illness."* It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

The Scottish Partnership for Palliative Care suggests that one way of considering palliative care is to talk in terms of providing good care to people whose health is in irreversible decline or whose lives are coming to an inevitable close: *Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision making.*

Care co-ordination in palliative and end of life care is the proactive, inter-connected and organised activity between the various people supporting someone with a life-limiting progressive illness. This is the working definition for the purposes of this document.

Rather than being an exhaustive evidence review, this document is a summary of the systematic review-level evidence that is available on the approaches to care coordination in palliative care and end of life care, which were identified from the [WHO practice brief on continuity and coordination of care](#) (WHO, 2018). A systematic review uses explicit methods to identify, select and summarise the findings from relevant primary research studies on a specific topic. By including all relevant primary studies that meet pre-defined criteria, a systematic review provides a more reliable assessment of an intervention's effectiveness than one study alone. Some of the evidence is not conclusive, as many changes that aim to improve care coordination have not been well evaluated.

We have also produced visual summaries which present the key information from systematic review-level evidence at a glance, together with links to further reading and some examples of local good practice. All of the visual summaries link to in-depth summaries of the evidence available from systematic reviews.

We hope that this evidence review will provide a useful overview of the high-level evidence on key approaches to care co-ordination in palliative and end of life care, and highlight the potential benefits of these approaches.

Visual summary guide

Approach

A brief description of the approach to care co-ordination in palliative and end of life care.

Rationale

The reasons for considering this approach. We have drawn on the WHO practice brief for many of the rationales.

Potential benefits

A list of the benefits that could potentially be derived from implementing this particular approach, with links to the reviews that contain this evidence

Enablers

Factors that could determine the success of implementing an approach or intervention.

Evidence

A brief summary of the strength of the evidence for this approach and associated interventions. The graph and speech-bubble icons indicate whether the available evidence is quantitative (graph), qualitative (speech bubble) or both.

Further reading and examples

Links to key systematic reviews, other reports and grey literature and examples of local good practice.

Approach	## Early integrated palliative care
	An early and integrated approach that joins up different services to optimal palliative care soon after diagnosis of a life-limiting illness, and which may involve co-location of teams.
Rationale	Expected to improve the quality of life, burden of symptoms and healthcare utilisation through earlier and more continuous communication and informed decision making.
Potential benefits	• Improves health-related quality of life and symptom intensity.
Enablers	• Trusted health and social care professionals are readily available to provide care.
Evidence	There is mixed evidence from systematic reviews to support the benefits of early integrated care which may improve health-related quality of life and symptom intensity to a small degree for people with cancer. People receiving early integrated palliative care may be also more likely to die at home. The strength of the evidence is low because of problems with the way studies have been carried out and differences between them.
Further Reading and examples	• Early palliative care for adults with advanced cancer • Integrated outpatient palliative care for patients with advanced cancer: A systematic review and meta-analysis • A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. • Best Supportive Care Model, NHS Fife • Enhanced Supportive Care • Best Practice in care coordination for palliative and end of life care services: information for commissioners • Co-ordination of palliative care in community settings

Approach	**Collaborative planning of care and shared decision making**
	Involving individuals, families and caregivers in care decisions.

Rationale	Person-centred, goal-oriented planning of care that enables individuals, families and informal carers to be fully involved in assessment and decisions about care is a factor in successful care co-ordination.

Potential benefits	*Advance/anticipatory care planning*
	• Increases documentation of end-of-life preferences.
	• Reduces outpatient visits and hospitalisation.
	• Increases compliance with individuals' end of life wishes.
	• Increases the likelihood of individuals dying in their preferred place of death.
	Tools to support shared decision making
	• Increases the frequency of discussions about advance care planning and completion of documentation.
	• Improves patient and family knowledge related to end of life decision making.

| **Enablers**	• Staff with the skills to recognise illness trajectories, initiate and respond to patients' initiation of Anticipatory Care Planning (ACP) conversations and perform individualised advance care planning.
	• Involvement of healthcare professionals who know the person well in ACP conversations.
	• Structured tools to support shared decision making.

Evidence	There is evidence from systematic reviews of a generally positive attitude towards advance/anticipatory care planning among older people and their families.
	Systematic reviews provide consistent evidence for a number of benefits of advance/anticipatory care planning and the use of structured tools to support shared end of life decision making.

Further reading and examples
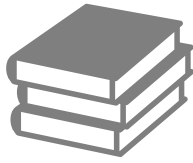
- [Patient care planning discussions for patients at the end of life: an evidence-based analysis](#)
- [Advance care planning: A systematic review of randomised controlled trials conducted with older adults](#)
- [Examining Interventions Designed to Support Shared Decision Making and Subsequent Patient Outcomes in Palliative Care: A Systematic Review of the Literature](#)
- [St Triduana's ACP](#)
- [ReSPECT](#)

Approach	Case management for people with palliative and end of life care needs
	Care and support are planned, reviewed and co-ordinated by a case manager.

Rationale	People who are approaching the end of life are likely to have multiple and changing health issues and care needs, and greater sustained need for continuity of care than many. Case management can reduce the likelihood of gaps in care.

Potential benefits	• Reduces the length of time spent in hospital.
	• Reduces use of inappropriate, aggressive, cure-oriented care.
	• Reduces caregiver burden and increase patient and family satisfaction with care.
	• Reduces the likelihood of admission to an institution after six months (for people with dementia).
	• Reduces chronic heart failure (CHF)-related readmissions for patients with CHF after 12 months follow up.

| Enablers	• Integration between health and social care services.
	• Intensity of case management (small case loads, frequent visits).
	• Integrating specialist expertise with primary and community care services and enabling transitions across settings, including residential aged care.

Evidence	There is evidence from systematic reviews that case management (as long as it is not low in intensity) is beneficial for individuals with progressive life-threatening illnesses and complex needs (particularly people with dementia), and also for their carers, particularly at later disease stages.
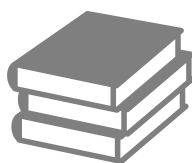
Further reading and examples	• Case management approaches to home support for people with dementia.
	• Examining End-of-Life Case Management: Systematic Review.
	• Clinical service organisation for heart failure.
	• Analysis of case management programs for patients with dementia: a systematic review.
	• Consequences of clinical case management for caregivers: a systematic review.
	• Testing a WISeR approach to community palliative care

Approach	Intermediate palliative care at home
	Enhanced palliative care and end-of-life care provided at home or in a homely setting, e.g. hospital at home approaches, as an alternative to hospital admission or as step-down care after a hospital stay.

Rationale	People approaching end of life are at risk of being admitted to hospital despite preferring to be cared for at home. Intermediate palliative care at home is expected to ensure quality of care, while reducing unnecessary acute hospital stays and facilitating choice about the most appropriate place of care and death.

| **Potential benefits**	• Hospital at home end of life care approaches can increase the likelihood of dying at home and may slightly improve healthcare costs and short term satisfaction with care.

Enablers	• Support for family caregivers.

Evidence	There is some evidence from a systematic review to support the use of hospital at home end of life approaches for increasing the number of people who die at home. A slight reduction in health service costs and improvement in short term satisfaction with care is also supported but the strength of the evidence is low due to problems with the way studies have been conducted. The effect on hospital admissions and caregiver burden is uncertain.
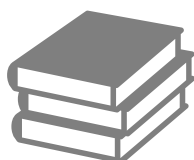
Further reading and examples	• Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. • Hospital at home: home-based end-of-life care. • The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. • An alternative place for palliative care (East Ayrshire care home palliative care bed) • NHS Lanarkshire Hospital at Home

Approach	## Technology to support continuity and care co-ordination
	Technology includes telehealth and telecare interventions encompassing a range of technological tools and resources to help people understand and manage their health conditions, and eHealth interventions, including information and communication technology that supports the management of people's care by enabling electronic communication among health and care professionals, patients, carers and multiple providers within health and care systems.
Rationale	Technological tools and platforms for exchanging information can enable the adoption of care interventions and the identification of individuals who could benefit the most from care coordination. New ways of sharing electronic health records can help ensure continuity of information for professionals delivering care.
Potential benefits	- Supports advance care planning. - Improves communication between patients and healthcare providers. - Improves the quality of care. - Improves outcomes for individuals and the psychological health of family caregivers.
Enablers	- Workforce skills and training. - Establishing and implementing standards to deliver interoperability and information sharing across different health and care systems. - Knowledge exchange. - Leadership. - Clinician buy-in. - Funding.
Evidence	Systematic reviews provide some evidence to support the use of eHealth and telehealth interventions in palliative care, but the strength of the research evidence is limited by a predominance of poor-quality studies with a high risk of bias.

Further reading and examples

- [The case for home based telehealth in paediatric palliative care: a systematic review.](#)
- [Effectiveness of eHealth interventions and information needs in palliative care: a systematic literature review.](#)
- [Perceptions of the use of a remote monitoring system in patients receiving palliative care at home.](#)
- [Project ECHO](#)
- [Project ECHO at Highland Hospice](#)
- [Scotland's Digital Health and Care Strategy.](#)

Approach	**Building workforce capacity** Scoping of workforce challenges Competence frameworks
Rationale	Education and training are required to strengthen the knowledge, confidence, skills and competence of patients, families, volunteers, communities and all staff involved in delivering continuity and care co-ordination. (WHO, 2018).
Potential benefits	• Communication skills training may improve clinicians' ability to show empathy and discuss emotions. • Communication training, compared to usual teaching, may increase medical professionals' self-efficacy, knowledge, and communication skills to support end-of-life decision-making. • Educational interventions for clinicians, informal caregivers and patients may improve symptom control. • Educational for patients and informal caregivers interventions may improve caregiver quality of life.
Enablers	• Informal and formal learning. • Individualised feedback as part of (communication) training. • Sector- and discipline-specific standards and frameworks.
Evidence	Systematic reviews show that there is low-quality evidence that educational interventions may improve self-efficacy, knowledge, and communication skills in staff. There is some evidence that this type of intervention could improve patient outcomes. Systematic reviews show some evidence that symptom management and coping skills education for informal caregivers and patients may improve informal caregiver quality of life, as well as patient symptom control.
Further reading and examples	• Educational interventions to train healthcare professionals in end-of-life communication: a systematic review and meta-analysis. • Educational Intervention in End-of-Life Care: An Evidence-Based Analysis. • Palliative and end of life care: A framework to support the learning and development needs of the health and social service workforce in Scotland. • Foundations in Palliative Care • Building on the Best • Compassionate Inverclyde

- EC4H (training – cost associated)
- Sage and Thyme training (cost associated)

Early integrated palliative care

Why focus on early integrated palliative care?

The WHO recommends palliative care early in the course of life-limiting illness beginning at or soon after diagnosis. **(1)** An integrated approach is considered to be essential for making early palliative care widely available to people with life-limiting illness through joined up services and planning. **(2)** Early integrated palliative care is expected to improve quality of life, burden of symptoms and reduce unnecessary hospital stays, through earlier and more continuous communication with health and social care professionals and more informed decision making. **(3)** Since people with life-limiting illness typically receive care from multiple health and social care professionals, an early integrated approach to palliative care is also important for ensuring continuity of care as result of more continuous relationships. Qualitative research suggests that relational continuity of care may be more likely to be experienced for people with life-limiting illness when a small number of trusted health and social care professionals are readily available to provide multidisciplinary care. **(4)**

Service delivery

Early integrated palliative care services typically relate to the integration of specialist palliative care and oncology care in outpatient settings, but can also include approaches that integrate outpatient or inpatient care and home-based palliative care and relate to colocation of teams providing care in the same space.

Evidence from published systematic reviews

Several systematic reviews have assessed the evidence for approaches to palliative care that consider early and integrated approaches simultaneously. These include early and integrated outpatient palliative care for people with advanced cancer and early integration of outpatient and home palliative care for people with advanced cancer and life-limiting illness.

A recent Cochrane systematic review evaluated the effects of early integrated palliative care approaches versus usual/standard cancer care on health-related quality of life, depression, symptom intensity, and survival among adults with a diagnosis of advanced cancer. **(2)** The review evaluated services that integrated and coordinated comprehensive palliative care in the early advanced stages of cancer, whether this was inpatient or outpatient or care provided at home. The comparator was usual/standard cancer such as no palliative treatment or delayed/later palliative treatment. The review included seven randomised and cluster-randomised controlled trials (1,614 participants). The majority of studies followed the integrated care model, and three followed the co-ordinated care model, with an advanced practice nurse acting as a co-ordinator and in linking care from different specialist disciplines, and four followed the integrated care model.

The results of meta-analysis found that **integrated palliative care may improve health-related quality of life and symptom intensity to a small degree.** There was no difference in survival and levels of depressive symptoms. The results suggest a significant improvement in health related quality of life scores and a small effect for significantly lower intensity of symptoms compared with control participants. One RCT reported potential adverse events of early palliative care, such as a higher percentage of participants with severe scores for pain and poor appetite; the remaining six

studies did not report adverse events in study publications. The small effect sizes were considered to be clinically relevant at an advanced stage of illness. The evidence was considered to be of low certainty because of a high risk of bias across the studies and the differences regarding interventions and populations.

A systematic review examined the integration of palliative care earlier in the course of illness trajectory for patients with advanced cancer as an outpatient and at home. **(3)** The review included 10 trials (2,385 patients) published between 2009 and 2016. Standard oncology care was the comparator in seven of the trials. The majority were conducted in the United States. Trials provided services during outpatient visits delivered by a multi-disciplinary team of two to five clinicians including nurses, three including a mental health professional. Five included telephone-based care.

The results of meta-analysis found that **integrated palliative care improved short-term quality of life.** There was no improvement in symptom burden and all-case mortality survival. In studies following patients from 6 to 35 months, **patients receiving palliative care were more likely to die at home.** There was no improvement in healthcare utilisation, which was qualitatively synthesised.

A systematic review evaluated the benefits of early integration of palliative care in outpatient and home palliative care settings for patients with life-limiting illness. **(4)** Narrative synthesis showed the results of trials were mixed**. Some suggested an improvement in symptoms and quality of life, and reduced hospitalisation and healthcare costs. A reduction in carers' burden and improvement in patient and family satisfaction were also suggested. However, some trials did not find an improvement in symptoms and quality of life or that costs were different from usual care.**

In summary, there are mixed results from systematic reviews of the benefits of early integrated palliative care. **Early palliative care was found to improve health-related quality of life for patients with cancer and reduce symptom intensity to a small degree.** People receiving early integrated palliative care compared with standard oncology care were also more likely to die at home. The effect on other outcomes including survival, depression, caregiver burden, acute care utilisation and costs is unclear. The certainty of this evidence is low due to a high risk of bias across studies and the differences between them.

Collaborative planning of care and shared decision making

## Why focus on collaborative planning of care and shared decision making?

Having **person-centred, goal-oriented planning of care** that enables individuals, families and informal carers to be fully involved in assessment and decisions about care is **a factor in successful care coordination** (WHO, 2018). This can be achieved through involving patients, their family and caregivers in holistic, anticipatory planning of care (WHO, 2018).

Service delivery

Anticipatory Care Planning involves supporting individuals living with a long-term condition to plan for an expected change in health or social status. An Anticipatory Care Plan (ACP) is a dynamic record that should be developed over time through an evolving conversation, collaborative interactions and shared decision making. It is a summary of thinking ahead discussions between the person, those close to them and the practitioner. The ACP is a record of the preferred actions, interventions and responses that care providers should make following a clinical deterioration or a crisis in the person's care or support. It can be reviewed and updated as the condition or the personal circumstances change and different things take priority. **(22)** Outside of Scotland, anticipatory care planning is referred to as advance care planning. The literature is predominantly North American, and advance care planning is the term that is used in systematic reviews.

A UK national guideline commissioned by NICE provides **recommendations on shared decision-making about clinical care for adults in the last days of life** in any setting that is covered by NHS services, based on evidence from a systematic review of qualitative studies and the consensus opinion of Committee members (National Clinical Guideline Centre, 2015). In reaching its recommendations the guideline considered facilitators and barriers to the multi-professional team, dying person and those important to them in being involved in shared decision-making to inform the development of personalised care plans. The Scottish Government's *Caring for People in the Last Days and Hours of Life* guidance **(23)** and associated four principles provide a framework for further planning and development across health and care settings in Scotland.

A National Action Plan supports implementation of ACP principles across Scotland (Cumming, 2017) and a toolkit has been developed providing guidance for health and social care professionals and advice for individuals (Healthcare Improvement Scotland). Details from the anticipatory care plan can be summarised in an individual's GP clinical record and shared with providers of unscheduled care via the electronic Key Information Summary (KIS).

ACP conversation → **Details added to KIS by GP team** → **KIS can be accessed by unscheduled care services**
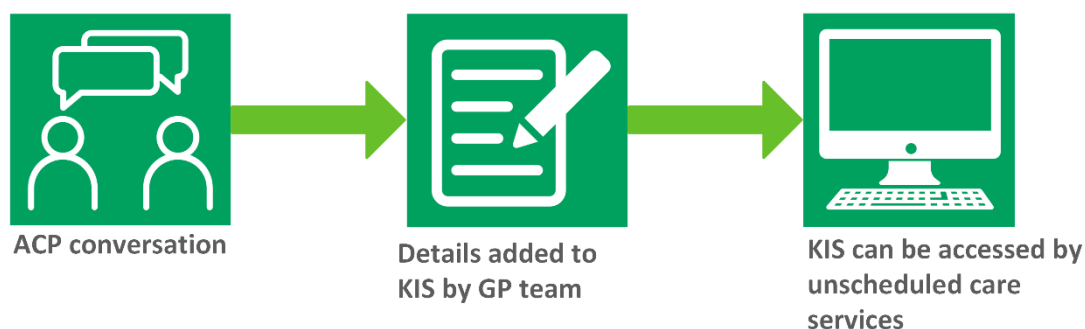
Evidence from published systematic reviews

Benefits associated with advance/anticipatory care planning

A systematic review of the effectiveness of care planning discussions on outcomes for people at the end of life included data from 13 randomised controlled trials (RCTs) and 17 observational studies (2004—2013) conducted largely in the USA; only two RCTs were conducted in the UK. **(2)** The review **found moderate to high quality evidence of increased completion of advance care plans, increased concordance between patient and family wishes and improved patient and family satisfaction with end of life care**, but insufficient evidence of benefit to patients' quality of life.

There was evidence from observational studies that care planning discussions with a multidisciplinary team (MDT) **reduced outpatient visits**, and that **care planning discussions occurring earlier in the course of illness were associated with less subsequent hospital care** than those occurring later. One RCT included in the review, that compared patient care planning discussions with usual care in a nursing home setting in the USA, reported fewer episodes of hospital care, reduced length of hospital stay and greater use of hospice services.

A recent systematic review of the effectiveness of advance care planning in improving end of life outcomes specifically for people with dementia and their carers included 18 studies (2000—2016) mostly based in care homes. **(9)** Two studies were conducted in the UK and most of the others in North America. Three of the included studies were RCTs, of which two were judged to be of low quality, and the others of a less robust study design. The included studies assessed various types of interventions including written advance directives, end of life conversations and staff training. In 10 studies advance care planning was undertaken with the person with dementia prior to losing capacity and eight studies included ACP conversations with carers.

The majority of studies found that **ACP was associated with some positive effects on end of life outcomes including death in usual place of care, reduced hospitalisation, and patient or carer outcomes such as satisfaction with care, concordance, and physical or emotional distress.** The studies varied in quality, their results were mixed, and their diversity made overall interpretation of the evidence difficult. The review concluded that although the evidence base is limited, **ACP is likely to be relevant and applicable to people with dementia and that it may, in some circumstances, be associated with a range of positive end of life outcomes.** There was less evidence for advance care planning in non-care home settings.

A systematic review of nine RCTs (1999—2010) of the impact of advance care planning on outcomes in older adults in community settings and their carers found **evidence of increased documentation of end of life care preferences and use of advance care directives, and increased patient and family knowledge of ACP, understanding of end of life preferences and concordance with end of life wishes. (21)** None of the trials, of which one was conducted in the UK, included in the review measured the effects of ACP on patient outcomes such as symptom management, or the quality of end of life care or the death and dying experience. The quality of the studies incuded in the review was judged to be poor with none being adequately free from bias.

A systematic review that focussed specifically on the effects of advance care planning interventions on nursing home residents included 13 studies (1988—2015), conducted largely in the USA. **(15)** One of the included studies was an RCT and the others of a less robust study design of which one was a UK study. The types of ACP interventions varied, mostly educational programmes or the introduction of a new ACP form. The review concluded that ACP has beneficial effects in the nursing home population, **including reducing hospitalisation, increasing the likelihood of residents dying in their preferred place of death, and care provided being consistent with resident's wishes.** The evidence supporting these findings was of generally low quality.

A systematic review of many different types of advance care planning interventions in various settings summarised the findings from 113 mostly observational studies (2000—2012). **(4)** It broadly found that complex advance care planning interventions (as opposed to stand-alone written advance directives, do-not-resuscitate and do-not-hospitalise orders) appeared to **increase compliance with patients' end of life wishes, and may be more effective in meeting patients' preferences than written documents alone.** The review however failed to provide further insight on the components or the effectiveness of different approaches. It also explicitly excluded studies where ACP was a component of a larger palliative care intervention.

In summary, there is consistent evidence from several systematic reviews for the benefits of advance care planning in terms of **improving patient and family knowledge, shared decision making, documentation of care preferences, and patient and family satisfaction with end of life care provided.** There is limited evidence of benefit in terms of improving patient outcomes including quality of life or reducing health service utilisation.

Effectiveness of tools to support shared decision making

Several systematic reviews have assessed the evidence for different types of tools and aids to support shared decision making in relation to end-of-life care. In these reviews **advance care planning was variously included among the interventions as a shared decision making tool or as an outcome following adminstration of other types of tools**. The main findings from these reviews are described below.

A systematic review of the effects of using structured communication tools with adult patients in ambulatory care settings used meta-analysis to derive pooled estimates of effect for outcomes relating to end of life decision-making. **(18)** The review's broad definition of a structured communication tool included decision aids in any format (such as paper, video, computer) and other structured approaches to help with decision making such as organised meeting plans, patient education interventions on end of life care options and reminders or mailing of advance directives.

This review included 67 studies (1991—2014) conducted mainly in North America, but used only data from RCTs judged to have a low or unclear risk of bias in the meta-analyses. The following findings are pooled estimates based on the results from those trials. Comparators included usual care and minimal/low intensity or sham interventions. **The use of structured communication tools resulted in a statistically significant increase in the proportion of patients with documented advance care planning discussions**; and **the proportion of patients with documented advance directives**; and **concordance between the care desired and the care received by patients at the end of life.**

The review also found a **statistically significant improvement in patient and family knowledge of advance care planning average scores in favour of structured communication tool use** and in **concordance scores between patients and family or substitute decision makers for level of end of life care desired** and in the quality of patient and health care provider communication scores. Variation in the type of interventions, comparators and the populations studied and the potential influence of publication bias limits the extent to which firm conclusions can be drawn from these pooled results.

The only RCT with a low risk of bias that reported patient and family satisfaction with end of life care found that **use of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end of life care made no difference.** The review found only very low quality evidence about health care resource utilisation. Overall, the review showed that **the use of structured communication tools may increase the frequency of discussions about advance care planning and completion of advance directives, and concordance between the care desired and the care received by patients**. It recommended the use of structured communication tools rather than an ad-hoc approach to end of life decision making; and that the selection and implementation of such tools should be tailored to address local needs and context.

A systematic review assessed the effects on patient-centred outcomes of advance care planning tools to promote shared decision making about major treatment decisions in serious illness intended for use by adults living with advanced-stage or potentially life-limiting diseases and their caregivers. (**1**) This review included six RCTs that tested tools for use without immediate clinician support and found what the review judged to be high quality evidence from three trials that **a short video on dementia to inform ACP discussions improved patient knowledge and changed immediate preferences**, but the trials did not assess documentation of preferences or discussion of preferences with health care practitioners.

In another trial judged to be of high quality **an advance directive tool modified for patients with lower health literacy was found to improve ease of use compared with a standard advance directive document, and patients who used the literacy adjusted version were more likely to have completed a written directive six months later.** In one lower quality trial an advanced care planning workbook was shown to increase the discussion of ACP with health care practitioners and the documentation of living wills. The review also included 11 RCTs that tested tools to support immediate treatment choices of which all but one improved users' knowledge. One of these trials, of **a booklet for patients with advanced cancer prompting communication about prognosis and palliative care, provided evidence of improved clinical communication with more questions being asked by patients during an initial palliative care visit.**

A systematic review examined the effects of interventions to support shared decision making at the end of life on psychological and behavioural outcomes of patients, caregivers and healthcare professionals. **(3)** This review included 12 studies (2008–2017) of which six were RCTs judged to be of moderate quality, the others of a less robust study design, and all but one were conducted in the USA. The format of the tools and modes of delivery varied, including technology-enabled tools (such as video, DVD, web-based), print materials, palliative care consultations and structured meetings.

The most commonly reported outcome was patient and caregiver knowledge related to end of life decision making, such as goals of care, advanced care planning and treatment options. **Most studies reported improvements in knowledge following the shared decision making intervention.** Two studies (one RCT and one single group pre and post-test study) of multimodal interventions comprising a video decision aid, print material and structured meeting in a nursing home setting reported significant improvements in the quality of communication between patients/caregivers and healthcare professionals. The review found **very little evidence on behavioural outcomes**, with one study reporting a significant increase in the documentation of goals of care, one reporting no difference in completion of an advanced healthcare directives, and one reporting no difference in the level of healthcare utilisation. The review concluded that optimal decision making and end of life planning can be enhanced by shared decision making between patients and healthcare professionals. However **the evidence of effects of shared decision making interventions on patient/caregiver outcomes was inconsistent.** It suggested that given the potential of health technology to improve patient care, further work was needed to develop individually tailored technology-enabled interventions to support patient-centred decision making.

A systematic review of the effectiveness of decision aids to enable informed choice for older patients at the end of life included 17 studies (1995—2015) conducted largely in North America, of which six were RCTs and the others of a less robust study design. **(5)** The format of the tools used varied widely, as did the decision process and participant support for decision making. The review highlighted that it was **not uncommon for treatment preferences to change over time**, particularly as death approaches. This can be due to a number of different factors such as new symptoms, and experience of the burden of treatment. Therefore **the use of decision aids should not be seen as a one-off activity, but should be revisited periodically over time** in line with disease progression. One RCT demonstrated low levels of regret and high satisfaction levels when decisions which were made over a period of time.

Overall, the review found **low level evidence that the available decision aids were generally acceptable to users and seemed to enhance patients or surrogate decision makers' knowledge of care options and reduce decisional conflict.** The studies that measured knowledge, either of the patient or their surrogate decision maker, generally reported small effects, and few studies provided data to reliably assess changes in decisional conflict or decision concordance between patients and their surrogates.

Few of the decision aids addressed values that might matter to patients at the end of life such as symptom burden, disruption to family and patient time, level of family involvement required in alternative care, consideration of the most difficult decision, quality of remaining life, and financial implications of relevant treatment choices. This suggested that future decision aids for end of life

care need more integration of patient values in order to be considered holistic and useful for improved decision making.

A systematic review of barriers, facilitators and interventions to support proxy decision making for family carers of people with dementia drew largely upon evidence from a subset of 11 studies that the reviewers considered to be of higher quality. **(14)** Nine of those studies were qualitative and two were small pilot RCTs, one conducted in the UK and the other in Australia. The review found that **family carers can find proxy decision making challenging and distressing, and that collaboration with trusted, informed healthcare professionals facilitated the decision making process for carers.** Evidence on whether manual interventions can improve the decision making experience for family carers was found to be lacking.

According to this review, no intervention has yet been shown in an RCT to significantly increase knowledge or reduce decisional conflict or carer burden. One RCT that piloted a palliative care assessment and advanced care planning discussion intervention with carers of hospitalised people with severe dementia in the UK found that it increased decisional conflict compared with usual care. In that trial, although discussions around the completion of advanced care plans with carers were well received, many were unwilling to make decisions about hypothetical future scenarios and few carers formalised any decisions made despite intensive healthcare professional support. One RCT that piloted a decision-making aid for dementia family carers deciding whether to use community services, particularly respite care, in Australia was unable to show a statistically significant difference in carer burden, decisional conflict or knowledge of dementia at 12 weeks follow up compared with providing no additional support. The review recommended further development and testing of decision aids targeting the decisions carers report finding most distressing, including where people should live, accessing services and end of life treatments; and that these aids should be carefully targeted to avoid increasing carers' feelings of conflict when trying to balance their needs and those of their relative.

A Cochrane systematic review, updated in 2016, failed to identify any relevant RCTs or controlled trials to inform practice recommendations on the use of interventions to promote participation in shared decision making for children with cancer aged four to 18 years. **(6)**

In summary, **several systematic reviews of various structured tools provide fairly consistent evidence that such tools can improve patient and family knowledge related to end of life decision making**. There is less, and less consistent, evidence of their ability to improve communication between patients, carers and health care practitioners and reduce decisional conflict for proxy decision makers. The recommended use of structured tools tailored to address local needs and context rather than ad-hoc approaches to end of life decision making seems reasonable given that clear conclusions cannot be drawn about particular approaches due to the wide variation in the types of interventions that have been studied. The evidence reviewed also supports **more integration of patient values and the decisions carers report finding most distressing in decision aids to improve their utility to support end of life decision making for patients and their family carers.** In some areas, including interventions to promote participation in shared decision making for children with cancer, there appears to be an absence of evidence to inform practice.

Service user and provider perspectives on advance planning of care, barriers and facilitators

Several systematic reviews have summarised evidence on service user and provider perspectives on advance care planning, including barriers and facilitators. Much of this evidence comes from qualitative studies, as described below.

A systematic review that focused on attitudes, barriers and facilitators to advance care planning discussions for frail and older people with no overriding medical condition summarised evidence from 26 mostly qualitative studies (1991—2012), five conducted in the UK and the remainder in North America. **(19)** This review found that **most, but not all, frail and older individuals would like the opportunity to discuss their end of life care; and that most saw the responsibility of initiating those discussions to lie with healthcare professionals**, although individuals' preferences for timing were highly variable. Evidence from a small number of studies indicated that **workload pressures and uncertainty about prognosis inhibited healthcare professionals initiating end of life care discussions** with this population of frail older people who have multiple comorbidities rather than a clear terminal diagnosis. This review identified the reluctance of family members to discuss end of life care as being the most common barrier to end of life care conversations. While cognitive impairment and a lack of decision making capacity were also felt to be important barriers to planning, the onset of dementia was identified as a prompt for early planning.

A systematic review of studies that explored the perspectives of older people living in long-term care facilities and their family members about advance care planning discussions identified a paucity of evidence from studies in these populations. **(16)** The review summarised the findings from nine qualitative studies (2008—2016), of which two were conducted in the UK. While most residents interviewed in these studies had never talked about their preferences for end of life care with their family or residential staff, they and their family members had generally positive opinions of ACP. **Evidence of family ambivalence toward ACP conversations signified that some relatives may appreciate their value but find them difficult to initiate.**

This review suggested **that barriers to ACP for older people living in long-term care facilities are more related to health care professionals' willingness to initiate ACP conversations than to patients' and family members' willingness to be involved.** Health care professionals who know the patient well were considered the ideal group of people to initiate ACP discussions, although opinions on the 'right time' to do this varied. Residents and their families desired an approach to ACP that was personalised and incorporated their preferences on non-medical matters as well as medical care. For family members of residents with dementia the barriers to ACP included not recognising the importance of ACP until their relative's cognitive impairment prevented them from having the conversations. The review found some evidence that residents with dementia or cognitive impairment were able to consistently express their preferences when offered the opportunity to express their thoughts.

A systematic review of patients' and relatives' perspectives and expectations on how doctors can improve end of life care in nursing homes concurred that **schematic plans such as advance care plans can be useful but must be individualised. (10)** This review synthesised the findings from 14 qualitative studies conducted in North America and Scandinavia (1999—2011). It found that nursing home residents and their relatives wanted doctors to be more involved in end of life care and expected the doctor to actively participate in the multidisciplinary nursing home team. They also expected healthcare personnel to anticipate and recognise their need for information, palliation and

guidance in decision making concerning end of life issues. An implication for practice from this review was that **high-quality end of life care in nursing homes relies on skilled staff, including available doctors who are able to recognise illness trajectories and perform individualised advance care planning.**

A systematic review of barriers and facilitators for General Practitioners (GPs) to engage in advance care planning with their patients about care at the end of life included eight qualitative studies, four of which were conducted in the UK, and seven cross-sectional studies that used questionnaires to gather quantitative data (1991—2011). **(8)** This review found evidence that **difficulties with defining the right moment to initiate ACP discussions, an attitude that it is the patient who should initiate ACP, and fear of depriving patients of hope were barriers; whereas skills to respond to a patient's initiation of ACP, a longstanding GP–patient relationship and the home setting were facilitators.** The review suggested that initiation of ACP in primary care may be improved by training aimed at GPs' skills and changing their attitudes and beliefs about engaging in advance care planning with their patients.

In summary, systematic reviews on service user and provider perspectives on advance planning of care report similar findings including a generally positive attitude towards advance planning of care among older people and their families, and a fairly common expectation of healthcare personnel to initiate ACP conversations. Evidence of family ambivalence toward ACP conversations offers an alternative perspective on studies that report relatives' unwillingness as one of the main barriers to having ACP conversations. **The evidence reviewed supports individualising care plans and incorporating preferences on non-medical matters. It also supports the involvement of health care professionals who know the patient well in ACP discussions.** It also indicates that dementia or cognitive impairment need not preclude involving an individual in shared decision making about their future care.

Case management for people with palliative and end of life care needs

Why focus on case management?

Case management is where *"care and support are planned, reviewed and coordinated by a practitioner case manager, who follows care over time and addresses both the physical and the mental health needs of people with complex multiple conditions or complicated circumstances."* **(9)** This is particularly pertinent as a person's health is declining.

According to Thomas, 2014 **(8)** case management as a practice arose primarily from a growing concern about discontinuity of care. It was first employed for individuals suffering from long-term serious conditions, such as mental illnesses, diabetes, heart failure, and chronic substance abuse, as well as those with complex or multiple health issues, such as older people with frailty. Regardless of whether the dying person is an older person with frailty, they are likely to have multiple and changing health issues and care needs, and greater sustained need for continuity of care. These factors, combined with a decline in informal caregiving **(3)**, indicate that case management has the potential to be helpful to these individuals.

Service delivery

As a practice, however, **there is considerable variation in case management**, both in terms of its detailed aims, and how it is delivered. The King's Fund reviewed the range of existing practices and concluded that *"rather than being a single intervention, case management refers to a package of care which covers a range of activities that can vary widely between programmes."* **(5)** One review proposes a model of three dimensions to describe case management:

1. The extent the intervention seeks to support and develop patient autonomy versus maintaining professional control,
2. the extent to which the case manager role is brokering care provision or is themselves delivering care, and
3. the extent to which the priority of the role is about identifying the cheapest providers versus meeting all patient needs. **(2)**

In palliative care there may also be differences where the case management programme is designed to address the needs of patients with a particular life-limiting disease (such as chronic heart failure or dementia), compared to a general palliative programme. The case manager's professional background varies in the studies examined. In the evidence available for end of life case management the case manager is most often a nurse, often with specialist disease or palliative care knowledge. Social workers, occupational therapists and psychiatric specialists are also found in this

role, so that whilst a clinical or therapeutic role is often combined, it is not necessarily delivered as part of case management.

Evidence from published systematic reviews

Four systematic reviews and a rapid review (including systematic reviews) were identified as having relevance to case management interventions for end of life care. Of these, two looked at case management for palliative care generally while three were disease-focused. Of the disease-focused studies, two addressed dementia and one heart failure.

Case management as a component of effective palliative care models

A rapid review of elements of effective palliative care models included 23 systematic reviews, 9 additional RCTs and 34 non-randomised comparative studies published between 2001 and April 2012. **(3)** Studies were identified from a search of electronic databases and grey literature for studies published in OECD countries in English on models of care providing a system for organising palliative care for people with *"progressive life-limiting illness in any setting."* This review was undertaken to inform the Australian approach and concluded that *"case management was the element most consistently reported in models for which comparative studies provided evidence for effectiveness."* **(3)**

It considers case management as a holistic patient-centred function, noting that it *"seeks to assess and meet the full range of each individual's palliative care and other needs, including those relating to activities of daily living (e.g. housework) and social wellbeing."* It therefore is likely to involve the coordination of services beyond the healthcare sector. This review's conclusion on case management as an element of effective models of palliative care is qualified: **all the studies combine case management with other types of care interventions, so firm conclusions are not possible about causal connection between case management and the effectiveness of the whole care given.**

The reviewers also note that the plethora of outcomes of interest to patients, family/caregivers, and care providers limited its ability to compare studies or do meta-analysis. As illustration, it cites one study which identified 15 patient-level domains alone – *"including quality of life, quality of care, symptoms and problems, performance status, psychological symptoms, decision-making and communication, place of death, stage of disease, mortality and survival, distress and wish to die, spirituality and personality, disease-specific outcomes, clinical features, meaning in life and needs."*

Benefits associated with case management

One systematic review of RCTs of case management approaches to home support for people with dementia included 13 studies published between 1987 and 2013 from a range of countries: the US, Canada, Finland, the Netherlands, Hong Kong, India and the UK. **(4)** All but three lasted 12 months or

more and six lasted 18 months or more. To be included, study participants were people living in the community with dementia of any type and stage, and the intervention was *"any case management intervention delivered in the community predominantly focused on the planning and co-ordination of care required to meet the identified needs of the person with dementia."* As the authors note, this minimal definition allows a variety of approaches to case management to be included along with multi-component interventions.

As well as a variety of approaches, **the interventions had varying specific goals, including: reducing carer depression and burden, improving carer quality of life, delaying institutionalisation, reducing the number of neuropsychiatric symptoms/behavioural problems, increasing early use of home care and other community services, facilitating long-term planning, and improving carer competence in caring.** It was found that **all interventions reviewed included carer education as a case management function, and most included participant education.** Seven of the 13 included medications review, and 11 emotional/therapeutic support. Some, but fewer case managers were involved in advocacy or providing advice on benefit, financial or legal issues. Case managers delivering the intervention were based in a variety of settings, were from a range of professional backgrounds (nurses, social workers, occupation therapists and psychiatrists), and the training they received as case managers also varied considerably.

Overall risk of bias in the studies reviewed was assessed as low to moderate. Key results included the finding that **case-managed patients were less likely to be institutionalised at 6 months**, but no significant findings for 12 or 24 months. For 12 months however, limiting the meta-analysis to (five) studies where delaying institutionalisation was an intervention goal, indicated that the case management group were significantly less likely to be institutionalised. Therefore, **there is evidence that case management reduces institutionalisation for people with dementia in the medium term, particularly if its explicit aim is to do so.** Note that the patient group included the full range of patients from mild to severe dementia and no subgroup analysis for this was carried out.

At 12 months there was some evidence that social support for carers had improved, and that they were more satisfied with the quality of care received (One study examined this outcome - individuals in the intervention group were significantly more satisfied. Note however that there was no significant difference between groups at 18 months). **Some studies indicated that case management was more effective than usual care at reducing behaviour disturbance at 18 months, reducing carer burden and depression, and improving carer well-being at six months and social support at 12 months.** There was also evidence that **case management increased the use of home care, day care, respite care, and domestic paid help and personal care. One study indicated a reduction in assisted living housing use at 12 months and pooled data from two studies showed a reduction in total cost of services.**

There was good data showing that there was no difference in mortality between case-managed and usual care groups at 12 months, and at 36 months.

Another systematic review which this review cites, indicates that **the factors that appear to be related to greater case management efficacy were the integration between the health and social service organisations and the intensity of case management**. (**6**) (Note that this review is not further detailed as aside from this consideration, its scope is very similar to Reilly and several of the same studies are included in both.)

Another systematic review specifically examining end of life case management of palliative or very frail patients included 13 studies on palliative care, and four focused on frail patients and drew from studies from English language research articles published between 1989 and 2012**. (8)** Fourteen studies focused on the value added by case management, with the remaining three addressing potential improvements to the approach.

Although restricted to these patient groups, there were no limitations on what exactly constituted case management from case management interventions and, aside from proposed explanations for inconsistent results, there is little discussion of this. This **review also provides very little information to support claims of significant findings, with no statistical analysis presented aside from some percentage results within tables, for example. Its quality cannot therefore be properly assessed.**

The authors state that **of the 14 studies reporting on added value, six (all US) report on hospital utilisation, four finding significantly reduced time in hospital due to case management.** The authors of the two studies which do not find hospital time reduced, suggest that nurse case managers acted as patient advocates and may have identified unmet needs as well as service gaps and there is some indication there was improved quality of life.

The remaining eight studies focused on other aspects of additional value – all designed differently with varying methods, aims and findings. Although reporting on different outcomes and measures, all but one of these reported benefits, according to the reviewers, including **increased patient and family satisfaction (several studies), increased appropriate use of hospice care with less use of inappropriate curative care, and improvements in quality of life indicators.** One study on lung and heart failure patients reported a range of benefits including, *"fewer symptoms, less symptom distress, more vitality, better physical health, higher self-rated health, and significantly better self-care management, awareness of resources, and legal preparation for the end of life."* In the study where benefit was not found, participants reported very little contact with case managers - for example out of 199 cases 21% were never visited or telephoned at home and case manager caseloads were high – which the review authors suggest may explain this result.

Another systematic literature review concerned care givers of older people with frailty or persons with dementia, and a model of case management in which *"a designated care manager combines the planning and coordination with a therapeutic, supportive role."* (1) This included randomised trials and quasi-experimental studies comparing case management with usual care. Sixteen studies were found, with 12 included after quality checks, ranging in publication date from 1999 to 2015. Although focusing on caregivers, this study does argue that this is relevant to those they care for, and also reports some patient outcomes (particularly where no caregiver benefits are found). This

review does not provide any quantitative information to support claims but does indicate where findings were considered statistically significant or not.

Seven of the 12 studies found at least one valid positive outcome for caregivers. Four of the 11 studies assessing it showed a **reduction in caregiver burden.** Four of the seven studies assessing quality of life for caregivers yielded positive results; one of three on caregiver social support showed positive results. The four studies that assessed depression in caregivers found no significant differences at the end of the intervention, although one found a significant result on depression score 6 months after the end of the intervention.

This study also includes an analysis of which aspects of case management could explain variation in efficacy, but does note that confounding factors (such as variability in context) limits the reliability of the results. The sub-group analysis explored intensity and integration, as well as patient groups (elderly, mild dementia, dementia). Intensity was measured by case load, frequency of home visits, the range of services, and the complexity of the needs of the target population. Levels of integration were estimated on the basis of the case managers' links with primary care practice, service providers, acute-care facilities, and long-term care facilities. Information about caregiver characteristics (gender, relationship) was also collected to inform this analysis.

They conclude that patient profiles are important determinants and higher intensity case management was associated with positive outcomes for care givers. None of the programmes aimed at older people with frailty showed positive effects for care givers, whilst six of the 10 programmes targeted to people with dementia found positive outcomes for caregivers. Five of the six studies with a "high" intensity level of case management achieved positive outcomes for caregivers, whereas only one of the five studies rated as a "moderate" level of intensity did so. Where there were no benefits found in dementia studies they were either aimed at people with mild dementia, or integration was low/moderate and intensity moderate/unclear.

While most studies showed positive or no effects on caregivers, one study did show increased burden on carers in case managed groups. The authors suggest this may be because carers are asked to do more by either the patient or the case manager. Another study suggested that information overload and confusion about personnel involved had potential to be a disbenefit of case management.

Finally, a systematic review of RCT studies of interventions in heart failure services included twenty five trials (5,942 people) ranging in publication dates from 1998 to 2008. **(7)** It classified studies into a typology of three types of interventions:

1. case management models,
2. clinic models, and
3. multidisciplinary models.

Eighteen of the 25 studies were considered to be of case management interventions which *"consist of intense monitoring of the patients following discharge from hospital, this is usually done by a nurse and typically involves home visits and/or telephone calls."* Although this study is not specifically end of life care, it notes that *"The frailty of the populations targeted by these interventions is*

evidenced by the high levels of baseline co-morbidity and the overall mortality rates in many of these studies."

Case management interventions were associated with reduction in all-cause mortality around 12 months follow up (although note that heterogeneity is moderately high across the 11 studies included in this calculation), but not at six months. No reductions were seen for deaths from chronic heart failure (CHF) or cardiovascular causes but **CHF-related readmissions were reduced at six-month, and at 12-month follow up,** though at 12 months the evidence is less robust due to high levels of heterogeneity.

The author concludes **"amongst chronic heart failure patients who have previously been admitted to hospital for this condition there is now good evidence that case management-type interventions led by a heart failure specialist nurse reduces CHF-related readmissions after 12 months follow up, all cause readmissions and all-cause mortality.** It is not possible to say what the optimal components of these case management type interventions are, however telephone follow up by the nurse specialist was a common component."

Factors mediating the effectiveness of case management

Again partly because of the variety of approaches to the intervention, the specific aspects of case management that lead to effectiveness are also not clearly evidenced. Additionally, **there is a lack of evidence around how case management works and what makes it effective in the context of different models of care and/or different health systems.** The studies in this review do provide some evidence on aspects of case management that might impact effectiveness:

- *Existing health system*: the extent of integration and co-ordination of health and social care services, and the extent of availability of local community resources **(4, 1)**

- *Case management intensity*: increased intensity, measured in terms of the caseload of the case manager and visit/contact frequency, appears to increase effectiveness **(1, 8** (Canadian study)**)**. One study found that where caseloads are relatively small, intensity measured on a more detailed scale was associated with efficacy. **(6)** There is a widespread assumption that where caseload exceeds 50-60 it is not likely to be effective – more work would be needed to investigate the evidence base for this.

- *Team disciplinary/skill mix*: Models of palliative care should integrate specialist expertise with primary and community care services and enable transitions across settings, including residential aged care. **(3)**

- *Increasing costs*: Nurse case managers may increase economic costs if they identify service gaps and unmet needs, and act as advocates for services to be provided. **(8)** There may also be a risk of case managers increasing the burden and / or information overload on caregivers. **(1)**

- *Target population*: for dementia, there is some evidence that more cognitively impaired patients and those with more complex needs and their caregivers benefit more, though benefit earlier in disease progression cannot be ruled out. **(6, 1)** There is a lack of evidence on how to identify patients who might benefit from case management.

Summary

The evidence that there is, is that **case management (as long as it is not low in intensity) is beneficial for patients with progressive life-threatening illnesses and complex needs, and also for their carers, particularly at later disease stages.** The rapid review **(3)** sought to identify effective palliative care interventions and concluded that *"Case management was the element most consistently reported in models for which comparative studies provided evidence for effectiveness"*, though it is not clear how these reviewers defined case management, nor how significant a component of the interventions it was, nor what outcomes it was thought to contribute to.

In other studies positive outcomes reported on were quality of life, satisfaction with care, increased appropriate use of hospice care, fewer symptoms and less symptom distress, self-rated health, self-care, awareness of resources, legal preparation for death, likelihood of institutionalisation and behavioural disturbance for people with dementia**,** reducing carer burdens and depression and improving social connection **(1**, **8**, **4)** and reduced readmissions for chronic heart failure. **(7)** Where positive effects were not identified there was no evidence of negative effects on outcomes measured, except one study where care giver burden was assessed as having increased (possibly because the case managers asked more of them. **(1)** There is also some evidence of economic benefits with reduced healthcare service costs (for example, reduced hospital utilisation **(8)**), but this was inconclusive in several studies too, perhaps explained by increased appropriate use of services **(8**, **4)**. Nurses and social workers are most frequently case managers in effective palliative care and dementia studies (but no conclusions can be drawn in relation to others in the role). For people with dementia there is good data showing no difference in mortality between case managed and usual care groups up to 36 months of intervention. **(4)**

This all comes with caveats. As explained above there are large variations in the details of interventions, including desired outcomes and whether it is part of a multicomponent intervention. In order to increase comparability one study only included interventions where the care manager combined *"the planning and co-ordination with a therapeutic, supportive role."* **(1)** Another required there to be planning and coordination as part of the intervention. **(4)** There is a very wide variety of outcomes of interest to patients/caregivers and providers. For patients alone, they include: *"quality of life, quality of care, symptoms and problems, performance status, psychological symptoms, decision-making and communication, place of death, stage of disease, mortality and survival, distress and wish to die, spirituality and personality, disease-specific outcomes, clinical features, meaning in life and needs."* **(3)** Thus, opportunities for meta-analysis were very limited and there is not a substantial body of evidence around any individual outcome or patient group.

Intermediate palliative care at home

Why focus on intermediate palliative care at home?

Intermediate palliative care is provided as an alternative to hospital admission or as step-down care after a hospital stay. Approaches to intermediate palliative care in the published literature typically relate to 'hospital at home' which aims to help people at end of life be cared for at home who would otherwise require admission to hospital or hospice inpatient care **(4)**. However, intermediate palliative care can also be provided in dedicated intermediate care beds in community hospitals or care homes. It is expected that intermediate palliative care at home can ensure quality of care while reducing unnecessary acute hospital stays and facilitating choice about the most appropriate place of care and death. It also has a role in increasing in the number of people who are supported to die at home instead of hospital, which most people have been found to prefer **(2).** Preferences in relation to home being the place of death may also change over time, depending on how well symptoms can be managed and the extent to which caregivers find they are able to cope and/or have the choice of alternatives such as hospice care.

Service delivery

Intermediate palliative care services evaluated in the published literature vary in their characteristics and components depending on the healthcare system and configuration of local services. Hospital or hospice at home as a model of end of life care can be physician or nursing led, providing multi-disciplinary care or focussing on 24-hour nursing care. National guidance recommends that palliative care at home is provided as an option for people in the terminal phase of an illness; however also recognises that there may be circumstances where managing the process of dying at home may not be feasible. **(3)** Local service arrangements are also recommended to include comprehensive holistic assessment of families and informal caregivers' changing needs and preferences and that appropriate support is offered as result of assessment. **(3)** Support provided to caregivers may be both emotional and practical, such as providing training on delivering aspects of care and information on how to seek out-of-hours support.

Evidence from published systematic reviews

Benefits associated with intermediate palliative care at home

A Cochrane systematic review assessed the clinical and cost-effectiveness of hospital at home approaches for individuals at end of life and requiring terminal care that would otherwise necessitate admission to hospital or hospice inpatient care **(4)** End of life care at home was defined as *"the provision of a service that provides active treatment for continuous periods of time by healthcare professionals in the patient's home for patients who would otherwise require hospital or hospice inpatient end-of-life care."*

The review considered if the provision of hospital at home end of life care reduced the likelihood of dying in hospital, and what the effect was on patients' and caregivers' satisfaction and health service costs, compared with being admitted to hospital or hospice. Pooled estimates of the effect were determined for likelihood of dying at home, admission to hospital, satisfaction with care and caregiver burden. Four trails were included in the review (1992—2007), two in the US, one in the UK and one in Norway. There was variation in the components and duration of end-of-life care. Three

trials involved multi-disciplinary care and one focussed on nursing care in the last two weeks of life. The studies highlighted the need for access to 24-hour care in order to be able to deliver home-based end of life care.

Meta-analysis identified **increased odds of dying at home** (seven trials with 1,222 participants, three of high quality). Narrative synthesis identified evidence of **a small beneficial effect on reducing symptom burden** (three trials, two of high quality) and **no effect on caregiver grief** (three RCTS, two of high quality). **Cost-effectiveness evidence from six trails was inconclusive.**

A Cochrane systematic review assessed the clinical and cost-effectiveness of a specific model of palliative care for individuals at end of life and requiring terminal care. **(4)** End of life care at home was defined as *"the provision of a service that provides active treatment for continuous periods of time by healthcare professionals in the patient's home for patients who would otherwise require hospital or hospice inpatient end-of-life care."* The review pooled estimates of the effect for outcomes relating to end of life care at home, including likelihood of dying at home, admission to hospital, satisfaction with care and caregiver burden. Four trails were included in the review (1992—2007), two in the US, one in the UK and one in Norway. There was variation in the components and duration of end of life care. Three trails involved multi-disciplinary care and one focussed on nursing care in the last two weeks of life. A range of outcomes were considered including patient symptoms, quality of life, health service costs, and caregiver symptoms such as stress and anxiety. The studies highlighted the need for access to 24-hour care in order to be able to deliver home-based end of life care.

Meta-analysis found an **increased likelihood of dying at home compared with usual care**. Admission to hospital while receiving care varied between trials, reflected by a high level of statistical heterogeneity. There was a **slight reduction in total health service cost** (2 trials; low quality evidence). There was **a slight improvement in satisfaction with care reported after one month but reduced satisfaction at six months** (2 trials; low quality evidence). **The effect on caregiver burden was inconclusive** (2 trials; low quality evidence), with caregivers reporting a decrease in psychological well-being when individuals survived more than 30 days.

Informal or family caregivers' perspectives

Informal or family caregivers have an important role in facilitating intermediate palliative care and end of life care. A review of preferences and perspectives of family caregivers towards place of care for their relatives suggests that these vary depending on the extent to which they can be supported and cope in their role. **(5)** For patients, preferring care in a hospice or hospital as opposed to home care can be related to their desire to not be a burden on family caregivers. For family caregivers, preferences may depend on whether there is adequate support available from healthcare professionals and if an acceptable alternative is available locally. Furthermore, despite preferences for receiving care at home, it may be become necessary to move to a hospital or hospice from home because family caregivers find they are unable to cope.

Summary

In summary, **there is some evidence to support the use of hospital at home approaches for increasing the number of people who die at home. A slight reduction in health service costs and improvement in short term satisfaction with care is also supported.** It is unclear if what the effect is on hospital admissions and caregiver burden. The strength of the evidence is limited by the quality of studies and differences in the approach to hospice at home. The provision of hospital at home, and whether preferences for receiving care and dying at home can be fulfilled depends on whether adequate support for people at end of life and their family caregivers can be provided, including provision of out-of-hours care.

Technology to support continuity and care coordination

Why focus on technology to support continuity and care co-ordination?

The availability of information and communication technologies that support the management of people's care makes it easier to ensure continuity and care coordination (WHO, 2018). Tools and platforms for the exchange of information facilitate adoption of practice interventions and identification of people who have the most to gain from care co-ordination (WHO, 2018). New ways of sharing electronic health records ensure the continuity of information for professionals in various care settings (WHO, 2018).

There is a need to harness the growing use of technology in health and social care in order to meet increasing challenges in service provision. This can help to improve communication between teams and with patients and carers and facilitate more timely interventions, which ultimately enhances the overall care experience. Anecdotally, there are indications that some staff are reluctant to use technology in end of life care as it could risk depersonalising care. However, there are areas where it can be very helpful, e.g. in rural areas, clinical teams can conduct consultations using video communication applications to continue to engage with the individual. Assessment and management of symptoms can be conducted via text message, and text messages and emails can be used for people with communication difficulties associated with conditions such as head and neck cancer.

The Scottish Government's Digital Health and Care Strategy asserts that the people of Scotland expect technology and information systems to be part of how health and care services are delivered, and acknowledges that there remains significant further opportunity for digital technology to support the way that services are delivered.

Service delivery

Technology encompasses telehealth (home monitoring, telemedicine, video consultations), telecare or assistive living equipment, mobile health and wellbeing applications, and online platforms, tools and resources to help people understand and manage their health conditions (WHO 2018). eHealth includes the information and communication technology that supports the management of people's care by enabling electronic communication among health and care professionals, patients, carers and multiple providers within health and care systems (WHO, 2018).

Information and communication technology can be aligned with predictive risk tools, decision support tools, algorithms and guidelines to target care coordination more carefully (WHO, 2018).

Evidence from published systematic reviews

Several systematic reviews have summarised evidence from a large number of primary research studies on the use of a wide variety of eHealth and telehealth interventions in palliative care. These reviews reported mainly on patient and caregiver outcomes and provided relatively little information about effects on system measures of care continuity or care co-ordination.

A systematic review of information and communication technologies in end of life care included 38 mostly non-randomised studies (1997—2013) that assessed the use of eleven different types of technology to variously provide information or education, serve as decision aids, promote advance care planning or relieve physical symptom distress. **(6)** Most of the included studies assessed video technologies and reported some benefits in relation to supporting advance care planning. As none of the studies of video technologies used mobile platforms or engaged patients via video sites on the internet, **the review authors suggested that the potential value of video in helping patients clarify their treatment preferences should encourage more providers to experiment with video interventions using mobile devices.** As well as noting a lack of unbiased published research in this field, the review could not compare the effectiveness of different technologies because the studies it identified were too dissimilar.

An earlier systematic review of eHealth interventions in palliative care found **limited evidence of their effectiveness for patients, caregivers or health care professionals. (2)** The review defined eHealth interventions as any information and communication technology designed to conduct measurements, enhance communications or deliver relevant information. The review failed to identify any RCTs of eHealth in palliative care but found **some evidence of positive effects** in eight observational and quasi-experimental studies (2004—2012) that were judged to have a significant risk of bias. Those effects included improvements in the quality of care and communication with care givers and reduction in documentation efforts. The only study conducted in the UK was a feasibility study of using mobile phone-based technology in rural Scotland to monitor and manage symptoms reported by patients being cared for at home in the advanced stages of their illness, which showed that **the Advanced Symptom Management System in Palliative Care (ASyMSp) was usable and acceptable to patients with palliative care needs and the health professionals who cared for them. (5)**

A recent systematic review that focussed on the effects of telehealth interventions in palliative care on patient-reported outcomes included 11 studies (2006—2015) largely conducted in the USA of which two were RCTs of uncertain quality and the others of a less robust study design. **(4)** There was considerable variation in the telehealth applications and technologies used, the populations served and the systems in which the care was delivered in these studies, and they all used different outcome measures. The only study conducted in the UK was the feasibility study of using mobile phone-based technology in rural Scotland, already described, that showed **the system was usable and acceptable to the patients and health professionals involved. (5)** Overall, all but one of the studies included in the review reported positive effects including patient quality of life, symptoms, anxiety and satisfaction. But these results were inconsistent across studies and, taking account of their methodological limitations, the review concluded that **the research evidence supporting positive patient outcomes for palliative telehealth interventions is weak.**

A systematic review that specifically assessed the effects of telehealth interventions in palliative care on caregiver outcomes **(7)** included nine studies (2007—2012), largely conducted in the USA. One of the included studies was an RCT, one a pooled analysis of results from two RCTs, and the others of a less robust study design. Most of those studies provided moderate to low quality evidence apart from the RCT, which was rated as high quality.

The studies tested various telehealth applications using video phones, regular phones and internet based interventions in various populations. **All five studies, including the RCT, that measured caregiver quality of life showed no significant difference after telehealth interventions. Two of three studies, again including the RCT, that measured caregiver anxiety showed a statistically**

significant decrease after the intervention; and one of two other studies showed a significant reduction in caregiver burden. The variety of instruments used to measure these outcomes made it impossible to assess effects across studies. The review concluded that telehealth interventions have the potential to improve the experience of caregiving for those who care for palliative patients, there being at least weak evidence to support the use of telehealth to improve quality of life and alleviate psychological distress for caregivers.

An earlier systematic review that assessed the effects of telehealth interventions intended to support and address the needs of family caregivers of adults and children included studies in all settings and life stages, not just palliative care, and for any type of clinical condition. **(3)** This review included 65 studies (1997—2014), largely conducted in the USA, spanning a wide range of study designs and interventions including video, web-based, telephone-based and telemetry/remote monitoring technologies**. The majority of those studies reported that caregivers had significant improvements in outcomes, the most commonly reported outcomes being enhanced psychological health variously reported as less anxiety, depression, stress, burden, irritation or isolation.** The strength of the evidence from many of these studies was judged to be low and the review did not provide further insight on the effectiveness of particular approaches.

A systematic review of home-based telehealth interventions in paediatric palliative care included 27 studies in adult care, together with the only six paediatric studies that it was able to find. **(1)** The included studies were mostly descriptive and varied widely in purpose, technology and participants. Most of them used dedicated videoconferencing equipment installed in the patient's home to deliver home-based palliative care interventions. **The outcomes reported included quality of life and anxiety in patients, carers or families, substitution of home visits (based on retrospective chart review studies), acceptability and satisfaction, but no two studies used the same outcome measure.**

The majority of the studies reported results that were supportive or partially supportive of the use of home telehealth in palliative care, although the review noted that this might reflect publication bias (whereby studies with positive findings are more likely to be published). The review concluded that home-based telehealth has the potential to improve services and outcomes for families, but suggested that assessing the fulfilment of patient and family needs could provide evidence of effectiveness that would be more easily attributable to a telehealth intervention than measures of quality of life or anxiety.

Summary

In summary, systematic reviews provide **some evidence to support the use of eHealth and telehealth interventions in palliative care in terms of their acceptability and potential to promote advance care planning and improve communication between patients and healthcare providers, care quality and patient and family caregiver outcomes.** The strength of the research evidence is however limited by a predominance of poor quality studies with a high risk of bias. Further, the diversity of technologies tested and outcome measures used makes it difficult to draw clear conclusions from the research evidence about the benefits of particular approaches.

Building workforce capacity

Why focus on workforce capacity?

Education and training are required to strengthen the knowledge, confidence, skills and competence of patients, families, volunteers, communities and all staff involved in delivering continuity and care coordination. **(9)** WHO quotes a patient perspective on how this looks: *"My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes."* **(9)**

Demographically, there is a major workforce challenge in providing care in general. If care cannot be accessed to support the provision of personal care in the community when someone is reaching the end of life, there is often no alternative but to admit to a local hospital, resulting in the person dying in hospital, rather than at home. It is therefore crucial that services review pathways and consider new ways of coordinating care to maximise benefit.

Service delivery

The NHS Education for Scotland and Scottish Social Services Council framework on learning and development for palliative and end of life care **(6)** shows that a range of factors need to be considered in assessing competence, and identifying and meeting training needs amongst a diverse workforce. It is underpinned by principles promoting a person-centred, outcomes-focused, human rights-based approach encompassing the WHO definition of palliative care. **(9)** The framework seeks to promote *"a consistent, inclusive and flexible approach to learning and development on palliative and end of life care for the health and social service workforce."* It acknowledges the place of informal and formal learning in supporting the workforce to develop knowledge and skills, and recognises sector- and discipline-specific standards and frameworks, such as National Occupational Standards and the NHS Knowledge and Skills Framework. It recognises the need for a workforce competent in both palliative care itself and its coordinated person-centred delivery across care settings. It is structured in five domains:

1. Fundamentals of palliative care.
2. Communication and conversations.
3. Loss, grief and bereavement.
4. Care planning and delivery.
5. Care in the last days of life.

It has been developed with wide-ranging consultation and is thus based on a considerable body of expertise, although there is a limited base of evidence in the published literature.

Evidence from published systematic reviews

Six systematic reviews relevant to workforce competence in palliative care were identified. Three found studies which moved beyond trainee self-assessment as a measure of outcome or found some impact on patient outcomes and these are discussed first.

A systematic review (8) of randomised control trials of the effect **of communication training interventions for generalist palliative care providers** on patient-reported outcomes and trainee behaviours included 19 articles (six rated medium and 13 high quality) deriving from 14 studies published between 2002 and 2014.

Patient outcomes most frequently reported on were anxiety, depression and satisfaction with care. Others included perceived empathy and satisfaction with communication. End of life care topics were defined broadly to include issues related to incurable progressive disease and the final stages of advanced disease (e.g. discussing poor prognosis, advance directives, end of life preferences and the dying process). Most interventions were palliative/end-of-life care courses for oncology staff with communication skills components, followed by courses on palliative/end of life care communication.

Results from the meta-analysis carried out as part of this review showed **no effect on patient outcomes and high levels of heterogeneity, but did show significant effect on trainees' ability to show empathy and discuss emotions in simulated patient consultations**. The effect however – in the four studies which reported on it – was smaller for interactions with real patients, and with a higher than 5% likelihood that the result was by chance (i.e. it was not statistically significant) and moderate heterogeneity.

The reviewers also tabulated outcome effect sizes with training and evaluation characteristics but found no distinct patterns in relation to use of role-play, personalised feedback on a recorded interaction, intervention duration, or outcome measurement timing. However, they note that **the two interventions with medium effects on showing empathy in real patient interactions included personalised feedback on recorded interactions.**

In summary, this review of moderate and high quality RCT studies concluded that **the effect of communication skills training for generalists on patient-reported outcomes remains unclear, but that training can improve clinicians' ability to show empathy and discuss emotions,** though this effect is greater in simulated patient consultations than with real ones. Including personalised feedback on recorded patient interactions as part of training may make training more effective in terms of changing behaviours in real patient interactions.

Another systematic review (3) included 20 RCT and observational studies published up to 2014 (ranging from 1993–2014), mostly low-quality, which evaluated educational interventions for mostly US medical trainees using a communication tool to assist adult patients in end-of life decision-making. 16 of the studies were either considered at high or unclear risk of bias or were uncontrolled before-after studies. Most interventions involved didactic lectures (17 studies), small group discussions (16 studies) and role-play with direct observation and feedback (16 studies). Ten studies distributed the learning over more than a day, ten were workshops or tutorials done within a day or less.

Eight studies (522 participants) found that **end of life communication skills training was associated with improved self-efficacy compared to usual training**. Four studies (290 participants), reported that **end of life communication skills training was associated with an increase in knowledge scores compared to usual training**. Eight studies (590 participants) found that **end of life communication skills training was associated with improvement in communication scores rated during standardised patient encounters.**

Only four studies reported patient-important outcomes but heterogeneity precluded pooling of data across studies. One study found **no statistically significant change in the overall proportion of advanced directives completed after a morning educational session** whilst another Intensive Care Unit (ICU)-based intervention showed a beneficial effect on earlier completion of advanced directives and a decrease in non-beneficial care. One study showed **improved patient satisfaction in advance care planning**, while another showed **no improvement in patient-reported quality of end of life care or quality of communication.**

A systematic review ([5]) included six RCTs (published 2003-2013) of educational interventions for healthcare providers and informal caregivers of adult patients nearing the end of life, intended to improve patient and informal caregiver outcomes, and to determine the effectiveness of educational interventions for improving quality of life in patients nearing the end of life and in informal caregivers.

Of the six included studies, five were in the US and one Spain and all were RCTs using pre/post cohorts. Four were hospital-based, one in a primary setting and one a home setting. Training interventions were targeted to healthcare professionals in three studies and to informal caregivers or patients in the other three. The studies examined a range of patient-important outcomes:

- patient quality of life and informal caregiver quality of life as measured with validated scales,
- patient pain control,
- patient symptom control,
- informal caregiver and health care provider satisfaction,
- number of hospital days, and
- emergency department visits and intensive care unit admissions.

All the evidence (from five RCTs) on quality of life was rated as low quality ("the true effect may be substantially different from the estimate of the effect"). Evidence for all other reported outcomes was rated as moderate quality ("the true effect is likely to be close to the estimate of the effect, but may be substantially different").

This review finds evidence that: **educational interventions for health care providers, focused on improving communication skills, knowledge, and attitudes towards end of-life care significantly improved patient symptom control** (moderate quality evidence) and that, **educational interventions for informal caregivers and patients, focused on symptom management and coping skills significantly improved informal caregiver quality of life (moderate quality evidence) and significantly improved patient symptom control (moderate quality evidence).**

The same training for healthcare providers did not however significantly improve patient pain control, informal caregiver quality of life or satisfaction, or health care provider satisfaction, nor did it improve resource utilisation, including number of hospital days, emergency department visits, or intensive care unit admissions (all moderate quality evidence). It also did not significantly improve patient quality of life (low quality evidence). Educational interventions for informal caregivers also did not improve resource utilization (moderate quality evidence), nor did it significantly improve patient quality of life (low quality evidence).

Other studies

There is supporting evidence from a further three reviews that **clinicians find that training in palliative care, in particular around communication, improves their skill levels (and confidence),** but the studies identified rely almost exclusively on self-assessment with the attendant risk of positive bias. **(1, 2, 4)** These three studies are outlined below.

A systematic review (1) of studies up to 2014 found no difference made by interventions and concluded that the training that is provided to non-medical staff in nursing homes is unlikely to make a difference to patient outcomes. The review shows only that, up to 2014, there is a lack of general (non-disease-specific) end of life care training for (non-medical) nursing home staff and that what training there is, is poorly designed and unlikely to make a difference anyway. The reviewers' opinion is that therefore there is an urgent need to design educational interventions that have the potential to improve end of life care in nursing homes.

A systematic review (2) of training for surgeons and anaesthetists in facilitating end of life conversations in acute settings shows that **training can probably improve skills**, and concludes there are significant gaps in end of life training provision for certain settings and professions. The objective of the review was to identify end of life communication training available to surgeons and anaesthesiologists, and to assess their methodological rigor to inform future curricular design and evaluation. It included 16 studies which were a mix of viewpoint pieces, and observational, qualitative, or case studies, but at best rated of moderate quality, and none were considered a good enough quality to be confident of the significance of the results. There was a lack of objective measures, no long-term evaluation and no patient outcome measures. Only one study sought views of patients/carers. Some objective measures around knowledge and communication skills showed that training/coaching can improve skills. There was pre-post survey evidence of improved confidence and (self-assessed) competence. Thus the strongest conclusions from this study are: on the current state of the literature and availability of evaluated training for surgeons and anaesthesiologists; that there are gaps in training in settings (studies found were mostly in Wards/ICU settings) including preoperative settings, and little for anaesthesiologists, and there is a heavy emphasis on role play.

A systematic review (4) of communication training for healthcare professionals in acute non-cancer settings, mostly of medical trainees, found that **training can improve confidence, attitude, self-efficacy and communication skills.** Ten studies were included ranging in date from 2006–2014, and were assessed to be of low-moderate quality. Most interventions involved medical students, but

three focused on nurses, and one was a mix of nurses, HCAs and consultants. Most studies were in the US, with one each in the UK, Australia and the Netherlands. The interventions were generally didactic, with role play/simulated patient interventions. Nine interventions were delivered in a healthcare setting, and one was a two-day retreat. All were face to face. Results - **there is evidence that training can improve confidence, attitude, self-efficacy, and communication skills in relation to patients at the end of life**. Most outcomes, however, were measured by self-assessment before and after questionnaires. One study measured communication skill using a coder, blind to the time point of data, to code videos of simulated patient encounters.

Summary

Overall, there is evidence, on balance of low quality, that **educational interventions to improve communication skills, knowledge, and attitudes towards end of life care amongst healthcare workers can improve self-efficacy, knowledge, and communication skills**. One review found **moderate quality evidence that this type of training intervention could improve patient** outcomes (in this case symptom control) and also reported that **educational interventions (on symptom management and coping skills) for informal caregivers and patients improved informal caregiver quality of life as well as patient symptom control.** Another review of lower quality studies found **neutral to some positive benefits to patients of training of healthcare workers.**

Other conclusions from the second three reviews above were that there is an urgent need to design educational interventions that have the potential to improve end of life care in nursing homes **(1)**, and that there are gaps in available training in preoperative settings and for anaesthesiologists. **(2)** Bakke et al. **(2)** observe that there is a heavy emphasis on (time consuming) role play in training approaches.

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