



Credit: Miriam Winsor

Best Practice in care coordination for palliative and end of life care services: information for commissioners

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1. Introduction and Background

This information resource is aligned to Ambition Four of [‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020’](#) and should be taken in the context of [NHS England’s Commissioning Toolkit for End of Life Care](#).

1.1 What do we mean by care coordination in end of life care services?

The terms ‘care coordination’, ‘care coordinator’ and ‘care navigator’ are often used interchangeably by those working in health and social care, making it confusing for people accessing/needing services, those involved in delivering services, and commissioners. For the purpose of this information resource, the three terms are defined below.

Our differentiator in talking about ‘care coordination’ is that we are talking about health and social care providers at a system wide level, and in talking about ‘care coordinators’ and ‘care navigators’ we are talking about professionals’ roles working within a defined provider system.

Care co-ordination refers to how health and social care systems coordinate people’s care. Palliative and end of life care services are provided by many different professional groups/staff from a variety of both statutory and voluntary sector organisations, often working together across sectors and across organisational boundaries, it is vitally important that care is well co-ordinated to support individuals to achieve their preferences and choices at the end of life as far as possible.

A Care co-ordinator is someone who has been identified to undertake a coordination role on behalf of the individual requiring support /family. They are usually a paid member of staff and have a practical ‘doing’ function.

A Care navigator is usually a non-registered carer or health professional and functions could be fulfilled by a well-informed/trained volunteer (including through Citizens Advice Bureau, libraries, etc.) or primary care administrative staff. The role provides a more supportive and signposting function.

As highlighted in the choice review, ‘care coordinator’ and ‘care navigator’ roles can be *‘invaluable in either navigating the health and care system on behalf of people or offering advice on services.’*¹

Top tip: [The General Medical Council define ‘end of life’ as people being likely to die within the next 12 months](#). For the purpose of this guide, and to enable care coordination systems to be effective, it is important to think more broadly about people approaching the end of their life as being in ‘the last years of life’.

¹ Department for Health (2015). *What’s Important to Me. A review of choice in end of life care*. London: DH. Available at: <https://www.gov.uk/government/publications/choice-in-end-of-life-care>

1.2 Care coordination systems review conducted by NCPC

Following on from a desktop review carried out by NHS England, The National Council for Palliative Care (NCPC) reviewed 66 palliative and end of life care co-ordination systems with the aim of identifying best practice systems for providing effective care coordination in this area of care.

The objective was then to develop helpful information for commissioners in designing and contracting optimal care coordination systems for their local areas.

1.3 Who is this guide for?

This information resource is for commissioners within local authorities, clinical commissioning groups (CCGs), hospices, and other voluntary sector organisations.

1.4 How will this guide help commissioners?

It provides a step-by-step practical approach to support commissioners to plan, design, commission and evaluate optimal end of life care coordination systems for their local areas.

1.5 'Commissioners cycle' info graphic

The diagram below shows the commissioning cycle in three main stages: **Strategic Planning**, **Procuring Services**, and **Monitoring and Evaluation** and identifies the different steps within each stage. This resource can be applied to end of life care coordination systems.



Courtesy of The NHS Information Centre for health and social care. Full diagram available at: www.ic.nhs.uk/commissioning

2. Making the case for change

2.1 Why is coordination of end of life care important?

End of life care affects everyone: it impacts on individuals, their families, children, carers and practitioners. With an increasingly ageing population and approximately a quarter of a million people dying each year in hospital², never has the need for improving end of life care been more important.

As outlined in the '[Government's National Commitment to End of Life Care](#)',³ and the '[Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020](#)'⁴, coordinating care around the individual is essential to good end of life care. The Ambitions Framework presents a vision for what this can mean for people and their families:

*'I get the right help at the right time from the right people. I have a team around me who knows my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.'*⁵

The benefits of well-coordinated care have been highlighted in other reports. [The King's Fund report](#) 'Co-ordinated care for people with complex chronic conditions' states that:

*'care co-ordination has the potential to improve collaboration within and between various parts of the health care enterprise; it can encourage patients to become more proactive in the management of their own care, and so enable the delivery of better quality services.'*⁶

Effective care coordination's cost effectiveness – Public Health England Economic Toolkit

In February 2017, Public Health England published guidance for commissioners on end-of-life care.⁷

The first half of the report provides a framework to better understand the health economics of end-of-life care. The second half of the report describes an economic tool which has been developed to help commissioners progress their strategy.

That document highlights two coordination systems which have been evaluated – including cost-effectiveness (see below).

² Public Health England – National End of Life Care Intelligence Network (2016-17) – available at: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

³ Department for Health (2016). *Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care*. Available at: <https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response>

⁴ National Palliative and End of Life Care Partnership (2015). *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. London: NHS England. Available at: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

⁵ Ibid

⁶ The King's Fund – Co-ordinated care for people with complex chronic conditions (2013) – available at: https://www.kingsfund.org.uk/sites/files/kf/field_publication_file/co-ordinated-care-for-people-with-complex-chronic-conditions-kingsfund-oct13.pdf

⁷ Public Health England – Cost effective commissioning of end of life care (2017) – available at: <http://www.yhpho.org.uk/default.aspx?RID=257011>

- (A) Sue Ryder. 2013. Partnership for Excellence in Palliative Support (PEPS). Evaluation of pilot. Sue Ryder Evaluation Series: Report No. 2. The evaluation highlights: ***'PEPS provides a 24 hours telephone point of access for palliative care services and a single point of contact for patients and their carer. 1,051 patients from NHS Bedfordshire were enrolled in the programme, of whom 620 patients have died. The emergency admissions prior to referral to PEPS were 256, however, after referral to PEPS were 178. Of the 256 admissions before referral to PEPS the average length of stay was 10.1 days compared to 6.9 days during PEPS. The average length of stay during the final four months of life was 8.8 days. The average cost per admission during the final four months of life was £3,359. This figure was higher before referral to PEPS (£3,388) compared to during PEPS (£3,075).'***
- (B) York Health Economic Consortium, 2016. Economic Evaluation of the Gold Line: Health Foundation Shared Purpose project, Airedale NHS Foundation Trust. The evaluation highlights: ***'The Gold Line started operating in November 2013 for Airedale, Wharfedale and Craven CCG and in April 2014 for Bradford CCGs, and is a single point of contact for patients and carers, allowing access to help and advice 24 hours a day, seven days a week. The authors compared the place of death and number of non-elective admissions before and after the implementation of the Gold Line and found a 23% reduction in admissions equivalent to a reduction of 390 bed days in a sample of 70 patients. They reported a slight decrease in hospital deaths falling from 36.8% to 35.3% and an increase in deaths in usual place of residence from 52.4% to 54.3%'***.

2.2 What can happen if people's care isn't well coordinated?

A recent CQC report identified that end of life care is often fragmented, and that individuals find having a number of different people involved in different aspects of their care is confusing. People often have to repeat information multiple times to different professionals and find that care provided by different staff and services is not consistent – this can lead to a loss of focus on the person and their wishes.⁸

The Ombudsman's report suggested that *'Failings in communication within and between clinical teams, and poor co-ordination of care, contribute to inadequate palliative and general care'*⁹ and additionally, uncoordinated care can also have a significant impact on carers, who may have to step in and attempt to coordinate health and care staff and services themselves.

3. Designing and planning services:

3.1 What would a good care coordination system look like?

As previously stated, the NCPC reviewed 66 end of life care co-ordination systems with the aim of identifying optimal systems for providing effective care coordination that will improve people's experience, choice and quality of care at the end of life. Each system was rated on whether it met the five building blocks within the fourth ambition in the [Ambitions framework](#) (for care to be effectively coordinated) and to what extent it had been evaluated.

⁸ The CQC – A different ending (2016) -

http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf

⁹ Parliamentary and Health Service Ombudsman. Dying without dignity. London: Parliamentary and Health Service Ombudsman (2015) – available at: https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf

The systems that scored highest all shared a number of core features:

- A care coordination system 'centre', with trained staff signposting and coordinating care for people across different services and sectors
- One single access telephone number to the system centre, accessible to professionals, individuals and carers (including 24/7 access to advice and support)
- Both non-clinical and clinical call-handling staff, with access to clinicians within the 'centre' if needed
- Non-clinical call handling guided by a script to support identification of clinical need - staff proactively calling back individuals to enquire on their well-being
- Integration with all other providers in the areas. For example, there will be evidence of joined up care with local acute services and discharge care
- Implemented EPaCCS and other digital tools to support coordination and record sharing of an individual's end of life care preferences. [EPaCCS guidance is available on the Ambition's Knowledge hub.](#)
- Consideration of the needs of 'hard to reach' groups and communities and how to build links with those communities
- Provides emotional support and interventions for individual's and their carers, where required
- Receives recurrent funding from a Clinical Commissioning Group.

Examples of good care coordination systems:

[Wandsworth End of Life Care Coordination Centre](#) (Winner of NCPC's Effective Coordination of Care Award 2017)

[North Manchester Macmillan Palliative Care Support Services](#) (Runner up of NCPC's Effective Coordination of Care Award 2017)

[My Care Co-ordination Team at Keech Hospice](#) (Runner up of NCPC's Effective Coordination of Care Award 2017)

[Midhurst Macmillan Community Specialist Palliative Care Service](#) – a community-based, consultant led, specialist palliative care service in a rural community in the south of England.

Case study – My Care Co-ordination Team at Keech Hospice

The Co-ordination team received a telephone call from a Doctor at the Local Hospital in the Emergency Department, an individual accessing palliative services had been brought into the hospital by his family on several occasions in two weeks. There had been no reason for the individual to be admitted so was sent home after assessment each time.

The doctor asked if the team could support the individual and family at home, the Co-ordination Team sent out a Palliative Care Support Worker to assess the situation at home. The family and individual were struggling with the Palliative Diagnosis and being able to look after the gentleman at home. They needed extra support within the home.

The Co-ordination Team helped organise a Care package, sent Palliative Care Support Workers in twice a day in the interim to give personal care. The wife and family were offered support through local carers groups which the family were unaware of. A referral was made to district nurses to assess for equipment to help with his mobility needs.

The individual has not attended the local Emergency Department since this support has been put in place. The family and individual now feel well supported and feel they have all the services they require to reduce the chances of hospital attendance.

3.2 Skills for care navigators / care coordinators

An integral element of any optimal care coordination system, will be the ‘care navigators’ or ‘care coordinators’ that support coordination of care on behalf of the person/family. It is important for all ‘care navigators’ and ‘care coordinators’ to be appropriately trained to enable them to undertake this role effectively. All ‘coordinators’ and ‘navigators’ should have:

- Excellent communication skills
- Excellent listening skills
- Empathy and understanding
- Some clinical knowledge
- Knowledge of the system

Top tips: useful resources to support workforce training:

[e-ELCA \(End of Life Care for All\)](#) - e-ELCA comprises over 150 sessions of interactive learning in bite-sized chunks of 20–30 minutes that are mapped to the competences required by staff.

[Health Education England - Core skills education and framework training](#) - developed in partnership Skills for Health and Skills for Care – the framework classifies key skills and knowledge for general end of life care needed to support an individual approaching the end of their life, and their family.

3.3 Defining your vision and needs analysis

When starting to plan and design your population’s optimum end of life care coordination system, it is important to remember that one-size does not fit all. Each system design should be tailored to the needs of their local population and on the existing long term conditions/end of life care service provisions in that area.

Top tip: Have you considered setting up a steering group to help you assess the needs of your local population? A steering group should be led by the relevant commissioners and involve people with lived experience, carers, health professionals (from health, social care and the voluntary sector), digital experts, training and development staff, and any other relevant stakeholders. These groups can help generate the knowledge and insight needed to effectively plan, design and deliver your locality’s optimal end of life care coordination system. Steering groups are essential in providing early integration, collaboration and co-production between all relevant stakeholders.

Useful resource: [Think Local Act Personal’s ‘Stronger partnerships for better outcomes’](#) report provides a protocol for local commissioning using a co-production and stakeholder engagement approach.

3.4 What are the needs of your local population?

Start by using all available data to build your local population profile. You will need to consider:

- Your local population? Collect demographic and epidemiological data on age, gender, ethnicity and deprivation
- Any identified groups of people that your care coordination system will support, for example, the frail and elderly and those with long-term conditions, dementia
- The present and future needs of your local population – what are the end of life care needs of your local population now? What do you expect your population’s needs to be like in 10 years? What resources do you have available to support those needs?

Questions you could consider:

- Where are local people dying, and where are they being cared for before they die?
- What local systems are already in place to ensure that people who may be approaching the end phase of their lives have been identified and plans about their care can be coordinated?
- What services are available locally “at any time of day and night” to enable people to be cared for in the place that they want to be?

Useful Resources to help:

- [NHS England’s commissioning toolkit for person centred end of life care](#)¹⁰
- [NHS London Strategic Clinical Networks Commissioner’s checklist for end of life care](#)¹¹
- [End of Life Care Profiles CCG level snapshots launched by Public Health England, October 2015.](#) The profiles provide data on deaths, place of death and deaths by place and cause in your local area¹²
- [NEoLCIN modelling tools provide a simulation of the likely end of life care needs for an average 200,000 population](#)¹³
- Health and Wellbeing Boards are required to produce a [Joint Strategic Needs Assessment](#) (JSNA) for the health and wellbeing of their community. JSNA’s provide a foundation for the production of a 'Joint Health and Wellbeing Strategy' for each locality.

3.5 What service provision is already available?

In considering the procurement of your care coordination system you should remember that you don’t need to start from scratch: you should build upon existing services and systems within your locality.

You might consider:

- Identifying existing services and coordination points such as those available for individuals with cancer, dementia, frailty and long-term conditions and plan how your end of life care coordination system will align and interface/integrate with these points - be careful to avoid duplication
- Creating a directory of services if one doesn’t already exist
- How your care coordination systems will integrate with any existing plans for end of life care as outlined in your region’s NHS transformation plans, including Sustainability Transformation Plans?

¹⁰ NHS England - Commissioning Person Centred End of Life Care (2016) – available at: <https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf>

¹¹ NHS London Strategic Clinical Networks – Commissioners’ checklist for end of life care (2016) – available at: <http://www.londonscn.nhs.uk/wp-content/uploads/2016/04/eolc-commissioners-checklist-042016.pdf>

¹² <http://fingertips.phe.org.uk/profile/end-of-life>

¹³ http://www.endoflifecare-intelligence.org.uk/end_of_life_care_models/

- Taking note of your locality digital technology plans, and how your coordination system will incorporate them. How many care coordinator posts already exist and what appropriate training is already available to staff to increase knowledge about end of life care.
- Thinking about how the voluntary and community sector will link into and add value your care coordination systems and focus on your community assets which can enhance and support individuals

4. Benefits and outcomes of good care coordination systems

Now that you have built your vision, the next stage is to plan and specify the outcomes and benefits that your locality's care coordination system will achieve for both the individuals requiring support and the health and social care system. This will need to be in terms of outcomes achieved by the system, the quality of care and system performance. Commissioners will recognise that integral to the business case is the need to specify that improved outcomes will not be realised immediately, and are more likely to be achieved over time e.g. in 2 to 3 years.

The list below represents some of the expected outcomes and performance measures that commissioners may wish to consider.

4.1 Improved health and well-being for both people accessing services and those providing end of life care – as highlighted in section 1, good care coordination of end of life care services means that people get the right help, at the right time, from the right people and therefore generally have a better experience of end of life care. For staff, it means more time spent focusing on the needs of the individual, less time and resource trying to navigate an individual through an uncoordinated service and potentially, less stress.

Measures: (a) Complaints recorded (in all settings) and general feedback of experience of care. A good tool that can be used for measuring individual's well-being is the [Edinburgh Warwick Well-being Scale](#). (b) Staff well-being should be measured by staff feedback/surveys on quality of care, confidence with provision of end of life care and stress levels.

4.2 People who are approaching the end of life are identified at the earliest opportunity and offered an opportunity for a holistic needs assessment. Sometimes conversations about end of life care only begin in the last few days of the individual's life, with 25% of GPs having never initiated a conversation.¹⁴ By engaging earlier with people with [dementia](#), cancer and other life limiting conditions about their future wishes and preferences for end of life care, plans can be made and care can be effectively coordinated and regularly reviewed.

Measures: (a) Consider the use of prognostic indicators to support early identification, for example, the [Gold Standard Framework Proactive Identification Guidance \(PIG\)](#) or the [Supportive and Palliative Care Indicators Tool \(SPICT\)](#) – these tools are only effective if used correctly (appropriate training should be provided before introducing these tools).

4.3 Individual person centred care plans have been recorded and care tailored to meet individual needs - having earlier conversations with people helps them navigate to the right care whether it be clinical care, shared decision making, [Advance Care Planning](#) (ACP)

¹⁴ National Council for Palliative Care Dying Matters Survey, undertaken by ComRes in April 2014. A summary of the survey findings is available online from: <http://comres.co.uk/polls/dying-matters-deathand-dying-survey-3/>

and holistic care. Assisting people to request [Personal Health Budgets](#) (PHB) and Continuing Healthcare (CHC) across both health and social care, can help this process – the role of personal assistants is then vital in supporting people accessing these types of care.

Measures: (a) The percentage of people supported on an end of life care register with a completed and up to date care plan. Within each setting, the number of: (b) care plans offered, care plans created, care plans regularly reviewed and updated, (c) fast track requests made for continuing health care, (d) individuals on an Electronic Palliative Care Coordination System (EPaCCS) (e.g. [Coordinate My Care](#) or Health Analytics).

Useful resources: [NHS Choices online resource for obtaining information about Continuing Healthcare](#) or [Marie Curie’s online resource about how to apply for Continuing Healthcare](#)

4.4 Reduced unwanted hospital admissions and people being empowered to discuss and arrange for their preferred place of death – better coordinated care means it is more likely that people will be able to die where they choose. This means continuing to improve community services to enable more home deaths and reducing unwanted hospitalisation and out-of-hours crises. Commissioners should collect appropriate data to enable system performance outcomes to be measured.

Measures: (a) The number of people dying in preferred place of death, (b) the number of deaths in hospital, (c) the number of deaths at home and the number of deaths in hospices.

4.5 Workforce trained and equipped to care – an effective care coordination system will require staff to be trained appropriately across both health and social care. There will be regular training and support for both clinical and non-clinical staff on, for example, how to discuss care planning and use of EPaCCS (see section 3.2 for useful resources for workforce training).

Measures: (a) Percentage of staff trained on call-handling at a care coordination ‘centre’, (b) Percentage of staff trained on using an EPaCCS system

4.6 Family and carers supported – families and carers will be identified and proactively supported before the death of a loved one, and after the bereavement.

Measures: (a) Use bereaved relatives’ surveys (including, but not only the [National Survey of Bereaved People \(VOICES\)](#)), (b) Availability of services for bereaved carers (c) the number of assessments offered/completed and the proportion of bereaved people who felt the care had been coordinated.

4.7 Equity and equality of access – for care coordination systems to meet the needs of the local population, it is vital that they reach out to all areas of the population – this means caring equally for all people with varying diagnoses. Presently, having a cancer diagnosis is the primary determinant of access to specialist palliative care despite there being comparable symptom burden in all types of advanced illness.¹⁵ Good coordinated care means that all diagnoses receive equal access to services.

¹⁵ London School of Economics and Political Science – Equity in the Provision of Palliative Care in the UK: Review of Evidence (2015) – available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

Measures: (a) Number of individuals who are supported by the end of life care register with a non-cancer diagnosis.

4.8 Individuals have timely access to required equipment and hospital discharges are not delayed by equipment requests – often people are left waiting for vital equipment to arrive. Your care coordination system should control, manage and ease this process (weekends and bank holidays should not cause additional delays).

Measures: (a) Time of response of equipment to request (differentiated by weekdays and weekends), (b) The availability of requested equipment and the number of delayed transfers of care due to lack of equipment.

Top Tip: read the [King's Fund's paper 'End of life care'](#) for more examples of the benefits of good care coordination and integration.

5. Monitoring and evaluation

Once your end of life care coordination system is live, you will need to monitor and evaluate its impact to enable you to continuously improve the system. You might consider utilising your stakeholder group to support this process.

Start by collecting data and measuring the performance and outcomes identified in section 4:

- Has it reduced inappropriate/unplanned hospital admissions?
- Has it improved health and well-being of both staff and people accessing services?
- Are people having earlier conversations about their future wishes and preferences for care?
- Be alert to change in local population needs and speak to the people being directed by coordination systems as much as possible - is their care working for them regardless of who they are?

Have you been in contact with other care coordination systems to help identify optimal end of life care coordination best practice and outcomes achieved?

Have you considered ['Walking the journey experience'](#) to see how the system is operating from an individual's perspective, including weekends and bank holidays?

6. How can NCPC help?

We want to hear from you. Please get in touch if you require further information or support in setting up your locality's care coordination system. Contact via enquiries@ncpc.org.uk or Hospice House, 34-44 Britannia Street, London, WC1X 9JG.

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