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SMALL STEPS, BIG VISION

This is your Grab-and-Go Guide for the Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 [↗](#)

The framework provides a vision and guidance around six ambitions and eight foundations to improve care. Launched in 2015, it is supported by [over 30 partners](#) and embedded in the [statutory guidance for ICBs](#) linked to the Health and Social Care Act 2022. Based on in-depth research conducted at The Open University, this guide focuses on the foundations necessary for realising the vision.

This version of the Grab-and-Go guide has been adapted to support children and young adults (CYA). It provides: a description, a space for your own prompts, and examples in action. You can use this guide for your own reflection, to facilitate team discussions, or in work with partners and across systems. We have added two areas to focus on (9&10) to promote collaborative and cross-sector working. This guide helps you to identify areas you can act on – a starting block to turn small steps into the big vision.

1. Personalised care planning

➤ **What:** Conversations/planning between the CYA, family, those close to them and professionals that explore and document the management of CYA health and care needs, considering the context of their life, identity and background, as well as family situation. It can include advance care planning and recording of preferences.

➤ **Ask:** What types of care planning are we already doing? What might improve the quality of the conversations/planning? How could we involve more people in care planning? How equitable and effective is care planning across our system? Do we consider education and employment in here?

➤ **Example in action:**

Advocating for CYA opting into surgical procedure to improve quality of life. Collaborative working with specialist teams at End of Life to support CYA dying in hospice during respite stay instead of transferring home.

2. Shared records

➤ **What:** Those who are caring for and supporting the C/YA can access records, such as care plans. It can include electronic systems to facilitate sharing across health and social care providers. It can refer to records created and shared by the person and those important to them.

➤ **Ask:** What information needs to be shared? How do we currently share information? What barriers do we currently have in accessing information within or across organisations e.g. different systems? Does the CYP, or those important to them, have access to the records in a version that they understand? Think about how to get the information when you do not have access too? What needs to be put in place to enable access?

➤ **Example in action:**

Advanced Clinical Practitioners reconciliation of medication process to ensure safe prescribing and administration of medications during stay, from multidisciplinary team using SystemOne.

3. Evidence and information

- **What:** The collection of data that can be used locally and nationally to understand service provision and evaluate interventions. It can include using and being involved in research.
- **Ask:** What routine data is being collected and how do we use it? Where are we currently using evidence to inform our actions? How do we collect feedback? Are we collating and listening to a wide range of voices through feedback? Do I know how to make sense of the information?

➤ **Example in action:**

Monthly feedback requested following stays, Feedback box, Staff & CYA Suggestion Box, 6 monthly and annual reviews, feedback collated in central hospice location, Adverse Events, Finding Lost Voices Research.

4. Involving, supporting and caring for those important to the dying person

- **What:** Focusing on those around the dying CYA, such as family, friends and carers. It includes supporting them in their caring role, pre-bereavement and bereavement care. It involves understanding peoples' social context, cultural background and support networks, and how they want to be treated and respected.
- **Ask:** Have we mapped who is important to the (dying or bereaved) CYP and what resources/capacities they have to provide care or support? Does our language reflect how those important to the dying CYA, including acknowledging their relationship? How do we find out what is important to the CYP /family, be that practical or location? How are we working in partnership with those important to the dying CYA, carer and/or bereaved person/family? How do we support those who will be bereaved.

➤ **Example in action:**

Working alongside Childrens Holistic Integrated Palliative Care Service (CHIPS) to ensure CYA die in appropriate environment suited to their families wishes, supporting symptom management plans, working closely with specialist teams involved in care, DNACPR discussions, bereavement referral as standard 6 weeks post. Sibling support days. Memory day and tree.

5. Education and training

- **What:** Education of staff and/or volunteers, ensuring they are competent in their knowledge about good end of life care and that this is maintained. It includes focusing on skills sets and quality assurance of training.
- **Ask:** What do people already know about end of life care? Are we making good use of existing educational resources? How can we invest in and embed training across our system? How do we keep staff up to date with their continual professional development?

➤ **Example in action:**

Structured induction with competencies outlined, Individual basis - Self Assessment document to ascertain where skills lie and where there are opportunities for development self-directed study, regular bereavement webinars shared with the team.

6. 24/7 access

➤ **What:** System-wide access to CYP end of life care support, including symptom management, at all hours and days of the week. This does not mean that each service must always be available, but that there is accessible and equitable coverage across a system/area to meet needs.

➤ **Ask:** Where would we direct someone out-of-hours? Who might need access to services out-of-hours and why? Are existing out-of-hour services accessible for all groups of CYA? Is there a clear point of contact?

➤ Example in action:

Clear documentation of communication plan, lead on each referral clarified and symptom management plans in place. One point of contact for families. Work closely with specialist link teams and CHIPS team. Advanced Clinical Practitioners.

7. Co-design

➤ **What:** Designing services in collaboration with CYA and their families including siblings who have personal and professional experience of palliative and end of life care. Methods of engagement can be creative, participatory, and experience based. Co-design should embrace diverse views and not be limited to service provision commissioning decisions.

➤ **Ask:** What knowledge do I have about co-design? Who are we involving (individuals and organisations)? How do CYA/families want to be engaged with? Who is best placed to facilitate co-design processes? In what ways do we actively involve CYA/families in designing a service and making decisions about how we provide care? How are we learning from CYA/families lived experiences, their support needs, and what care and support they access and want to access?

➤ Example in action:

CYA involved in build design process, CYA involved in staff recruitment in interviewing and questions.

8. Leadership

➤ **What:** People and organisations who have the capacity and remit to identify what needs to happen, communicate visions, and motivate others to realise the Ambitions. Leadership is not limited to those with formal positions of authority.

➤ **Ask:** Who am I expecting to take this forward? In what ways can I instigate change? How can I support others to realise the Ambitions? What strategic leadership is needed for system-level changes?

➤ Example in action:

Strategy group with a clear structure of interlinking groups e.g. management forum, and future group which enabled involvement in strategy development and implementation at all levels of the organisation.

9. Collaboration and partnership working

- **What:** Working with others (within and beyond your organisation) on a common goal. Partnership may involve sharing resources and responsibilities.
- **Ask:** Who do we need to be working with? How knowledgeable are our potential partners with the Ambitions or end of life care? Have we discussed our expectations about roles and responsibilities? What barriers do we have to working together?

➤ Example in action:

Working closely with each local authority's Pathway Coordinator to ensure appropriate referrals are dealt with efficiently and effectively and pertinent information is shared.

10. Sharing learning

- **What:** The process of exchanging information and insights with others with the intention of achieving a common objective or goal over time. It can involve acquiring new knowledge and skills as well as becoming part of a community.
- **Ask:** Where can I find out about what others are doing? How can I tell others about what my organisation does and lessons learned? In what ways do I reflect on what others have done and try it out in my own practice? Am I open to learning from people with different experiences, perspectives, and roles (including from non-professionals)? What is needed to facilitate more intentional learning in the environments I am part of?

➤ Example in action:

Bi-annual study days arranged to include professionals from all over the country to share their knowledge and experience. We work closely with local NHS Trusts, Community services, and Hospices across the North East.

Interested in knowing more about these examples? The contact is:

This guide has been adapted by St Oswald's Hospice using the guide developed by Dr Erica Borgstrom, Claire Henry MBE, Dr Joanne Jordan and Dr Una St-Ledger of [Open Thanatology](#) at The Open University. Marie Curie funded the research the original guide is based on. For more information project findings and outputs, visit: <https://tinyurl.com/ambitionsframework>. For more resources about the Ambitions, check [FutureNHS](#). This guide does not replace statutory or [NICE guidelines](#).

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