

End of life care planning with people who have a personal health budget

Discussion paper September 2010

Produced by the Department of Health's personal health budgets pilot programme and the NHS National End of Life Care programme



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1. Introduction

The Department of Health's personal health budget pilot programme team commissioned this discussion paper, which builds on the earlier discussion paper *Key elements of personalised care planning in long term conditions and personal health budgets*¹. The paper was planned and delivered in partnership with the NHS National End of Life Care programme team.

In June 2010, a group of people came together to discuss the issues described in this paper². This group included people who use services, family members, people from the personal health budgets pilot sites, hospices, key partners from the health, social care and voluntary sectors and the Department of Health.

The group explored the current context of practices and policies that impact on end of life. They heard about existing good practice and identified key issues that need to be explored in end of life care planning with people who have a personal health budget. The term support plan is also used in some areas to describe a care plan, and for the purposes of this document the terms will be used interchangeably.

This is not a DH policy document or a prescriptive guide to end of life care planning with people who have a personal health budget, but it is intended to offer a summary of the learning described and developed on the day with the aim to provide a useful framework to pilot sites.

¹ Department of Health, *Key elements of personalised care planning in long term conditions and personal health budgets*, 2010

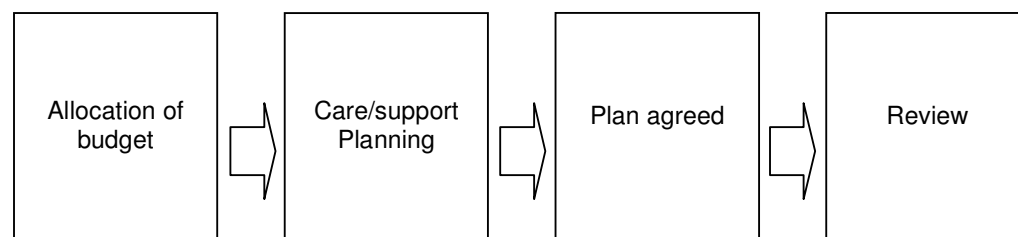
² Jo Harvey and Helen Sanderson of Helen Sanderson Associates facilitated the day.

2. Background

Personal health budgets can be seen as part of a wider drive to personalise public services, which dates back to the 1970s and the campaign by disability groups for people to be allowed to control their own funding. A pilot involving around half the Primary Care Trusts (PCTs) in England is currently underway, testing out personal health budgets in the NHS. Twenty of these pilot sites have been selected for an in-depth study as part of a wider evaluation exploring the potential of personal health budgets to benefit different groups of people.

The key characteristics of a personal budget are:

- a clear, upfront allocation of resources
- encouraging and helping the person, with the people who know them best, to plan their care and support in a way that suits their individual circumstances
- the provision of more choice by a person as to how the budget is managed
- greater flexibility over how money can be spent.



This paper will focus on the care planning path of the personal health budgets process. It does not address other important issues such as funding or commissioning; further discussion papers will be produced over the course of the pilot as learning develops.

At the heart of a personal health budget is a care plan, which is the agreement between the PCT and the individual that sets out the person's health needs, the amount of money available to meet those needs and how this money will be spent. This paper recognises that there are many contributions to good care planning with a person at the end of their life. It also draws on the work of the National End of Life Care programme, support planning techniques and person-centred approaches, specifically:

- the End of Life Care pathway
- holistic common assessment
- advance care planning
- person-centred thinking tools
- an approach that has been developed in the personal health budgets pilot sites.

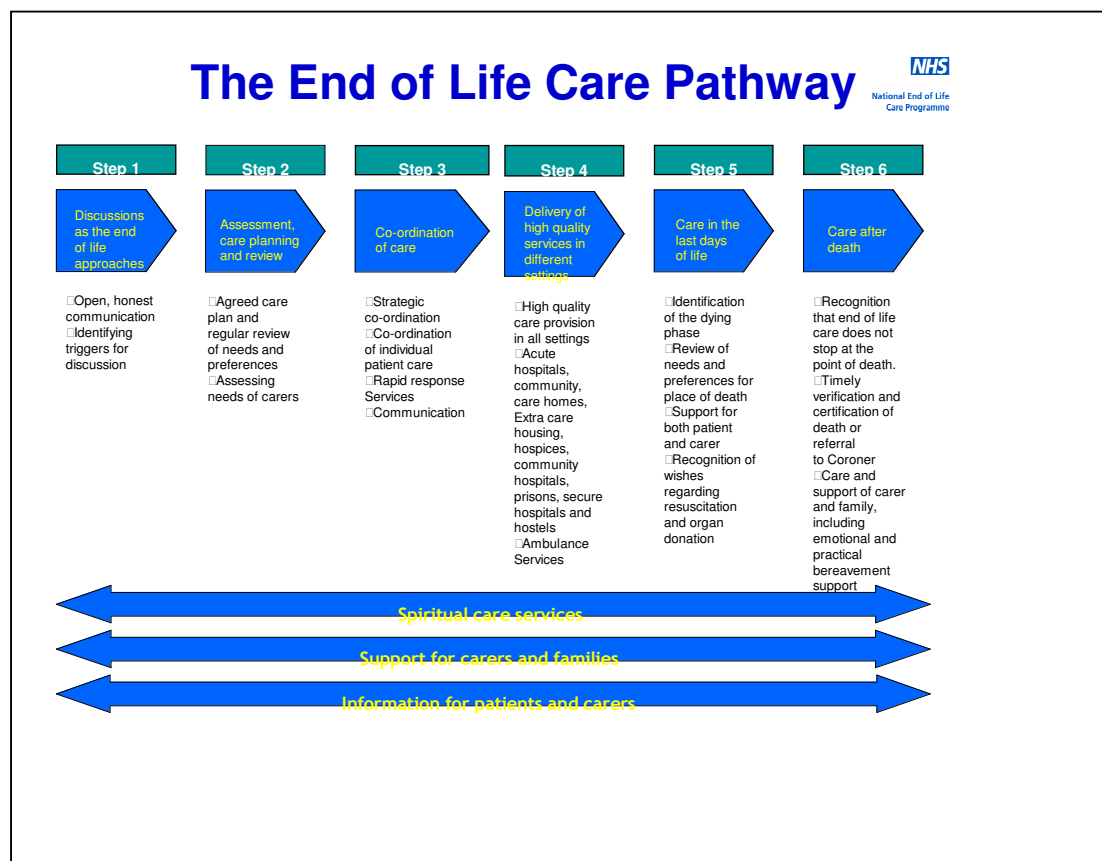
The aim is to identify the key elements of good practice that support personalised care/support planning from all of the approaches and any additional elements that may be required for a personal health budget.

This work has become even more relevant in light of the recent publication of the NHS White Paper *Equity and excellence: Liberating the NHS*³, which sets out the Government's long-term vision for the future of the NHS. Patients will be “put at the heart of everything we do” so they will have more choice and control and be in charge of making decisions about their care. Shared decision-making will become the norm, while the Secretary of State for Health has set out proposals on how patients, locally elected councillors, local authorities, public health experts and others will work side by side with GP consortia to make health services meet the needs of people in local areas and improve health outcomes.

2.1 The End of Life Care pathway

A suggested working definition for end of life care is “... care that helps all those with advance, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support”⁴.

One way to think of end of life is through a pathway, which is shown here and at the end of this document.



³ Department of Health, *Equity and excellence: Liberating the NHS*, 2010

⁴ Department of Health, *National End of Life Care Strategy*, 2008

There is no simple way to define the start of the End of Life Care pathway. Some people may be receiving palliative care. The World Health Organisation definition of palliative care describes it as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. This is done through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. A person suffering long term conditions will be under continual review for deterioration of their condition. Other people may be identified as approaching end of life through the 'triggers' for discussion. For example, professionals could ask themselves the 'surprise' question:

*"Would I be surprised if this patient died in the next six months?"*⁵

If the answer is no, then this would suggest that opening a discussion about the end of life care and the person's wishes and preferences may be appropriate (Step 1 of the pathway).

2.2 Holistic common assessment

The Department of Health's National End of Life Care strategy stresses the importance of a person having a holistic assessment of their end of life care needs. Assessment is seen as a continual process, often beginning at Step 2 of the pathway. A holistic common assessment should include the person's physical, psychological, social, cultural, environmental, spiritual and financial needs in the last phase of their life.

2.3 Advance care planning

Advance care planning⁶ is a process of discussion between an individual and their care providers, irrespective of the profession or discipline. This can take place at any time, but may occur as a result of a care planning assessment. It starts at steps 1 and 2 of the End of Life Care pathway, but is continually reviewed all the way through the other steps.

The difference between advance care planning (ACP) and general planning is that the purpose of ACP is to make clear the person's preferences and wishes in the context of their condition deteriorating and the likely loss of their capacity to make decisions or communicate their wishes to others. It is advised that the results of ACP discussions are documented and regularly reviewed, and with the person's permission, are communicated to everyone who may be involved their care.

"Advance care planning has been defined as a process of discussion between an individual, their care providers and often those close to them, about future care. The discussion may lead to:

- *an advance statement (a statement of wishes and preferences).*
- *an advance decision to refuse treatment (ADRT –a specific refusal of treatment(s) in a predefined potential future situation.)*
- *the appointment of a personal welfare Lasting Power of Attorney (LPA).*

⁵ Lynn J, Schuster JL, Kabcenell A. *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*, New York: Oxford Univ Pr, 2000.

⁶ Royal College of Physicians, *Advance Care Planning National Guideline*, 2009

*All or any of these can help inform care providers should the individual lose capacity. These terms supersede previous phrases such as 'living wills' and 'advance directives'.*⁷

Preferred Priorities for Care⁸ is the national validated tool for advance care planning.

2.4 Person-centred planning, thinking and end of life care

*Putting People First*⁹ expects that person-centred planning is embedded across adult social care.

Person-centred planning is a way of discovering what people want, the support they need and how they can get it. It is evidence-based practice that assists people in leading an independent and inclusive life; it's both an empowering philosophy and a set of tools for change at an individual, a team and an organisation level. It shifts power from professionals to people who use services.

The guidance *Delivering personalisation through person-centred [l]anning*¹⁰ states that:

"The foundation for person-centred planning is a range of simple, practical person-centred thinking skills and tools. When person-centred planning is combined with an upfront allocation of money (a personal budget), it is called support planning. Together, person-centred planning and support planning are practical ways to deliver personalised services and self directed support."

One example of a person-centred tool which can support someone approaching end of life is *Living well before you die, and planning for the end of your life*¹¹ - an approach that has been developed in conjunction with Lancashire County Council and NHS Hull (a personal health budgets pilot site). It includes information on how a person wants to be remembered after death. Other materials include Dying Matters¹² – a website with information that aims to help start conversations around death and dying.

⁷ Royal College of Physicians, *Advance Care Planning National Guideline*, 2009

⁸ Lancashire & South Cumbria Cancer Network, *Preferred Priorities for Care*, 2004
www.endoflifecare.nhs.uk

⁹ Department of Health, *Putting People First: a shared commitment to the Transformation of Adult Social Care*, 2007

¹⁰ Department of Health, *Delivering Personalisation through Person-centred Planning*, 2010

¹¹ Sanderson H., *Living well before you die, and planning for the end of your life (draft 1)*, 2010

¹² Dying Matters www.dyingmatters.org.uk

Below is a brief description of how some of the person-centred thinking tools can be used in end of life care. Appendix 1 shows a real example of how these and other tools have been used to help improve Edna's quality of life and care in the last phase of her life.

Tool	What it does	How this tool helps in end of life care
Relationship circle	Identifies who is important to the person.	Knowing who the important people are – that you might want to see, visit or reconnect. Helps the person think about who they want to play what role at the end of their life. For example, who they may want to be with them at the very end, or who they want to contribute to their funeral.
Sorting important to/for	Sorts what's important TO a person (what makes us happy, content, fulfilled) from what's important FOR a person (health and safety, being valued) while working towards a good balance.	Helps us to stay focused on what matters to the person in the context of medical issues and interventions. Keeps the focus on who the person is, not just the medical care that they need. It helps to see the person beyond the patient.
Sorting what's working/ not working	Analyses an issue/ situation across different perspectives. Provides a picture of how things are right now, or can be used to reflect on the past or plan for the future.	Helps a person to clarify what they want and what they don't want now, and to use this as a basis for action planning. Using this tool from different perspectives is a way to ensure that family and carers views are heard and can be discussed. Can also be used to reflect on the past, for example something that has worked for the person in the past that they would like to do again. Also useful for planning for the future – what a person both wants and does not want at the end of their life, and a way to get the family's perspective on this.

A list of other person-centred thinking tools and how they are used in end of life care can be found in Appendix 2.

3. Key elements of good planning at end of life

The following information builds on the work done as part of the Long Term Conditions group¹³ and was further developed at the end of life care event in June 2010. This information builds on the good practice in planning and end of life care that has been described in this discussion paper.

This is not a prescriptive or exhaustive list but a broad framework of what we see as the essential components of any personalised care planning conversation discussion or consultation.

The following key elements have been developed:

- timely and relevant information available beforehand
- knowing who is involved
- clear goals and outcomes
- identification of services to be bought or commissioned that can meet the need
- contingency and change planning and risk management
- how and when the plan will be reviewed
- planning for step 6 – after death.

In addition, for personal health budgets the care plan should record:

- How the budget is going to be spent
- How the budget is going to be managed.

3.1 Timely and relevant information available beforehand

There are a range of triggers that result in a person starting to think about planning for the end of their life and they may look to websites like NHS Choices to find out more information¹⁴. These triggers may include the ill health or death of a spouse, moving into a care home, family history or a review of the patient and their care. Triggers may be provided by the person themselves, consultant or professional. As stated earlier, one such trigger is for professionals to ask themselves “*Would I be surprised if my patient died in the next 6 – 12 months?*”

There are a wide range of possible triggers and disease specific clinical triggers as specified by the national Gold Standards Framework prognostic indicators¹⁵.

To be fully involved and engaged in care planning at end of life, the person needs to have information about their condition, about personal health budgets, the care planning process and the options available to them. This should include clear information on anything that their budget cannot be spent on. Stories and examples from other patients can be very helpful in understanding what is possible in buying and using support and services at the end of life.

¹³ Department of Health, *Personalised Care Planning with People Who Have Long Term Conditions*, 2009

¹⁴ NHS Choices Live Well <http://www.nhs.uk/Livewell/Endoflifecare/Pages/Endoflifecarehome.aspx>

¹⁵ NHS Gold Standards Framework <http://www.goldstandardsframework.nhs.uk/>

Learning from support planning in social care and person-centred thinking with a person at the end of their life has shown that presenting them with information in a form and manner that makes the most sense to them is crucial if they are to fully engage in decision making within the planning process. There are some person-centred tools that can support this. For example, Decision Making Profiles ask the person how they like information presented to them, how they can be supported to understand that information and the best and worst times to ask them to make decisions.

3.2 Knowing who is involved

The person clearly needs to be at the centre of their planning process and choose who else to involve. This could include carers, family and friends as well as the relevant professionals. The group created a long list of other individuals or organisations a person may also choose to involve in their care plan at end of life. This included people from faith communities and spiritual advisors, therapists, people from buddy groups or support networks and possibly funeral directors.

Ideally, there would be one person who co-ordinates the person's journey along the end of life care pathway. One group suggested that there should be a 'conductor' appointed, for example, a community matron, or a care coordinator or key worker. Another group stressed the importance of the support a person may need to manage their finances around a personal budget and the possible role of a financial manager.

3.3 Clear outcomes/goals and how people will achieve these

Once a person has the information they need and have decided who they want to involve, the next step is to have conversations and make decisions about what the person wants to happen as they near the end of their life. It is vital that all other plans and care plans dovetail into one document, rather than having several care plans being used by different professionals. This is particularly important if the person is also in receipt of a personal budget and support plan, via social care. Without careful coordination of plans and funding streams there is a risk of duplication in interventions and care provision. The information should be accessible to all professionals and all who are dealing with the person's care with consent of the individual.

Any planning conversation needs to address what is important to and for a person, and what is working and not working for them, as well as what they hope to achieve or how they want to be supported. This may cover how to live well before death, maintain dignity and respect, manage symptoms and pain and include family and friends. It should be acknowledged that a person's outcomes and choices may change as their condition and journey progresses.

Learning from support planning and the use of person-centred thinking provides some useful questions or areas to consider:

- who is important in my life and what role might I ask them to play at the end of my life? Who do I want to say goodbye to, and how?
- what does/will a good day and a bad day look like for me? How can I have more good days towards the end of my life?
- what is working and not working in my life and what do I want to change?
- 'if I could, I would...' what would I still like to do or experience or achieve?
- what do I want and do not want in the future around my treatment and care?

- what is my history...my important memories and how would I like to be remembered?
- what decisions need to be made and how must I be involved?

Appendix 2 has examples of different person-centred thinking tools that can be used to help a person answer these questions.

These conversations can be used to support holistic care planning and advance care planning, and lead to identifying clear outcomes and how the person wants to use their personal health budget to achieve them. There should be a clear link between the developments of specific outcomes to the assessed needs of the person. The care plan must set out how the services to be bought should achieve these outcomes.

Being truly person-centred is about recognising a person within the full context of their lives and how they live them, and not just focusing on their health condition and the end of their life. Outcomes will need to be based on what is important to a person within these contexts and specifically relate to them as individuals.

At this stage of the process/conversation, the person and the healthcare practitioner should agree a set of action points, deciding who will be responsible for achieving each of the actions and deciding how and when the actions will be reviewed. Actions are more likely to be undertaken if they are detailed, specific and set out within a given timescale. All plans should be regularly reviewed – both in general conversations and in pre-arranged review meetings. Healthcare professionals should be proactive in arranging these review sessions.

3.4 Services to be bought or commissioned

A key part of the end of life care planning conversation is providing the person with the opportunity to explore solutions and options to meet their agreed outcomes. Consideration should be given to the impact it will have on the family. People need to have information about the local options available, what they cost and how they can buy these services or have them commissioned on their behalf. Of course, a person can spend their money on more than just existing services, and can think - and be supported to think - creatively about different ways that they can use their budget to achieve their outcomes. It is also important to note that many of the services for people at the end of life are free of charge, for example, the health and social services provided by a hospice.

One of the critical success factors for personal health budgets will be achieving an optimum level of flexibility and room for innovation and creativity to unlock better solutions for individuals than the current system provides. Therefore the care planning process at end of life must provide opportunities to discuss these creative solutions. The care plan then needs to record the services the person will be using.

It is expected that staff dealing with personal health budgets in the context of end of life care should have training in how to deal with conversations around end of life issues. They will need to be able to open up conversations about what matters to people and deal sensitively with the response. They also need training in where to access information, for example, about how to make a will.

3.5 Contingency or change planning and risk management

The end of life care plan must include plans for contingencies, as the person's needs increase. One approach to this is to describe in the plan what the triggers would be for the plan to be reviewed. It should also be noted that there may not always be predictable triggers, so flexibility remains important. The contingencies could include both changes to the person's health and changes to the person's capacity to make decisions. Changes in capacity for decision making would need to be assessed in the light of the Mental Capacity Act.

There will also need to be a discussion about the management of risk within the care planning process and exploration of whom or what this risk might be to. For example, are there separate risks for the individual's well-being, resources being used appropriately or an impact on other people, such as the person's carer? Being overly risk averse can prevent a person from achieving their goals. Creative and innovative solutions should be considered and discussed, for example, the use of assistive technology to support independence.

Any discussion about risk should be realistic and aimed at enabling the person to make the decisions that are right for them and their family. This may require balancing potential risks and consequences with the benefits associated with any particular decision. There is a delicate balance between empowerment and safeguarding, choice and risk.

3.6 Planning for after death

One of the significant differences between care planning with a person, and planning where they are facing the end of their life, is step 6 on the end of life care pathway: care after death.

A care plan can include what a person wants to happen in relation to purchases, equipment and services bought through the personal health budget. Carers in the group talked about the importance of sensitive communications around returning equipment and how distressing this is when not handled well. A system needs to be in place for the completion of services and how the organization, services and key people involved will be notified.

3.7 How often and who will review the plan?

Reviews with people at the end of their life care will need to happen more frequently (compared to other patient groups) with a clear process to trigger reviews. One possibility, as indicated earlier, is that when the plan is agreed, decisions are made about when and how a review could be called. This could include:

- who the person would contact to get an urgent review
- who else may need to be involved in the review, such as social care or care providers
- who the family, carer or professionals would contact
- what level of change in the person's condition or capacity, of if the plan was not meeting the person's needs, would automatically suggest that a review was needed, and who would make that judgment.

The review would need to consider what is working and not working from the person, carer and professionals perspectives, and in the context of the outcomes that the person wants to achieve (as described in their care plan). Reviewing should therefore be flexible, proportionate and focused on reviewing outcomes. It will need to take into account various factors including lasting powers of attorney and anticipatory prescription of 'just in case' drugs.

4. Additional elements required for personal health budgets

There will be some additional elements required for a person receiving a personal health budget at the end of their life.

4.1 How the budget is going to be spent

Pilot sites will need to explore how they set the budget and be able to offer the person an indication of the resources available before they begin the care planning process. It is essential that in setting the indicative budget, that the costs of charitably provided services are also factored in. It should not simply be a budget based on statutory service expenditure.

The care plan for end of life care will also need to have a clear record of how the personal health budget is going to be spent. This should include:

- the amount of the personal health budget
- clear costs for support either through employing personal assistants or services or through organisations or agencies
- if a person employs their own personal assistants, the costs related to insurance, training and expenses
- one off purchases for equipment, tele-healthcare or technology
- contingency costs.

Information about what money can be spent on should be very clear. Any required accounting or reporting systems should be easy to fill in and there should be a named contact if a person is concerned or confused about how the budgets work or financial management generally. Help should also be provided for filling in any forms.

4.2 How the budget is going to be managed

As part of the care planning process, the practitioner will have to discuss with the person how they wish their allocated personal health budget to be managed. These are the options proposed for managing personal health budgets that are being tested through the pilots (either singularly or in a combination):

Notional budget – This is where an individual understands the amount of funding available to them and decides how the budget is used. The PCT still commissions services, manages contracts etc. Notional budgets could be an option for individuals who want more choice and control over their healthcare but who do not feel able or willing to manage a budget.

Real budget managed by a third party – This is where the individual knows how much funding is available to them but a third party holds the funding. This maybe a budget-holding lead professional, a GP practice, a provider organisation, an NHS Trust or an organisation like a community interest company.

Direct healthcare payment – This is where the individual receives the funding that is available to them as a direct payment for them to manage themselves. This is only available to authorised pilot sites. More information on specific requirements around direct payments is available in the document *Direct payments for health care: information for pilot sites*¹⁶.

We expect people to use personal health budgets to purchase a range of services; from traditionally commissioned services to more personalised and individualised options. Different options will give people different levels of choice and control.

¹⁶ Department of Health, *Direct payments for health care: information for pilot sites*, 2010

5. Further information

Further information can be found on these websites.

www.dh.gov.uk and www.dh.gov.uk/personalhealthbudgets

For all the Department of Health documents referenced in this discussion paper, and other early learning from pilot sites.

www.endoflifecareforadults.nhs.uk

“Holistic common assessment of adults requiring end of life care”

“Advance care planning – A guide for health and social care staff”

“Advance decision to refuse treatment – A guide for health and social care professionals”

“Planning for your future care – A guide for patients” (currently being revised)

“Practical guidance for best interests: decision making and care planning at end of lif”

www.rcplondon.ac.uk

“Concise guidance to good practice – advance care planning”

www.gmc-uk.org/guidance/ethical_guidance/6858.asp

“Treatment and care towards the end of life: good practice in decision making, 2010”

www.resus.org.uk/pages/dnar.pdf

“Decisions relating to cardiopulmonary resuscitation”

www.ncpc.org.uk/publications

“The Mental Capacity Act in Practice”

“Good decision making – the Mental Capacity Act and end of life care”

www.dca.gov.uk/legal_policy/mental-capacity/publications.htm

Mental Capacity Act – Information booklets

www.publicguardian.gov.uk/mca/code-of-practice.htm

“Mental Capacity Act – Code of Practice”

www.dyingmatters.org.uk

“Dying Matters – a resource for end of life conversations and planning”

Appendix 2: An approach developed in two personal health budgets sites that supports person-centred thinking and end of life care

Tool	What it does	How this tools helps in end of life care
Relationship circle	Identify who is important to the person.	Knowing who the important people are – that you might want to see, visit or reconnect. Helps the person think about who they want to play what role at the end of their life, for example who they may want to be with them at the very end, or who they want to contribute to their funeral.
Sorting important to/for	Sorts what's important TO a person (what makes us happy, content, fulfilled) from what's important FOR a person (health and safety, being valued) while working towards a good balance.	Helps us to stay focused on what matters to the person in the context of medical issues and interventions. Keeps the focus on who the person is, not just the medical care that they need. Seeing the person beyond the patient.
Good days and bad days	Helps a person reflect on what makes a good day and a bad day, to inform action planning and identify what is important to the person and how they want to be supported.	Identifies the elements of days that are good and days that are bad, to enable the person and their supporters to work out what they can do together to ensure that they person has less bad days and more good days. This also provides information about what is important to the person and how they want to be supported.
Sorting what's working/ not working	Analyses an issue/ situation across different perspectives. Provides a picture of how things are right now, or can be used to reflect on the past or plan for the future.	Helps a person to clarify what they want and what they don't want now and to use this as a basis for action planning. Using this tool from different perspectives is a way to ensure that family and carers views are heard and can be discussed. Can also be used to reflect on the past, for example something that has worked for the person in the past that they would like to do again. Also useful for planning for the future – what a person both wants and does not want at the end of their life, and a way to get the families perspective on this.

If I could, I would	Gives a person an opportunity to think about what they would still like to do, achieve, or experience.	Acknowledges that there may still be things that the person wants to do i.e. 'The bucket list' of what you want to do before you die.
The doughnut sort	Identifies specific responsibilities- core responsibilities, using judgment and creativity, not a paid responsibility.	It clarifies the roles of the different professionals and agencies supporting people and families. It helps a person to be clear about what they must do, and where they can be creative.
Histories/how I want to be remembered	A way to help a person reflect on and record the past. Helps a person to begin to think about how they want to be remembered and their legacy.	A way for the person and family to capture their life and how the person wants to be remembered. Provides an opportunity for achievements to be celebrated and acknowledged. Offers a different way of knowing the person and informing their funeral and how they are seen by future generations.
Communication charts	A quick snapshot of how someone communicates. A way of recording a richness of information for a person who uses words to speak and particularly for a person who doesn't.	Helps us focus on a person's communication whether they use words to speak or not, and understand what we think they mean and how we should respond. Vital to inform any decision making process.
Decision making agreement	Helps us to think about decision making and increasing the number and significance of decisions a person makes.	Enables a person to be in control and make the decisions they want to make at the end of their life. Can inform best interest decision making and advance decision making.
Matching staff	A structure to look at both what skill/supports and what people characteristics make for good matches for staff or volunteers.	Helps a person think about what kind of person they want to support them. This is important information for recruiting personal assistants or using with a provider agency. Can form the basis of a person specification and inform a job description.

<p>Learning log</p>	<p>A way to record what people are learning on a day-to-day basis.</p>	<p>Provides a way for people to record ongoing learning (focused on what worked well, what didn't work well) for any event or activity. This can add to information about what is important to the person and how best to support them.</p> <p>Can replace traditional progress notes or records to help us focus more clearly on critical information about the person. Can be used to focus on someone's whole life or specific areas of their life, e.g. someone's health.</p>
<p>4 + 1 questions</p>	<p>Helps a person focus on what they are learning and what to do next.</p>	<p>A way to reflect on what has been tried and the impact of this and what could be tried next. Important in areas such as medication and keeping the person comfortable. A way to explore what is being tried and learned with the person, family, carers and professionals to review progress and at reviews.</p>
<p>Person-centred reviews</p>	<p>A person-centred way to meet, review progress and agree actions.</p>	<p>A way to reflect on what is important to the person, how they want to be supported and what is working and not working from their perspective, the families/carers' perspective and staff/professionals' perspective. This review process focuses on the whole of the person's life. The 4+1 tool is an excellent way to focus on one area of the person's life.</p>

Appendix 3: End of life care pathway

The End of Life Care Pathway

National End of Life Care Programme

