

Progress for Providers

Checking your progress
in delivering personalised
support at end of life

Acknowledgements

Progress for Providers End of Life, was developed by Philip Ball (Palliative Care Services Manager, Sue Ryder), Nicky Monks (Clinical Ward Manager, St Ann's Hospice), Anne Torkington (Macmillan Occupational Therapist, St Ann's Hospice), Tracy Meyerhoff (Assistant Head of Service, Hull City Council) and Helen Sanderson (Chief Executive Officer, Helen Sanderson Associates).

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kerry@helensandersonassociates.co.uk

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Sue Ryder



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Forewords



Heather Richardson National Clinical Lead, Help the Hospices

Personalised care and support for someone approaching the end of their life is not a new idea. Indeed it is at the heart of hospice care – arguably the gold standard of end of life care and without doubt a shared aspiration by all those who seek to provide high quality services for those who are dying and bereaved.

Even so, it can be a difficult notion to understand and apply in practice. At times a truly personalised approach can feel a somewhat illusive concept. Engaging with someone to learn more about their needs and preferences is an important start, but even then we can only respond effectively to what they require if we have the right skills, relationships, team and context in which to deliver our care.

This publication goes a long way to making personalised support an achievable goal. It offers comprehensive and concrete suggestions about how we approach the person who needs our help, how we create a supportive environment for them in physical and social terms, how we develop ourselves individually and as part of a team, and how good practice is assured in organisational terms. It is most welcome for these reasons.

Personalised support will be increasingly important as we consider future needs for care and support at the end of life. It is a future that will be characterised by increasing numbers of people who are dying, and who present with multiple and complex needs and preferences, often hugely diverse in nature. This self-assessment tool will be invaluable to a whole range of providers who wish to engage in this future and I commend it to them.

Heather Richardson





Claire Henry MBE
Head of Programmes Long Term Conditions and End of Life Care NHS Improving Quality

I'm pleased to welcome this really important and useful guide to support people on thinking about, and planning for, the end of their lives.

As a society, many of us struggle with the idea of dying. We don't like to think about it and we don't like to talk about it.

This often means that, when it comes to living well towards the end of their lives, people can find it hard to know what they want and express that to family, friends and carers, as well as health and social care professionals. This can sometimes mean that people's wishes and desires are not met.

This new guide offers some pragmatic and sensible suggestions. Its sensitive approach will help those using it to explore what is important and what is not; what is helpful and what is not; and who they want to be supporting them as they head towards the end of their lives.

It covers the key things that are important to all of us – from memories and relationships, through to making changes in our lives, and decisions about treatment and support.

This will be a helpful aid to people who are planning their end of life care, and I am pleased to give it my support.

A handwritten signature in black ink, appearing to read 'Claire Henry', written in a cursive style.

NHS
Improving Quality



Philip Ball
Palliative Care Services Manager,
Sue Ryder, Thorpe Hall Hospice, Peterborough, UK

Sue Ryder, has joined Helen Sanderson Associates in taking forward the personalisation of care for those nearing the end of life. Our work together has led to the development of this Progress for Providers End of Life self-assessment tool. The aim is to take a person-centred approach to people's care and apply that thinking to the delivery of end of life care.

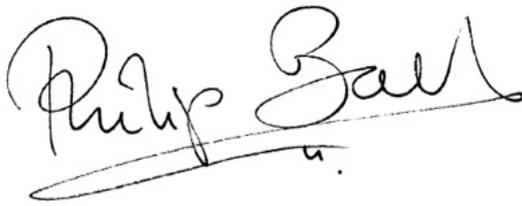
Everyone should be able to choose the care that they want at the end of their life; our two recent research reports, developed in collaboration with think-tank Demos, highlight how this is far from reality. Your diagnosis, where you live, or who your doctor is shouldn't pre-determine whether or not you have the opportunity to direct the care that you want at the end of your life, in order to have a good death. The care provided should meet all of a person's needs and wishes, not just the preferred place where they'd like to spend their last few months, weeks and days of life.

End of life is universal and inevitable but skilled and compassionate care, including effective communication, can enable individuals and their families to achieve what is important to them.

This tool allows organisations to check what stage the end of life services they provide are at in relation to person-centred thinking. It offers a range of levels, referenced to best practice and aspirations for services showing what improved services look like. The creators of this tool enable clinicians and managers to accurately assess their current provision of person-centred care and give those delivering care a set of next steps to aim for.

The sections can be used to influence team discussions, service improvement plans, as well as the daily business of caring for those nearing the end of life within the framework of person-centred care.

Our shared hope is that those who are facing the end of life have personalised care which enables them to die how they wish, with what is most important to them and to their families or loved ones recorded and acted upon. This is essential to offering people dignity, respect and peace at the end of life and to help them to achieve the kind of death that is due to them as individuals and that we would all wish for ourselves.

A handwritten signature in black ink that reads "Philip Ball". The signature is written in a cursive style and is underlined with a single horizontal stroke.The name "Sue Ryder" is written in a blue, stylized, cursive font. The letters are connected and have a fluid, handwritten appearance.

About Sue Ryder

Sue Ryder provides incredible care for people with life-changing illness. Whether it's bringing comfort to someone's final days or enabling them to make the most of their life, we are here for them and their loved ones. We treat everyone in our care as an individual, taking the time to see the person not the condition. We do this in our hospices, in our neurological care centres, in the community and in people's homes. www.sueryder.org

Introduction

Progress for Providers End of Life is a self-assessment tool, primarily for managers and teams who are delivering end of life care at home, hospice or care home.

Being person-centred in your approach to end of life care helps the people you support to have more choice and control, and for staff to provide the best support they can in ways that reflect what is important to the person. Working in this way is not about doing more, but doing things differently.

This tool will help you to reflect on existing practices and plan future approaches. It is one of a series of Progress for Providers frameworks that have been developed to assist providers in delivering person-centred support.

End of life care is care that “helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both the 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.” We are using the term ‘end of life’ to mean the likely last twelve months of the person’s life.¹

Progress for Providers End of Life is divided into five sections looking at:

- The person.
- The environment.
- Family, friends and relationships.
- Person-centred practices and approaches at end of life.
- Using person-centred practices to create a person-centred culture within your team.

How was the Progress for Providers developed?

Progress for Providers was developed by a group who included hospice managers, palliative care services managers, health professionals, and an adult social care commissioner. We consulted widely on the first draft through the Executive Clinical Leaders in Hospices and Palliative Care group (of nurses and clinical directors), Help the Hospices, hospice managers and social care staff. We then adapted this based on feedback and have tested it in a range of hospices and care homes.

In developing this Progress for Providers tool we have taken into account the Department of Health End of Life Strategy (2008); Supporting People to Live and Die Well – a framework for social care at the end of life (2010); the National Institute for Clinical and Healthcare Excellence (NICE) Quality Standard for End of Life Care for Adults (2011); The Gold Standards Framework; Advanced Care Planning: A Guide for Health and Social Care (2008); learning from the Liverpool

¹ National Council for Palliative Care 2006

Care Pathway for the Dying Patient; 'Making it Real' from Think Local Act Personal; The Adults Social Care and Public Health Outcomes Frameworks (2012) and Preferred Priorities for Care (2011); Patient Experience and the NHS Outcomes Framework – Domain 4 'Ensuring that people have a positive experience of care' (2011); CQC Outcomes and the Francis Report (2013). In the Appendices you can see how this Progress for Providers reflects a sample of these frameworks and guidance.

We use the term colleagues to refer to both staff and volunteers.

Using Progress for Providers for End of Life is one of the recommendations from the Demos report (2013) called Service Journeys at the End of Life.

How to use it

The self-assessment tool asks you to look at the practices, policies, knowledge and skills of you and your team, and at the experience of the person at the end of their life and the people who matter to that person. It takes about 40 minutes to complete the self-assessment.

Each topic enables you to score yourself on a scale of 1 to 5:
If you tick boxes 1 or 2 then you are **starting to look at and act** on the topic.
Tick 3 or 4 if you are **delivering person-centred care** in that area.
Tick 5 if you are **delivering truly personalised services and using person-centred practices** in that area (including individualised funding).

Once you have scored yourself on these criteria, you can record your next steps on the summary sheets on pages 32–35 which then provides an overview of how you are doing.

You can use this assessment tool:

- By yourself, for individual self-reflection.
- With your manager, to agree goals.
- With your team, to agree team and individual goals.
- With other managers, for example as a practice group, or as part of an organisational development programme.

We mention specific person-centred thinking tools and approaches in Progress for Providers, you can find these in the person-centred guide called 'Living Well – Thinking and Planning for the End of your Life', <http://www.helensandersonassociates.co.uk/media/38837/livingwellweb-final.pdf>. These are recommended in the Department of Health Guidance (2010) on using person-centred practices to deliver 'Putting People First'. At the end of the booklet we provide a description of each of these and where you can get further information.

If you are supporting people in their own home, then do not use section 2, as this focuses on hospices and care homes.

Section 1

The person

1 We see and treat the person as an individual, with dignity and respect

Tick one box ✓

1	We only have very basic information about the person and their needs. Staff are solely focused on getting the daily tasks done.	
2	We see the person as an individual as much as possible, but only have information about their care needs recorded. Most of the time people are talked about respectfully.	
3	We see the person as an individual with strengths and qualities. Staff try to give people the time to talk about what matters to them. People are consistently described and treated with dignity and respect.	
4	We describe people positively. We have recorded information about the qualities and strengths of each person we support. We don't just record this, we try and use it in our day to day support and in our conversations with the person. Dignity is seen as everyone's business and every staff member sees themselves as a Dignity Champion.	
5	We know and have a record of each person's gifts and qualities. We use a variety of ways to communicate how we value each person. We use the information about what we know about individuals in their day-to-day support. People are described and treated respectfully and positively, as individuals, by all staff.	

2 We know and act on what matters to the person now

1	We focus on keeping people clean, comfortable, fed and safe. We do not know what matters to each person. Our priority is to look after them.	
2	We know we need to recognise what is important to people, but we don't have the time to do this.	
3	We have started to find out and record what is important to the person in relation to their wellbeing, and using person-centred thinking tools to help us do this (for example, good days and bad days, relationship maps, learning about people's routines). This information is starting to change how we support people.	

4 Most people have a record of what matters to them, and we pay attention to their emotional and spiritual wellbeing (and this is recorded, for example, in a one-page profile). Staff use this information in conversations and in how they support people. New staff use this to get to know the person quickly.

5 We pride ourselves that people experience the best quality of life which is possible for them, whatever the stage of their illness. We recognise when a person is in emotional pain or distress and support them with this. We know what is important to each person. This is clearly recorded and includes specific information, for example, routines, relationships, sexuality, spirituality, and interests. Each person has a one-page profile. Staff intentionally work to make sure that what is important to the person is happening purposefully and is present. Where there are obstacles to achieving this, these are shared with the relevant people who help to find ways around this.

3 We know and act on what the person wants and does not want in the future

1 Our job means focusing on the here and now.

2 We think it would be good to plan for the future but we are not sure if it is our role and we don't have the time to do this.

3 We are trying to help some people think about their future and what we may need to do to help with this.

4 We help everyone who wants or is able to think about their future and what they may like to try or do. We have a record of this and actions that we are working on.

5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.

4 We know and act on the person's end of life decisions

1	We do not know, nor have a record of any decisions concerning end of life.	
2	We know if the person has had a conversation about Advanced Care Planning.	
3	We ask each person questions about the end of their life decisions and check these are up to date and recorded.	
4	We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.	
5	We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').	

5 We know and respond to how the person communicates

1	We expect staff to follow our policies and procedures; we do not specifically record how the person communicates.	
2	We realise that we need to understand more about how people communicate and what they are trying to tell us.	
3	We have started to introduce communication charts, tools and aids, as a first step. Staff are now beginning to understand that all behaviour is communication and are developing their skills in observing, recording and communicating with people.	
4	We use communication charts, tools and aids with the majority of the people we support who need them. Increasingly staff understand their own role in effective listening and communication.	

5 We know and respond to how the person communicates. This is clearly recorded (for example, using communication charts, tools and aids) and staff know what a person means when they behave in certain ways and how staff should respond. When a person is unable to demonstrate a response to communication, staff will continue to use ways of communication that are respectful of privacy and dignity. The ways of communication used are kept up to date and used consistently by all staff. We use interpreters when required, and try to ensure that they are matched to the person.

6 The person is supported to make choices and decisions in everyday life

1 The people we support are not involved in significant decisions about their life.

2 We realise that people should be involved and included in any decisions about their life. We also recognise that this could help people feel more in control. We do not know how to do this yet. We use best interest discussions and meetings.

3 We have started to develop decision-making agreements and profiles with people and tried out different approaches to help people to make decisions. We are using best interest discussion meetings and engaging families to assist in the process.

4 The use of decision-making agreements and profiles is common, and we have many examples of people making decisions about what is important to them. We are struggling to ensure that this is for all people with capacity or communication issues. Staff are engaged and support people to record their decisions.

5 Staff know the decisions that are important to the person and how to support the person with these decisions. This is recorded, for example, in a decision-making agreement. We make sure each person gets representation if they need it, and use best interest discussions and meetings. We have supported some people to make decisions that we don't agree with and manage the tension in this. We support each person to extend the range and importance of the decisions that they make, to have more control over their life and death.

7 We know and act on exactly how the person wants to be supported in everyday life

1 We have established policies and procedures for how we support people and we support everyone in the same way.

2 We know that to support each person effectively, we need to find out how they would like to be supported. We are unsure how to do this and record the information. Currently our approach is not flexible enough to allow this to happen. We are task orientated rather than people orientated but we want to change this.

3 We acknowledge the importance of finding out from each person what good support looks like for them individually. We have begun to explore with people what this looks like and have developed a plan to gather this information for everyone, using person-centred thinking tools and approaches.

4 Everyone in the team is clear about what good support looks like for each person they support. We have started to record this (for example, in one-page profiles). Staff understand what this means for their practice on a day to day basis and are using this information to inform how they support people. This includes supporting people to look after their appearance and staff are particularly aware of body image issues and support people to cope with these.

5 We pride ourselves that people have the best quality support. We know and act on how the person wants to be supported. This is clearly recorded, is detailed, specific to the person and staff use this to deliver individual support. The information includes the support people want in their routines, in relationships and interests. This includes support specific to the person's culture and religion. We review staff performance on their ability to provide support in the way that someone wants (e.g. as described in a one-page profile). We use a range of relevant resources (technology, equipment, advice, and people) to get our support right for the person. The person is as active in their own care as possible.

8 We know what is working and not working for the person, and we are changing what is not working

1 We do not know what is working or not working for the people we support.

2 We want to learn what the person thinks is working and not working in their life. We are not sure how to do this and are fearful we will not be able to respond and make the changes they want.

3 We have started to routinely ask the person what is working and not working from their perspective about their life and the service they receive (for example, as part of a person-centred review).

4 Staff are confident in supporting the person to tell us what is working and not working. This happens for everyone at least once during their involvement with the service. There is an action plan developed from this. We have created a system that will gather this information from people so that we can plan strategically what needs to happen in the service.

5 We have a process to learn what is working and not working for the person, from their perspective (for example, through person-centred reviews). We have actions (with a date and a named person responsible) to change what is not working. The actions are regularly reviewed with all key people (e.g. multidisciplinary team in a hospice), including the person where they are able and/or family and people who matter to the person.

9 We support people in their family relationships and friendships

1 The only people in the person's life are paid staff. We don't see it as our responsibility to support people with relationships.

2 We realise that the person might want to meet and make more friends, but we are fearful that this could expose them to harm and risk, and we are not prepared to accept the responsibility for this. We are not sure how we would begin to find out who is important in the person's life.

3 We have started to work out how we can support the person to build and maintain relationships. We are still worried about the risk and how to manage this. We have started to understand what's in the local community and we are developing relationship maps. Staff are putting a greater focus on people's interests and friendships.

4 We have tried a number of approaches to support people with their friendships and relationships. We know who is already important in the person's life (for example, by using a relationship map) and they are now having opportunities to meet new people (who are not paid to be with them). We are gathering the learning and sharing good practice.

5 We support the person to refresh/revisit/reignite and or maintain relationships that are important to them (including sexual relationships). We can offer to support the person to make new relationships with people in their place of care (and with their wider community). We have a culture that creates positive and valued relationships.

10 We support the person to be part of their community

1	It is not our job to connect people in the community.	
2	We think it would be good if people we support were out and about in the community more but we can't see how we can do this within our current resources.	
3	We are committed to exploring ways of people being part of their communities, and we have started thinking about how to do this with a few people we support (for example, using community maps, recording gifts and presence to contribution).	
4	We support some people to go out and be part of their community and we use person-centred thinking tools in the way that we approach this.	
5	We support people to be involved in their community. We use community maps that show the places that are important to the person, and we actively support people to be a part of their community and make a contribution in whatever way works for them.	

11 We support the person to be as comfortable as possible, promoting their quality of life

1	We know people have aids and equipment that are important to their comfort – but these regularly go missing.	
2	We try to get the person moving about when we can and try to keep them as comfortable as possible. We recognise that people may need specialist equipment and we try and get this.	
3	We look out for any signs that the person may be in pain or distress, and provide, for example, pressure area care.	
4	We intentionally have conversations with the person about how their symptom management can be optimised. We have all equipment easily and quickly available (for example, pressure relieving equipment). When someone's condition or behaviour changes, we look at potential causes and look out for indications that the person is in pain or distress.	
5	We pride ourselves on ensuring each person is as comfortable as possible. We know and have a record of the best ways to support each person to be comfortable and how we will know if they are in pain or distress. We actively seek holistic ways to reduce pain and distress and promote their quality of life. We recognise when it is important to have a discussion with the family about the person's individual end of life care plan or equivalent.	

12 We support the person to share or record important memories

1	The only information that we have about the person is in the care plan. Any record about history is likely to be in the context of negative experiences or behaviour.	
2	We know it is important to know about the person's history but we don't have time to do this.	
3	We are committed to finding out about each person's history and have started work with a few people to write their histories when we have time.	
4	We offer the opportunity for each person to have a record of their important and significant memories. We have different ways to record and share their history according to what the person wants. We are starting to use this information in our conversations with people. We have a plan to complete histories for people who want this.	
5	We have recorded histories or memories for people who want them. These will be recorded in a way that works for the person (for example, on a history map, life story book, timeline, scrapbook, memory box or DVD). We use this information in our day to day conversations and support. Staff are comfortable sharing their own histories and experiences when this is helpful.	

13 We ensure there is a record of how the person wants to be remembered after they have died

1	We do not know, nor have a record of any decisions about how the person wants to be remembered.	
2	We help the person with their Advanced Care Planning but this does not include how the person wants to be remembered.	
3	We talk to the person about all aspects of end of life and this often includes how the person wants to be remembered.	
4	We sensitively and proactively talk about and record how the person wants to be remembered.	
5	We know and have a record of how the person wants to be remembered. This is recorded in a way that works for the person, e.g. history map, life story-book, timeline, scrapbook, memory box or DVD. We ensure that this information is shared with the people who can make it happen.	

Section 2

The environment

1 The environment is welcoming and homely

Tick one box ✓

1 The environment looks and feels sterile and just has pictures on the wall. People look bored or distressed.

2 We have tried to make things look 'homely'. The chairs are all the same and around the outside of the room.

3 Chairs are arranged to enable people to talk to each other easily. There are a few things to occupy people.

4 The environment is comfortable and is arranged to suit people (for example, where people like to sit). There is a range of things for people to do.

5 The environment is pleasant and homely. People have as much control over their physical environment as possible (for example, the temperature, noise levels, music). There is a wide variety of opportunities to do things (for example, hobbies, games). There are spaces inside and outdoors for relaxation and hobbies. The environment supports a person's privacy and dignity. Staff understand the importance of how the living environment affects people.

2 People have their personal possessions around them

1 Everything is treated communally and occasionally it means that people end up wearing other people's clothes or footwear.

2 Most clothes are labelled and we do our best to make sure people have their own clothes. People have a few personal possessions in their room, for example, photographs.

3 We encourage the person to have the personal possessions that they want in their room. We ensure that the person has their own clothes and shoes and that these are looked after.

4 Everyone has a range of personal possessions in their room, and we support people to take care of them.

5 We know which possessions are important to the person. We ensure people have support to have their possessions around them and we will have a record of what will happen to the possessions, or who will take responsibility for carrying out the person's wishes, with regards to their possessions. We also recognise that pets and animals are important to many people and we support people to see and be with them.

3 Meal times are pleasurable and flexible occasions

1 We have one meal on offer each mealtime. We have fixed times for meals, and have to work hard to make sure that everyone eats then.

2 We have fixed times for meals, with one meal available (we accommodate dietary needs like halal meals etc). Mealtimes feel rushed, but we try and talk to people as well as feed them.

3 We are as flexible as we can be around mealtimes, and usually have a couple of options for people. We help the person (as much as possible) to choose the one they want. We try to make meal times sociable occasions.

4 We support people to choose from several meal options. We pay attention to the presentation of the food so that it looks appetising. People can take as long as they want over their meals. We recognise that we need to sensitively support people who can no longer eat or drink or whose appetite is waning.

5 Mealtimes are pleasurable, flexible, sociable occasions. People choose when, where and what they eat, and who they want to eat with. The meals are delicious and attractively presented, in appropriate portion sizes. People can take as much time as they want over their meals. A range of foods and snacks is always available. People get the support they need to eat and drink in a respectful, dignified and unobtrusive way. People who can no longer eat or drink, or whose appetite is waning, are supported sensitively.

4 There are opportunities for privacy

1	When the service is full, there are limited options for privacy.	
2	We understand the person may want privacy and we try to identify spaces to support this.	
3	We take into account how the person likes to spend their time and try to identify the most suitable spaces if they want privacy. We ask the person if they want private space, and if their treatment requires this, and we try to accommodate this.	
4	We try to facilitate the person and their families and friends having access to private space. We ensure that each person has privacy for treatments, for example, rehabilitation programmes in a space which is not overlooked, or during mealtimes if people want privacy.	
5	The environment has plentiful and varied spaces for privacy. The person chooses where they want to be and is supported in this wherever possible. There are pleasant spaces both indoors and outdoors which allow privacy for the person and the people who matter to them (for example, their family, spiritual leader, solicitor, friends). There is privacy for the person and families after death. Staff understand the need for privacy, what this means to each person, and support the person to obtain it.	

Section 3

Family, friends and relationships

1 The people who matter to the person have good information

1	We do not see our role as providing information for people. We answer questions that people have when we have time.	
2	We try and help people when they ask questions as much as we can.	
3	We know who the person wants to share information with. We have leaflets and information that we tell people about when they ask questions. We provide information about what is happening on notice boards and in a variety of ways.	

4 We proactively make sure that people have good information about what is happening, with the explicit consent of the person (or within the person's best interests). We have interpreters or advocates who can help. We support people to have information and conversations about death and dying.

5 We have made sure that family and friends have information about death and dying. Family, friends and important people have all the information they need, with the person's consent (or within the person's best interests), when they want it, in everyday language. This is through a range of sources, such as one-to-one sharing, leaflets, bedside booklets, newsletters and social media. Family members and friends know what is happening generally, as well as in the life and death of their family member, and how to get support after death and in bereavement.

2 People who matter to the person contribute their knowledge and expertise

1 We get our information from the files, we don't ask other people.

2 We know that families have information about the person and we try and get this when we can.

3 We make sure that we talk to the people who matter to the person and get all the information that they have for our records.

4 We work with the people who know the person well to learn about the person from their past as well as who they are today. We are sensitive to who the person wants us to talk to. We record this information in a person-centred way. We support the person to decide which family and friends to invite to reviews, if they choose.

5 We acknowledge the expertise of families and friends as those who know and care most about the person. We are led by the person about who they want to be involved in sharing information. Families and friends contribute to our understanding of the person – for example, the person's history, communication preferences, knowing what matters to the person, their aspirations for the future, how they are best supported and their connection to the community. We proactively work with family and friends to enable them to contribute to person-centred reviews, for example, by arranging them at times that suit the family and actually providing care and support to the person if they choose.

3 We support the person’s important relationships to continue and develop

1	It is not our role to get involved in relationships with the family and the person.	
2	We try and help families stay in touch but there is not much that we can do.	
3	We do what we can to help families and friends stay connected by, for example, talking to the person about who is important to them.	
4	We spend time working out how the person can stay in contact with the people who are important in their life, what we can do to help this, for example, using a relationship circle, and making sure that the person is supported to send birthday and celebration cards. We are sensitive to where there are tensions in relationships.	
5	We support the person to remain an active part of their family and other important people continuing with relationships and family celebrations that are important to them. We support families as circumstances and relationships develop and change over time and on into bereavement. We facilitate difficult conversations where there are tensions and differences of opinion.	

Section 4

Person-centred practices and approaches at end of life

1 Knowledge, skills and understanding of person-centred practices at end of life

1	No one in my team has any understanding or experience of using person-centred practices at end of life.	
2	I know that we need to develop our skills, knowledge and understanding of person-centred practices at end of life, but have not developed any plans to do this and I am not sure how to begin.	
3	I have a plan to develop our understanding of person-centred practices at end of life and some of the team have begun to use person-centred thinking tools and approaches. We have started to look at some of the information available on person-centred thinking (for example, Michael Smull’s podcasts on YouTube).	
4	I am using person-centred practices myself, and all the team know and are successfully using several of the tools. I have a one-page profile and so do each of the team, and we are using this in our work together.	

5 We all have our own one-page profile and we use this to inform our practice, and we are all confident and competent in using person-centred thinking tools. Everyone can describe at least 5 person-centred thinking tools (why and how you can use them and the benefits to the person) and talk about their experience of using them and the outcomes doing so achieved. As a manager, I demonstrate enabling the people who are supported to have as much choice and control as possible in their lives. I do this by working in a consistently person-centred way and proactively and competently using person-centred thinking tools in all areas of end of life care.

2 Supporting team members individually to use person-centred practices at end of life

1 No one in the team has a Personal Development Plan or equivalent and we are not using any process to reflect on how we work and how to develop our skills.

2 I recognise that all colleagues need ongoing support and opportunities for development to build their skills and knowledge and a way for their progress to be monitored. I am not sure how to go about this.

3 I have started to talk to each team member about how they are doing in using person-centred thinking tools and approaches in their work. This is on an adhoc basis.

4 I talk to each team member on a regular planned basis about how they are developing their skills in using person-centred thinking and approaches and how I can support them in this. I have a record of the progress that team members are making (for example, using the person-centred thinking rating scale).

5 All colleagues have a regularly reviewed Personal Development Plan or equivalent, which includes how they are developing their competence in using the person-centred thinking tools and approaches. This includes celebrating successes as well as noting problem solving difficulties. I ensure that each team member reflects on their own practice and is accountable for this. I use a range of ways to ensure each team member has individual support in using person-centred thinking tools and approaches (for example, peer support, mentoring and person-centred thinking), as a standing agenda item for supervision. There is a mechanism for recording and sharing best practice across the organisation.

3 Support and development as a team in using person-centred practices at end of life

1	We don't meet as a team and when we do, we solely focus on processes and procedures.	
2	I recognise that it is important that we meet and reflect about the team's ongoing development but we are struggling to prioritise this or find the resources to allow this to happen.	
3	I make sure that we set aside time during team meetings to reflect on practice and sometimes this includes how we are using person-centred thinking tools and approaches.	
4	We use person-centred thinking tools and approaches in our team meetings. We also have other ways that we work together to develop our understanding of person-centred thinking tools and approaches, and to reflect on successes and challenges together.	
5	We have a strong culture of reflective practice around our experience of using person-centred thinking tools and approaches. In the team we have a variety of ways (for example, standing agenda item in team meetings, sharing best practices and problem solving, practice groups, person-centred thinking tool of the month) to support team members to develop their skills in using person-centred thinking and approaches. The information is gathered to inform organisational training and development planning.	

Section 5

Using person-centred practices to create a person-centred culture within our team

1 Clear purpose

1	We have an organisational mission or purpose statement created by the senior manager/management team/owner. This complies with requirements. We have not considered how this should be reflected in the way we work.	
2	I think it would be helpful for the team to think about our purpose as a team but I am not sure how to go about this.	
3	I have begun to talk with colleagues about what our purpose is and to think about how we can record this.	

4 I am clear about our team’s purpose and how this fits with the organisation’s mission statement. We have developed this together as a team and with people using the service.

5 The organisation’s mission statement informs the team’s purpose. Everyone understands the connection between the mission and their individual purpose and role. The team know what their team purpose is and what we are trying to achieve together. All team members know their purpose in relation to the people they support, their team and the rest of the organisation. This is recorded, for example, in a purpose poster or team purpose statement. The team’s purpose informs the work of the team and there is evidence of this in practice.

2 An agreed way of working that reflects values

1 We don’t really think about values, we just get on with the job.

2 I realise that we need to explore our values and beliefs as a team and how this can inform our practice.

3 We have started to think together about our team values and how we work together. We know what is working and what needs to change.

4 We have agreed our values and team principles and, in partnership with the people we support, developed an action plan that addresses what needs to change.

5 The team has a shared set of beliefs or values which underpin its work, and agreed ways of working that reflect these. These reflect working in a person-centred way and include working in ways that ensure people have maximum choice and control in their lives, as part of their local community. The team principles and ways of working are clearly documented (for example, ground rules, team charter, person-centred team plan, team procedure file etc.). The team regularly evaluates how it is doing against these agreed ways of working (for example, by using what is working and not working from different perspectives).

3 People know what is important to each other and how to support each other

1 My team do not know each other very well.

2 I have started to work on ways that I can help the team know more about each other; what matters to them as people and how they can support each other at work (for example, starting with one-page profiles for everyone).

3 I am learning what is important to my team and how best to support them. We are all aware of how to support each other and what is important to each other and we are working at putting this into practice.

4 My team and I have all documented how best to support each other and what is important to each of us. We know how we make decisions as a team and the best ways to communicate together.

5 As a team we know and act on what 'good support' means to each person and take into account the emotional consequences of working in end of life care. This information is recorded, for example, in a person-centred team plan. We regularly reflect on what is working and not working for the team, and what can be done about this. We have a culture where we appreciate each other's gifts and strengths and use these in our work wherever we can.

4 Colleagues know what is expected of them

1 All colleagues have a generic job description and work to organisational policies and procedures.

2 Colleagues know what tasks they are responsible for within our team.

3 I know that colleagues need to be clearer about what their important or core responsibilities are and where they can try out ideas and use their own judgement. We have started to have discussions in the team about this.

4 Some colleagues are clear about what is expected of them and where they can make decisions themselves. There are still some grey areas that we need to explore more. We are using person-centred thinking tools (for example, the doughnut) in clarifying expectations and decision making.

5 Colleagues know what is expected of them – they are clear about their core responsibilities and where they can try new ideas in their day to day work. Colleagues are clear about their role in people's lives and know what they must do in their work around the people they support. They are also clear about any team, admin or finance responsibilities they have. Colleagues know how to use person-centred thinking to deliver their core responsibilities. Colleagues know where they can use their own judgement and try new ideas or approaches and record what they are learning about what works and does not work when they use their own judgement. Roles and responsibilities are clearly recorded (for example, in a doughnut) and this is reflected in job descriptions.

5 Colleagues feel that their opinions matter

1	I make all decisions; I don't involve my team. I chair meetings and set the agenda. I set the agenda for supervision and appraisals.	
2	I recognise the need to find a way to listen to my colleagues, value their opinions and engage them in decision making. I am trying to improve how I do this.	
3	My team have some involvement in setting team meeting agendas. I still make most of the decisions.	
4	I regularly meet with my team and discuss issues that they raise (in team meetings and other day to day opportunities). They contribute to team meetings agendas and make suggestions for supervision discussions. Some colleagues make suggestions for new ideas or changes. We are starting to use person-centred thinking tools to listen to each other.	
5	Colleagues feel that their opinions are listened to. Team members are asked for their opinions and consulted on issues that affect them. Team members feel confident in suggesting new ideas or changes to me. We regularly use person-centred thinking tools in the team to listen to each other's views and experiences (for example, 4 plus 1 questions).	

6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported

1	I write the rotas based upon colleagues' availability. The rota meets the requirements of the service. There is a system for colleagues and people who use the service to make requests.	
2	Sometimes the person who is supported is matched to colleagues to meet individual needs.	
3	I have identified the preferences of the person who is supported and colleagues (for example, using the matching tool and one-page profile). I write the rotas and take these preferences and needs into consideration wherever possible.	
4	My team and I know what each person's preferences and needs are, how they like to be supported and what is important to them. These preferences and needs are acknowledged in the way that the rota is developed, so that we get a good match between the person and the colleague who supports them. The rota times are based around how the person wants to be supported.	

5 Decisions about who works with whom are based on both who the person supported wants, as well as who has the skills to support them (for example, named nurse or keyworker). Where the team leader makes this decision, it is also based on which colleagues get on the best with different individuals. This takes into account what the person and individual colleagues have in common (for example, a shared love of trains and railways), as well as personality characteristics (for example, gregarious people and quieter people). Rotas are flexible and adapted to account for individual and/or complex need and matched with colleagues with necessary skills.

7 Recruitment and selection is person-centred

1 Colleagues are recruited to the team based on formal job descriptions that have been developed by the organisation.

2 I know I should involve the people who receive a service in recruitment but I am not sure how to go about this.

3 I have started to look at 'good practice' examples of ways to involve people in recruiting their support staff. We have started to explore how we can develop job descriptions that reflect what is important to the people we support.

4 Our job descriptions are person-centred. We have worked with people and identified ways for them and the people who matter to them to be involved in recruitment and selection of colleagues if they choose to be (for example, patient/carer groups). This happens some of the time.

5 Our recruitment and selection process demonstrates a person-centred approach. We recruit people who can deliver our purpose by selecting people for their values and beliefs and characteristics, not just their experience and knowledge. It is common practice for people to be involved in recruiting colleagues in a way that works for them.

8 Enabling risk

1	I encourage my team to make sure people are safe and do not take risks. We adhere to all required legislation.	
2	I am aware that I need to encourage my team to become less risk averse. I am not sure how to do this.	
3	I am working with the team to help them take a responsive and person-centred approach to risk. We are starting to use this in some situations.	
4	We use a person-centred approach to risk most of the time. We involve the people, family and others in thinking this through. We ensure everything is documented and adheres to the relevant legislation.	
5	We ensure that risks taken are thought through in a person-centred way that reflects what is important to the person and decisions are clearly recorded. The person (and/or those who matter to them, particularly if there are issues around capacity) is centrally involved in the way that we do this.	

9 Learning and development

1	All training is based on statutory requirements. We make sure that we meet minimum legal and statutory requirements.	
2	I recognise that we need to find a way for training and development opportunities to reflect the needs of the service we provide to people and motivate the staff.	
3	We have started to think about how we can introduce learning and development opportunities to colleagues, that will reflect the needs of people who receive a service, and also engage and develop team members. We have begun to look at what is working and what is not working for individuals and also researching what is available.	
4	We have identified all training needs, learning and development opportunities and have a plan in place. Training and development opportunities reflect the needs and wishes of people who receive a service and have been agreed with team members. Person-centred thinking and approaches are central to our approaches to training. We are compliant with all legal and statutory requirements.	

5 We provide development and learning opportunities to all colleagues that focus on increasing choice and control for people we support and delivering an individual, person-centred service. Within a few months of starting with the organisation, new colleagues have induction training that includes using person-centred thinking and approaches to deliver the service which best meets the person's needs. Our learning opportunities enable colleagues to be up to date with best practice in delivering choice and control. This is reflected in using person-centred thinking to enable people to live the life and death they want and have the best quality of life possible whatever the stage of their illness. We know that the first line managers are key to delivering a person-centred service. We have specific training and support to enable them to use a person-centred approach in all aspects of their role and to be able to coach their colleagues in using person-centred thinking skills.

10 Supervision

1 I set the agenda and make the arrangements for colleagues' supervision. I meet the minimum requirement.

2 I am aware that colleagues' support and supervision practice needs to be reviewed. I am not sure how I can change the current arrangements.

3 I give colleagues specific feedback on how I have seen them working in supervision.

4 All colleagues are supervised and I make sure that there is feedback from other people as well to share in supervision. Supervision results in actions and the meetings are documented. I have started to use person-centred thinking tools in supervision sessions.

5 Each team member has regular, planned, individual supervision. Supervision includes giving colleagues individual feedback on what they do well, as well as what they can improve on (for example, coaching staff to develop their skills in working in a person-centred way). There is a clear link between learning and development and supervision and what people do when they are at work. For example, when colleagues have attended training, managers expect to see a difference in their work. This can be discussed in their individual supervision.

11 Appraisal and Personal Development Plans

1	Most of my colleagues have an appraisal on an ad-hoc basis. I set the agenda and assign objectives.	
2	I have a plan to make sure all colleagues have an annual appraisal. Colleagues have an appraisal but do not really contribute to the agenda or any Personal Development Plan.	
3	I have a plan in place to ensure that each colleague receives an annual appraisal. Where possible, I try to seek the views of others to contribute to this.	
4	There are a variety of ways for people who receive a service and others to contribute their views to colleague's appraisals (e.g. 360 degrees). All colleagues are asked to reflect on what they have tried, what they have learnt, what they are pleased about and where there are any concerns. We then agree what actions need to be taken from all the information gathered.	
5	Team members get positive feedback about their work and have annual appraisals and Personal Development Plans or equivalent. Annual appraisals include feedback from a range of relevant people. We use staff within appraisals, and ask what is working and not working about the support they receive. This results in a Personal Development Plan with clear goals that build on strengths, focus on working in a person-centred way, and further developing skills.	

12 Meetings

1	There are occasional team meetings but not everyone attends or contributes.	
2	There are frequent team meetings. I set the agenda and chair the meeting. There is little structure to the meeting and they are not as well attended as they could be.	
3	Regular team meetings are scheduled. The meeting tends to be an information giving forum and does not often include problem solving or celebrating successes.	
4	There are regular structured team meetings which are documented. Actions are agreed, recorded and followed up on. They are well attended and most people contribute.	
5	Our team has regular, productive team meetings that provide opportunities for everyone's views to be heard and everyone contributes. Team meetings include sharing what is going well and problem solving difficulties (for example, practicing using person-centred thinking tools to solve problems).	

Summary of actions

	What we want to work towards (the next statement in the section)
Section 1 - The person	
1 We see and treat the person as an individual, with dignity and respect	
2 We know and act on what matters to the person now	
3 We know and act on what the person wants and doesn't want in the future	
4 We know and act on the person's end of life decisions	
5 We know and respond to how the person communicates	
6 The person is supported to make choices and decisions in everyday life	
7 We know and act on exactly how the person wants to be supported in everyday life	
8 We know what is working and not working for the person, and we are changing what is not working	
9 We support people in their family relationships and friendships	
10 We support the person to be part of their community	
11 We support the person to be as comfortable as possible, promoting their quality of life	
12 We support the person to share or record important memories	
13 We ensure there is a record of how the person wants to be remembered after they have died	
Section 2 - The environment	
1 The environment is welcoming and homely	
2 People have their personal possessions around them	
3 Meal times are pleasurable and flexible occasions	
4 There are opportunities for privacy	

	What we want to work towards (the next statement in the section)
Section 3 - Family, friends and relationships	
1 The people who matter to the person have good information	
2 People who matter to the person contribute their knowledge and expertise	
3 We support the person's important relationships to continue and develop	
Section 4 - Person-centred practices and approaches at end of life	
1 Knowledge, skills and understanding of person-centred practices at end of life	
2 Supporting team members individually to use person-centred practices at end of life	
3 Support and development as a team in using person-centred practices at end of life	
Section 5 - Using person-centred practices to create a person-centred culture within our team	
1 Clear purpose	
2 An agreed way of working that reflects values	
3 People know what is important to each other and how to support each other	
4 Colleagues know what is expected of them	
5 Colleagues feel that their opinions matter	
6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported	
7 Recruitment and selection is person-centred	
8 Enabling risk	
9 Learning and development	
10 Supervision	
11 Appraisal and Personal Development Plans	
12 Meetings	

Detailed action plan

Top priority

Why is this your top priority?

First steps

Who

By when

Who else needs to know/help this to happen?

How will I get their help?

What support will I/we need?

From inside the organisation

From outside the organisation

How will I know I have been successful?

What will have changed? What will you see? What will you feel? What will you hear?

Detailed action plan

Next priority

First steps

Who

By when

Who else needs to know/help this to happen?

How will I get their help?

What support will I/we need?

From inside the organisation

From outside the organisation

How will I know I have been successful?

What will have changed? What will you see? What will you feel? What will you hear?

Detailed action plan

Next priority

First steps

Who

By when

Who else needs to know/help this to happen?

How will I get their help?

What support will I/we need?

From inside the organisation

From outside the organisation

How will I know I have been successful?

What will have changed? What will you see? What will you feel? What will you hear?

Detailed action plan

Next priority

First steps

Who

By when

Who else needs to know/help this to happen?

How will I get their help?

What support will I/we need?

From inside the organisation

From outside the organisation

How will I know I have been successful?

What will have changed? What will you see? What will you feel? What will you hear?

National End of Life Care Pathway

Where this is addressed in Progress for Providers End of Life

1 Discussions as the end of life approaches

- 1.1 We see and treat the person as an individual, with dignity and respect
- 1.2 We know and act on what matters to the person now
- 1.3 We know and act on what the person wants and does not want in the future
- 1.4 We know and act on the person's end of life decisions
- 1.5 We know and respond to how the person communicates
- 1.6 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life
- 1.12 We support the person to share or record important memories
- 2.4 There are opportunities for privacy
- 3.1 The people who matter to the person have good information
- 3.2 People who matter to the person contribute their knowledge and expertise

2. Assessment, care planning and review

- 1.1 We see and treat the person as an individual, with dignity and respect
- 1.2 We know and act on what matters to the person now
- 1.3 We know and act on what the person wants and does not want in the future
- 1.4 We know and act on the person's end of life decisions
- 1.6 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships
- 1.10 We support the person to be part of their community
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life
- 2.4 There are opportunities for privacy
- 3.1 The people who matter to the person have good information
- 3.2 People who matter to the person contribute their knowledge and expertise

- 3.3 We support the person's important relationships to continue and develop
- 4.1 Knowledge, skills and understanding of person-centred practices at end of life

3 Coordination of care

- 1.1 We see and treat the person as an individual, with dignity and respect
- 1.2 We know and act on what matters to the person now
- 1.3 We know and act on what the person wants and does not want in the future
- 1.4 We know and act on the person's end of life decisions
- 1.5 We know and respond to how the person communicates
- 1.6 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships
- 1.10 We support the person to be part of their community
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life
- 2.1 The environment is welcoming and homely
- 2.4 There are opportunities for privacy
- 3.1 The people who matter to the person have good information
- 3.2 People who matter to the person contribute their knowledge and expertise
- 3.3 We support the person's important relationships to continue and develop
- 4.1 Knowledge, skills and understanding of person-centred practices at end of life
- 4.2 Supporting team members individually to use person-centred practices at end of life
- 4.3 Support and development as a team in using person-centred practices at end of life
- 5.1 Clear purpose
- 5.2 An agreed way of working that reflects values
- 5.3 People know what is important to each other and how to support each other
- 5.4 Colleagues know what is expected of them
- 5.5 Colleagues feel that their opinions matter
- 5.6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
- 5.7 Recruitment and selection is person-centred

	5.8	Enabling risk
	5.9	Learning and development
	5.10	Supervision
	5.11	Appraisal and Personal Development Plans
	5.12	Meetings
4 Delivery of high quality services in different settings	1.1	We see and treat the person as an individual, with dignity and respect
	1.2	We know and act on what matters to the person now
	1.3	We know and act on what the person wants and does not want in the future
	1.4	We know and act on the person's end of life decisions
	1.5	We know and respond to how the person communicates
	1.6	The person is supported to make choices and decisions in everyday life
	1.7	We know and act on exactly how the person wants to be supported in everyday life
	1.8	We know what is working and not working for the person, and we are changing what is not working
	1.9	We support people in their family relationships and friendships
	1.10	We support the person to be part of their community
	1.11	We support the person to be as comfortable as possible, promoting their quality of life
	2.1	The environment is welcoming and homely
	2.2	People have their personal possessions around them
	2.3	Meals are pleasurable and flexible occasions
	2.4	There are opportunities for privacy
	3.1	The people who matter to the person have good information
	3.2	People who matter to the person contribute their knowledge and expertise
	3.3	We support the person's important relationships to continue and develop
	4.1	Knowledge, skills and understanding of person-centred practices at end of life
	4.2	Supporting team members individually to use person-centred practices at end of life
	4.3	Support and development as a team in using person-centred practices at end of life
	5.1	Clear purpose
	5.2	An agreed way of working that reflects values
	5.3	People know what is important to each other and how to support each other
	5.4	Colleagues know what is expected of them

- 5.6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
- 5.7 Recruitment and selection is person-centred
- 5.9 Learning and development
- 5.10 Supervision
- 5.11 Appraisal and Personal Development Plans
- 5.12 Meetings

5 Care in the last days of life

- 1. We see and treat the person as an individual, with dignity and respect
- 1.2 We know and act on what matters to the person now
- 1.3 We know and act on what the person wants and does not want in the future
- 1.4 We know and act on the person's end of life decisions
- 1.5 We know and respond to how the person communicates
- 1.6 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life
- 1.12 We support the person to share or record important memories
- 1.13 We ensure there is a record of how the person wants to be remembered after they have died
- 2.1 The environment is welcoming and homely
- 2.2 People have their personal possessions around them
- 2.4 There are opportunities for privacy
- 3.1 The people who matter to the person have good information
- 3.2 People who matter to the person contribute their knowledge and expertise
- 3.3 We support the person's important relationships to continue and develop
- 4.1 Knowledge, skills and understanding of person-centred practices at end of life
- 4.2 Supporting team members individually to use person-centred practices at end of life
- 5.1 Clear purpose
- 5.2 An agreed way of working that reflects values
- 5.3 People know what is important to each other and how to support each other

- 5.4 Colleagues know what is expected of them
- 5.6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
- 5.9 Learning and development
- 5.10 Supervision

6 Care after death

- 1.1 We see and treat the person as an individual, with dignity and respect
- 1.13 We ensure there is a record of how the person wants to be remembered after they have died
- 2.1 The environment is welcoming and homely
- 2.2 People have their personal possessions around them
- 2.4 There are opportunities for privacy
- 3.1 The people who matter to the person have good information
- 3.2 People who matter to the person contribute their knowledge and expertise
- 3.3 We support the person's important relationships to continue and develop
- 4.1 Knowledge, skills and understanding of person-centred practices at end of life
- 4.2 Supporting team members individually to use person-centred practices at end of life
- 5.1 Clear purpose
- 5.2 An agreed way of working that reflects values
- 5.3 People know what is important to each other and how to support each other
- 5.4 Colleagues know what is expected of them
- 5.10 Supervision

Advance care planning (ACP) –a voluntary process of discussion about future care between an individual and their care providers

Where this is addressed in Progress for Providers End of life

Section One

- 1.5 We know and have a record of each person's gifts and qualities. We use a variety of ways to communicate how we value each person. We use the information about what we know about individuals in their day-to-day support. People are described and treated respectfully and positively, as individuals, by all staff.
- 2.5 We pride ourselves that people experience the best quality of life which is possible for them, whatever the stage of their illness. We recognise when a person is in emotional pain or distress and support them with this. We know what is important to each person. This is clearly recorded and includes specific information, for example, routines, relationships, sexuality, spirituality, and interests. Each person has a one-page profile. Staff intentionally work to make sure that what is important to the person is happening purposefully and is present. Where there are obstacles to achieving this, these are shared with the relevant people who help to find ways around this.
- 3.3 We are trying to help some people think about their future and what we may need to do to help with this.
- 3.4 We help everyone who wants or is able to think about their future and what they may like to try or do. We have a record of this and actions that we are working on.
- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person, and take into account any issues of capacity.
- 4.2 We know if the person has had a conversation about Advanced Care Planning.
- 4.3 We ask each person questions about the end of their life decisions and check these are up to date and recorded.
- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
- 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').
- 5.5 We know and respond to how the person communicates. This is clearly recorded (for example, using communication charts, tools and aids) and staff know what a person means when they behave in certain ways and how staff should respond. When a person is unable to demonstrate a response to communication, staff will continue to use ways of communication that are respectful of privacy and dignity. The ways of communication used are kept up to date and used consistently by all staff. We use interpreters when required, and try to ensure that they are matched to the person.

- 6.4 The use of decision-making agreements and profiles is common, and we have many examples of people making decisions about what is important to them. We are struggling to ensure that this is for all people with capacity or communication issues. Staff are engaged and support people to record their decisions.
- 6.5 Staff know the decisions that are important to the person and how to support the person with these decisions. This is recorded, for example, in a decision-making agreement. We make sure each person gets representation if they need it, and use best interest discussions and meetings. We have supported some people to make decisions that we don't agree with and manage the tension in this. We support each person to extend the range and importance of the decisions that they make, to have more control over their life and death.
- 13.3 We talk to the person about all aspects of end of life, and this often includes how the person wants to be remembered.

Section Three

- 1.3 We know who the person wants to share information with. We have leaflets and information that we tell people about when they ask questions. We provide information about what is happening on notice boards and in a variety of ways.

NICE Quality standard for end of life care for adults 2011

Where this is addressed in Progress for Providers End of life

Section One

- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
- 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').

Statement 2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences

Where this is addressed in Progress for Providers End of life

Section One

- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.

- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this, and ensure this is reflected in their Advanced Care Plan.
- 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').
- 5.4 We use communication charts, tools and aids with the majority of the people we support who need them. Increasingly staff understand their own role in effective listening and communication.
- 5.5 We know and respond to how the person communicates. This is clearly recorded (for example, using communication charts, tools and aids) and staff know what a person means when they behave in certain ways and how staff should respond. When a person is unable to demonstrate a response to communication, staff will continue to use ways of communication that are respectful of privacy and dignity. The ways of communication used are kept up to date and used consistently by all staff. We use interpreters when required, and try to ensure that they are matched to the person.
- 6.4 The use of decision-making agreements and profiles is common, and we have many examples of people making decisions about what is important to them. We are struggling to ensure that this is for all people with capacity or communication issues. Staff are engaged and support people to record their decisions.
- 6.5 Staff know the decisions that are important to the person and how to support the person with these decisions. This is recorded, for example, in a decision-making agreement. We make sure each person gets representation if they need it, and use best interest discussions and meetings. We have supported some people to make decisions that we don't agree with and manage the tension in this. We support each person to extend the range and importance of the decisions that they make, to have more control over their life and death.

Section Three

- 1.4 We proactively make sure that people have good information about what is happening, with the explicit consent of the person (or within the person's best interest). We have interpreters or advocates who can help. We support people to have information and conversations about death and dying.
- 1.5 We have made sure that family and friends have information about death and dying. Family, friends and important people have all the information they need, with the person's consent (or within the person's best interest), when they want it, in everyday language. This is through a range of sources, such as one-to-one sharing, leaflets, bedside booklets, newsletters and social media. Family members and friends know what is happening generally, as well as in the life and death of their family member, and how to get support after death and in bereavement.
- 2.3 We make sure that we talk to the people who matter to the person and get all the information that they have for our records.
- 2.4 We work with the people who know the person well to learn about the person from their past as well as who they are today. We are sensitive to who the person wants us to talk to. We record this information in a person-centred way. We support the person to decide which family and friends to invite to reviews, if they choose.
- 2.5 We acknowledge the expertise of families and friends as those who know and care most about the person. We are led by the person about who they want to be involved in sharing information. Families and friends contribute to our understanding

of the person – for example the person’s history, communication preferences, knowing what matters to the person, their aspirations for the future, how they are best supported and their connection to the community. We proactively work with family and friends to enable them to contribute to person-centred reviews, for example, by arranging them at times that suit the family and actually providing care and support to the person if they choose.

Statement 3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment

Where this is addressed in Progress for Providers End of life

Section One

- 1.4 We describe people positively. We have recorded information about the qualities and strengths of each person we support. We don’t just record this, we try and use it in our day to day support and in our conversations with the person. Dignity is seen as everyone’s business, and every staff member sees themselves as a Dignity Champion.
- 1.5 We know and have a record of each person’s gifts and qualities. We use a variety of ways to communicate how we value each person. We use the information about what we know about individuals in their day-to-day support. People are described and treated respectfully and positively, as individuals, by all staff.
- 2.5 We pride ourselves that people experience the best quality of life which is possible for them, whatever the stage of their illness. We recognise when a person is in emotional pain or distress and support them with this. We know what is important to each person. This is clearly recorded and includes specific information, for example, routines, relationships, sexuality, spirituality, and interests. Each person has a one-page profile. Staff intentionally work to make sure that what is important to the person is happening purposefully and is present. Where there are obstacles to achieving this, these are shared with the relevant people who help to find ways around this.
- 3.4 We help everyone who wants or is able to think about their future and what they may like to try or do. We have a record of this and actions that we are working on.
- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
- 4.3 We ask each person questions about the end of their life decisions and check these are up to date and recorded.
- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
- 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own ‘Living Well – Thinking and Planning for the End of Your Life’).

Statement 4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment

Where this is addressed in Progress for Providers End of life

Section One

7.5 We pride ourselves that people have the best quality support. We know and act on how the person wants to be supported. This is clearly recorded, is detailed, specific to the person and staff use this to deliver individual support. The information includes the support people want in their routines, in relationships and interests. This includes support specific to the person's culture and religion. We review staff performance on their ability to provide support in the way that someone wants (e.g. as described in a one-page profile). We use a range of relevant resources (technology, equipment, advice, and people) to get our support right for the person. The person is as active in their own care as possible.

Section Two

4.5 The environment has plentiful and varied spaces for privacy. The person chooses where they want to be and is supported in this wherever possible. There are pleasant spaces both indoors and outdoors which allow privacy for the person and the people who matter to them (for example, their family, spiritual leader, solicitor, friends). There is privacy for the person and families after death. Staff understand the need for privacy, what this means to each person, and support the person to obtain it.

Statement 5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible

Where this is addressed in Progress for Providers End of life

Section One

- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
- 4.3 We ask each person questions about the end of their life decisions and check these are up to date and recorded.
- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
- 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').
- 10.3 We are committed to exploring ways of people being part of their communities, and we have started thinking about how to do this with a few people we support (for example, using community maps, recording gifts and presence to contribution).
- 10.4 We support some people to go out and be part of their community and we use person-centred thinking tools in the way that we approach this.

- 10.5 We support people to be involved in their community. We use community maps that show the places that are important to the person and we actively support people to be a part of their community and make a contribution in whatever way works for them.
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Statement 6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences

Where this is addressed in Progress for Providers End of life

Section One

- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
- 4.3 We ask each person questions about the end of their life decisions and check these are up to date and recorded.
- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
- 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').
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Statement 7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences

Where this is addressed in Progress for Providers End of life

Section Three

- 1.3 We know who the person wants to share information with. We have leaflets and information that we tell people about when they ask questions. We provide information about what is happening on notice boards and in a variety of ways.
- 1.4 We proactively make sure that people have good information about what is happening, with the explicit consent of the person (or within the person's best interest). We have interpreters or advocates who can help. We support people to have information and conversations about death and dying.
- 1.5 We have made sure that family and friends have information about death and dying. Family, friends and important people have all the information they need, with the persons consent (or within the persons best interest), when they want it, in everyday language. This is through a range of sources, such as one-to-one sharing, leaflets, bedside booklets, newsletters and social media. Family members and friends know what is happening generally, as well as in the life and death of their family member, and how to get support after death and in bereavement.

Statement 8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences

Where this is addressed in Progress for Providers End of life

Section One

- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
 - 4.3 We ask each person questions about the end of their life decisions and check these are up to date and recorded.
 - 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
 - 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').
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Statement 10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night

Where this is addressed in Progress for Providers End of life

Section One

- 3.4 We help everyone who wants or is able to think about their future and what they may like to try or do. We have a record of this and actions that we are working on.
 - 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
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Statement 11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication

Where this is addressed in Progress for Providers End of life

Section One

- 3.5 We know what people want in the future – their dreams, hopes and aspirations, and what they do not want to happen in what is likely to be their final year of life. We have gathered this information from the person and those who know, love and care about them. We are clear about our role in this and how to support the person to make changes themselves. We review progress with the person or those who matter to the person and take into account any issues of capacity.
- 4.3 We ask each person questions about the end of their life decisions and check these are up to date and recorded.

- 4.4 We spend time with the person to talk about their decisions for the end of their life. We know what we need to do to help them with this and ensure this is reflected in their Advanced Care Plan.
 - 4.5 We know what the person wants at the end of their life. We have gathered this information from the person and those who know, love and care about them. There are specific measurable, achievable and timely actions for us to help people achieve their wishes. We are clear about our role in this and how to support the person to make their own decisions. We review progress with the person. We have person-centred advance decision-making processes in place for end of life care and arrangements (e.g. the individual has their own 'Living Well – Thinking and Planning for the End of Your Life').
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Statement 14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences

Where this is addressed in Progress for Providers End of life

Section One

- 5.4 We use communication charts, tools and aids with the majority of the people we support who need them. Increasingly staff understand their own role in effective listening and communication.
- 5.5 We know and respond to how the person communicates. This is clearly recorded (for example, using communication charts, tools and aids) and staff know what a person means when they behave in certain ways and how staff should respond. When a person is unable to demonstrate a response to communication, staff will continue to use ways of communication that are respectful of privacy and dignity. The ways of communication used are kept up to date and used consistently by all staff. We use interpreters when required, and try to ensure that they are matched to the person.

Section Three

- 1.3 We know who the person wants to share information with. We have leaflets and information that we tell people about when they ask questions. We provide information about what is happening on notice boards and in a variety of ways.
 - 1.4 We proactively make sure that people have good information about what is happening, with the explicit consent of the person (or within the person's best interest). We have interpreters or advocates who can help. We support people to have information and conversations about death and dying.
 - 1.5 We have made sure that family and friends have information about death and dying. Family, friends and important people have all the information they need, with the persons consent (or within the persons best interest), when they want it, in everyday language. This is through a range of sources, such as one-to-one sharing, leaflets, bedside booklets, newsletters and social media. Family members and friends know what is happening generally, as well as in the life and death of their family member, and how to get support after death and in bereavement.
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Statement 15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers

Where this is addressed in Progress for Providers End of life

Section Four

- 1.3 I have a plan to develop our understanding of person-centred practices at end of life and some of the team have begun to use person-centred thinking tools and approaches. We have started to look at some of the information available on person-centred thinking (for example, Michael Smull's podcasts on YouTube).

- 1.4 I am using person-centred practices myself, and all the team know and are successfully using several of the tools. I have a one-page profile and so do each of the team, and we are using this in our work together.
- 1.5 We all have our own one-page profile and we use this to inform our practice, and we are all confident and competent in using person-centred thinking tools. Everyone can describe at least 5 person-centred thinking tools (why and how you can use them and the benefits to the person) and talk about their experience of using them and the outcomes doing so achieved. As a manager, I demonstrate enabling the people who are supported to have as much choice and control as possible in their lives. I do this by working in a consistently person-centred way and proactively and competently using person-centred thinking tools in all areas of end of life care.

Section Five

- 2.5 The team has a shared set of beliefs or values which underpin its work, and agreed ways of working that reflect these. These reflect working in a person-centred way and include working in ways that ensure people have maximum choice and control in their lives, as part of their local community. The team principles and ways of working are clearly documented (for example, ground rules, team charter, person-centred team plan, team procedure file etc.). The team regularly evaluates how it is doing against these agreed ways of working (for example by using what is working and not working from different perspectives).

Statement 16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support

Where this is addressed in Progress for Providers End of life

Section Five

- 6.5 Decisions about who works with whom are based on both who the person supported wants, as well as who has the skills to support them (for example, named nurse or keyworker). Where the team leader makes this decision, it is also based on which colleagues get on the best with different individuals. This takes into account what the person and individual colleagues have in common (for example, a shared love of trains and railways), as well as personality characteristics (for example, gregarious people and quieter people). Rotas are flexible and adapted to account for individual and/or complex need and matched with colleagues with necessary skills.

Preferred Priorities of Care

Where this is addressed in Progress for Providers End of Life

A tool used to discuss and record a person's end of life care wishes. Health – what has been happening to you?

Section One
1.11 We support the person to be as comfortable as possible, promoting their quality of life

Preferences and priorities for your future care

Section One
1.2 We know and act on what matters to the person now
1.3 We know and act on what the person wants and does not want in the future
1.4 We know and act on the person's end of life decisions
1.7 We know and act on exactly how the person wants to be supported in everyday life

Future Care

Section One
1.2 We know and act on what matters to the person now
1.3 We know and act on what the person wants and does not want in the future
1.4 We know and act on the person's end of life decisions
1.6 The person is supported to make choices and decisions in everyday life
1.7 We know and act on exactly how the person wants to be supported in everyday life
1.11 We support the person to be as comfortable as possible, promoting their quality of life

Contacts

Section Three
3.2 People who matter to the person contribute their knowledge and expertise
3.3 We support the person's important relationships to continue and develop

**Adult Social Care
Outcomes Framework
(ASCOF)**

**Where this is addressed in
Progress for Providers End of Life**

Domain 1: Enhancing quality of life for people with care and support needs.

Outcome measure: People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.

- Section One
- 1.2 We know and act on what matters to the person now
 - 1.3 We know and act on what the person wants and does not want in the future
 - 1.4 We know and act on the person's end of life decisions
 - 1.6 The person is supported to make choices and decisions in everyday life
 - 1.7 We know and act on exactly how the person wants to be supported in everyday life
 - 1.8 We know what is working and not working for the person, and we are changing what is not working

People who use services and their carers have as much social contact as they would like

- Section One
- 1.9 We support people in their family relationships and friendships
 - 1.10 We support the person to be part of their community
- Section Two
- 2.3 Meal times are pleasurable and flexible occasions
- Section Three
- 3.3 We support the person's important relationships to continue and develop

Domain 2: Delaying and reducing the need for care and support. Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs.

- Section One
- 1.2 We know and act on what matters to the person now
 - 1.4 We know and act on the person's end of life decisions
 - 1.5 We know and respond to how the person communicates
 - 1.6 The person is supported to make choices and decisions in everyday life
 - 1.7 We know and act on exactly how the person wants to be supported in everyday life
 - 1.8 We know what is working and not working for the person, and we are changing what is not working
 - 1.11 We support the person to be as comfortable as possible, promoting their quality of life
- Section Three
- 3.1 The people who matter to the person have good information

When people develop care needs, the support they receive takes place in the most appropriate setting and enables them to regain their independence.

Section One

- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.10 We support the person to be part of their community
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life

Section Two

- 2.1 The environment is welcoming and homely
- 2.4 There are opportunities for privacy

Domain 3: Ensuring that people have a positive experience of care.

Carers feel that they are respected as equal partners throughout the care process

Section One

- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships

Section Three

- 3.1 The people who matter to the person have good information
- 3.2 People who matter to the person contribute their knowledge and expertise

Section Two

- 2.4 There are opportunities for privacy
- 2.3 Meal times are pleasurable and flexible occasions

Section Three

- 3.3 We support the person's important relationships to continue and develop

People including those involved in making decisions on Social Care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.

Section Four

- 4.1 Knowledge skills and understanding of person-centred practices at end of life

Section Five

- 5.2 An agreed way of working that reflects values.
 - 5.4 Colleagues know what is expected of them
 - 5.6 Rota's – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
 - 5.10 Supervision
-

**Domain 4: Safeguarding
Adults whose
circumstances make them
vulnerable and protecting
from avoidable harm.**

**People are supported to
plan ahead and have the
freedom to manage risks
the way that they wish.**

Section One

- 1.3 We know and act on what the person wants and does not want in the future
- 1.4 We know and act on the person's end of life decisions
- 1.5 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life
- 1.12 We support the person to share or record important memories
- 1.13 We ensure there is a record of how the person wants to be remembered after they have died

Section Five

- 5.8 Enabling risk
- 5.9 Learning and development

1. Information and advice: having the information I need, when I need it.

“I have the information and support I need in order to remain as independent as possible.”

“I have access to easy-to-understand information about care and support which is consistent, accurate, accessible and up to date.”

“I can speak to people who know something about care and support and can make things happen.”

“I have help to make informed choices if I need and want it.”

“I know where to get information about what is going on in my community.”

Section One

1.6 The person is supported to make choices and decisions in everyday life

1.9 We support people in their family relationships and friendships

Section Three

3.1 The people who matter to the person have good information

2 Active and supportive communities: keeping friends, family and place.

“I have access to a range of support that helps me to live the life I want and remain a contributing member of my community.”

“I have a network of people who support me – carers, family, friends, community and if needed, paid support staff.”

“I have opportunities to train, study, work or engage in activities that match my interests, skills and abilities.”

“I feel welcomed and included in my local community.”

“I feel valued for the contribution that I can make to my community.”

Section One

1.9 We support people in their family relationships and friendships

Section Three

3.2 People who matter to the person contribute their knowledge and expertise

Section Five

5.2 An agreed way of working that reflects values

5.4 Colleagues know what is expected of them

3 Flexible integrated care and support: my support, my own way.

“I am in control of planning my care and support.”

“I have care and support that is directed by me and responsive to my needs.”

“My support is co-ordinated, co-operative and works well together and I know who to contact to get things changed.”

“I have a clear line of communication, action and follow up.”

Section One

- 1.1 We see and treat the person as an individual, with dignity and respect
- 1.2 We know and act on what matters to the person now
- 1.3 We know and act on what the person wants and does not want in the future
- 1.5 We know and respond to how the person communicates
- 1.6 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships
- 1.11 We support the person to be as comfortable as possible, promoting their quality of life

Section Three

- 3.2 People who matter to the person contribute their knowledge and expertise

Section Five

- 5.1 Clear purpose
- 5.6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
- 5.7 Recruitment and selection is person-centred

4 Workforce: my support staff.

“I have good information and advice on the range of options for choosing my support staff.”

“I have considerate support delivered by competent people.”

“I have access to a pool of people, advice on how to employ them and the opportunity to get advice from my peers.”

“I am supported by people who help me to make links in my local community.”

Section One

- 1.1 We see and treat the person as an individual, with dignity and respect

Section Three

- 3.2 People who matter to the person contribute their knowledge and expertise

Section Four

- 4.1 Knowledge, skills and understanding of person-centred practices at end of life
- 4.2 Supporting team members individually to use person-centred practices at end of life

Section Five

- 5.1 Clear purpose
- 5.2 An agreed way of working that reflects values

- 5.3 People know what is important to each other and how to support each other
- 5.4 Colleagues know what is expected of them
- 5.5 Colleagues feel that their opinions matter
- 5.6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
- 5.7 Recruitment and selection is person-centred
- 5.8 Enabling risk
- 5.9 Learning and development
- 5.10 Supervision
- 5.11 Appraisal and Personal Development Plans
- 5.12 Meetings

5 Risk enablement: feeling in control and safe.

“I can plan ahead and keep control in a crisis.”

“I feel safe, I can live the life I want and I am supported to manage any risks.”

“I feel that my community is a safe place to live and local people look out for me and each other.”

“I have systems in place so that I can get help at an early stage to avoid a crisis.”

Section One

- 1.1 We see and treat the person as an individual, with dignity and respect
- 1.2 We know and act on what matters to the person now
- 1.3 We know and act on what the person wants and does not want in the future
- 1.5 We know and respond to how the person communicates
- 1.6 The person is supported to make choices and decisions in everyday life
- 1.7 We know and act on exactly how the person wants to be supported in everyday life
- 1.8 We know what is working and not working for the person, and we are changing what is not working
- 1.9 We support people in their family relationships and friendships

Section Four

- 4.1 Knowledge, skills and understanding of person-centred practices at end of life
- 4.2 Supporting team members individually to use person-centred practices at end of life

Section Five

- 5.1 Clear purpose
- 5.2 An agreed way of working that reflects values
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- 5.6 Rotas – colleagues are thoughtfully matched to people and rotas are personalised to people who are supported
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- 5.8 Enabling risk
- 5.9 Learning and development
- 5.10 Supervision
- 5.11 Appraisal and Personal Development Plans
- 5.12 Meetings

6 Personal budgets and self-funding: my money.

“I can decide the kind of support I need and when, where and how to receive it.”

“I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it’s my own money, direct payment, or a council managed personal budget).”

“I can get access to the money quickly without having to go through over-complicated procedures.”

“I am able to get skilled advice to plan my care and support, and also be given help to understand costs and make best use of the money involved where I want and need this.”

Section One

- 1.3 We know and act on what the person wants and does not want in the future
- 1.6 The person is supported to make choices and decisions in everyday life

Section Five

- 5.4 Colleagues know what is expected of them



Section

Publication

Section 1 The person

A Practical Guide to Delivering Personalisation – Person-Centred Practice in Health and Social Care
www.hsapress.co.uk/publications/books.aspx
Living Well – Thinking and Planning for the End of your Life
www.helensandersonassociates.co.uk/media/38837/livingwellweb-final.pdf

Section 2 The environment

The Kings Fund Enhancing the healing environment (EHE) – Hospices brochure
www.kingsfund.org.uk/sites/files/kf/ehe-hospices-capital-grant-programme-brochure-2012.pdf
The Kings Fund Enhancing the healing environment brochure
www.kingsfund.org.uk/sites/files/kf/field/field_gt_document_link/enhancing-healing-environment-2012-brochure.pdf
Protected mealtimes & Patient safety (NPSA)
www.dignityincare.org.uk/_library/Protected_Mealtimes.pdf

Section 3 Friends, family and relationships

SCIE – Dying well at home guide
www.scie.org.uk/publications/guides/guide48/index.asp

'Living without Emma'
www.amazon.co.uk/dp/0091923743
and 'I want my mummy back' both by Jon Nicholson
www.amazon.co.uk/Want-My-Mummy-Back-Familys/dp/0091923735/ref=pd_sim_b_2

Section 4 Person-centred practices

Habits for highly effective staff – making person-centred thinking a habit
www.helensandersonassociates.co.uk
Department of Health Guidance (2010). Personalisation through person-centred planning
www.dh.gov.uk

Section 5 Creating a person-centred culture

Person-centred organisations – what are we learning?
www.helensandersonassociates.co.uk



Web resources

NPCPC (2006). End of Life Care Strategy –The National Council for Palliative Care Submission. National Council for Palliative Care, August 1st 2006.
www.endoflifecare.nhs.uk/assets/downloads/Social_Care_Framework.pdf
<http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13>
www.endoflifecare.nhs.uk/assets/downloads/pubs_Advance_Care_Planning_guide.pdf
[www.nhs.uk/Livewell/Endoflifecare/Documents/Planning_your_future_care\[1\].pdf](http://www.nhs.uk/Livewell/Endoflifecare/Documents/Planning_your_future_care[1].pdf)
www.endoflifecare.nhs.uk/tools/core-tools/preferredprioritiesforcare
www.patientexperience.co.uk/understanding-the-patient-experience/patient-experience-and-nhs-outcomes-framework/

The Kings Fund – Enhancing the Healing Environment www.kingsfund.org.uk/projects/enhancing-healing-environment
 Social Care Institute for Excellence (SCIE) Dignity – Eating and Nutrition www.scie.org.uk/publications/guides/guide15/factors/nutrition/index.asp
 SCIE – Dignity – Privacy www.scie.org.uk/publications/guides/guide15/factors/privacy/index.asp
 SCIE – Dignity – Social inclusion www.scie.org.uk/publications/guides/guide15/factors/socialinclusion/index.asp
 The Kings Fund – National End of Life Care Programme www.endoflifecare.nhs.uk/assets/downloads/RTS_Environments_final.pdf
 gov.uk – Guidance on patient-led assessments www.gov.uk/government/news/guidance-on-patient-led-assessments

What Matters Now – an online space for those with life changing illness to keep families and friends up to date www.whatmattersnow.org/
 Booklet about home care for a hospice patient www.partnersagainstpain.com/patient-resources/Home%20Care%20of%20the%20Hospice%20Patient.pdf
 Macmillan Cancer Support www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunication/Relationshipscommunication.aspx
 NHS Choices www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx
 How to Care for Carers via eHospice www.ehospice.com/uk/ArticlesList/Howtocareforcarers061113015427/tabid/7131/ArticleId/5217/language/en-GB/View.aspx
 The new normal isn't normal (illness changes everything) <http://blog.chron.com/loveandrelationships/2011/12/the-new-normal-isn%E2%80%99t-normal-illness-changes-everything/>
 The needs of carers www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/Topic/1197/

Michael Smull. A series of films on each person-centred thinking tool www.youtube.com/user/helensandersonHSA
 Think and Plan – a free website for people to use person-centred thinking online. www.thinkandplan.com
 Mary Beth Lepkowsky. A series of films on person-centred coaching. www.youtube.com/user/helensandersonHSA

Michael Smull films for managers. 'A Rock in a Pond' and 'Person-centred plans that make a difference'. www.youtube.com/user/helensandersonHSA



Courses or consultancy

Person-centred thinking tools at end of life
www.helensandersonassociates.co.uk

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www.helensandersonassociates.co.uk

Carers courses – information link via NHS Choices www.nhs.uk/CarersDirect/workandlearning/learning/Pages/courses-for-carers.aspx
 Carers Trust – information on courses and support www.carers.org/
 Carers Direct www.nhs.uk/Carersdirect/Pages/CarersDirectHome.aspx

Person-centred thinking for managers – Transforming Teams
www.helensandersonassociates.co.uk

Transforming teams, Person-centred teams, Positive and productive meetings, Person-centred supervision, Person-centred risk, Person-centred recruitment.
www.helensandersonassociates.co.uk

