Better Lives, Better Endings

A suite of resources for staff in extra care housing

March 2022

The results of a project co-run by **Octavia** and **St Christopher's CARE** and funded by **Women in Fellowship**

About the organisations

St Christopher's Hospice is a charity providing health and social care for people approaching the end of their lives. The organisation was established by Dame Cicely Saunders who is credited with establishing the modern hospice movement over 50 years ago.

Octavia is a not-for-profit organisation that provides homes, support and care to thousands of people in central and west London. Founded by the Victorian philanthropist Octavia Hill in the 1860s, they support Londoners of all ages, giving them opportunities that will help them lead a better life. Octavia operates seven extra care housing schemes across west London.

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Better Lives, Better Endings project team: the project co-leads are Neil McCarthy, Assistant Director (Care, Support and Communities), Octavia and Liz Bryan, Senior Associate, St Christopher's CARE. Antonia Bunnin is Project Facilitator, and Lianne Joy, Head of Care Quality at Octavia is a key member of the team.

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Introduction

Introduction

This publication is part of *Better Lives, Better Endings*, a collaboration between St Christopher's and Octavia. We initiated the *Better Lives, Better Endings* project to explore how staff and residents in extra care housing might be empowered to improve residents' quality of life and experiences at the end of life.

Why we created this publication

The purpose of this publication is to share resources that help extra care staff think and talk about the nature of death, dying loss and grief for residents, as well as factors that can improve their quality of life. We have shared the story of our approach, and how we have used some of these resources, in the hope that they will act as an inspiration (not a prescription!) to others.

Through our joint work, we recognised the need for a collation of resources that are meaningful to busy staff who care deeply about improving residents' quality of life and experience of death, but who don't have the time or desire to study academic articles or lengthy reports. Our emphasis is on resources that are 'bite-sized' and easy to use. We have included resources in a variety of formats: short films, case studies, tools and templates.

Who is it for?

Our publication is for anyone working in extra care or other supported housing settings where care is provided. Individuals can use it to deepen their understanding of death, dying, grief and end of life care and ways of supporting residents throughout their time living in extra care housing. We think it will be particularly useful when used by a whole team or organisation to learn, discuss and explore together, and consider what changes to introduce in their own workplace.

The publication is also for hospices and other expert providers of palliative and end of life care. We hope they may use it to inform their own relationships with extra care and housing associations. It could be used to support educational work, or it might stimulate hospices and housing providers to initiate new local collaborations.

What is extra care housing?

'Extra care' means housing made up of self-contained homes (usually flats) with design features and support services available to enable self-care and independent living. Extra care comes in different forms, and is sometimes described as: 'housing with care', 'very sheltered housing', 'retirement villages' or 'retirement communities'. People living in extra care may be tenants, owners or part-owners. Extra care housing is used by older people, people with learning disabilities, people with physical disabilities and people with dementia[1].

A co-designed approach

From the outset we took a co-designed approach to creating the *Better Lives, Better Endings* programme. Extra care staff undertake significant amounts of mandatory training, often focused on factual knowledge that they are expected to memorise then apply in specified circumstances. We took a fundamentally different approach: one that emphasises reflection, open discussion, practice-based learning and real-life application. We began by asking extra care staff about their experiences and concerns, as well as talking to Octavia's residents. As we were designing the staff development programme, we involved Octavia staff throughout in shaping the programme to address their needs. Our aim was not to impart a set of facts, but for staff to gain confidence, skills, knowledge and a greater sense of agency in supporting residents to have better lives and better endings. We say more about our co-design approach in **Theme 1: Recognising the need for cultural change**.

How to use this publication

The publication is organised into several themes. For each theme, we talk about:

- Why it is important
- What we did in the *Better Lives, Better Endings* programme
- Putting change into practice – what Octavia is doing
- Useful resources.

We also share insights from Octavia extra care staff – sometimes about issues and challenges they have experienced, and sometimes about the impact of the *Better Lives, Better Endings* programme and resulting changes in practice.

There is no single way to use this publication. You can read it all the way through, or dip in theme by theme.

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[1] The Housing LIN gives more information about extra care: **https://www.housinglin.org.uk/Topics/browse/HousingExtraCare/**

We have shared the outline of our pilot nine-week staff development programme, not to be prescriptive, but in the hope that it may stimulate others interested to design their own learning programmes with extra care staff. We suggest you view the resources using the hyperlinks; you may want to use these in your own workplace or seek out additional resources of your own.

Some of the ways that we envisage the publication being used are:

- To stimulate thinking for people designing structured learning programmes with extra care staff, or other staff in care and support roles
- To support use of the Care Certificate[2] during inductions and with existing staff
- To offer groups of staff a starting point and 'way in' for discussing and doing some work on a particular theme or topic
- Through sharing ideas about what changes can be made, to inspire action and change elsewhere
- For work-based discussion groups/learning groups, to consider together
- For hospices and extra care providers to consider creating new collaborative relationships.

About the *Better Lives, Better Endings* project

Octavia and St Christopher's began *Better Lives, Better Endings* in autumn 2019, following other joint work between our organisations. Our project's focus was on facilitating conversations, decisions and plans for how people in extra care housing want to live in the last years of life, then making sure people's wishes are understood, documented and acted on. Doing this effectively meant drawing on the voices and experiences of people living in extra care housing, and of the staff who support them. A key element was to develop and test a programme for extra care staff to build skills and confidence around difficult conversations, advance care planning and engagement with the health system and others, to enable residents to achieve their wishes.

Our underpinning premise is that if individuals coming to the end of their lives have identified their ambitions and goals for the last years of life and articulated them clearly, then people around them (staff, volunteers, family members, friends and the people they live with) can help them achieve these. They will have greater choice and feel greater control; all involved will feel empowered in their efforts to help individuals live well.

Better Lives, Better Endings was originally intended as a one-year project, with significant co-design by residents as well as staff. Five months in, the arrival of Covid-19 threw our plans into upheaval. We paused the project whilst Octavia staff focused on the huge immediate challenges of running services during the first wave. After exploring various possibilities, we reluctantly recognised that ongoing engagement with residents was no longer realistic given Covid-19 restrictions. We decided to use the findings from our initial work with residents, but focus the remaining project on co-design with staff. In July 2020, Liz, the St Christopher's co-lead, ran three online hour-long evening sessions for staff at two of Octavia's extra care schemes, including reflection, guidance and discussion based on real people that staff had cared for. This was a response to Covid-19 and not formally part of the project, but was valuable in informing our subsequent nine-week programme.

In May, June and July 2021, we tested the nine-week *Better Lives, Better Endings* programme with 26 staff. From the outset we stressed that this was not a traditional training programme. Participants came from all seven Octavia extra care schemes: managers, deputy managers, team leaders, and care staff as well as the newly-formed central quality team. The continuing pandemic meant we ran it online using zoom, in two-hour sessions over eight consecutive weeks, with a ninth week for reflections and feedback. In between sessions, participants were given short activities to complete. We held a further session six months later, in November 2021, to discuss what difference the programme was making for individual staff, at workplace level in different extra care schemes and most importantly, for residents.

Better Lives, Better Endings is situated as part of Octavia's wider agenda of transformation and culture change. It is part of embedding a shift from task-based to relationship-based care and support. It is not just about end of life, but about exploring how staff can better support residents throughout their whole time at Octavia. The aim is to ensure that care and support for each resident reflects an understanding of what is important to that person and their individual needs, preferences and wishes as they age, experience change and prepare for their end of life. As our work evolves, it is ever clearer how this cultural change is essential to creating the conditions for staff to feel confident to talk openly with residents about death, dying and loss and empowered to respond to those conversations in meaningful ways.

Our Housing LIN case study gives more information about the collaboration: https://www.housinglin.org.uk/Topics/type/Better-Lives-Better-Endings-A-collaboration-between-extra-care-housing-and-a-hospice/

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[2] The Care Certificate was developed jointly by Skills for Care, Health Education England and Skills for Health. It sets out 15 standards that are expected of health and care staff in certain roles, and that should be addressed in induction programmes. We have mapped our themes to the Care Certificate Standards in the section Mapping our themes to the Care Certificate standards.

Context and need

The UK has an ageing population. Increasing numbers of people are living with a long-term health condition, and often with several conditions at the same time (multimorbidity). This includes people living with frailty, and those in the last 12 months of life who may have non-reversable conditions such as dementia, advanced heart disease or progressive neurodegenerative disease.

Organisations that provide extra care housing – along with the rest of the health and care system – are responding to the increasing complexity and higher levels of need in the people they support. Whereas in the past extra care providers might have required someone to move out to a nursing home if their health deteriorated and their needs rose, now increasingly extra care providers are offering a home for life. For many residents of extra care, their home is the place where they would prefer to die.

Extra care is adapting to society's demographic changes by increasing the skills and capabilities of staff, to equip them to provide care and support for people as their needs change, right up to the end of life and as they die. As the Housing LIN[3] says:

"Dying is not just a physical reality, but a social event too and it is important to address the emotional, social, cultural and spiritual needs of people and their families. Providing effective, high-quality care for someone during the end of their life is a highly-skilled role and a challenging one. While it's a team effort and does not all fall upon the shoulders of one individual, without support and information, staff and informal carers can find the experience overwhelming."

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[3] The Housing LIN gives more information about extra care: https://www.housinglin.org.uk/Topics/browse/HousingExtraCare/

Theme 1: Recognising the need for cultural change

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Why it is important

The *Better Lives, Better Endings* project grew from an existing relationship between Octavia and St Christopher's. It was soon apparent that our organisations had similar values, but differing experience and skills. Both also recognised the need to evaluate effectiveness and, if necessary, to change. This openness to change on both parts played a key role in the approach to creating *Better Lives, Better Endings*.

Octavia was increasingly aware of the importance of providing supported housing for people right up to the end of their lives, and ensuring a good quality of life to the end. However, in practice Octavia was finding best efforts were being frustrated by blocks and obstacles, without really understanding the root causes. Frontline staff often felt powerless, with little confidence or agency when supporting people at the end of life. Staff wanted to act as advocates for residents, but felt ignored or over-ridden by external health and care services. St Christopher's was increasingly aware of the need to share its expertise with partner organisations, in ways that empower others and enable them to significantly improve the experience of people in their care at the end of life.

Better Lives, Better Endings offered both organisations an opportunity to experiment. We knew we had a lot to learn from each other. We also recognised that to gain lasting benefit from the project, both organisations must be open to adapting and working in new ways.

St Christopher's CARE: approach to learning

St Christopher's approach to supporting learning is based on four principles: learning must be **collaborative**, **current**, **challenging** and **context-specific**. It should also be underpinned by positive ongoing relationships. Learning that results in real and sustainable change is transformative: the 'meaning perspectives' of both individuals and teams have been changed or transformed so they are more likely to be able to change behaviours.

To facilitate learning that would be transformative as part of *Better Lives, Better Endings* we endeavoured to:

1. establish a safe environment for staff to share their perspectives
2. provide engaging and varied ways of presenting the content so that staff could make their own sense of what they were hearing and seeing
3. encourage staff to discuss and critically evaluate the material that was presented. We invited staff to relate the material and discussions to their own experiences, care settings and extra care schemes
4. provide opportunities for reflection, including space to explore any changes to their original perspectives
5. challenge staff to identify actions that they could take to put their learning into practice

What we did in the *Better Lives, Better Endings* programme

We began our project by speaking with staff and residents. Two residents took part in sessions with a Creative Facilitator, using collage to share something of their lives, families and friendships, priorities and wishes for the future. Both residents found the sessions rewarding and we would have held more, had Covid-19 not intervened. Some residents were keen to talk about their hopes and wishes for the end of life, and have these documented so they could be acted on. Many residents spoke about their current quality of life, citing loneliness, isolation, boredom, and limited mobility. This reinforced the importance of focusing on both 'better lives' and 'better endings'.

We spoke with 28 extra care staff in a range of roles. Some were eager for more open conversations with residents about death, dying and future wishes. Others were reluctant, because it made them feel uncomfortable or they feared upsetting residents and families. We heard about the long-standing relationships with residents, often formed over years. When residents are seriously ill or dying, staff are often anxious and lack confidence in caring or advocating for them. When residents die, staff grief can be strong and lasting, sometimes heightened by lack of systematic support. These conversations with staff provided the basis for deciding together the key themes for the staff development programme.

In July 2020, our Project Co-Lead ran a mini-programme of three one-hour sessions: *Ensuring Dignified and Compassionate Care at the End of Life at Octavia*. These were for staff at two extra care schemes wanting expert support in light of experiences during the pandemic. These were interactive and discussion-based. Drawing on recent situations, we considered what aspects had gone well, what might have been done better, and what needs to change to support more person-centred care at the end of life. These discussions and the ideas they generated informed the nine-week programme.

Drawing on everything we had learnt from the earlier stages, we worked with Octavia staff in designing the nine-week programme. We sought staff involvement in deciding what would be most valuable and what to include, at the first session and iteratively throughout the eight weeks and afterwards. We held a ninth session for staff reflection and feedback at the end of the programme, and a further follow-up session six months later. We invited staff to feel free to share comments by email, phone or text. We spoke openly throughout about testing the programme and wanting to learn from participants about whether it was meeting their needs and how it could be improved.

Putting change into practice: what Octavia is doing

Wider organisational change Octavia realised that to have lasting effect, *Better Lives, Better Endings* must be part of a wider shift across the organisation, away from task-based care, and towards relationship-based care. In early 2021, Octavia established a Quality Team of three people, working across all the extra care schemes to support and embed these changes in culture and ways of working.

Staff ideas for change Near the end of the nine-week programme, staff identified ideas for change to try out individually and in teams. In keeping with the ethos of co-design, it was important that these ideas came from staff themselves, and that they be supported and encouraged – not told – to try putting them into practice. Each extra care scheme came up with at least one idea for change. Ideas varied across schemes, and included: creating a memorial garden; introducing music sessions with residents; setting up a residents' knitting group; introducing a Namaste programme for residents with dementia; strengthening relationships with GPs, local hospices and other parts of the health and care system; and creating a 'traffic light system' to incorporate into assessments and Care and Support Plans to more systematically identify residents with increasing levels of need.

Turning staff ideas into action Now the Octavia Quality Team is supporting teams in each scheme to put the changes into practice. Some are more complex than others, and some will take longer than others. Some ideas will be initiated by one scheme with the intention of piloting and rolling out if successful, across all schemes. But there is a desire and commitment to build on the enthusiasm of staff and to create meaningful change that will improve the lives of residents. The next themes contain more information about some of these changes.

> **"We had a good time, discussion, conversation, we were free to talk about what we feel, what concerns us, I think we were a good team together. And you [the facilitators] were good, we really appreciated it and enjoyed it. The difference is it was on zoom, not face to face, I think for myself I prefer face to face, you can discuss more, you can demonstrate things. But because of the situation we did appreciate that."**
> Reflections on the *Better Lives, Better Endings* programme, six months later

Useful resources

Website The Point of Care Foundation

The Point of Care Foundation has information about the principles and practice of co-design in health and care: https://www.pointofcarefoundation.org.uk/

Website and video (four minutes)
St Christopher's CARE

St Christopher's CARE webpage includes a video describing St Christopher's vision for supporting learning:
https://www.stchristophers.org.uk/about-care/

Theme 2: Understanding dying and what happens at the end of life

Theme 2: Understanding dying and what happens at the end of life

Why it is important

Staff wanted to learn about what happens at the end of life and when someone is dying. Many did not feel confident to identify that someone might be near the end of life, or understand what dying looks like and what to expect. Some were fearful of being with or providing care for dying residents. Even those who had cared for people as they were dying wanted to understand more, and contextualise their experiences. Staff recognised that demystifying death would help them feel able to talk more openly about these things with residents. It will also help them be more confident and knowledgeable when communicating with GPs, hospices and the ambulance service about sick residents.

What we did in the *Better Lives, Better Endings* programme

Our work with staff included reflecting together on the experience of death and dying from both a personal and a caregiver perspective. We invited staff to consider recent cases of residents who had died, as well as fictional case studies and scenarios. We discussed in small groups what staff would need in order to provide the best possible experience for residents as they approach the end of life. One was: an understanding of how to identify someone might be coming to the end of life, and what dying looks like. We talked about changes, signs and symptoms that might indicate that someone is coming to the end of their life, and what they mean. Staff reported often feeling 'helpless' when a resident is dying due to lack of knowledge and their perception that external medical professionals have control in these situations.

As part of the nine-week programme we shared the film by Dr Kathryn Mannix, *In my humble opinion – dying is not as bad as you think*. Guest speakers from the local hospice and from End of Life Doula UK talked to participants and answered questions. All of this helped to create reassurance and understanding that death can be gentle and peaceful, and that staff can gain confidence as they learn what to expect and how to best support dying residents.

Putting change into practice: what Octavia is doing

Confidence to talk about death and dying Staff who have been through the nine-week programme told us they feel more confident to talk about death and dying with residents, and to care for people who are dying.

End of life awareness as part of induction Octavia now believes that all extra care staff should have a basic level of understanding about dying, death, grief and end of life care. Octavia is developing content based on the themes of this publication which will become part of induction mapped to the standards of the Care Certificate for all extra care staff, to provide this foundation-level awareness.

"When we started [working in extra care], we were not aware of how advanced it would get, that we will be required to deal with end of life. We never had the education, the training, any workshops to deal with end of life. It was more about maintaining independence, they would set targets. All these years you don't come across a conversation about end of life. Now it is changed. There is more end of life now. Then, seven, eight years ago, it was that once someone deteriorated, then they would move to a care home. Their care package would change and they would move to a nursing home. Through the years that has changed, now it is their home to the end of their life."

"We used to have a tenant, and I used it [what I learnt on Better Lives, Better Endings] for that special time, at the end of his life. I was working at night and he was a very private person, but that night when I went to check on him, he wasn't like himself. I looked after him really well. He always said: 'how are you?' 'nice to see a smiling face' and this and that. That night he wasn't himself, all his clothes were on the floor, he was getting moody. I gave him water to drink, he said thank you. I didn't see him after that night, he had a fall and went to hospital and we didn't see him. He died after that night. After about three days. We knew he was going to die ... You think about the tenants, whether their life is ending, to give them good service, better service, you give the best care you can."

Useful resources

Video (four minutes) *In my humble opinion – dying is not as bad as you think*. BBC Ideas film (2019)

Palliative care doctor and author Dr Kathryn Mannix explains that in our society, death is no longer part of daily life. Many people do not know what the normal dying process looks like. We have become detached from death and scared to talk about it. She describes the gentle process of a normal death in clear, straightforward language and gives reassurance that death is probably not as bad as we have imagined.

https://www.youtube.com/watch?v=CruBRZh8quc

Video (11 minutes) *Holding Space.* mote of dust films (2018)

This short documentary is made by Rebecca Kenyon, an end of life doula and film-maker. It shows three people preparing for death, and the support they receive through their intimate and tender relationships with end of life doulas.

https://www.youtube.com/watch?v=l7nvTzDEwDQ

Theme 3: Relationship-based care in practice

Theme 3: Relationship-based care in practice

Why it is important

Good extra care is not just about meeting people's personal care and physical needs; it is about supporting their emotional, psychological and spiritual needs too. Like many extra care providers, Octavia has a varied mix of residents, each with their own distinct take on what's important to them, and what could improve their quality of life. Providing person-centred care means understanding each individual, and their personality, preferences, wants and needs. This may start with formal assessments, but it is through ongoing conversations and relationships that it builds into a rich picture and deep understanding of each person.

Previous work by Octavia found that supporting people with increasingly complex needs in extra care housing was having a significant emotional and physical impact on staff. Individuals and teams needed more time, support and space to manage the array of demands on them. Part of Octavia's response was a commitment to organisational change, supporting front line managers to provide a more holistic service through a shift from task-based to relationship-based care. The *Better Lives, Better Endings* programme is part of this change. Relationship-based care is more rewarding and meaningful for staff too.

What we did in the *Better Lives, Better Endings* programme

We wanted to move beyond 'worthy words' to explore what relationship-based care looks like in practice – to make it feel real and meaningful for staff. Early in the nine-week programme we asked participants to share thoughts about the differences between task-based care and relationship-based care, drawing on their own experiences to illustrate the contrasts.

Next we considered **Bob: a fictional case study illustrating the use of the Circles of Support tool**. During the five years that he lives in extra care housing, Bob's health deteriorates and his needs change. We talked about Bob at various stages of his time in extra care, including how he can be supported to live as he wishes, and eventually to die as he wishes.

We introduced **Circles of Support** (see **Guidelines and template for using the Circles of Support tool in extra care housing**) as a simple visual tool for thinking about the different people in our lives who are important to us, the different relationships we have with them, and ways that we might gain support from them. Staff talked about who might be in Bob's Circle of Support, and how this might change over time. We talked about how loneliness, loss, anxiety and deteriorating physical health might all affect Bob's Circle of Support – who is in it, and how close Bob feels to them. Everyone was invited to draw their own Circle of Support, for themselves and their life as it is now, and to bring it to share and discuss with the group.

We watched a video introducing the concept of **rehabilitative palliative care** and showing how dependency increases and the Circles of Support can decrease as we age or become frailer due to advancing illness. We discussed the importance of regularly reviewing a person's Circles of Support to ensure that what most matters to a person is understood and that staff act to help that person continue living as fully as possible until they die.

Later we considered the power of music to create emotional response and connection, including with people who are very frail or have dementia or limited communication. Participants watched the video ***Alive Inside***, showing a man called Henry who responds powerfully and movingly when played music he loves. They were asked to think how they might find ways to draw on the power of music and personalised playlists to enhance the quality of life of people living in Octavia's extra care schemes.

We invited two end of life doulas as speakers on the nine-week programme. They explained the concept of end of life doulas – people who offer presence, care, support, compassion and guidance to those nearing the end of life, and to those close to them. End of life doulas are not clinicians. They are not part of formal health and social care systems, but work with individuals and families to give practical and emotional support. They advocate for a different approach to end of life care, based on the centrality of relationships, demystifying dying, and being alongside people as they move towards death. We watched the film ***Holding Space***, and discussed how neither end of life doulas nor extra care staff are clinicians, but how both forge relationships with the people they are caring for.

Through talking with end of life doulas and discussing how music can enhance residents' lives, staff were able to see the immense value and potential of their relationships with residents. We wanted to show that you do not need to be a clinical expert to make a meaningful difference to people's lives and deaths – much of what makes a difference is about relationship and connection, rather than medical knowledge.

Putting change into practice: what Octavia is doing

Using Circles of Support Octavia is integrating Circles of Support into its Care and Support Plans, recognising that as residents become frailer, or illness progresses, their capacity to do things for themselves can diminish and social circles can shrink, risking social isolation. Staff will work with all extra care residents: asking who are the people most important to the resident, and having conversations about the role each plays in their life and the kinds of support they derive from them. Together, the resident and staff member will use the Circle of Support tool to capture this information visually; these will be treated as dynamic documents and updated as residents' lives, needs and relationships change. Staff will act on what they learn: finding new ways to support residents to maintain their interests, continue contact with those important to them, or to engage with new people, for example through befriending schemes.

The power of music Staff have been inspired to introduce more music into the daily life of the different extra care schemes.

"They are playing music a lot now throughout the day, and you can see a difference with residents, they want to come into the communal area more. One scheme has an opera group coming in, with singers and musicians. It is really lovely for the residents and the staff. But it doesn't need to be live music, they are also sometimes just playing a CD or something, it can be very simple."

"The idea of the personalised music: you just assumed someone likes Elvis because they are elderly. But you might play some crazy music, something totally different, and they get up and are dancing all of a sudden!"

"The musical thing we tried, with a tenant who passed away, he loved music. A woman was really depressed, she was not eating or drinking, she was getting dehydrated. I used to come in for some music, I knew she'd like it because it was what my grandmother liked. I could see her eyes open up when we played her music. All the staff helped. I enjoyed it because I could be the person who speaks the same language, and she was telling me about her family, and the music she liked when she was little."

Namaste Care Octavia is piloting introducing Namaste Care, starting with a small group of residents with dementia. Namaste means 'to honour the spirit within'. Using simple techniques, the structured Namaste Care programme focuses on sensory connection, compassion, empathy and kindness. The programme includes physical, sensory and emotional elements. Namaste Care was developed to give comfort and pleasure to people with advanced dementia through sensory stimulation, especially the use of touch. It has been adapted for people with a broad range of long-term conditions, as well as dementia.

Useful resources

Video (four minutes) ***Rehabilitative Palliative Care.*** **All Ireland Institute of Hospice and Palliative Care (AIIHPC) and St Christopher's (2016)**

Video introducing the concept of rehabilitative palliative care. The film explains the relationship between our capacity, needs and wishes: as our capacity becomes reduced because of illness, our ability to meet our own needs and wishes decreases, and our dependence on others increases. The ethos of rehabilitative palliative care is about: what can I enable you to do for yourself, rather than what I do for you.

https://www.youtube.com/watch?v=cM6OcREjCXI

Publication ***Rehabilitative palliative care: enabling people to live fully until they die. A challenge for the 21st century.*** **Hospice UK (2015)**

Available at the Hospice UK weblink below.

Website Hospice UK

This has a page of resources about rehabilitative palliative care:

https://professionals.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care/resources-for-rehabilitative-palliative-care

Website Helen Sanderson Associates

This contains lots of useful information and free resources to help support person-centred care. The website includes a webpage about Relationship Circles (another name for Circles of Support) including a video and template:

http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/relationship-circle/

Video (seven minutes) ***Alive Inside – featurette: Henry.*** **Music & Memory (2014)**

This short film is taken from a longer feature film: *Alive Inside: a story of music and memory*. Filmed in a nursing home in the USA, it shows the power of music and personalised playlists to animate and improve quality of life. It depicts care home staff taking simple steps to help residents hear the music that has meaning for them. The film shows how listening to music can benefit the wellbeing of frail older people, including people with dementia.

https://youtu.be/fyZQf0p73QM

Video (five minutes) ***Namaste Care: Seeing Is Believing – short version.*** **Sean Macreavy Media for the Association for Dementia Studies (2019)**

This short film explains Namaste Care, created by Joyce Simard as a structured way of giving sensory stimulation, comfort and pleasure to people living with advanced dementia. It shows Namaste Care in action and includes perspectives from care staff, managers and relatives.

https://www.youtube.com/watch?v=Bt-e3UGpXBE

Video (23 minutes) ***Namaste Care: Seeing Is Believing – full version.*** **Sean Macreavy Media for the Association for Dementia Studies (2019)**

This is a longer version of the film introducing Namaste Care, showing it in action and explaining the ethos, principles and practice as well as its impact for the people who experience it. The film shows how to implement Namaste Care, and make it part of a daily routine. Care home managers explain that introducing Namaste Care has not required more staffing, and how over time staff have increasingly seen the benefits to residents.

https://www.youtube.com/watch?v=2kSnvJxScUM

Publication ***Toolkit for implementing the Namaste Care programme. For people with advanced dementia living in care homes. Second edition.*** **St Christopher's (2021)**

This explains the principles and ethos of Namaste Care, and how to introduce a Namaste Care programme.

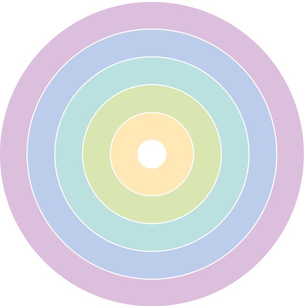
https://www.stchristophers.org.uk/wp-content/uploads/2021/10/Namaste-Toolkit-2021.pdf

Bob: a fictional case study illustrating the use of the Circles of Support tool

When Bob moves in

Bob was diagnosed with multiple sclerosis (MS) in his late 40s. He was a bus driver, and took early retirement on health grounds. His MS was relatively stable, but he developed depression and there are concerns about social isolation and self-neglect. At the age of 62, Bob enters one of Octavia's extra care housing schemes. Bob is single with a disabled sister living in Manchester who he speaks to regularly on the phone.

Bob's Circles of Support on arrival



- ○ Bob
- ● Neighbours
- ● Social care, including a social worker
- ● Ex-colleagues
- ● Sister
- ● Neurologist

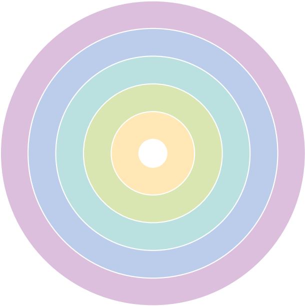
Reflection

Bob has an important and well-established support system comprising professionals, friends and a family member. Knowing about this will help Octavia staff to monitor how well Bob retains these connections as he settles into his new tenancy. At this stage, the importance of Bob's relationship to football is not fully apparent to staff.

After a year living at Octavia

After a year living at Octavia, Bob stills spends a lot of time in his own flat. There are one or two male residents who he watches football with in the communal living space. He has a couple of friends who visit occasionally and who take him out in his wheelchair to the local pub for a pint and to watch football. He can still walk about unaided but he is slow and he prefers to be pushed when going out with friends. Some of the staff have noticed that Bob sometimes struggles to remember what day or time it is or forgets that he has planned with people to do things. He notices this himself but is reluctant to see a doctor. He still speaks to his sister at least once a month but she is now often the one to call him.

Bob's Circles of Support after a year



- ○ Bob
- ● Social care and Octavia staff
- ● Octavia residents/ football
- ● Ex-colleagues/ ex-neighbour/football
- ● Sister
- ● Hospital neurologist/ social worker/GP

Reflection

Bob remains fairly independent and although he can be low in mood at times, he has good social interaction with friends, both within the scheme and outside. Octavia staff have observed that they do sometimes have to remind Bob about social arrangements he has made, but he appears engaged and happy to socialise. Staff give a warm welcome to his friends and ensure that access with the wheelchair is facilitated.

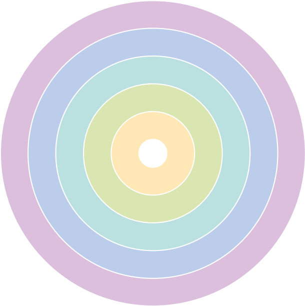
After three years living at Octavia

Bob has been with the scheme for three years when he doesn't get up one day and complains of feeling very lethargic, sick, hot and it hurts when he passes urine. The doctor is called, and it is suggested that he might have a urinary tract infection, so a sample is collected and taken to the surgery. Meanwhile, he is started on antibiotics.

The symptoms get worse, and Bob becomes drowsy and confused. He refuses to get out of bed and when 111 are called they say to call an ambulance. He is admitted to hospital with an acute bladder infection and dehydration. There is also concern that he may have an enlarged prostate that is causing an obstruction. A PSA test is raised but Bob refuses a biopsy. He agrees to a scan which confirms a very enlarged prostate probably cancer but this diagnosis cannot be confirmed.

Bob is discharged home fully recovered from his infection but advised to drink plenty, and with a referral to attend the oncology department at the local hospital. The oncologist again offers investigations but Bob refuses and he is assessed as having capacity to make his own decision. The GP is informed.

Bob's Circles of Support on discharge from hospital



- ○ Bob
- ● Octavia staff/GP
- ● Octavia residents/ ex-colleagues/ ex-neighbour/football
- ● Oncologist
- ● Sister
- ● Hospital neurologist/ social worker

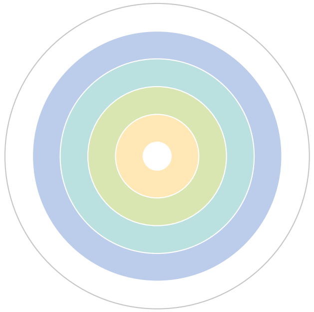
Reflection

Octavia staff have noted the physical deterioration and the probable diagnosis of prostate cancer and have initiated a conversation with the GP. Bob's wishes to not be investigated further are respected and recorded in his Care and Support Plan. The scheme manager has requested that the GP visit and in partnership they ensure that Bob understands that his symptoms may recur or develop and that there is a recorded plan for staff to act upon and that his decision is not related to depression. Regular reviews with the GP are requested. Since his discharge, Bob's friends are now only visiting him in his own flat and bringing him beer in. Phone calls with his sister are always now initiated by her and Octavia has informed her of Bob's recent admission to hospital with his permission. Knowing how important friends and his sister are to him, Octavia staff ensure that they have his permission to keep them informed of his general wellbeing although he is clear that he does not want anyone knowing about his cancer. This is recorded in his Care and Support Plan.

Bob's health deteriorates

Bob becomes increasingly muddled and begins to get up and walk about at night saying he needs to go out to get shopping. The GP refers Bob to a memory clinic and he is diagnosed with dementia, probably related to his MS. He also complains of lower abdominal pain which the GP, on examination, decides is due to constipation. Bob is prescribed aperients, but the pain persists and he is seen again by the oncologist who confirms that the prostate cancer has spread. He warns that Bob is at risk of pathological fracture as prostate cancer often spreads to the bones, so a falls risk assessment is undertaken. Management of constipation and pain seem to help with his confusion.

Bob's Circles of Support as his dementia is diagnosed



- ○ Bob
- ● Octavia staff/GP/football
- ● Octavia residents/ex-colleagues/ex-neighbour
- ● Oncologist/memory clinic
- ● Sister
- ● Hospital neurologist/social worker

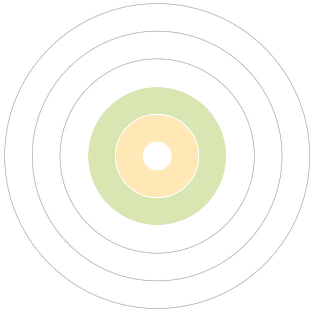
Reflection

Bob is now not able to initiate any social interaction himself and is dependent on his friends and sister contacting him through Octavia. He is also now requiring far more physical support on a daily basis but this also gives opportunity for more social interaction with Octavia staff who are able to talk about those things that matter to him, for example, his football team and his sister. Although muddled at times, Bob still has mental capacity to discuss his wishes and his Urgent Care Plan has been reviewed with the GP and recorded. Bob has made it clear that he does not want to go to hospital if it can be avoided. The scheme manager has spoken to Bob about possibly setting up his sister or a close friend as a Lasting Power of Attorney (LPA) so that person can speak on his behalf if he is unable to do so for himself, but he declines.

Bob's final months and weeks

Bob is now chair bound and requires assistance with all activities of daily living. The GP has prescribed regular analgesia for the pain but has explained to the staff that Bob's prognosis is only a few months, possibly less.

Bob's Circles of Support as he is diagnosed as approaching the end of life



- ○ Bob
- ● Octavia staff/GP/district nurse/hospice/LAS
- ● Octavia residents/ex-colleagues/ex-neighbour/sister

Reflection

Bob is now almost entirely dependent on Octavia staff. They are confident that they have a clear plan for how to manage his symptoms as his physical health deteriorates. Team meetings have acknowledged that Bob is probably now dying and that regular contact and support is established with the GP, district nurses and the local Specialist Palliative Care Team. An electronic Urgent Care Plan is updated and accessible to the ambulance service should they be called in an emergency. Bob's sister who is named as his next of kin has had a conversation with him and he was able to confirm that he knows he is very ill. Bob's friends continue to visit and sit with him to watch the football.

Theme 4: Understanding what is important

Theme 4: Understanding what is important

Why it is important

Central to person-centred care is appreciating what matters most to each person as an individual, with their own unique personality, history, wishes and preferences. This theme was woven throughout our work and nine-week programme. We talked about different ways of opening up conversations with residents, and the importance of staff documenting what they know about a person's wishes, so that others can share in that knowledge. The value of this is highlighted when a resident is unable to communicate – perhaps because they are unconscious, very sick or dying – and staff need to be confident in their understanding in order to honour those wishes and ensure others know them too.

What we did in the *Better Lives, Better Endings* programme

It was quickly apparent that many staff wanted to talk about these things – with residents and each other – but felt nervous and didn't know where to start. Although many staff had personal experience of caring for residents or their own relatives who had died, few had formal training in end of life care. Staff recognised the need for conversations with residents to better understand their wishes and preferences, but did not feel confident about initiating these, or in knowing how to respond when residents spoke about these things. Staff understood the importance of documenting residents' wishes in their Care and Support Plans, but in practice, little was recorded.

In our nine-week programme we explored the value and purpose of opening up such conversations. Using the mix of real-life and fictional case studies, we considered the differences when supporting someone whose wishes are well known and documented, compared to someone whose wishes are unknown or not recorded.

Art and creativity offer people new ways to explore their feelings and express themselves. They provide rewarding ways of connecting with others, enhancing quality of life and expressing individuality and personhood. They can be enjoyed by everyone, including people who are frail, or have learning disabilities, dementia, or are near the end of life.

We asked an experienced Creative Facilitator to lead a session on our nine-week programme, so staff could experience these creative approaches directly. Staff brought paper, pens, pencils or glue and old magazines for collaging to the online session. The Facilitator guided everyone through a process of art-making, drawing on memories and feelings related to their work. Participants were invited to show and explain their artwork to the group, but only if they wanted to. We watched the short film ***Creativity in Older Age***.

In this session, staff experienced for themselves using art to express their personality and feelings. We talked about how art enhances residents' quality of life, and can be a different route to exploring difficult or sensitive topics, including end of life care wishes and what matters most to each person.

We introduced **Conversation Cards** as a tool to help guide and enable conversations about what is important, and what would matter most to people if they were unable to communicate or near the end of life. Early in the project, we had tested these with a few residents, and sought feedback from staff to gauge interest. After considering various options, we had chosen the ***Conversations for Life***™ **Cards**. These were developed with and for people (residents and staff) with a mix of backgrounds, including people whose first language is not English, people with learning disabilities, and people with limited education or literacy. They have been well evaluated, used in research internationally, and specifically adapted for the UK. They offer considerable flexibility and can be used in multiple ways, whilst also providing structure and guidance for conversations that might feel daunting. In the nine-week programme we discussed how these can be a valuable tool in supporting conversations with residents and their families, and deepening understanding of each individual's wishes, preferences and priorities. We also talked about ways of capturing and documenting what's important and what matters most to each person.

Staff spoke of their frustrations when they attempted to advocate for residents based on detailed knowledge of the person, but were ignored or overridden by other parts of the health and care system, such as GPs or paramedics. This led to discussions about ensuring residents' wishes and preferences are recorded on the London-wide digital platform for sharing end of life and urgent care plans across health and social care services. At the time of our project this platform was **Coordinate My Care (CMC)**, but from April 2022 CMC is being replaced by a new **London Urgent Care Plan** programme and platform. People's existing CMC plans will be carried across to the new platform.

One major difficulty is that – despite being part of the care system – extra care staff are not currently granted access to CMC, so cannot see residents' CMC plans nor directly assist them – this has to be done by GPs. Our discussion of these challenges led to staff deciding to invest time in developing their relationships with GPs. Staff felt more confident and determined to initiate dialogue with GPs about improving collaboration to ensure individual residents' wishes, including for end of life, are understood and documented in Octavia's Care and Support Plans and on the necessary shared NHS platforms and electronic palliative care co-ordination systems (EPaCCS).

We gave a presentation about CMC, but wanted to go further, and help participants use experiential learning to connect at a deeper, more emotional level with the process of filling in such a plan. Coordinate My Care has developed **MyCMC**, for members of the public to initiate their own CMC plan; although it must still be completed and submitted by a doctor or nurse.

We asked staff to visit the MyCMC webpage, look at the supporting video and guide, and start creating their own CMC record and plan. We made clear this was to understand the questions and process, and they were not expected to submit their plan. We asked staff to reflect on how they might support a resident to make sure their wishes and preferences are documented and agreed with a GP, using MyCMC.

Putting change into practice: what Octavia is doing

Talking more openly about death, dying and what's important One of the most notable impacts of *Better Lives, Better Endings* is the increase in participants' confidence to talk openly about death, dying and what is important to people. Staff say they are much more confident in initiating such conversations, and in responding positively when residents raise these topics. Staff now recognise that these conversations do not need to take place all in one go, or as part of a form-filling exercise. With their increased confidence comes a more skilled and nuanced ability to have the conversations at a pace and time that works for each resident, whilst making sure people's wishes are documented.

"With the Brazilian lady, I had the confidence to ask her about end of life, it was so beautiful what she said – she said how she wanted to be buried, the music she wants us to play, she never gave anybody that. She gave me her full address in Brazil, I want to get some people to sing there when she dies. I never imagined it would be like that talking to her about end of life. When we did the MyCMC for ourselves: thinking about what I would want, it gave me the confidence to speak to her. She is not *old* old, she is such a lively person, I wouldn't have felt confident to talk to her before. I felt it was really good, she gave the answers without hesitation. The song is beautiful that she chose, it is in Portuguese, one of my favourite songs."

Care and Support Plans Previously the pages on end of life wishes were left empty in many residents' Care and Support Plans, with staff shying away from these conversations. Now, increasingly, staff are confident to introduce the subject and finding many residents keen to talk about what is important to them, now and for the future, and to have their preferences and wishes understood. Together with the integration of the Circles of Support tool it is hoped that what matters most to residents will be better understood and will more effectively inform planning.

"I've heard managers, and actually more team leaders, saying they definitely feel more confident talking about end of life, having the conversations and starting the conversations. It has made people more ready to talk about it and not just leaving that page blank…before, that page was blank a lot. Before if a resident said 'I don't want to talk about that' it was just left. Now staff are having more sensitive conversations, they can think of how to approach it differently. The advance planning pages in the Care and Support Plans – people are actually starting to use that and fill them in."

Communications skills training Staff who took part in our programme now feel more skilled and confident in having conversations with residents about their wishes for the end of life. There is a need for other staff to gain these skills, so that it becomes more widely embedded in Octavia's culture and ways of working; Octavia is looking into communications skills training for a broader group of extra care staff.

Creating Champions Octavia is considering creating a number of Champions amongst its staff team. They will be drawn from staff who have taken part in the *Better Lives, Better Endings* programme and have the confidence and motivation to engage in more complex conversations with residents about what is most important to them and their end of life wishes. The Champions will receive more training in facilitating sensitive conversations and act as role models and support to other staff. The idea is at an early stage, and the Quality Team intend to work with staff to develop it. Octavia is also looking at how Conversation Cards could be introduced into care practice, and this may be something that the new Champions start in the first instance.

Art and creativity Stimulated by the programme, staff are introducing more creative and arts-based activities. One staff member is planning to set up a knitting group.

"With the activities we looked at, the music and art, that is being implemented more now. It is about the 'better lives' bit coming in: realising someone is amazing at art and no one knew. There is one resident, the art he did is great, he is an amazing artist. I took a picture of his art and put it in his care plan. It is amazing."

Useful resources

Video (four minutes) *Creativity in older age.* Age & Opportunity (2019)

This film made in Ireland is about Age & Opportunity's Artist in Residence in A Care Setting Initiative. It shows how artists nurtured creativity in care homes, underlining the value of the arts and artists to the residents. The film shows the possibility of artistic engagement and its value in any care setting.

https://www.youtube.com/watch?v=Oywb6i9stmc

Video (eight minutes) *No Barriers Here.* Mary Stevens Hospice (2021)

No Barriers Here is an innovative approach to Advance Care Planning, using arts-based approaches to having creative conversations about what people want and don't want at the end of life, and what is important to them. It was co-developed through collaboration between Mary Stevens Hospice, Dudley Voices for Choice, art psychotherapist Jed Jerwood and by people with learning disabilities.

https://www.youtube.com/watch?v=vNYB3LjlOzM

Website Coordinate My Care (CMC)

CMC is the London-wide platform for coordinating urgent care for patients (until 31 March 2022). CMC plans are completed online by doctors or nurses, and include an individuals' diagnosis, medical details, resuscitation status, medications and recommendations for urgent care services to follow in an emergency. Individuals can share their own wishes and preferences using an online questionnaire called MyCMC, and the clinician completing CMC can take these into account and choose to include them. CMC plans are visible to all urgent care services including 111, out of hours GPs, the ambulance service (in their vehicles) and emergency departments. However, extra care staff do not have access to them.

CMC: https://www.coordinatemycare.co.uk/

MyCMC: https://www.coordinatemycare.co.uk/for-patients/mycmc/

Similar platforms for sharing urgent care plans exist in other parts of the country – contact your local NHS to find out more.

From April 2022, CMC is due to be replaced in London with a new platform for recording and sharing urgent care plans. Individuals' existing CMC plans will be carried across to the new platform. At time of writing, details of the new London Urgent Care Plan programme are still emerging, but can be found from the **South and West London Health and Care Partnership** website:

https://www.swlondon.nhs.uk/ourwork/connectingyourcare/urgent-care-planning-application/

https://blog.better.care/procurement-of-a-shared-care-plan-for-london

Resource Conversation Cards

Various card packs are available to support conversations about what matters most to people and their wishes and preferences for the end of life. We chose to use **The Conversation Game™** cards, available in the UK from Conversations for Life™. These were originally developed in the USA by The Coda Alliance as Go Wish cards, and have been translated and adapted for use in various languages and countries. They are evidence-based, well evaluated and have been used internationally in research and care practice in many settings. However, there are many other options available, and you may investigate and prefer to use a different set of conversation cards.

Website Conversations for Life in the UK

https://conversationsforlife.co.uk/

Website The Code Alliance in the USA

https://codaalliance.org/

Theme 5: Acknowledging grief and loss

Theme 5: Acknowledging grief and loss

Why it is important

Conversations early in our project revealed grief and loss often going unacknowledged, for both residents and staff. Extra care staff form long-standing relationships with residents, and get to know them well, sometimes over many years. When residents die, staff grief can be strong and lasting; sometimes heightened by weaknesses in organisational acknowledgement and lack of systematic support or debriefing.

We heard of examples when residents had died, or gone to hospital and never returned, and their flats were emptied with no communication or explanation to other residents. Staff told us of coming back onto shift to find that a resident had 'gone', but with no spoken acknowledgement of the death from colleagues. The lack of open communication about residents' deaths left staff feeling distressed and confused, but believing they were expected to 'just get on with it' by management. It meant staff felt unable to inform other residents about the death – because they themselves did not know what had happened, and because of a culture of 'not mentioning it'. Even staff who were aware of the death believed that they shouldn't speak of it to other residents, for fear of upsetting them.

Staff also struggled to know how to respond when residents were bereaved or grieving for a family member or friend. They told of their awkwardness, in wanting to give support, but not knowing what to say. This includes situations of 'anticipatory grief', for example when a resident found out that her daughter was terminally ill. Staff were very aware that often residents are not able to see relatives or friends who live far away – sometimes in other countries – and of their own role in providing comfort and human connection; they wanted to feel better equipped and more confident in supporting residents during these situations.

"When you find out someone has gone to hospital and died, you might say a prayer, grieve in silence. The next day you just get on with the job. Sometimes you feel really and utterly helpless. You think, could I do anything more?"

"There was one lady, I always used to talk to her, say: 'How are you? How are you feeling?'. Then at the weekend, she died. When I came in to work the next time, my manager took me to her flat. She had passed away. I had thought maybe she was not well. I feel horrible, very bad … I felt very bad that day. I can't cry in front of anyone. I cried when I got home in front of my son. I kept crying, I couldn't stop. My son said 'why are you crying?' I told him a resident at work had passed away, she was a very nice lady. When I see her flat in the corridor, Flat X, I still feel very sad."

What we did in the *Better Lives, Better Endings* programme

We very deliberately placed recognition of staff's feelings at the forefront of the nine-week programme, and gave it continued emphasis and attention. We saw this as the key to creating a programme with lasting impact for staff, that would bring about change for Octavia's residents. To be effective, our programme needed to address head-on the varying emotions experienced by extra care staff in their attempts to support residents to have better lives and better endings: sadness, frustration, grief, anxiety, anger, fear, uncertainty … and also at times joy, pleasure, satisfaction and a powerful sense of reward.

Our invitation to take part said: *"We know it can be difficult talking openly about death, dying and grief. It can be challenging and emotionally demanding to care for residents towards the end of their lives … Interacting with other health and care services, so that everyone understands an individual resident's needs and wishes, is often hard and frustrating. And how do we respond to staff and other residents' feelings of grief when a resident dies? Our* Better Lives, Better Endings *programme offers time and space to explore these issues together, supported by experienced facilitators."*

From our first session, we spoke of the programme being about "heart as well as head" and "feelings as well as facts". Acknowledging staff as humans, as individuals with their own emotional responses, was woven through. In inviting staff to talk about their feelings related to experiences at work, we took care to acknowledge that these emotions can be complex, sometimes contradictory, and differ for different people. We wanted to create a safe space where people could bring these to the surface, share and talk about them. In reflecting on residents' experiences and feelings in various situations – real and imagined – it made sense and felt natural to reflect on staff members' feelings too.

We introduced the idea of self-care and threaded this through the programme. We discussed the importance of attending to one's own needs and wellbeing, to be able to provide the best care for others. We talked about ways of supporting and caring for each other as part of a team. Participants generated ideas for rituals and ways to memorialise residents who died, and for more openly acknowledging feelings of grief with residents and each other.

Putting change into practice: what Octavia is doing

Memorial garden One of Octavia's extra care schemes, Miranda House, has created a memorial garden. The idea came from a resident during discussions prompted by *Better Lives, Better Endings*. Staff and residents worked hard to make the idea a reality. Together they painted the outside courtyard walls: adding colourful butterflies, a remembrance poem and a memorial tree. The bright colours and seating make the memorial garden a welcoming place, where residents sit to have tea and coffee. Its launch at a special event in November 2021 represents a significant shift towards openly recognising grief and loss, and incorporating these things into daily life. Miranda House is creating new rituals to memorialise residents who die, such as painting their names into the leaves of the memorial tree.

"The memorial garden: we all came together and we spoke with our tenants and they actually had the idea of the garden. It was beautiful, it was so much fun but very sentimental at the same time, remembering people who are no longer here with us. [*Better Lives, Better Endings*] helped us make the decision to have that garden. It benefited all of us, tenants and staff. It was amazing."

New ways to memorialise and remember Staff at Octavia's other schemes are inspired by the memorial garden, and interested in doing something similar. But they recognise that a 'cookie-cutter' approach would not generate enthusiasm from their own residents and staff, and risks feeling inauthentic and imposed. Rather than replicating exactly what Miranda House has done, they are opening up discussions with their own scheme's residents and staff to explore different ideas for using spaces to memorialise and remember.

Supporting staff Octavia is communicating more clearly and frequently to staff that if they experience trauma or grief through their work then counselling is available. Although this was previously the case, staff were not always aware of this or about how to take up this support.

Useful resources

Video (three minutes) *Launch of Miranda House memorial garden.* Octavia (2021)

https://vimeo.com/683855442

Video (three minutes) *What do people say before they die? The final goodbye – as told by Macmillan nurses.* The Video Lounge (2017)

Made by The Video Lounge: a team of Macmillan Palliative Care Nurses from Royal Stoke University Hospital and video journalists Catherine Mackie and Simone Stewart. The film shows Macmillan nurses sharing things people have said to them before they died, grouped under various themes. It also highlights the mutual support that Macmillan nurses give to each other.

https://www.youtube.com/watch?v=Tw3OP5GXbCo

Website, publications and videos Cruse Bereavement Support and The ExtraCare Charitable Trust

Cruse and The ExtraCare Charitable Trust ran the Bereavement Supporter Project, a five-year project funded by the National Lottery Community Fund (2017-2021). The project worked to improve bereavement support for older people, including those with dementia, in ExtraCare retirement villages and housing schemes. The webpage shares information about the project, how it was designed and implemented, the evaluation report and a range of resources, including some short videos.

https://www.cruse.org.uk/about/our-work/bereavement-supporter-project/

Theme 6: Building relationships with external services

Theme 6: Building relationships with external services

Why it is important

Throughout our project, relationships between Octavia staff and external health and care services were a recurring theme. In some cases, staff have forged very good and productive relationships, for example with particular local GP surgeries. In other cases, staff are frustrated by poor relationships marked by professionals who are patronising, don't respond to their messages or listen, and are unwilling to communicate with them about residents.

Extra care staff often lack confidence when engaging with other services on behalf of residents, a feeling sometimes compounded by professional hierarchies and attitudes and behaviours of those they were seeking to engage with. Staff are left feeling over-ridden and disempowered by external services, despite knowing their residents' personalities, preferences and needs extremely well, having cared for them often over a period of years. Staff want to advocate for residents, to help them receive the best care possible, but feel external services often ignore them, to the detriment of their residents' wellbeing and care.

When a resident is diagnosed as terminally ill and 'needing palliative care', this has often been a time when extra care staff hand over authority and decision-making to external professionals with palliative care expertise. Again, extra care staff can feel sad, bewildered and disempowered – they want to continue caring for the resident, but feel that 'palliative care' is a mystery and best left to palliative care specialists. One of the changes we wanted to achieve through the nine-week programme was for staff to understand their important role and that most aspects of palliative care need not be a mystery. Quality care for the person at the end of life can be delivered through ongoing relationship connection, using the same skills that they already possess and use routinely to ensure good quality of life.

"With palliative care, the communication is very difficult. We have a resident who has one-to-one care on a 24-hour care package, and an outside care agency comes in to provide this. We are left aside, but we still have to give the medication, but the doctors, the hospice staff, they do not communicate with us, we are left aside. We do a lot, we administer the meds, we check their wellbeing, but the hospice staff talk to the care agency worker but not us. There is a lot of miscommunication."

What we did in the *Better Lives, Better Endings* programme

Through facilitated discussions, participants talked about their own experiences of engaging with various external services, and reflected on situations where this had gone well, and why, and where it had not gone well, and why. Using fictional and real-life case studies, we explored how staff could become more confident in identifying signs and symptoms that might indicate someone was very ill or close to death, and could be more confident in their communications with external agencies.

During the nine-week programme we invited guest speakers from: a local GP surgery with a good established relationship with an Octavia extra care scheme; a local hospice, and the London Ambulance Service. The speakers were briefed not merely to give a presentation, but to take a conversational approach, including questions, discussion and honest exploration of real-life difficulties that can occur in the interactions between extra care and the services they represent.

Putting change into practice: what Octavia is doing

Renewed ambition to develop relationships: as a result of the *Better Lives, Better Endings* programme, and a realisation of the importance of their role as advocates for residents, Octavia staff in several schemes have articulated a renewed ambition to develop good relationships with other local health and care services. They realise there are not always easy ways to do this, and much hinges on the attitudes and willingness to engage of other parties – some GP surgeries have excellent relationships with Octavia extra care schemes, and some do not! However, staff have the motivation and greater confidence to initiate contact with external services, and to suggest that investing time in developing the relationship and getting to understand each other's role, responsibilities and ways of working is a worthwhile thing to do for the benefit of residents. Where a scheme does not have a local hospice, they are looking at how they can build relationships with other community palliative care teams that serve their local area.

Working with Multi-Disciplinary Teams (MDTs): the Quality Team is looking at how Octavia's different extra care schemes currently work with MDTs, with a view to supporting and strengthening such work. Using a questionnaire, they are finding out whether and how each scheme makes use of regular MDT meetings, and which other professionals, agencies and services are involved. They are also finding out from staff at each scheme how they currently assess the quality of their relationships with external agencies, and will draw on the results to formulate ways of supporting staff to build and strengthen those relationships as needed.

Useful resources

Website Hospice UK

The Hospice Care Finder page on the Hospice UK website enables you to find your nearest hospices. Extra care providers can use this to identify the hospices closest to them, searching by postcode, place or organisation name.

https://www.hospiceuk.org/hospice-care-finder

The Housing LIN and Skills for Care may be particularly useful for organisations planning a programme of learning or skills development on end of life care.

Website Housing Learning and Improvement Network (LIN)

This has a webpage dedicated to bereavement and end of life care, with links to a range of further resources and reports.

https://www.housinglin.org.uk/Topics/browse/CareAndSupportatHome/EndOfLifeCare/

Publication *End of life care in extra care housing: learning resource pack for housing, care and support staff.* Housing LIN and NHS national end of life care programme (2013)

https://www.housinglin.org.uk/Topics/type/End-of-life-care-in-extra-care-housing-learning-and-resource-pack-for-housing-care-and-support-staff/

Website Skills for Care

This has a webpage dedicated to end of life care, with links to a range of resources that can be used for staff training and skills development.

https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/End-of-life-care/End-of-life-care.aspx

Dee: a case study example for group discussion

See information about using fictional and real-life case studies in [What we did in the *Better Lives, Better Endings* programme].

Dee (not her real name) was in her 80s and had dementia. She had been an extra care resident for several years and attended a day centre run by Octavia. She was well known to many Octavia staff. She had family in Ireland, but was very reliant on Octavia care and support services for her advocacy and wellbeing.

At the beginning of 2020 Dee's advancing dementia was resulting in a number of physical challenges for staff. She was having problems with chest infections and before lockdown had been admitted to hospital to be treated for pneumonia. She was discharged from hospital as the NHS pressure caused by the pandemic was emerging. Staff were shocked when she returned from hospital, carried on a stretcher. The scheme was not equipped to provide her with continuous nursing care (the stretcher didn't even fit in the lift to get her back into her home). There was an urgent review to increase her to 'double up care' to meet her needs.

Though comfortable in her own surroundings Dee remained unwell and it was thought that she was 'slipping away'. Her GP was involved in making decisions for her end of life and it was decided that a 'Do Not Attempt Resuscitation (DNAR)' decision was best and, if possible, to avoid any further hospital admission. Within days Dee deteriorated, she had become restless and staff felt she may be reaching the end of her life. Because she was very religious, staff took the decision to call a priest to give her the last rites. Shortly afterwards, her breathing became worse and on the advice of her GP, staff called 111 for support. An ambulance was called and because paramedics could find no information on their system about the end of life plan for Dee, and despite the concerns of Octavia's care staff, they took her to A&E. Octavia staff were not able to accompany her and Dee arrived at the hospital at 10pm and died 45 minutes later, on her own on a hospital trolley.

The undignified end to Dee's life had a profound impact on the care staff who had looked after her for the last years of her life. They were very upset that she had to die this way and felt disempowered in how the end of her life was managed. Counselling support was made available. All the agencies, the NHS hospital team and her GP, had agreed that Dee was going to die, and how this should best be managed, but because database systems (in London this would be CMC) were not utilised effectively, Octavia staff felt that the 'system' had failed Dee.

Questions for discussion

1. At what point in Dee's care journey could extra care staff begin to plan with external professionals (and Dee, if she still has some capacity) an 'urgent care plan' for a resident like Dee who has advancing dementia? What prevents this from happening?
2. Is extra care housing appropriate accommodation for someone like Dee at the end of life? If not, why not? If it is appropriate, what relationships with external professionals are essential? In your situation who or what agencies would these be?
3. For a resident like Dee to remain in her own home within extra care housing, what protocols, support or training might be needed for staff? What do you already have in place in your organisation to support residents to die in their own homes? What could be improved?

The nine-week *Better Lives, Better Endings* programme for extra care staff

The nine-week *Better Lives, Better Endings* programme for extra care staff

Week	Outline	Objectives
Pre-programme activity	**Pre-Programme Questionnaire** Complete confidential questionnaire to assess degree of comfort and confidence in various aspects of role	
Week 1	**Introduction and welcome to the programme** • Purpose, focus, what it is and what it is not • Share findings: earlier stages of *Better Lives, Better Endings* • Group discussions about Octavia's priorities and rationale, and own role and other participants' roles in the programme • Co-designing the input – interactive exercise to generate ideas, including for additional guest speakers.	1 Understand the purpose of the programme 2 Develop a sense of team and understanding of responsibility of participants 3 Participants input to co-design the programme.
Week 1 activity	**Expectations, hopes and fears about taking part in the programme** Six questions, with collated responses anonymised	
Week 2	**Relationship-based care in practice: how we care and support residents for the whole of their time at Octavia** • Discussion of five-year fictional case study: Bob, a resident who moves in, has wishes and preferences, whose health changes and deteriorates and how he can be supported to live as he wishes • Introduce Circles of Support including all who matter to Bob.	1 Explore the differences between relationship-based care and task-based care 2 Consider how to achieve relationship-based care in practice, for the whole of each resident's time at Octavia 3 Joining up all those supporting the person to work together as they want.
Week 2 activity	**Circles of Support** Draw your own Circles of Support for yourself and bring to next session **Video** From St Christopher's Hospice that explains rehabilitative palliative care (three minutes)	

Week	Outline	Objectives
Week 3	**Relationship-based care in practice: how we care and support residents for the whole of their time at Octavia (continued)** Continue discussion of five-year fictional case study of resident called Bob. Explore how staff can support Bob through various stages, including through and after death, including: • Identifying changes/signs that might indicate non-reversible symptoms of general health deterioration (including dementia and changes to mobility). • Impact of loneliness, loss and anxiety on physical health • Consider design of a simple assessment tool and integrate its use into current care review and planning • Role of the GP • Role of the hospice. The theme of **self-care** is threaded through this and future weeks: importance of attending to own needs and wellbeing, to be able to provide the best care for others. Importance of supporting and caring for each other as a team. Creating a culture that enhances self-care and mutual team support. **Speaker: local hospice Deputy Community Palliative Care Manager** Supporting the discussions, offering insights, ideas and advice from her professional perspective.	1 Consider how to achieve relationship-based care in practice, for the whole of each resident's time at Octavia 2 Joining up all those supporting the person to work together as they want 3 Understand and identify signs that a person may be approaching the end of life and the kinds of action that may be appropriate to take 4 Understand what physical signs to look for that might indicate that someone is coming to the end of their life and what they mean 5 Design a simple assessment tool that would fit easily into current review practice 6 Discuss and identify a protocol (who to refer to, how to collect and record data etc), should signs be identified that might indicate non-reversible symptoms of dying 7 Consider how care for the resident who is approaching the end of life should be managed and what should be the priorities 8 Discuss and understand the importance of keeping connected with the staff team, including during times when a resident is in hospital ('stay connected plan' in hospital – part of allocation) 9 Understand importance of self-care and being part of teams that support each others' wellbeing.
Week 3 activity	**Video** *In my Humble Opinion – dying is not as bad as you think* by Dr Kathryn Mannix (four minutes)	

Week	Outline	Objectives
Week 4	**Working with the ambulance service** Speakers from London Ambulance Service (LAS) Macmillan team. **The importance of understanding and documenting wishes, wants and preferences** • Introduce idea that everyone can find value in reflecting on our own wants and preferences, should we need urgent care or in an emergency situation – never know when situation might arise • Reflect on our own individual wants and preferences • Importance of wants and preferences being documented so emergency services and others can know and act on them • Introduce Coordinate My Care (CMC) and MyCMC.	1 Explore the relationship between extra care schemes and the LAS, and how to build the relationship and ways of working to achieve the best care and support for each resident 2 Deepen understanding of the role of the LAS, how ambulance crews and paramedics work, and the implications for extra care staff, including how extra care staff can be effective advocates to the LAS on behalf of their residents 3 Consider how effective joint working between extra care staff and LAS can avoid or mitigate urgent care crises involving Octavia residents 4 Consider how effective joint working between extra care staff and LAS can ensure unnecessary hospital admissions for residents are avoided 5 Understand the value of thinking ahead about one's own wishes and preferences, and in documenting these 6 Understand the role of CMC and MyCMC in creating a digital record of a person's urgent care wishes and preferences, and how this is used by GPs, the LAS and wider health and care system in urgent care situations 7 Through experiential learning, deepening understanding of the process involved in creating a MyCMC record.
Week 4 activity	**Coordinate My Care and MyCMC** Visit Coordinate My Care (CMC) website and start to complete a MyCMC record for yourself. This is to understand the questions and experience the process - you do not need to fully complete and submit it. Think how you might support a resident to make sure their wishes and preferences are documented and agreed with GP, using MyCMC.	

Week	Outline	Objectives
Week 5	**Creative ways to connect, open up conversations and express what's important:** **Session led by Creative Facilitator experienced in working with people to explore issues of death, dying, grief and loss** • Creative session enabling all participants to experience using creative methods such as drawing and collaging to explore and share their own feelings and responses. • **Video** *Creativity in Older Age* **Using Conversation Cards** • Introduce idea of Conversation Cards and demonstrate the Conversation for Life™ Cards • Discuss these as a tool in supporting conversations with residents and their families, and deepening understanding of individual's wishes, preferences and priorities • Discuss ways of capturing and documenting what's important to each person.	1 Explore how creative approaches can be valuable methods for enhancing individuals' quality of life and expression of personhood, including people who are frail, cognitively impaired, have dementia or are near the end of life 2 Consider how creative approaches can enable people to explore difficult topics, including thoughts, wishes and preferences regarding purpose, loneliness, depression, anxiety, serious illness, death or dying 3 Consider various ways in which such approaches can be used to support Octavia residents: to enhance quality of life, enable creative expression, unlock conversations about emotionally significant topics and difficult issues, and express what is important 4 Consider how such approaches can be used with groups as well as one-to-one 5 Acknowledge that such conversations are not easy, and emotions and feelings are an important part of the exploration: it is not just about eliciting facts 6 Give participants a 'taster experience' of a creative approach, and reflect on the experience.
Week 5 activity	**Video** *Alive Inside* (six minutes) about a man called Henry. Think about how you might find ways to draw on the power of music and personalised playlists to enhance the quality of life of people living in Octavia's extra care schemes.	

Week	Outline	Objectives
Week 6	**Working with primary care services** Speaker from local GP surgery: a chance for participants to ask the speaker questions, and explore from their perspective, what could GP surgeries do differently, to help them provide the best care and support for residents, including when urgent care is needed, in a crisis, or towards the end of life. **Group discussions** Reflecting on: • What works well in your relationship and communications with the GP surgeries you work with, in supporting residents? • What could be improved in your relationship and communications with the GP surgeries you work with, to better support residents? • What actions and information would you like from the GP surgeries you work with, to be able to jointly provide the best possible care and support for individual residents? • How might you make these changes happen?	1 Explore the relationship between extra care schemes and GP surgeries, and how to build these relationships and ways of working to achieve the best care and support for each resident 2 Deepen understanding of the kinds of information GPs need from extra care schemes to best support their patients, and the role that extra care staff can play in this 3 Explore how extra care staff can be effective advocates on behalf of their residents, when communicating with primary care 4 Consider how effective joint working between extra care staff and primary care can reduce unnecessary hospital admissions for residents 5 Understand how extra care staff can work and communicate with primary care services to jointly support residents in completing CMC and MyCMC digital records of their urgent care wishes and preferences, and how this is used by GPs 6 Gain understanding of the *My Care, My Way* scheme used in North West London to provide integrated support to frail older people.
Week 6 activity	**Exploring grief and loss** Ahead of next week's session, reflect on: • If any residents have died while you have been working at Octavia how did you feel? What affects how you feel about a resident's death? • How did you speak to the other residents about the death? • How did you speak to colleagues about the death? • How does the scheme honour the person who has died? • What other losses do residents experience?	

Week	Outline	Objectives
Week 7	**Broader approaches to relationship-based care:** **End of life doulas** Speakers: End of Life Doula UK • Introduce concept of end of life care doulas – what they do, how they work, and how they might be able to support individual residents towards the end of life • Examples of end of life doula practice (practice examples/case studies) to illustrate how caring for someone at end of life can be done in many different ways, and examples of what relationship-based, person-centred care can look like, including some that are creative or unusual, and showing that it does not require specialist/clinical expertise • Opportunity to ask questions, and discuss how Octavia residents, their families and staff might be able to draw on the skills and support that end of life doulas offer. **Exploring grief and loss** • Discussion session: thoughts and reflections from last week's activity	1 Introduce concept of end of life care doulas: who they are, what they do, how they work and share examples of end of life doula practice to illustrate how caring for someone at end of life can be done in many different ways, and examples of what relationship-based, person-centred care can look like; some that are creative, unusual, but also showing that it does not require specialist/clinical expertise 2 Discuss ways in which end of life doulas might be able to support Octavia extra care residents towards the end of life 3 Explore participants' experiences and feelings about grief and loss 4 Support participants to generate ideas for how they can work together to better acknowledge and respond to bereavement, grief and loss that they encounter, and that is experienced by residents and families.
Week 7 activity	• Look back and think about everything we'd covered in this programme. You may want to rewatch or reread some of the material. • Think of one thing that you will try out or do differently this week, as a result of the programme – go ahead and try it • Think of two more things that you might want to try out or do differently at work, as a result of this programme • Think of three things that your scheme could try out or do differently – together as a team – as a result of this programme • Think of three things that Octavia could try out or do differently, as a result of this programme • Come to the next session prepared to discuss these ideas and potential actions as a group.	

Week	Outline	Objectives
Week 8	**Closing session** • Positioning what we have learnt as part of Octavia's wider programme of transformation and culture change • Connecting what we have learnt with Octavia's ways of working, including Octavia's Care and Support Plans • Some time for reflection together on what we've learnt and experienced, on how participants have applied their learning during the last eight weeks, and what further actions they commit to taking in their working practice.	
Week 8 activity	**Video** *What do people say before they die?* by Macmillan nurses (three minutes)	
Week 9	**Reflections on process and ideas for further resources** • Facilitated discussion.	1 Invite and share process reflections on how the programme went, and how it was experienced by participants: what were the highlights for people; what was most useful; what could be improved 2 Gain participants' input and ideas on what further resources would be helpful to them: • in terms of format (videos, audio/podcasts, blogs, articles etc) • in terms of length • In terms of content and subject matter.

After six months	Outline	Objectives
Activity	**Post-Programme Questionnaire** Complete confidential questionnaire to assess degree of comfort and confidence in various aspects of role	
Session	**Facilitated discussions** • What stood out or has stuck with you from the programme? • What difference has it made for you – individually? • What difference has it made in your scheme? • Taking forward the programme at scheme level: translating ideas into actions • Further support and resources, and next steps • Thank and close.	1 Hear from staff about what stood out for them, what were the most memorable and/or useful elements of the programme 2 Hear from staff about whether and how they have applied what they learnt on the programme, in real-life working practice 3 Refresh memories of what each scheme said they would do at a scheme level, and whether and how those ideas have been translated into practice; including exploration of what has worked well, what has not worked so well, and if actions have not yet been taken, what the barriers have been 4 Hear from staff about what further resources and kinds of support would be helpful, in taking forward change 5 Invite staff to take part in one-to-one qualitative interviews to provide further feedback and evaluation.

Guidelines and template for using the Circles of Support tool in extra care housing

Guidelines and template for using the Circles of Support tool in extra care housing

Why use

Loneliness and social isolation can affect people of all ages and can have a significant impact on quality of life. Social isolation is a separation from social or familial contact, community involvement, or access to services. This may or may not result in the subjective experience of loneliness, but it is important to assess social circles with tenants and to regularly review if circumstances change. If tenants become frailer, or illness progresses, their capacity to do things for themselves can diminish and social circles can shrink, risking social isolation. If alert and aware, extra care staff can respond by offering alternative social connections and activities.

When to use

Social support networks can be impacted by significant changes in circumstances, for example, moving home or illness. It is therefore suggested that a Circles of Support assessment be undertaken when a person moves into extra care and that it is included in the initial Care and Support Plan as a base-line assessment for comparison with future assessments. Subsequent assessments can be undertaken at the discretion of staff.

How to use

The Circles of Support tool should be used in discussion with the person. Staff will work with all extra care tenants: asking who are the people most important to them (beginning with the first circle as most important), the role each plays in their life and the kinds of support they derive from them. The tool can also show interests and hobbies that are important to the person, and play a meaningful part in their life. Together, the tenant and staff member will use the Circle of Support tool to capture this information visually; these will be treated as dynamic documents and updated as tenants' lives, needs and relationships change.

The **Circles of Support tool** template can be printed off and discussion recorded by hand, writing straight onto the circles. It can then be included in the Care and Support Plan or scanned and saved electronically. The tool should be used flexibly to reflect each individual's life, relationships, interests and needs. It is not necessary to write something in each circle. On the other hand, it is fine to add more circles too. A circle might include just one person, service or interest, or it could include many. Circles can be combined if an individual has many people in their life that are all equally important to them and supportive and/or a range of services involved in their care.

Leroy: a Circles of Support example

Leroy is 55 and has learning disabilities. He has been living with his mother who has recently died. He is physically independent but is diabetic and has been assessed by social services as requiring supported housing.

● **First Circle of Support** Leroy has a wide group of friends from the day centre he attends, his church and his married siblings who all live locally. They are all equally important to him, so make up his first circle.

● **Second Circle of Support** Leroy's second circle comprises his social worker, the staff at the day centre and the extra care staff.

● **Third Circle of Support** Leroy loves anything mechanical, engines, motorbikes, old aeroplanes, locomotives, etc. and enjoys watching anything related on the TV or internet or visiting museums. He also enjoys listening and dancing to reggae music. He puts these interests that mean so much to him in his third circle. Leroy includes in his third circle his Uncle Cyril. Leroy is fond of him, but does not see or speak to him very often.

●● **Fourth and fifth Circles of Support** Leroy has chosen not to put anyone in his fourth and fifth circles – this is his decision.

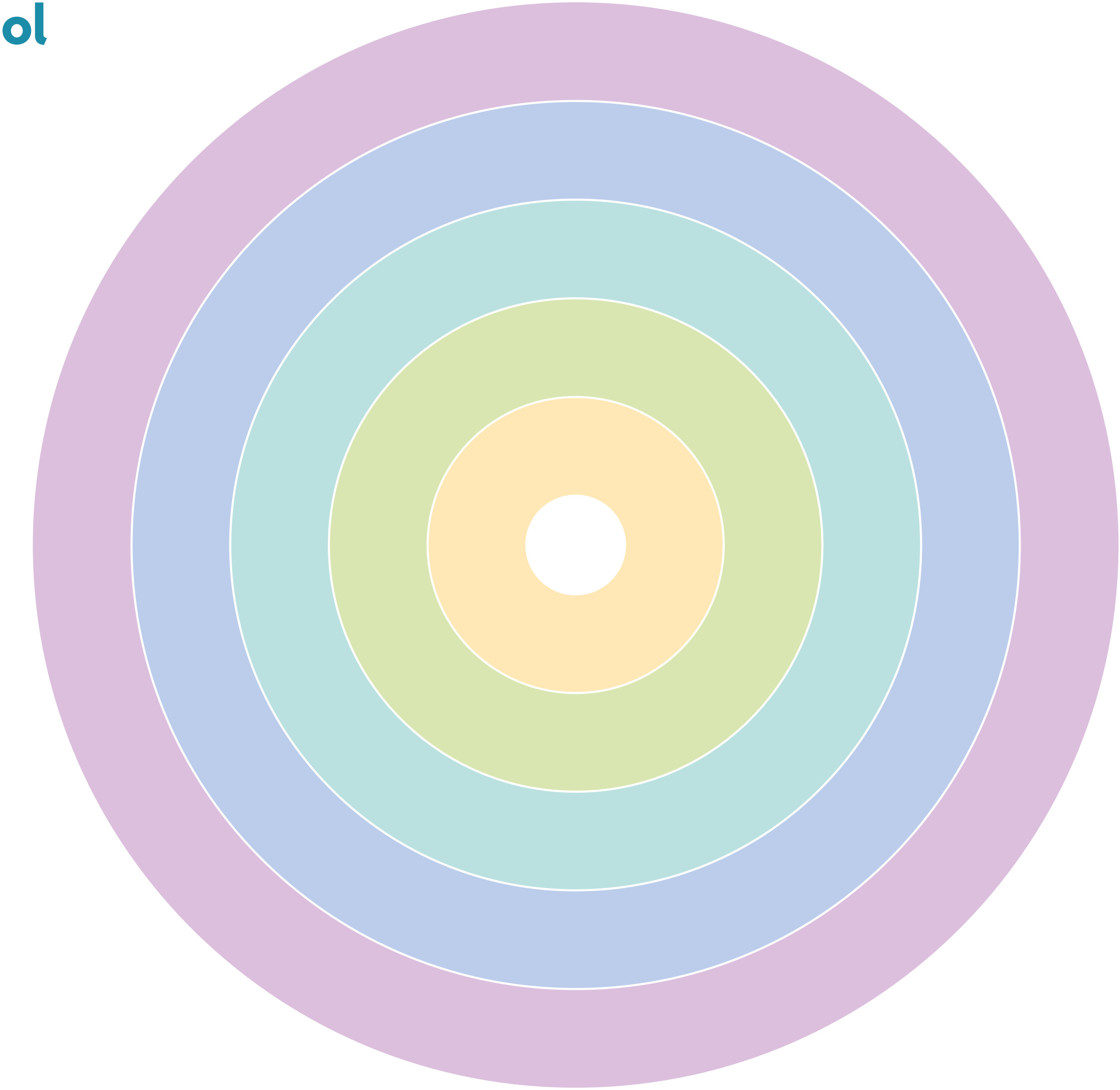
Circles of Support tool

Name

Date

Reason for assessment or review

Any additional useful information about the people or interests in each Circle of Support



Mapping our themes to the Care Certificate standards

Mapping our themes to the Care Certificate standards

We show here how our themes can be mapped to the standards in the Care Certificate[4] developed jointly by Skills for Care, Health Education England and Skills for Health.

Better Lives, Better Endings **theme**	**Care Certificate standard**
Theme 1: Recognising the need for cultural change	Standard 1: Understand your role Standard 2: Your personal development
Theme 2: Understanding dying and what happens at the end of life	Standard 5: Work in a person-centred way Standard 6: Communication Standard 7: Privacy and dignity Standard 8: Fluids and nutrition Standard 12: Basic life support
Theme 3: Relationship-based care in practice	Standard 3: Duty of Care Standard 4: Equality and diversity Standard 5: Work in a person-centred way Standard 6: Communication Standard 7: Privacy and dignity Standard 8: Fluids and nutrition Standard 14: Handling information
Theme 4: Understanding what is important	Standard 3: Duty of Care Standard 4: Equality and diversity Standard 5: Work in a person-centred way Standard 6: Communication Standard 7: Privacy and dignity Standard 13: Health and safety Standard 14: Handling information

Better Lives, Better Endings **theme**	**Care Certificate standard**
Theme 5: Acknowledging grief and loss	Standard 3: Duty of care Standard 5: Work in a person-centred way Standard 6: Communication Standard 9: Awareness of mental health, dementia and learning disabilities Standard 10: Safeguarding adults
Theme 6: Building relationships with external services	Standard 1: Understand your role Standard 3: Duty of Care Standard 4: Equality and diversity Standard 5: Work in a person-centred way Standard 6: Communication Standard 14: Handling information

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[4] Reference: https://www.skillsforcare.org.uk/Developing-your-workforce/Care-Certificate/Care-Certificate.aspx

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