Conversations that matter:

Talking about the end

Healthwatch Milton Keynes

About us

Healthwatch Milton Keynes is your local health and social care champion.

We ensure that NHS leaders and decision-makers hear your voice and use your feedback to improve care. We can also help you find reliable and trustworthy information and advice.

Our vision

People's lived experiences are used to design and improve health and social care services.

Our mission

To champion people's rights and access to high-quality health and social care.

Our recipe for success:

Grounding everything we do in our values. We are always independent, inclusive and committed.

Focus on equity, prioritising listening to those that suffer the greatest inequalities in health and social care outcomes.

Promoting your rights to be informed and involved in your care and designing services in collaboration with health and social care teams.

Partnering with local health and care leaders, service providers, the VCSE sector and the Healthwatch network to amplify your voice and drive change.

Setting goals and actions that support the sustainability and growth of our organisation.

Overview

Reaching out:

Healthwatch Milton Keynes were asked, by the BLMK Integrated Care Board End-of-Life (EoL) Care Transformation team, to hold a series of conversations with local residents about their experiences of palliative and end of life care.

We wanted to hear from people whose voices are not always included in these discussions. Using local insight, engagement work and available data, we focused on speaking with people living with mental ill health and people with experience of addiction, to better understand what matters to them and make sure their views help shape future services.

Championing your voice:

We identified these key themes and issues:

- **Understanding of palliative care and EoL:** Mostly understood through lived experience.
- **Helpful vs. challenging care:** Compassionate staff help; poor information and sudden decisions create stress.
- **Emotional, spiritual, cultural support:** Largely inadequate; emotional care valued as much as physical care.
- **Awareness of services:** Low outside major charities; clearer guidance desired.
- **Conversations about death:** Rare but useful; written wishes help when prompted.
- **Planning & decision-making:** Limited understanding; families struggle without prior guidance.
- **Equity, inclusion, respect:** Services not always accessible; diverse needs often overlooked.

Summary

Across our conversations, we found that people generally have a strong understanding of palliative and end-of-life care, but that it is mostly shaped by personal or family experiences rather than clear explanations from professionals.

Palliative care is seen as comfort-focused support that can start alongside illness, while end of life care is understood as the final phase when death is expected. That said, this understanding is informal, inconsistent, and often only clarified after going through difficult experiences.

A major theme that comes through is poor communication. Many described not being told what to expect, feeling unprepared for physical changes, and being left out of decisions. Instead, decisions often felt like they were made about them or their loved ones, rather than with them. This lack of communication caused distress, family conflict, and a sense of powerlessness.

Emotional and mental health support also comes up as a big gap. While clinical care was often described as kind and competent, respondents felt that emotional, psychological, and spiritual needs were often sidelined or treated as optional extras. Chaplaincy support was valued by some, but for those who weren't religious, it could never replace proper emotional or psychological care.

These are groups (such as people experiencing mental ill health, people with life limiting conditions and experience of addiction) where end of life is not talked. Instead, the focus is on 'cure' or 'life' rather than dying. Addiction brings its own challenges, particularly when the addiction affects the treatment options that can be offered, or taken.

Summary

Awareness of planning tools like ACP (Advance Care Plans), DNACPR (Do Not Attempt Resuscitation), and ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) forms was very low. Even when people had heard of them, understanding was limited, and few had been supported to actually complete them.

Some also shared that ambulance or hospital staff didn't always follow documented wishes, which undermined confidence in the system. Part of this was caused by people not understanding that being able to request a DNACPR did not mean people could request a 'You Must Resuscitate' order.

Equity and inclusion were another major concern. Many respondents doubted that all communities receive the same quality of end-of-life care. People with addictions, mental ill health, minority faiths, LGBTQ+ identities, or English as a second language were seen as especially vulnerable to being misunderstood or overlooked.

When compassionate, flexible care did happen, like hospices being tolerant of addiction, it was praised, but it was seen as inconsistent and dependent on individual providers or staff members rather than a system wide approach.

Finally, there was a clear desire for earlier, calmer, and more normalised conversations about death and dying. Conversations should ideally happen when people are well, not in crisis. Many said they were surprised at how helpful it felt to talk about these things when given the chance, even if they were initially resistant or fearful.

Summary by topic

Understanding of palliative care and end-of-life

Participants generally had a clear, practical understanding of the terms. Palliative care was viewed as "comfort care" when a cure is no longer possible, while end-of-life was defined as the final stage of "actively dying."

"It's when it is final, when there is no hope and they are definitely going to die." – Participant, The Mix

What was helpful or challenging?

Helpful: compassionate staff, hospice environments, continuity, being treated as a person, respect for beliefs.

Challenging:

- Lack of information, poor explanations, family conflict, feeling unheard, and sudden decision-making without consultation.
- Families didn't know what clinical deterioration looks like (e.g., eating/ drinking/ speaking changes). This led to shock and a sense of 'fighting the system' to honour preferences such as dying at home.

Addiction lens: Hospice was perceived as pragmatic about substance use, whereas "proper" medical services were seen as avoiding the addiction issue altogether.

"The medical people never even tried to help with the addiction... He couldn't ever stay in hospital because he needed to drink." – Bereaved family member

Summary by topic

Awareness of services

- Low awareness beyond major cancer charities and local hospice.
- Many unsure where to go for help, especially for non-cancer conditions.
- Desire for clearer, more visible information and guidance.

"I just felt lost. MacMillan were lovely, but no one really explained anything" – Participant, The Mix

Emotional, spiritual, and cultural support

- Widely felt to be inadequate.
- Emotional and mental health support seen as equally important as physical care but not treated that way.
- People valued small, personalised acts (e.g., nails painted, window opened) and recognised post-death needs (rapid burial, post-mortems). Yet few had documented these, and many were unsure how services would even know.

"It's what the NHS can give at the moment... not what you want, and I don't think it's what staff want to give, but its all that there is." – Participant, The Mix

Conversations about death and dying

- Rarely happen proactively and are often avoided due to fear, trauma, cultural norms, or emotional overload.
- When conversations do happen, people find them useful and grounding.
- Writing wishes down seen as helpful but rarely acted on without prompting.

'We should have something like Death Doulas. Or the GP should at least invite a conversation – but not when they have just told you that you need certain diagnostics or have just given you some terrible results!" - Participant, long term/ life-limiting condition

Summary by topic

Equity, inclusion, and respect

- People hoped for equal access but doubted this was a reality. Widespread concern that services are not equally accessible or inclusive.
- Cultural, faith, addiction, disability, mental health, and LGBTQIA needs not consistently recognised.
- Respondents want professionals to ask, not assume.

"Within a few months I had someone who was nearing the end of their life, most of the time it was within hospital, so they were well looked after. We had someone come in to talk about palliative care, but I was told not to be involved in it by family and the family decided not to tell me about it, it was challenging not knowing what was going to happen, but I didn't get any support only by close friends" – Participant – Q:Alliance

Planning and decision-making

- Very limited understanding of ACP, DNACPR, and RESPECT forms.
- Planning seen as important but emotionally difficult.
- Strong preference for conversations when people are well, not during diagnosis or crisis.
- Families struggle to make decisions without written guidance, especially when there is limited awareness of what decisions they can make or services they can choose.

"If it was just a thing, you know? Perhaps [talk about EoL] at the over 50s health check. If one of them [Clinicians] would ask me to talk about it – but, and I can't stress this enough, when I am well! Don't tell me you think I need tests and then ask! – Participant, Long Term/ Life Limiting Condition

How to improve care

- **The "Death Doula" or navigator model:** Explore the use of "Death Doulas" or community navigators who are "matter-of-fact and calm" to bridge the gap between clinical medical staff and overwhelmed families.

- **Normalise early conversations about death and dying:** Introduce routine, optional conversations at well-person touchpoints (e.g. over-50s health checks, long-term condition reviews). Avoid initiating these conversations immediately after delivering serious or distressing diagnostics or diagnoses.

- **Comprehensive "What to Expect" guides:** Create simple, jargon-free resources (or 'guidebooks') that explain the physical process of dying to families, including the loss of speech, appetite, and thirst.

- **Improve communication and expectation setting:** Ensure patients and families are clearly told what to expect physically and emotionally, especially in the final stages. Use plain language and check understanding. Build in time for questions and emotional processing.

- **Strengthen emotional and mental health support:** Treat emotional and psychological support as core, not optional. Provide alternatives to purely spiritual care, including counselling, peer support, and trauma-informed approaches. Train staff to respond confidently and compassionately to distress.

How to improve care

- **Increase awareness and understanding of planning tools:** Proactively explain Advance Care Plans, DNACPR, and RESPECT forms. Provide simple written and digital guides. Emphasise that plans protect families from having to guess or carry guilt. Remember that talking about death doesn’t cause it.

- **Support families as decision-makers:** Acknowledge how difficult surrogate decision-making is. Encourage people to write wishes down to relieve family burden. Offer facilitated conversations where appropriate.

- **Embed inclusion:** Train staff to ask about beliefs, values, identity, addiction, and cultural practices. Avoid assumptions based on diagnosis, background, or appearance. Ensure translated materials and interpreters are available and visible.

- **Improve visibility of services:** Create clear, accessible pathways showing who supports end-of-life care, and who can access it. Use posters, websites, and community spaces despite the topic being emotive. Frame information as empowering rather than alarming or morbid.

- **Learn from what works well:** Hospice practices that respect individuality, autonomy, and lived reality (including addiction) should inform wider practice. Person-centred, holistic care consistently left the strongest positive impressions.

Who took part?

Gender

9 women, 2 men, and 2 people who preferred not to say.

Age

5 were under 40yrs; 8 were between 50 and 60yrs.

Ethnicity

- 1 person was Arabic British
- 1 was Indian
- 10 were White British
- 1 person was Black British

Religion

- 1 person was Pagan
- 2 were brought up Catholic but now identify as Christian
- 2 were Christian
- 1 person had both Muslim and Jewish parentage
- 1 person was a Hindu
- 4 had no religion
- 2 people were Atheist

Who took part?

Sexuality/gender identity

- 3 people were LGBTQ+

Long-term conditions

- 12 people had lived experience of mental ill health
- 5 people had serious and enduring mental ill health diagnoses
- 1 person had a learning disability
- I person had a dementia diagnosis
- 1 person had a relative who had lived, and died, in active addiction
- 3 people had long term and life-limiting conditions
- 5 people had attempted suicide and/ or had self harmed.**

** These figures reflect conditions and identities, not individual people. Many participants shared more than one lived experience, highlighting why it is important to engage with people as individuals rather than reducing them to a single diagnosis.

healthwatch
Milton Keynes

Healthwatch Milton Keynes
Room 1-2, The Vaughan Harley Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA

www.healthwatchmiltonkeynes.co.uk
01908 736005
info@healthwatchmiltonkeynes.co.uk
/HealthwatchMK
/Healthwatch_MK
/HealthwatchMiltonKeynes