Kirklees Council

Director of Public Health
Annual Report 2023/24

Inequalities in the experience of death and dying

What are the assets and opportunities within Kirklees communities?

ACHIEVING INCLUSION

Kirklees
COUNCIL

EXECUTIVE SUMMARY

Introduction from Rachel Spencer Henshall, Director of Public Health

Death touches us all throughout our lives but can often be a subject which is hard to discuss or plan for – even with the people we are closest to.

Over 3,800 people in Kirklees die every year. For three quarters of these people, death is a gradual process. In these cases, dying becomes an evolving part of life that may lead to rising administrative and financial burdens, complex conversations with family and friends, and increasing contact with health and social care.

Death and dying is experienced uniquely; Kirklees has a wealth of diverse communities who all have different customs and rituals in relationship to death. We also know that some people are able to plan for and experience a death which is within their control, in a setting of their choosing and with the people who they love.

Sadly, evidence shows us that some groups of people are more likely to experience a traumatic, stressful or unplanned death. I wanted to be able to understand these inequalities more comprehensively at a local level, so I arranged direct conversations with a range of people and organisations across the Kirklees system.

These conversations have been remarkable. They have included colleagues from large anchor organisations through to smaller grassroots community organisations across Kirklees. All the contributions have been powerful, insightful and thought-provoking.

My report aims to examine and understand these local inequalities and develop recommendations for across the Kirklees system.

By reading the report and recommendations you are gaining an improved understanding of the inequalities experienced around death and dying. By listening to the stories and experiences of our partners and by working together, we can help to reduce these inequalities and reduce the impact on individuals, families and communities. Finally, by talking about this report to family, friends, colleagues, partners and communities we are working together to help normalise these challenging conversations. Thank you.

Why 'dying well' matters

When addressing end-of-life care challenges for the health and social care system, it is vital to consider the full impact on individuals, families, and society, including:

- The care of those nearing the end of life
- Supporting people with life limiting illnesses to live as well as they can, with a focus on quality of life
- Supporting people whose illness is progressing, to better understand their priorities for care
- The experiences of where and how people die
- Supporting people living with loss and bereavement.

Prioritising 'dying well' aligns with NHS core values of compassion, respect and dignity for all. Unfortunately, it is often the most disadvantaged and vulnerable who suffer most from the imbalance in care when dying and grieving. The recommendations in this report look at how we can start to address this imbalance.

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Groups experiencing inequalities in end-of-life care and support

People who identify as LGBTQ+

National evidence shows:

- Discrimination and stigma manifesting as bias from healthcare staff, resulting in inadequate or inappropriate care; fear of discrimination may prevent LGBTQ+ individuals from seeking the care they need or disclosing their identities.

- Legal issues may impact end-of-life care, for example same-sex partners not receiving visitation rights, being involved in medical decision-making, or being legally recognised as next of kin.

Kirklees organisations also told us:

- Current heteronormative approaches mean gender identity and sexuality are assumed, rather than confirmed. This can create awkwardness in openly supporting loved ones, and may limit bereavement support options.

- Previous negative experiences of healthcare services lead to an apprehension about accessing end-of-life care services.

- Transgender individuals may face challenges related to gender-affirming care or respectful use of pronouns, extending to a fear for how they will continue to be referred after their death.

People experiencing homelessness

National evidence shows:

- Homelessness has a significant impact on both physical and mental health, with life expectancy 30 years lower than the general population.

- Increased exposure to death – particularly violent, early or traumatic deaths - can lead to a strong acceptance or aversion to death, as well as differing perceptions on what a 'good' or 'bad' death might be.

- A mistrust of organisations, based upon many years of feeling isolated from mainstream society, may prevent homeless people from seeking end-of-life support.

Kirklees organisations also told us:

- A lack of availability of suitable accommodation may mean homeless people are either discharged into unsuitable or temporary accommodation or remain in hospital when they are medically fit for discharge. For those with accommodation, it is generally unsuitable for end-of-life care.

- Engagement with services is an issue, due to a lack of trust stemming from previous trauma.

- Sudden or traumatic deaths are more common amongst this population group, with significant implications for family, friends and supporting staff.

People with learning disabilities

National evidence shows:

- People with a learning disability are more likely to die at a younger age and to die suddenly. This makes it more difficult to predict when people with a learning disability are approaching the end of their life, and less likely they will be referred for palliative care.

- Other issues include difficulties with cognition, understanding and communication, along with challenges in decision-making processes, co-morbidities and mental health issues.

- Lack of communication can extend to the health condition of a primary carer. The death of a carer may then come as a sudden shock, and could lead to an unplanned change in living circumstances.

Kirklees organisations also told us:

- Not all staff will have had training to recognise the signs of end-of-life for people with a learning disability, leading to a lack of co-ordinated care.

- Due to coexisting health conditions, it may be more difficult for people with a learning disability to die in a setting of their choosing.

- It can be hard to navigate the additional cost of increasing packages of care.

People with non-malignant (non-cancerous) long-term health conditions

National evidence shows:

- Palliative care continues to be more often linked to the care of people with cancer, as the symptoms and progression of cancer are often more predictable. The non-linear progression of other diseases can delay or prevent discussions about end-of-life care preferences.

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- The association with social determinants of health for non-malignant conditions influences end-of-life care by affecting decision-making, care preferences, and the ability to navigate healthcare systems.

Kirklees organisations also told us:

- Local hospitals are now doing more advance care planning for patients with other life-limiting health conditions, supported by dedicated hospice staff. The Kirkwood has seen an increase in their proportion of non-cancer patients.

- If hospice referrals could be more automated (triggered when other treatment ends), this would reduce some of the inequalities seen in hospice referrals.

- There is lots of work going on within primary care around early identification of patients, although there is still inequity in palliative care referral rates across the district.

- It is important to have patient and public involvement in planning and delivering care services.

People with serious mental illness or addiction issues

National evidence shows:

- End-of-life care for individuals experiencing addiction or serious mental illness is often marked by inequalities and challenges stemming from stigma, limited resources, and systemic barriers within healthcare systems.

- This stigma can influence treatment decisions, including access to palliative care services.

- Individuals with addiction or serious mental illness may experience chaotic lifestyles and find it difficult to plan or think longer term.

Kirklees organisations also told us:

- The difficulty that people with serious mental illness or addiction issues may have in making or attending appointments can place extra pressure on primary and secondary care.

- There are good local examples of strong partnerships working to tackle barriers to access, but these are only beneficial for people already engaged with services. Those with an unmet need around problematic drug or alcohol use are less likely to access these services.

- There is a perception that palliative care focuses purely on dying, rather than living well at the end of life.

- There is a training need, both for mental health staff in palliative care support pathways and palliative care staff in mental health support.

People living in poverty or deprivation

National evidence shows:

- Low income is associated with increased risk of death in hospital rather than in the community and more emergency hospital admissions in the final months of life.

- Having the opportunity to die at home is often considered as an indicator of a 'good death'. When you are living in poverty, your housing is more likely to be inadequate to meet the needs of the household – it is more likely to be cold, damp, and overcrowded.

- Having a terminal illness increases your risk of falling into poverty.

Kirklees organisations also told us:

- People who are living in poverty will often be juggling multiple pressures which will make planning for end of life increasingly challenging.

- The support provided by local neighbours and organisations is invaluable for individuals and families.

- For people living in poverty, death and dying often comes with an additional and unaffordable cost. This can cause significant amounts of worry for families.

Diverse experiences by race, ethnicity or faith

National evidence shows:

- Ethnic and cultural differences can influence patterns of advanced disease, illness experiences, healthcare seeking behaviour, and the use of healthcare service.

- Barriers to accessing palliative care include lack of cultural sensitivity amongst healthcare providers, a greater prevalence of non-malignant (non-cancerous) conditions in minority ethnic groups, language barriers, past experience of racism and fear of discrimination, and a deep-rooted cultural expectation that family members will care for people at home.

- Faith-based communities are a substantial asset due to the spiritual and practical support provided, but observing faith rituals at end of life may require flexibility from service providers.

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Kirklees organisations also told us:

- End-of-life services are generic, and don't necessarily accommodate specific cultural practices.
- End-of-life care and planning should be personalised to the individual, without making assumptions or generalisations about needs or preferences based on race, ethnicity or faith.
- More people are now living alone or without family support, as family members seek higher quality work outside of the family home, contradicting a misconception that Black and Asian families are usually an extended unit.
- A whole community supports the dying. They often identify and then advocate for the dying, requesting services and practical support. They recognise gaps that services do not.

Unpaid carers

National evidence shows:

- Although they may not always feel knowledgeable about the process, unpaid carers often take on the role of unofficial coordinator of care to help communication between professionals.
- Unpaid carers must balance emotional turmoil with practicalities associated with providing daily care, in some cases having to give up work or reduce their hours, causing additional financial pressures.
- Responsibility for sharing information may fall on the carer, which can have implications for the carer's wellbeing and the patient's right to make their own decisions.
- Carers may also have health issues of their own; those in receipt of care may experience an abrupt change in their support and living arrangements following the death of their primary carer.

Kirklees organisations also told us:

- There is a need for guidance for carers on referral pathways and the availability of funding and support, depending on the person's situation.
- The importance of caring for carers, and not removing carer support networks as soon as the cared-for person dies.
- Understanding that some carers are not visible to the system, either because they don't identify as a carer or because the cared-for person has declined medical support. Also, a carer's voice may not be heard if the carer does not have power of attorney.

Recommendations for action

Recommendations for those working across the system include:

- Encourage conversations about death and managing a life-limiting condition, to better understand people's wishes and help them put plans in place; focus on what matters most to them.
- Educate staff in how to have death-positive conversations, and raise awareness of services and options amongst patients, carers, relatives and staff.
- Engage with palliative and hospice care across services, to support those with a life-limiting illness from the point of diagnosis. This essential aspect of healthcare supports quality of life and a good death for everyone in every place.
- Enable people to make decisions that suit their individual needs, by using a person-centred approach and developing improved support mechanisms.
- Expand the support currently offered and provided, by building on existing community assets and examples of good practice.
- Evolve services as population demographics and generational attitudes change, co-designing with communities to ensure language and support are inclusive and equitable; recognise how good palliative and end-of-life care can have a positive impact on every part of the health and care system.
- Read this report in conjunction with other local and regional evidence.

What individuals can do

Not everyone is able to plan ahead. However, where it is possible, there are several steps we can take to make things easier for ourselves and our loved ones:

- Make a will and other financial arrangements.
- Make a funeral plan.
- Plan for your future care.
- Decide about organ donation.
- Think about your digital legacy (what you want to happen to your online information).
- Write everything down, and let your loved ones know.
- Ask your loved ones about their end-of-life preferences too!
- The 'Tell Us Once' service can help if you need to report a death.

Read the full report:
www.kirklees.gov.uk/dying-well-matters