End of Life JSNA

Health and Wellbeing Board

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Level of Need

Indicator	Leicestershire (2020)	Trend over preceding 5 years	England
Mortality Rate	973 per 100,000	-	1,042 per 100,000
Premature Mortality Rate	310.8 per 100,000	-	358.5 per 100,000
Preventable Mortality Rate	118.8 per 100,000	-	140.5 per 100,000
Deaths occurring in hospital	39.7%	⬇	41.9%
Deaths occurring at home	30.2%	⬆	27.4%
Deaths occurring in care homes	24.0%	-	23.7%
Deaths occurring in a hospice	3.6%	-	4.5%

■ Significantly better then England
■ Not significantly different from England
■ Significantly Worse then England

⬆ Increase from previous time period

⬇ Decrease from previous time period

Level of Need

Based on results of a survey undertaken as part of the JSNA End of Life chapter:

- 69% of bereaved people do not believe it was easy for their loved one to access support services.

- 65% of bereaved people were unhappy with the care and support their loved one received.

- 58% of bereaved people did not feel they had a good understanding of the support services available to them.

- 61% of bereaved people felt it was not clear how they access support services.

- 86% of informal carers felt they did not receive sufficient support or training to care for someone near the end of life.

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Level of Need

Quotes from local people:

"We were left to our own devices to deliver the care regardless of the fact not one of us are medically trained or even had any idea how to safely help move and transport our family member! None of us knew what to expect or what was coming and found the lack of support very distressing!"

"If you are strong enough to reach out, there is some support available. However, it the is ones who don't/can't reach out who are the most vulnerable, and absolutely no one followed up on aftercare after my loss."

"As a carer and a cared for person you become invisible. You become worthless"

"It is not always easy to access help and know where to go. There are so many different agencies involved that it is confusing, especially at such a difficult time. I do not always know what each agency knows so that I have to explain our situation to each person who comes to help."

Unmet Needs / Gaps

- People need to be supported in having conversations about death and end of life preferences.

- There is a lack of coordination of services, with the burden often falling on those nearing the end of life and their loved ones.

- People are often unaware of sources of support, and accessing these can be complex.

- There are limited out of hours services available for people in the community.

- Following a bereavement, people may feel abandoned by health and social care staff due to a lack of routine follow up.

- Informal carers do not feel sufficiently supported, particularly with regards to the training and advice they receive.

- Health and social care staff do not always feel they have sufficient training to support them in working with those approaching the end of life.

Recommendations: Further Exploration of the Issue

- Undertake a tailored piece of engagement to capture the views, preferences, and experiences of those who are themselves approaching the end of life.

- Produce a health equity audit to further explore inequalities in end of life care and how services can be tailored to better address the needs of disadvantaged groups.

- Further explore the reasons for deaths taking place at hospital / hospice / home / care home, to better understand if this is due to patient choice or factors such as a lack of community services meaning there is insufficient capacity to support people dying at home. To particularly consider those who live elsewhere but die in a care home.

Recommendations: Facilitating Conversations

- Seek to modify social norms by utilising behaviour change theory and social marketing, to improve the acceptability of discussing death and end of life preferences.

- Consider how conversations relating to end of life preferences and planning can be initiated at times surrounding major life events, by incorporating a Making Every Contact Count Plus (MECC+) approach.

- Seek to increase the number of people with an advance care plan.

- Encourage healthcare staff to initiate advance care planning discussions during early interactions, particularly for those with degenerative conditions such as dementia who will be less able to contribute meaningfully as their condition progresses.

Recommendations: Increasing Public Understanding

- Undertake local campaigns aimed at enhancing the public's understanding of what is meant by end of life, the terms frequently used in relation to it, and the role of different services.

- Improve awareness of existing, locally available services.

- Build on work by Dying Matters to provide a central source of information and signposting advice to end of life and bereavement services.

Recommendations: Developing Services

- Develop a more robust community out of hours offer so that support for those approaching the end of life and their carers is available throughout the week.

- Improve the coordination of services working together to deliver end of life care, to reduce the burden currently placed on patients and their loved ones.

- Promote continuity of care within services, particularly with primary and community services, to support the building of trusted relationships between patients and their health or social care provider.

- Consider how to introduce a form of routine follow up with those who have undergone a recent bereavement.

- Consider the need for a paediatric palliative care consultant and the need for community paediatric and nursing support that responds to the rising numbers of children and young people on end of life pathways with increasing complexity.

Recommendations: Supporting Carers and Staff

- Improve the advice and support available to informal carers, so that they feel better equipped with the skills and knowledge to support their loved one.

- Consider how regular check-ins with informal carers can take place.

- Support informal carers in taking respite care, so as to ensure their own wellbeing.

- Ensure training is available and accessible for staff who do not regularly deliver end of life care as a core part of their role.

Conclusion

- The Board is asked to support the recommendations of the Joint Strategic Needs Assessment on End of Life.

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