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Rutland County Council  
**JSNA End of Life Chapter**  
Health and Wellbeing Board  
October 2022

## Level of Need

Indicator	Rutland (2020)	Trend over preceding 5 years	England
Mortality Rate	780 per 100,000	-	1,042 per 100,000
Premature Mortality Rate	205.8 per 100,000	-	358.5 per 100,000
Preventable Mortality Rate	68.2 per 100,000	-	140.5 per 100,000
Deaths occurring in hospital	33.9%	-	41.9%
Deaths occurring at home	33.9%	-	27.4%
Deaths occurring in care homes	27.5%	-	23.7%
Deaths occurring in a hospice	3.1%	-	4.5%

	Significantly better than England
	Not significantly different from England
	Significantly Worse than 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:

- 67% of bereaved people do not believe it was easy for their loved one to access support services.
- 67% of bereaved people were happy with the care and support their loved one received.
- 62% of bereaved people did not feel they had a good understanding of the bereavement support services that were available to them.
- 61% of bereaved people felt it was not clear how they access bereavement support services.
- 57% 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:

*"I had to cope alone. The only support received was when my partner was receiving oncology treatment or was admitted to PCH/the hospice. It would be far better if additional support at home was offered upfront. You have enough on your plate without*

- 1. Having to try and find out what help is available*
- 2. Keep pestering, when no help is forthcoming. I was supporting my partner alone, and taking him to all his medical appointments"*

*"I was not aware of any services. From diagnosis we were mostly alone in organising all care. Social services refused to advise on appropriate care as we were 'self funding'. We were not made aware of any end of life care or bereavement services outside of the care we were paying for privately."*

*"Lack of explanation regarding medication from hospital at discharge, lack of information regarding the roles and responsibilities of the district teams, lack of equipment ( walker ) that was promised from hospital, lack of communication and explanation of the CHC system/status."*

*"I feel that the main gap in services is that if a person wants to die at home, clinical services overnight are not available at a level which is required or in a timely manner"*

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## 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.

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## 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.
- Explore how accurately advance care plans are being followed and enacted, particularly for patients attending hospitals outside of LLR which may have different systems to those used locally.

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## 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.

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## 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: Delivering 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.
- Work to introduce beds specifically for end of life care provision locally in Rutland, to ease travel burdens and facilitate respite care.
- Consider how to introduce a form of routine follow up with those who have undergone a recent bereavement.

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## 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 Health and Wellbeing Board is asked to:

- Endorse the recommendations arising from the JSNA End of Life chapter
- Note that the JSNA End of Life chapter will be used to inform the refresh of the LLR End of Life Strategy which will be undertaken by the Integrated Care Board