End-of-life care for people with severe mental illness: the MENLOC evidence synthesis

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Plain English summary

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In this study we brought together evidence from research, policies, guidance and case studies in the area of end-of-life care for people with severe mental illness. End-of-life care refers to the help given to people with life-threatening conditions in their expected last 12 months of life. Severe mental illness refers to a range of issues for which care is usually provided by specialist mental health services.

An advisory group, which included people who had experience of mental health and end-of-life care, helped us throughout our project. We searched research databases, journals and online sources. We assessed research articles for their quality and summarised their content. In one review we combined content from research with content from policy and guidance. In another review we combined the content of the case studies. We wrote synthesis statements summarising the research evidence, and assessed how much confidence decision-makers should have in these statements.

We included 104 documents overall. We synthesised research, policy and guidance under themes reflecting their content: the structure of mental health and end-of-life care services; professional practice; providing and receiving care; and living with severe mental illness. We synthesised case studies under themes relating to delays in diagnosis, making decisions, treatment futility, supporting people and the experience of care.

Our project has implications for care. The evidence suggests that partnerships should be built between mental health and end-of-life care staff, and that people should be supported to die where they choose. Care staff need education, support and supervision. A team approach is needed, including support for advocacy. Physical health care for people with severe mental illness needs to be improved so that life-threatening conditions can be recognised sooner.

Future research should involve people with severe mental illness at the end of life and their carers. Research is also needed to evaluate new ways of providing and organising care.
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