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End of life care for people with  
severe mental illness: an evidence  
synthesis (the MENLOC study)

**Accessible summary**





## Background

People with severe mental illness often have significant physical health problems, and reduced life expectancy. Against this background, in this project 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 cancer or other life-threatening conditions in their expected last 12 months. Severe mental illness refers to a range of issues for which care and treatment is usually provided by specialist mental health services.

## Methodology

An advisory group, including people with experience of mental health and end of life care, helped us throughout our project. We searched research databases and supplementary sources (including relevant journals, websites of government departments, charities and other organisations) for relevant evidence published in the English language. We assessed research articles and case studies for their quality, and summarised their content. In the first of two syntheses we combined content from the research articles with content from the policy and guidance documents. In a second synthesis we combined content from the case studies. We assessed how confident decision-makers should be in our summaries of the research evidence, and identified the implications of our review for health care policy, services, practice and research.

## Research findings

We included 104 documents in our overall review, comprising 34 research publications, 42 case studies and 28 non-research items. The majority of the research items and the case studies were of acceptable or high quality.

Research, policy and guidance material was synthesised using four themes and case study material was synthesised using five themes. These are summarised below:



## Summary of thematic syntheses

### Structure of the system

#### Policy and guidance

Separate commissioning, management and organisation

- Accessing and navigating the system
- Access for homeless and vulnerable groups
- Care coordination across systems
- Resources

#### Partnership

- Funding and flexibility to work in partnership
- Multidisciplinary teamwork
- Ongoing interprofessional communication

#### No right place to die

- Dying at home
- Dying in a mental health hospital
- Dying in a hostel
- Dying in an acute hospital
- Dying in a nursing home or residential facility
- Dying in a hospice

### Living with severe mental illness

Complexities of end of life care

Familiarity and trust

- Trust and rapport
- **Supporting people in familiar environments**

Recognising physical decline

- Identifying signs of declining health
- **The impact of late diagnosis**
- **Identifying an EoLC trajectory for those who are homeless**

### Professional issues

Relationships between health care professionals and people with severe mental illnesses

- Connecting relationships
- Talking about death and dying
- Attitudes and beliefs of health care professionals

Mental health professionals doing end of life care

- Experience, knowledge and skills
- End of life care not being mental health work
- Emotional distress

End of life care professionals doing mental health care

Training and education

- Educational needs
- Core professional preparation
- In-service education
- End of life and mental health staff learning from each other

### Diagnostic delay and overshadowing

Receiving late diagnoses

### Decisional capacity and dilemmas

Capacity, consent and dilemmas in care and treatment

### Key

Evidence from synthesis of research, policy and guidance

Evidence from synthesis of case studies

### Contexts of care

Managing the interface between mental health and end of life care

- General practitioners managing care
- The role of medical specialists
- Referral
- Mental health assessment at the end of life

Health care services and treatment utilisation in the last year of life

- Ambulatory visits to GP or medical specialists
- Palliative care services
- Long term institutional care
- Acute care
- Intensive care unit admissions
- Emergency department visits
- Invasive interventions
- Chemotherapy
- Advanced diagnostic examinations
- Use of medications at the end of life

Meeting individual and family needs

- Spiritual and psychosocial support
- Families and their involvement
- Advocacy
- End of life care preferences

### Medical futility

Exhausting the optimism of health professionals

### Individuals and their networks

The importance of support in the community

### Care provision

Care across different settings and by different groups of professionals

## What are the implications for policy, services and practice?

The implications of our project's findings are:

1. Formal and informal partnership opportunities should be taken and encouraged across the whole system, and ways should be found to support people to die where they choose.
2. Education, support and supervision for all staff caring for people with severe mental illness at the end of life is needed.
3. Programmes and services for people with severe mental illness at the end of life require a team approach, including advocacy.
4. Proactive physical health care for people with severe mental illness is needed to challenge the problem of delayed diagnosis.

## What are the recommendations for future research?

Recommendations for future research are:

1. Patient and family-facing studies are needed to establish factors helping and hindering care in the UK context.
2. Studies are needed which explicitly co-produce and evaluate new ways of providing and organising end of life care for people with severe mental illness, including for people who are structurally disadvantaged.

## Publications and further information

### Complete monograph

Hannigan B., Edwards D., Anstey S., Coffey M., Gill P., Mann M. and Meudell A. (2022) End of life care for people with severe mental illness: the MENLOC evidence synthesis. *Health Services and Delivery Research* 10 (4)

<https://doi.org/10.3310/ULTI9178>

### Derived article: case studies

Coffey M., Edwards D., Anstey S., Gill P., Mann M., Meudell A. and Hannigan B. (2022) End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study). *BMJ Open* 12 e053223

<http://dx.doi.org/10.1136/bmjopen-2021-053223>

### Derived article: research, and UK policy and guidance

Edwards D., Anstey S., Coffey M., Gill P., Mann M., Meudell A. and Hannigan B. (2021) End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis (the MENLOC study). *Palliative Medicine* 35 (10) 1747-1760

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