

Sussex Palliative and End of Life Care Needs Assessment 2025/26

Key findings webinar

Nick Bottomley - Director of Programmes

Sussex Hospice Alliance

Ross Boseley- Health Improvement Principal

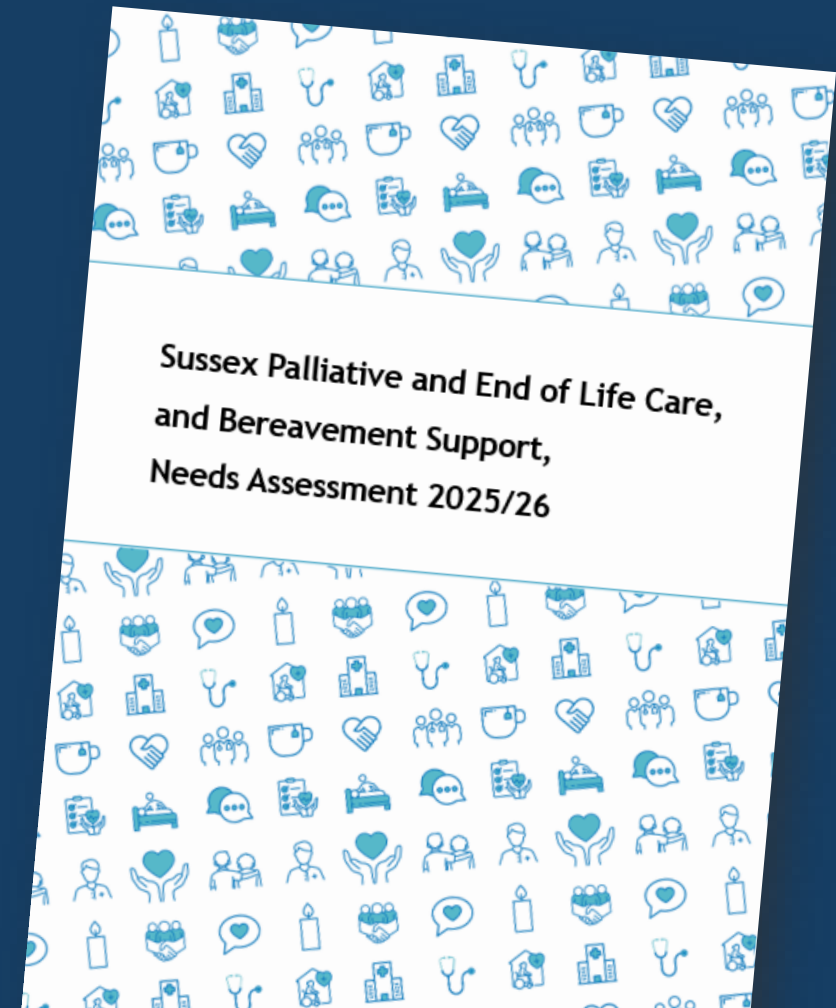
East Sussex County Council

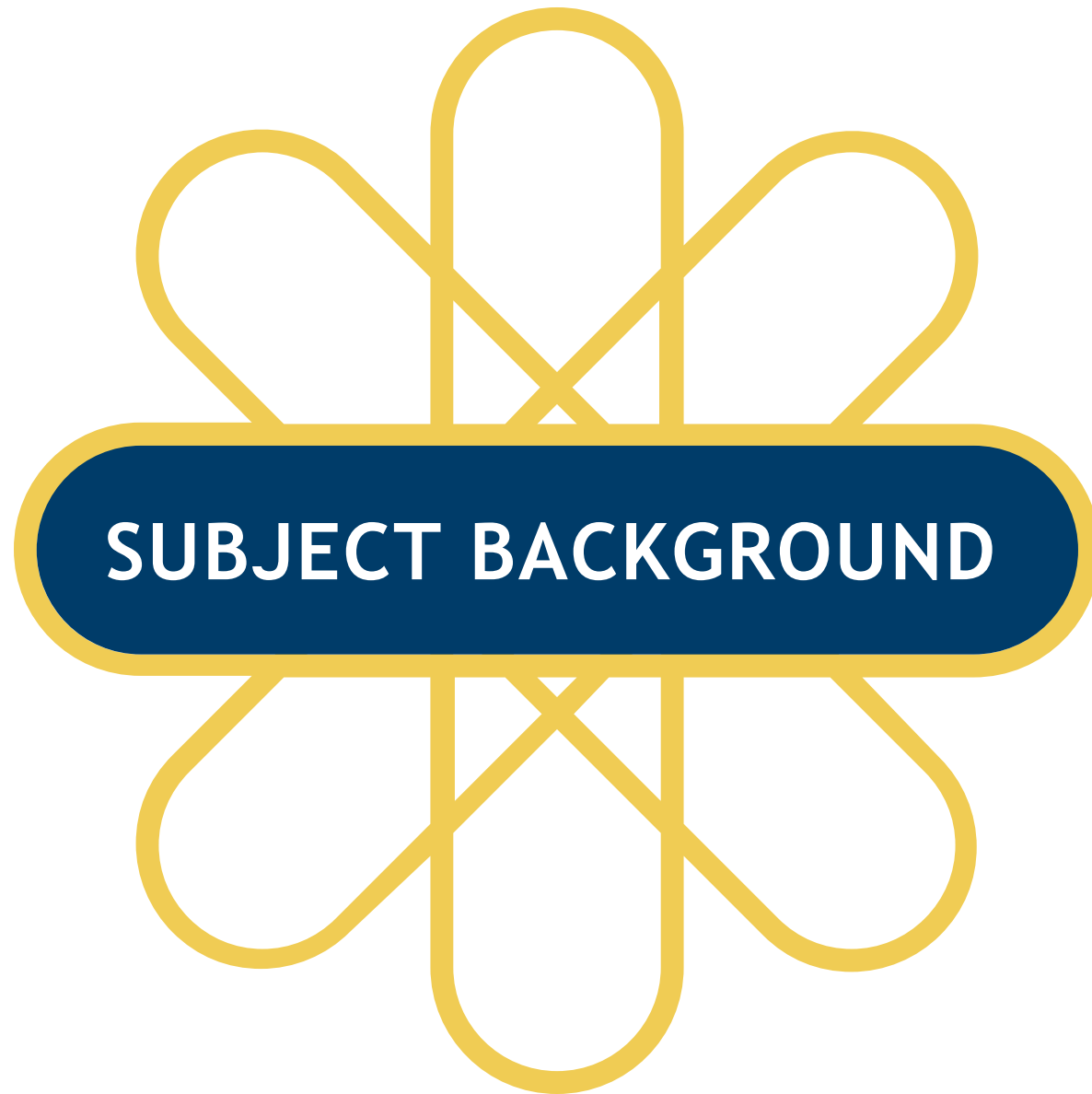
Faye NelSenior Commissioning Manager Palliative and End of Life Care

NHS Surrey and Sussex

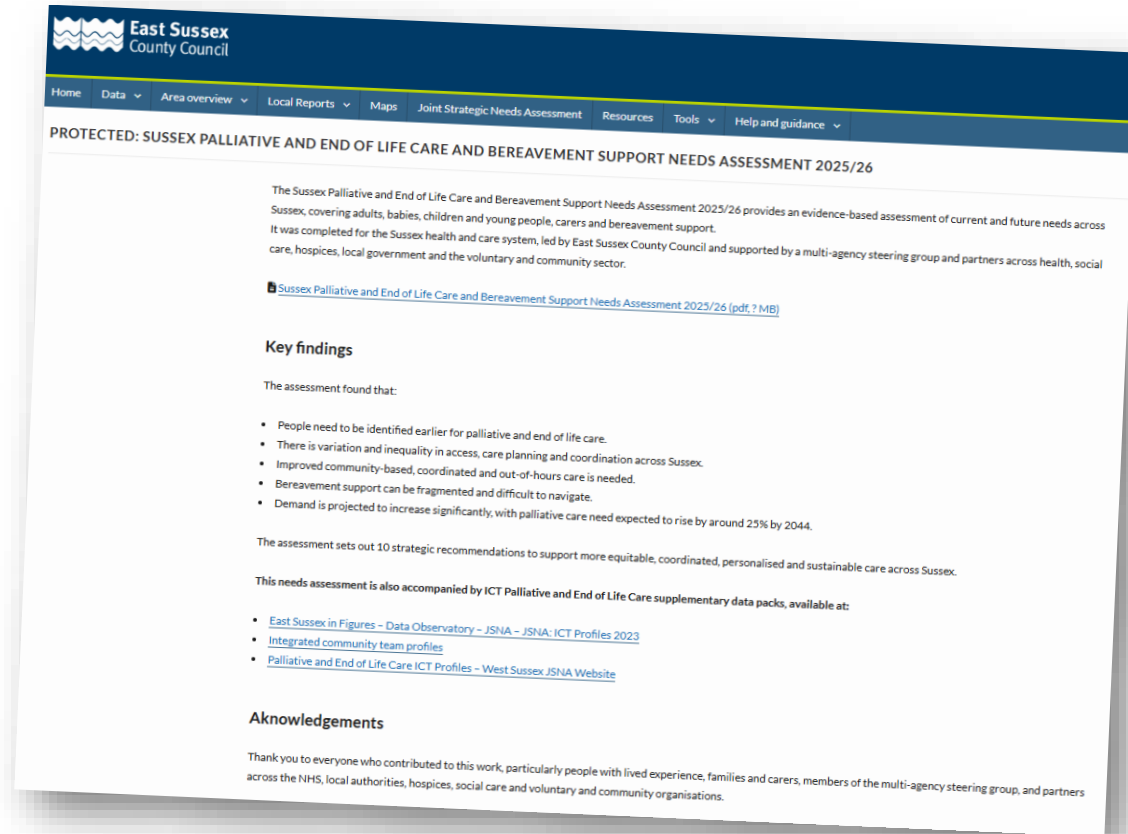
Date: October 2026

Location: MS Teams





JSNA East Sussex web page



JSNA: Sussex Palliative and End of Life Care and Bereavement Support Needs Assessment 2025/26

Celebrating compassionate care across Sussex

Acknowledging the people and partnerships supporting **individuals** and families at the end of life



Thank you to colleagues across the NHS, local authorities, hospices, social care, care providers, ambulance services, primary care, community services and the voluntary and community sector. The report recognises dedicated staff who deliver compassionate, person-centred and coordinated care, often at the most difficult time in people's lives.

“

“The staff were compassionate... I felt the compassion from the whole team.”

Focus group participant

“

“I can't fault the care - they were just brilliant.”

focus group participant

“

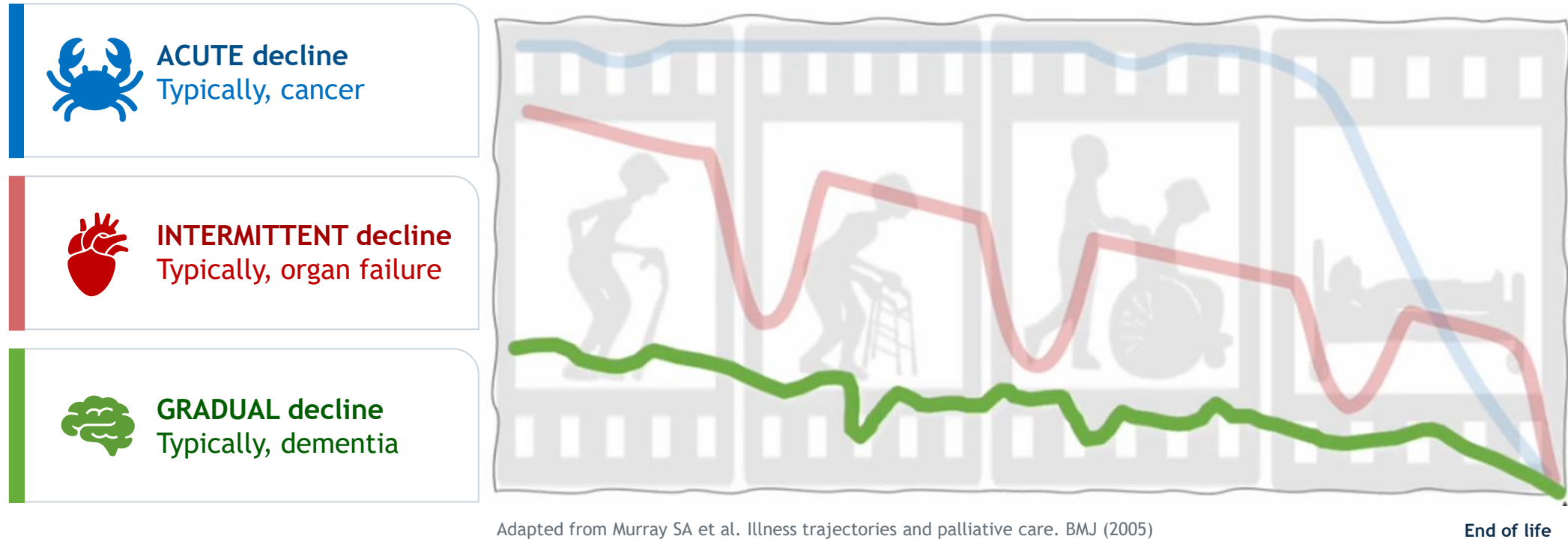
“The hospice was very good - they were kind, supportive, and made a really difficult time easier.”

Focus group participant

Workforce skill, kindness and commitment make dignity, comfort and choice possible many people and families across Sussex.

Physical decline and illness trajectories

Different conditions can follow distinct patterns of decline towards the end of life



Key headline: The pattern of decline differs by condition, so recognition, planning and coordinated support must be responsive.

[Using illness trajectories to inform person centred, advance care planning | The BMJ](#)

Physical decline in older people with multimorbidity

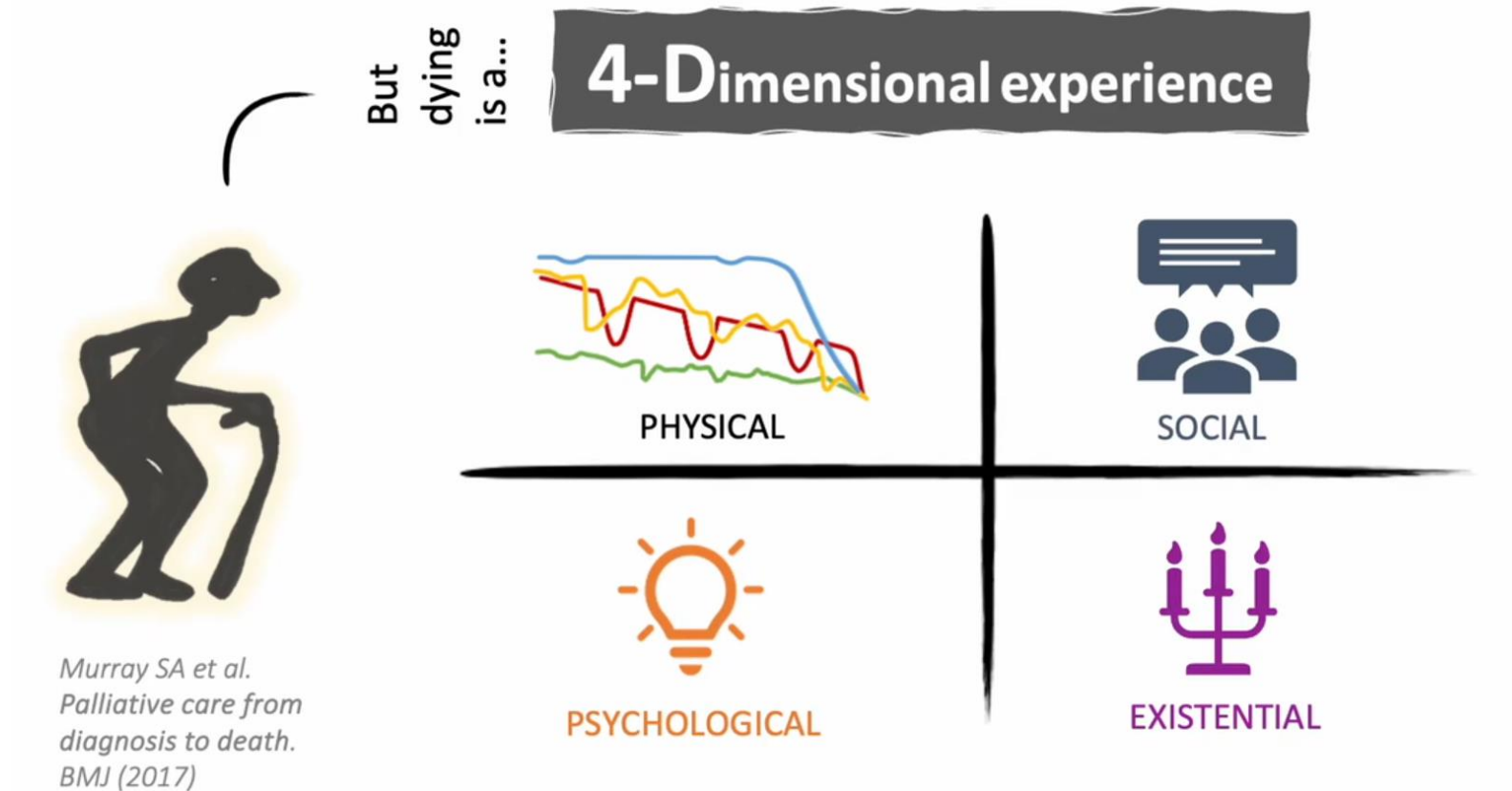
Older people may experience repeated deterioration and partial recovery, followed by a final decline



Key headline: Multimorbidity can create an uneven decline, requiring earlier recognition, flexible planning and coordinated support.

[Using illness trajectories to inform person centred, advance care planning | The BMJ](#)

Physical decline in older people with multimorbidity: slide 2



[Using illness trajectories to inform person centred, advance care planning | The BMJ](#)

Sussex and England comparison

Sussex is broadly similar on register prevalence and days known, but the service-contact pattern differs.

69

Days know

70 England

2

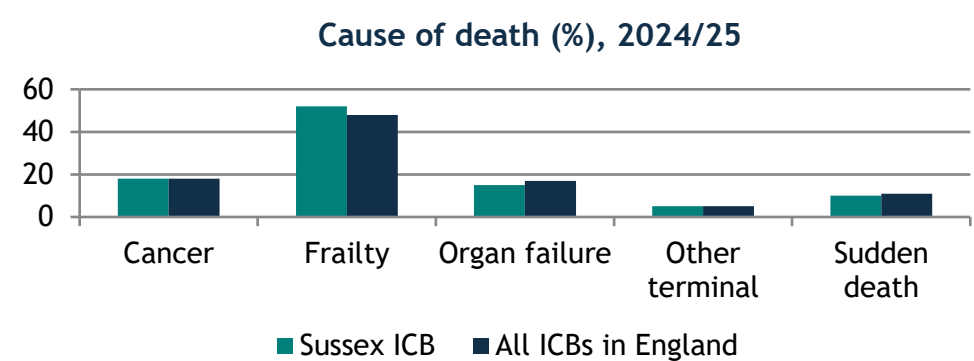
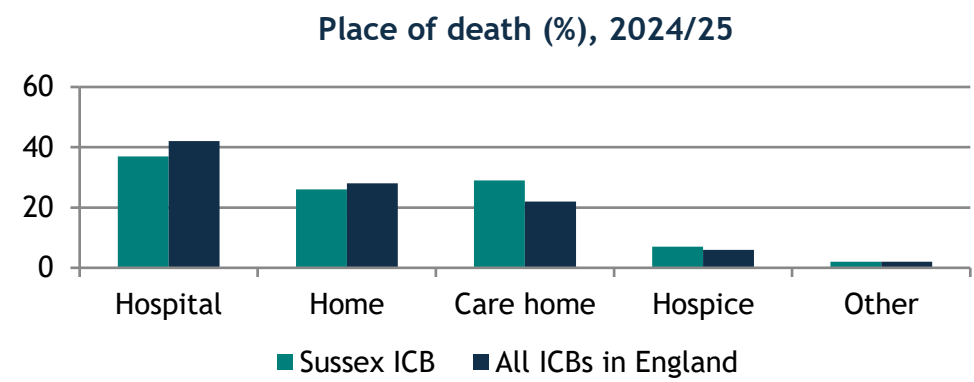
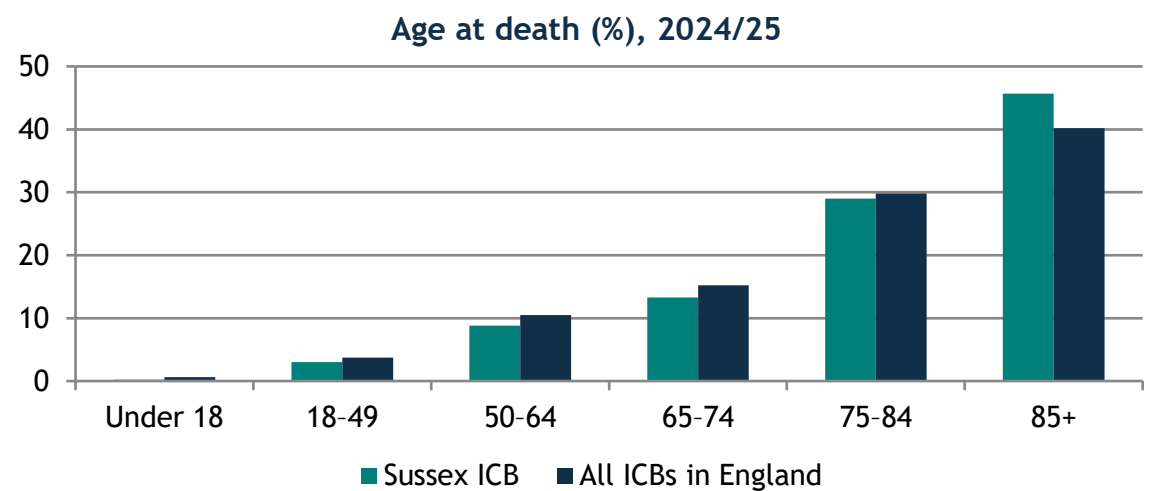
Contacts in last 90 days

3.4 England

0.54%

register prevalence

0.55% England

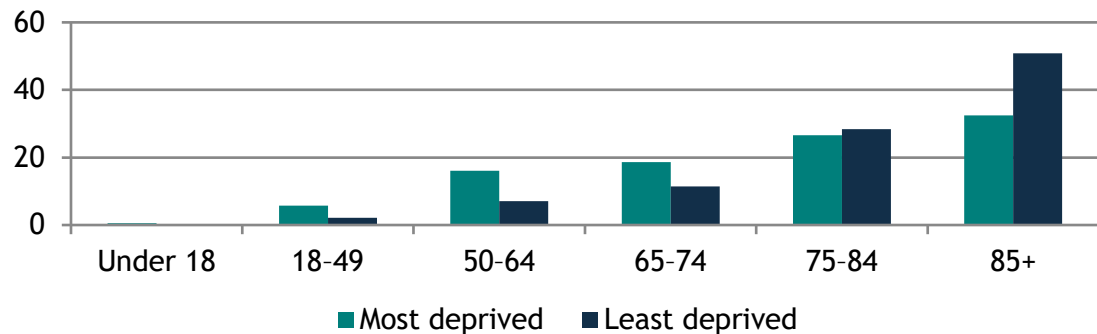


Key headline: Sussex has fewer hospital deaths and more care-home deaths than England, alongside a higher share of deaths at age 85+.

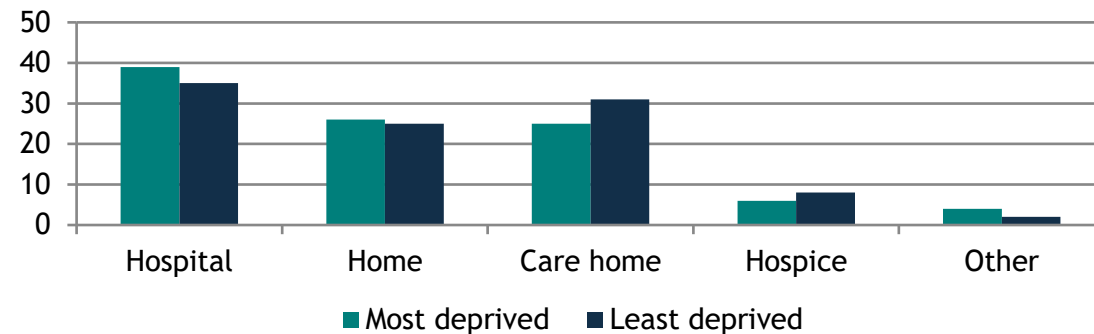
Comparing our most and least deprived

Deprivation is associated with a younger age profile at death and greater emergency-service contact.

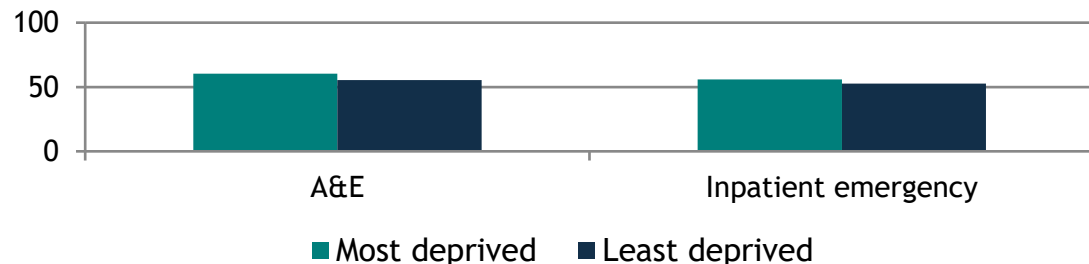
Age at death (%), 2024/25



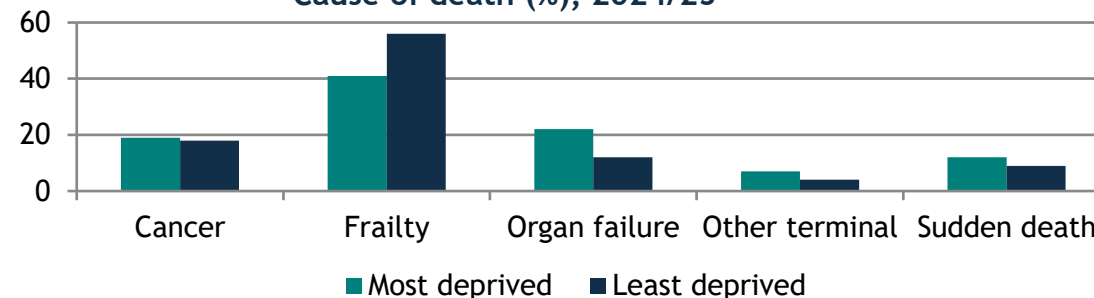
Place of death (%), 2024/25



Contact with urgent services (%)



Cause of death (%), 2024/25



Key headline: The most deprived group dies younger, has more hospital deaths and records higher A&E and emergency inpatient contact.

Rising demand, increasing complexity and a need to plan early

25%

Potential increase in demand
by mid-century

5.7

Long-term conditions at the
end of life, projected average

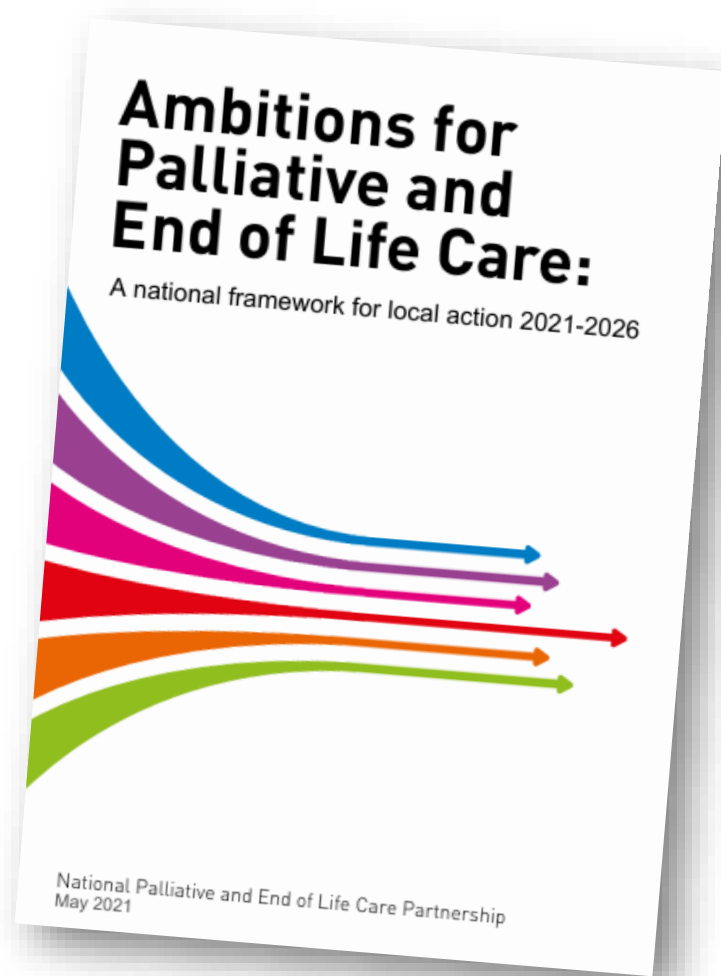
Now

Start planning the community,
workforce and digital response

The challenge is not only more people needing care. It is more people living longer with frailty, dementia and multiple conditions, requiring coordinated support across settings.

Key headline: Future demand and complexity require a planned shift towards proactive, community-based care.

National Palliative and End of Life Care Partnership



01

Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02

Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03

Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04

Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05

All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06

Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Ambitions 1 and 2

See each person as an individual and ensure fair access to care

1 Each person is seen as an individual

- People want comfort, dignity and care reflecting what matters to them
- Respect chosen family, faith, culture and no-faith preferences
- Earlier identification and better-quality ACP/ReSPECT planning
- Reduce variation between practices, PCNs and ICTs

2 Each person gets fair access

- Inequalities follow deprivation, diagnosis and inclusion needs
- Rural access is especially relevant for many ICTs in Sussex
- Improve data on ethnicity, social care and underserved groups
- Make navigation easier after discharge and across services

Key headline: Personalisation and equity must be designed into every pathway, not added afterwards.

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment, a personalized emergency care planning process used across parts of the UK

Advance care planning (ACP) is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care.

Ambition 1: Each person is seen as an individual

Care should reflect identity, wishes and what matters most

1 Care should reflect identity, wishes and what matters most

“

Coming from and working in a marginalised community, there is a lot to be done to improve services.

Workforce | Services Manager

“

One size does not fit all, and care must reflect individual needs, preferences and circumstances.

Resident | Focus group participant

Key headline: Personalised care requires earlier conversations and consistent recognition of each person's identity and preferences.

Ambition 2: Each person gets fair access to care

Access should not depend on place, diagnosis or ability to navigate services

2 Access should not depend on place, diagnosis or ability to navigate services

“

We need more learning disability support for bereavement, more literature, more leaflets and more one-to-one advocacy support.

Workforce | Day service manager

“

There was nobody I could contact around the clock. Even someone on the end of the phone would be helpful.

Resident | East Sussex Citizens Panel representative

Key headline: Fair access means simpler navigation, inclusive information and dependable support outside normal hours.

Ambitions 3 and 4

Maximise comfort and wellbeing through coordinated care

40% of adult deaths
occur in hospital

- Hospitals often recognise expected deaths, but experience and holistic support vary.
- Delays in medicines or specialist advice can cause avoidable distress.

3 Comfort and wellbeing

- Timely pain and symptom control
- Emotional and psychological support
- Reliable medicines and pharmacy access
- Use innovation to share comfort and symptom information

4 Care is coordinated

- Single Point of Coordination and 24/7 advice
- Interoperable shared records
- Neighbourhood, ICT and MDT working
- Faster discharge and fewer avoidable admissions

Key headline: Comfort depends on responsive medicines, specialist advice and information that follows the person.

Ambition 3: Maximising comfort and wellbeing

Timely symptom control and planning shape the experience of care

3 Timely symptom control and planning shape the experience of care

“

We noticed the patient had deteriorated, planned a visit and the patient had a good death at home later in the week.

Workforce | Clinician

“

A peaceful and pain-free death is a priority.

Resident | Focus group participant

Key headline: Comfort depends on pain relief, reliable medicines, proactive planning and support that enables choice of setting.

Ambition 4: Care is co-ordinated

Information and support should follow the person across settings

3 Information and support should follow the person across settings

“

Handover from secondary care, oncology and medical specialties, could be improved

Workforce | GP

“

Everything goes back through the GP, even when you've been under hospital care, and I didn't realise that.

Resident | Focus group participant

Key headline: Shared information, a clear point of contact and responsive out-of-hours coordination can prevent avoidable crisis.

Ambitions 5 and 6

Support prepared staff and communities

5 All staff are prepared to care

- A compassionate and committed workforce is a major system asset
- Build confidence in sensitive conversations and clinical judgement
- Strengthen skills in frailty, dementia, inclusion and bereavement
- Provide supervision and access to specialist advice

6 Each community is prepared to help

- Build on VCSE, faith, peer and neighbourhood assets
- Develop compassionate communities and death literacy
- Improve accessible information and consistent signposting
- Strengthen community-based bereavement support

Key headline: Skilled staff and confident communities are both essential to sustainable end-of-life support.

Ambition 5: All staff are prepared to care

Compassionate staff need confidence, skills and specialist support

5

Compassionate staff need confidence, skills and specialist support

“

Clinicians who are well trained in ReSPECT and advance care planning ensure better outcomes for end-of-life care.

Workforce | Hospice staff

“

Our residents might have to go to another service as their health deteriorates, where staff might not know them and care for them like we do.

Resident | Disability focus group participant

Key headline: Workforce development must combine clinical competence, sensitive communication and inclusive practice.

Ambition 6: Each community is prepared to help

Visible community and bereavement support should be easy to find

6

Visible community and bereavement support should be easy to find

“

I have very little to do with bereavement support. All we have is a leaflet we can give, and this is often forgotten.

Workforce | Survey respondent

“

People value being heard, validated and emotionally supported, rather than receiving advice.

Resident insight | Summary of public evidence

Key headline: Communities need coordinated signposting, trusted local support and space for people to be heard.

The BCYP perspective

Babies, children, young people and families need a distinct, connected programme

1

Distinct population

Recognise life-limiting and life-threatening conditions explicitly in planning.

3

Coordinated pathway

Link tertiary, paediatric, community, hospice, primary care, social care and education.

2

24/7 response

Provide equitable specialist advice, urgent response and clear escalation routes.

4

Family support

Coordinate psychological, practical and bereavement support, including transition.

Key headline: BCYP needs should be visible across all six ambitions and delivered through a distinct Sussex programme.

What the findings mean locally

Four practical considerations and opportunities for neighbourhood & community delivery

1

Identify earlier

Use deterioration, frailty, dementia, repeated admission and palliative coding as some key prompts

2

Plan well

Improve the quality, quantity, and visibility of ACP and ReSPECT plans.

3

Coordinate locally

Connect general practice, community nursing, social care, hospices, care homes and pharmacy.

4

Act equitably

Rural-proof access and monitor experience and outcomes for underserved groups such as ethnic minorities, people with disabilities and LGBTQ+ groups

Key headline: Collaboration is central to earlier identification, proactive planning and joined-up community support.

The 10 strategic recommendations

A focused Sussex programme linking the detailed all-age and BCYP actions

- 1 Single Point of Coordination and 24/7 support
- 2 Interoperable PEO LC digital record
- 3 Demand, capacity and investment plan
- 4 Neighbourhood, MDT and ICT models
- 5 ReSPECT and Advance Care Planning improvement
- 6 PEO LC workforce strategy
- 7 PEO LC equity programme
- 8 Compassionate Communities and Death Literacy Strategy
- 9 Oversight Group and implementation plan
- 10 Distinct BCYP PEO LC programme

Next steps...

- Disseminate findings
- Partners exploring implementation
- Additional care homes research project

What's next?

