# Experiences of Palliative and End of Life Care

## in the East of England

## Summary Report

March 2025

NHS
England
East of England

# Key Findings

> “The Ambitions for Palliative and End of Life Care set out a vision to improve end of life care through partnership and collaborative action between organisations at a national and local level throughout England.”

The central question of the study was to understand to what extent the ambitions were being met in the East of England, identifying what was working well, as well as priority areas for improvement.

This study which was conducted across all the six integrated care systems in the region has highlighted:

**55%**

Just over half of people who completed our survey rating their overall experience as **‘Very good’** or **‘Good’**.

**22%**

More than one fifth rating their overall experience of care as **‘Poor’** or **‘Very poor’**.

**21%**

A further set of people rated it as only **‘Fair’**.

> “We have some way to go to achieve this vision in the East of England.”

# Overview

Marie Curie believes that everyone deserves the best possible care at end of life. Sadly research shows that this is not the case. Our national *Better End of Life Time to Care* report highlighted that that there is a gap in the provision of care and too often people who are approaching the end of life experience difficulties accessing the care and support they need.

Committed to working in partnership at the local level, Marie Curie was pleased to have the opportunity to conduct a regional study on behalf of NHS East of England to understand experiences of palliative and end of life care across all six integrated care systems in the East of England.

## 6 Integrated Care Systems (ICS) in East of England

1. **Bedfordshire, Luton & Milton Keynes ICS**
2. **Cambridgeshire & Peterborough ICS**
3. **Hertfordshire & West Essex ICS**
4. **Mid & South Essex ICS**
5. **Norfolk & Waveney ICS**
6. **Suffolk & North East Essex ICS**

The study was structured around the **Ambitions for Palliative and End of Life Care 2021-2026 (Ambitions)**, a national framework designed to guide local action and establish a collaborative vision for improving care in this vital area.

Structured around six core Ambitions, this framework encourages professionals and local leaders across health and social care to work together, regularly assess their performance and hold themselves accountable for achieving these standards.

## Ambitions of Palliative and End for Life Care 2021-2026

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.*

With limited data on personal perspectives across the region, NHS East of England commissioned Marie Curie to conduct a study to understand to what extent the Ambitions were being achieved in terms of people's lived experience of palliative and end of life care in the East of England.

By inviting local people affected by terminal illness – whether as a patient, carer or someone recently bereaved - to share their experiences, we were looking to identify what was working well, as well as priority areas for improvement, at both a regional and local integrated care system level.

## Target audience

The target audience for this study were self-selecting members of the public affected by terminal illness in the East of England.

This included adults who were:
- **currently living with a terminal illness** who may or may not have been receiving palliative or end of life care (patients)
- **supporting and/or caring for someone** living with a terminal illness – whether family, friends, volunteers or health or social care professionals (carers)
- **bereaved family or friends** of someone who had died from a terminal illness in the last 2 years (ie. post Covid period) (bereaved)

## Methodology

The study was conducted between Friday 5 July to Monday 7 October 2024 and included:
1. An online survey
2. Semi-structured virtual interviews and semi-structured in-person small group discussions

## Participants in the study

There was strong engagement with the study with a total of 625 valid survey responses across the 6 ICS' in the East of England. In addition, over 50 individuals participated in a virtual interview or in-person group discussion.

With regards to the survey participants:

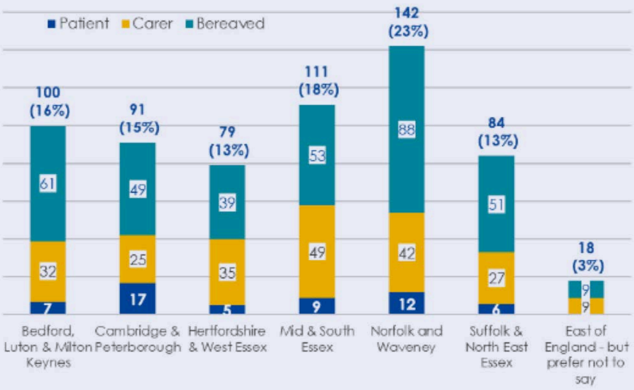
- Nearly a tenth (9%) of responses were from patients themselves, just over a third (34%) from carers and just over a half (57%) from recently bereaved family and friends.

- The five most prevalent patient conditions identified were cancer, dementia, frailty, lung/respiratory disease and heart disease, with 29% selecting more than one condition, indicating just under one third with comorbidities.

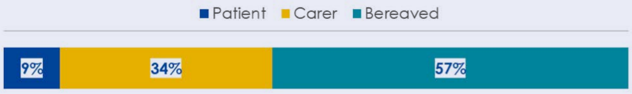
- Over three-quarters (77%) of patients lived in their own home and their care was mostly received at home, in hospital and/or from the GP surgery. Only one in five people had received care in a hospice.

## About the participants

### Participants by ICS

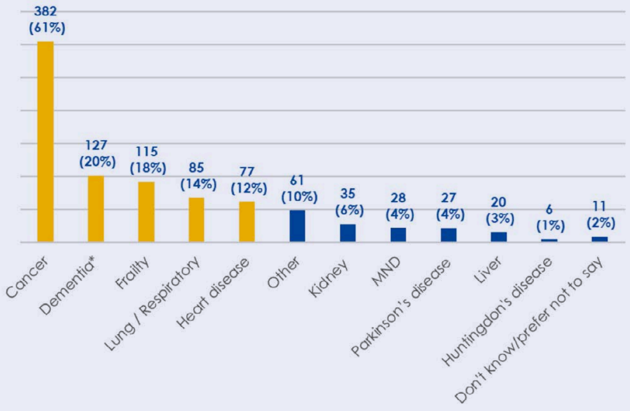


### Breakdown by perspective

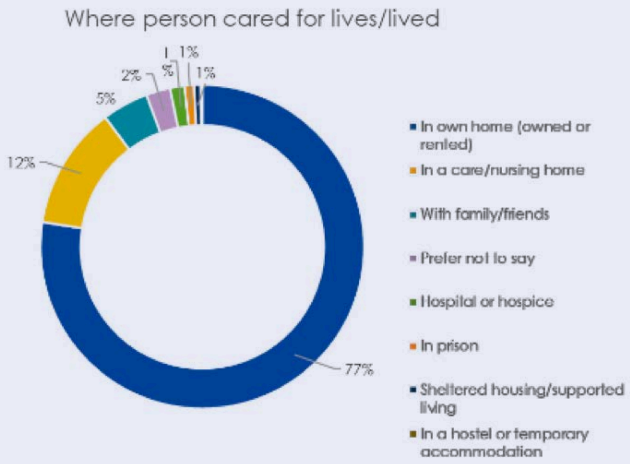


> **“I feel very grateful to have had the opportunity to talk with the team at Marie Curie about what my sister went through at the end of her life. It has not only helped me to process things a little, but also given me the opportunity to speak out for her – something I was not able to do at the time. I hope my contribution to this study can ensure more people receive the dignity and respect we all deserve at end of life.”**
>
> **Sister of patient who died from cancer in Bedfordshire.**

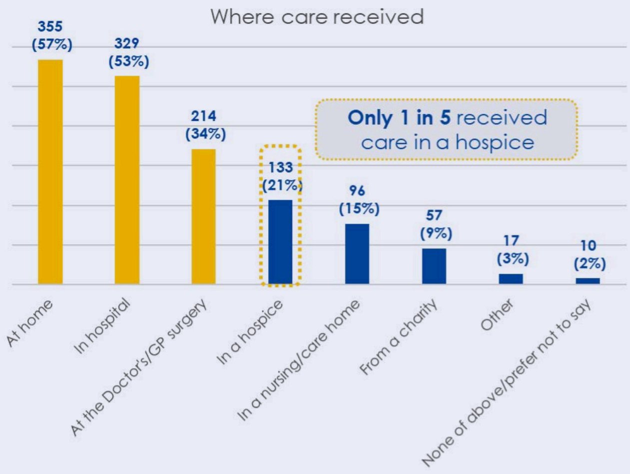
### Most prevalent patient conditions



### Where patient lived



### Where patient received care



**Only 1 in 5** received care in a hospice

## A mixed and inconsistent picture

In response to our central survey question, 55% rated their overall experience of care for their terminal illness as 'Very good' or 'Good'. With over a fifth (22%) of respondents rating their experience as 'Poor' or 'Very Poor' and 86% identifying challenges with their care, it is clear much more still needs to be done.

Findings presented a mixed and inconsistent picture, with some respondents likening experiences of care to 'a roll of the dice', 'a game of snakes and ladders' and 'a postcode lottery'. The in-depth comments shared in this study through the free-text responses and interviews revealed a full spectrum of experiences.

While there were uplifting accounts of positive care, many stories were deeply challenging and highlighted areas where the provision of end of life care in the East of England was falling short of the Ambitions.

## Overall experience

**55%** Just over half of people rated their overall experience of care as **'Very good'** or **'Good'**.

**22%** Over a fifth rating their overall experience of care as **'Poor'** or **'Very poor'**.

**86%** Cited at least **'one challenge'**.

**62%** Selected **'multiple challenges'**.

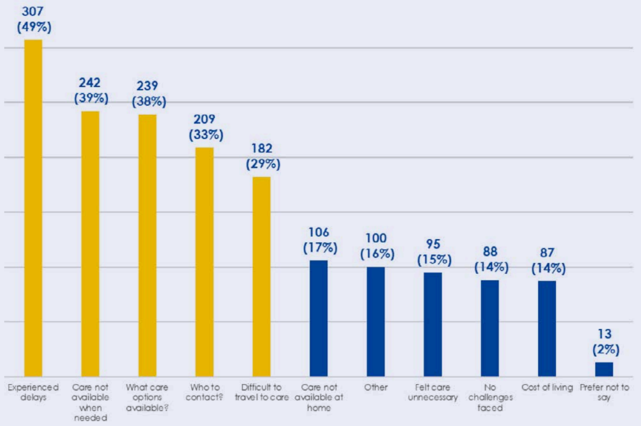
**49%** **'Most common challenge':** Experienced delays in care, treatment or transfer between services.

Responses where patients were cared for in a hospice were generally more positive than responses where patients were cared for in hospital, with 74% describing their experience as "Good" or "Very Good", compared to 49% for hospital care.

## Challenges

The vast majority (86%) had experienced challenges with their care, with nearly two-thirds (62%) identifying multiple challenges. Nearly half of participants (49%) said they had experienced delays in care, treatment or transfer between services, whilst 39% said care was not available when needed or quickly enough (eg at night), and at least a third experienced challenges in navigating the system, not knowing what care options were available (38%) or who to contact (33%).

**Most commonly identified challenges**



# Ambitions

## Ambition 1
## Treated as an individual

### Not everyone feels treated as an individual

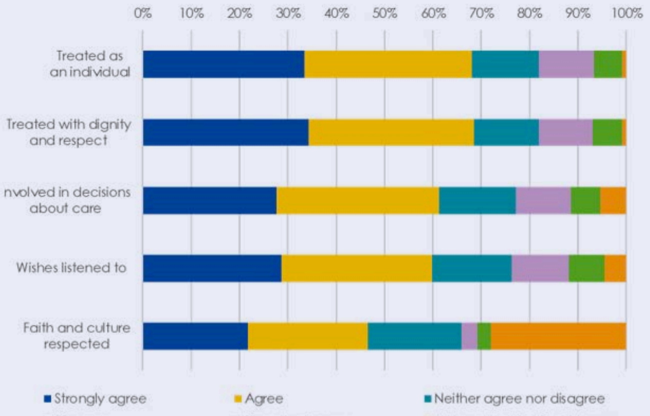
- Personalised care was generally good. Just over two-thirds of respondents agreed that the person cared for was treated as an individual (68%) and/or treated with dignity and respect (68%).

**However:**

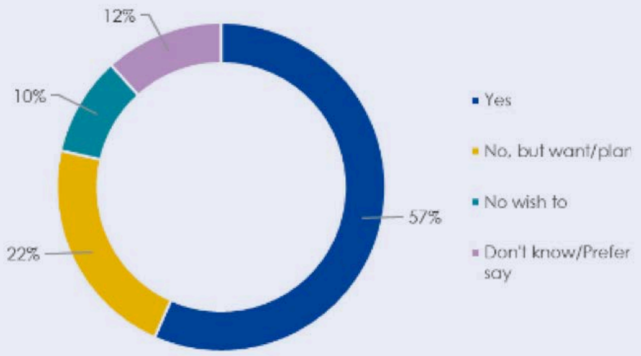
- Respondents called for more opportunities for open and honest conversations about palliative and end of life care, including with healthcare professionals.
- Only just over half (57%) said they had had the opportunity to discuss their end of life wishes and of these only just over half (53%) had discussed the important topic of their care in final weeks and days.
- Patients often felt they were not treated as a 'whole person' and their care wishes not always listened to. Family carers frequently felt they were neither respected nor supported.

> “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.”

### How care recipient is/was treated



### Opportunity to discuss end of life wishes



> “At no point did anyone mention any palliative care. In the last 2 years we spent a lot of time contacting doctors to say the medications were not making my mother-in-law feel better. I basically had to ask for palliative support before the GP even suggested it. The GP just wanted to change her medications again but even my mother-in-law was aware that this wasn't what she needed.”

## Ambition 2

# Fair access to care

### Not everyone has access to good end of life care

- Geographic and financial inequities contribute to a ‘postcode lottery’ in accessing care, with limited services in rural areas and outside of working hours.

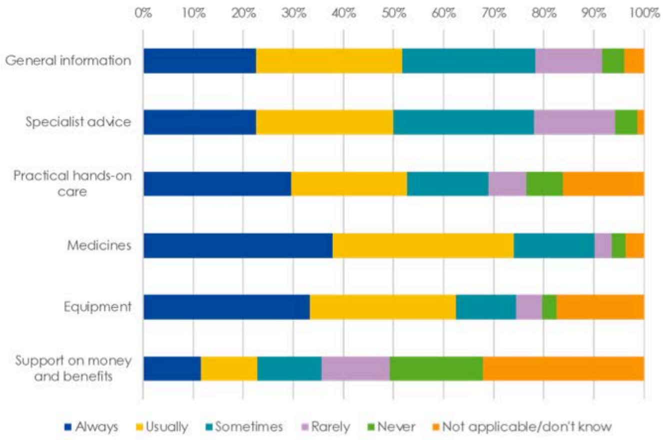
- Out of hours provision is not sufficient. Nearly 40% said that care was not available when needed or quickly enough and was the second most frequently identified challenge.

- GPs can be difficult to access. Nearly half of respondents (49%) said they only ‘Sometimes’, ‘Rarely’ or ‘Never’ had access to specialist advice from a doctor or healthcare professional.

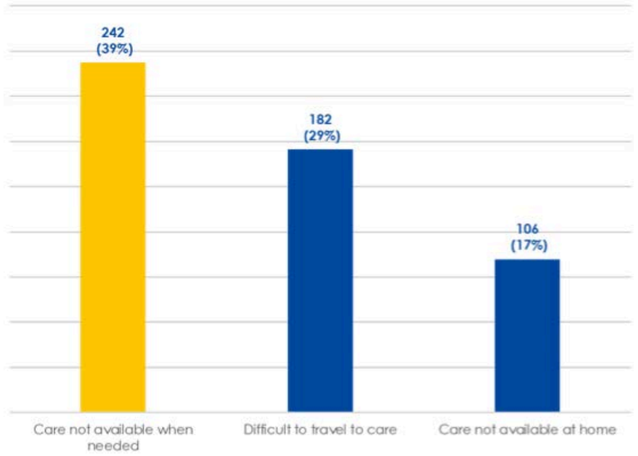
- Provision of support and advice on money and benefits relating to their illness and care is limited. Almost half (47%) said they were ‘Rarely’ or ‘Never’ able to access this.

> **“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.”**

**Access to the following when needed**



**Challenges accessing care**



> **“As the carer/spouse I had to fight the whole time to get timely treatment for my partner, such as consistent district nurse visits. I often spent hours on the phone with problems arranging correct equipment or getting/finding repeat or newly prescribed drugs especially around weekends/bank holidays.”**

# Ambition 3
# Maximising comfort and wellbeing

## More could be done to maximise physical and emotional comfort and wellbeing

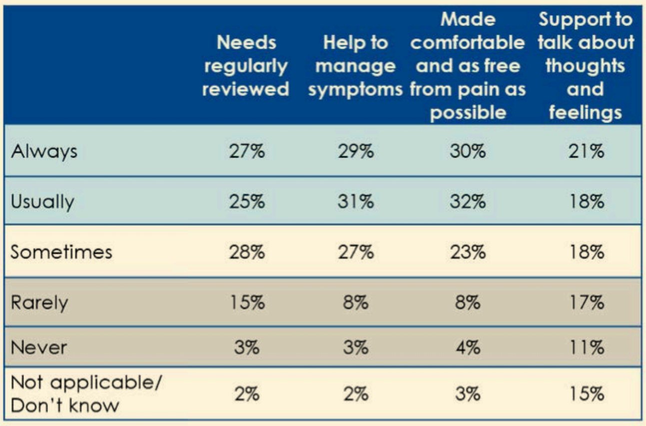
- Pain management for those receiving end of life care at home can be a challenge, particularly for those in rural areas.

- There is poor recognition of when people are nearing the end of life, often leading to unnecessary interventions. 15%reported receiving care they felt was unnecessary, with many sharing distressing accounts of their experiences.

- Counselling and emotional support for those diagnosed with a terminal illness and their carers is lacking. Over a quarter (27%) said that support to discuss thoughts and feelings was ‘Rarely’ or ‘Never’ provided.

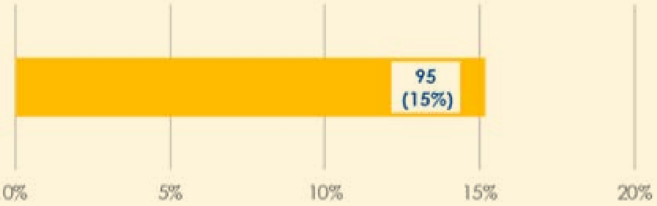
> “My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible”

### How care recipient is/was treated



| | Needs regularly reviewed | Help to manage symptoms | Made comfortable and as free from pain as possible | Support to talk about thoughts and feelings |
|---|---|---|---|---|
| Always | 27% | 29% | 30% | 21% |
| Usually | 25% | 31% | 32% | 18% |
| Sometimes | 28% | 27% | 23% | 18% |
| Rarely | 15% | 8% | 8% | 17% |
| Never | 3% | 3% | 4% | 11% |
| Not applicable/ Don't know | 2% | 2% | 3% | 15% |

### Care or treatment felt to be unnecessary



> “My Dad only wanted to die with dignity and pain-free, and I had to fight for both of those. It was clear he was in the last hours of life, yet I had to argue with the medical team to stop trying to catheterise, cannulate, send him for x-rays, and just give him analgesia.”

# Ambition 4
## Care is coordinated

### Care is often poorly coordinated

- Once triggered, palliative care is generally good, with services working together to deliver care.

**However:**

- Patient care is not regarded as joined up. Over forty percent (43%) disagreed that different healthcare professionals knew their medical history and talked to one another.

- Delays are a significant challenge. Ranking first in a list of challenges, nearly half (49%) had experienced delays in their care, treatment or transfer between services.

- Patient and families find it difficult to navigate the system. At least a third were unsure of what care options were available (38%) or who to contact (33%).

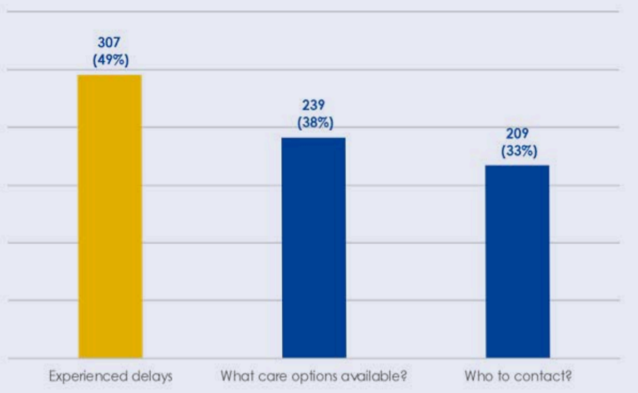
- Many patients and families felt they had to figure things out on their own with a reliance on family members to advocate and champion for the care needed.

> **“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.”**

### Communication between healthcare professionals

| Different healthcare professionals know my medical history and talk to one another | No. of responses | % of total (625) |
|---|---|---|
| Strongly agree | 91 | **15%** |
| Agree | 135 | **22%** |
| Neither agree nor disagree | 112 | **18%** |
| Disagree | 166 | **27%** |
| Strongly disagree | 104 | **17%** |
| Not applicable/ Don't know | 17 | **3%** |

### Challenges with coordination of care



> **“There were challenges with coordination or care between different departments in the hospital and then between hospital and community (GP and community teams) leaving family members confused as to what was done/put in place/ who to go to etc... It required family members to be on the ball and follow up everything with the relevant health professionals.”**

# Ambition 5

## All staff are prepared to care

### Not all staff are skilled or experienced in end of life care

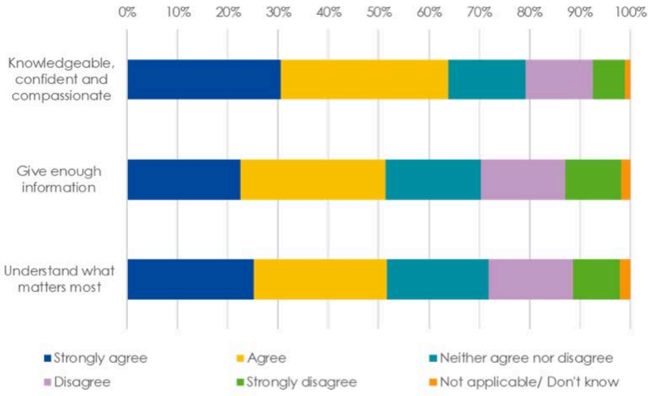
- Specialist palliative care teams including hospice and community nursing teams were generally praised for their readiness to provide expert, compassionate care.

**However:**

- Respondents felt that generalist healthcare professionals, including consultants and GPs, were often not proactive or knowledgeable enough about end of life care.
- Under two-thirds (64%) agreed those who provided care were knowledgeable, confident and compassionate, whilst a fifth (20%) disagreed.
- Identification of terminal diagnosis was often delayed and respondents indicated that communication was often insensitively delivered.

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

### Staff knowledge



> “A challenge has been the GP not always knowing what mum’s situation is. They need a better understanding and to give some more priority to palliative patients to make things a bit smoother.”

## Ambition 6

## Each community is prepared to help

### There is not enough community support

- There are limited community resources, especially for carers who feel isolated or overwhelmed.
- Only just over one third (36%) said they ‘Always’ or ‘Usually’ received emotional and practical support from groups in the community.
- There is a need for better public awareness of palliative care, improved volunteer networks and stronger local community engagement.

> **“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.”**

**Emotional and practical support**

| Emotional and practical support from people and groups in the community | No. of responses | % of total (625) |
|---|---|---|
| Always | 102 | **16%** |
| Usually | 126 | **20%** |
| Sometimes | 122 | **20%** |
| Rarely | 78 | **12%** |
| Never | 99 | **16%** |
| Not applicable/ Don’t know | 98 | **16%** |

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> **“It would be really helpful to be told about the ‘process of dying’ and all the different stages. My family and I weren’t prepared for the changes/ deterioration/reactions/the ways that a body shuts down. There were lots of occasions towards the final stages that were horrific and harrowing, and we just weren’t prepared.”**

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# Conclusions

This study presents a regional perspective of the experiences of people affected by terminal illness across the East of England. In assessing the extent to which people's experiences are aligned to the Ambitions for Palliative and End of Life Care, it has highlighted that whilst there are areas of clear progress, many of the Ambitions continue to remain aspirational rather than fully realised. It is clear that targeted and continued effort is required to address persistent gaps.

The study has also brought to light a number of themes common to those identified in Marie Curie's national *Time to Care* report from the Better of End of Life research programme, published in September 2024.

**These include:**

- **Examples of excellent care:**
  Some people, especially those with access to specialist palliative care, reported positive experiences of high quality care.

**However:**

- **Poor overall experience**
  Only just over half (55%) of people who completed our survey rated their overall experience as 'Very good' or 'Good', more than a fifth (22%) rated it as 'Poor' or 'Very poor' and 86% identified challenges with their care.

- **Lack of open conversation about death and dying:**
  A notable reluctance, particularly among consultants and GPs, to discuss palliative care or address death and dying openly.

- **Challenges navigating the system**
  People not knowing what care and support was available and how to access services – particularly out of hours.

- **Poor coordination of care:**
  Systems and different parts of the healthcare system not communicating or working together.

- **Insufficient GP support**
  A perceived lack of willingness or capacity to engage, often attributed to time constraints and limited expertise in end of life care.

- **Delays in care**
  The most frequently cited challenge in this study, including delays in treatment, care delivery, or service transitions.

- **Distressing hospital experiences**
  Reports of hospital staff being too busy to provide compassionate care, often compounded by a lack of knowledge about palliative care needs.

- **Lack of capacity**
  Insufficient provision of palliative and end of life care in the community including limited access to hospice care.

- **Inadequate carer support**
  Family carers often felt excluded, undervalued, and underappreciated despite their essential role in providing care.

# Recommendations

In light of these common themes, we reiterate some of the recommendations made in the **Better End of Life Policy Summary**[2] and other Marie Curie policy reports, which would particularly respond to findings on patient experiences in the East of England:

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## 1

**Use a consistent and systematic approach**
to identify patients approaching the end of life and add these patients to the supportive palliative care register.

## 2

**Strengthen equitable access to palliative care**
through increased investment in primary care and community nursing services.

## 3

**Ensure 24/7 access to palliative and end of life care**
including through a single point of access offering advice, guidance and support.

## 4

**Increase availability of core palliative care medicines**
particularly in the community settings and facilitate prescribing through shared care records.

## 5

**Make palliative and end of life care training a compulsory part of training**
and continuing professional development for all health and care workers.

## 6

**Increase support for carers**
of people at the end of life through better identification, needs assessment, financial and bereavement support.

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Moving forward, we encourage all those responsible for shaping and delivering palliative and end of life care services in the East of England to review the data and insights from this study. We urge them to work together to develop actionable strategies that drive improvements and ensure a high-quality, consistent experience of care. It will take a collective effort, and only by doing so can we fulfil the promise of the Ambitions, ensuring that all individuals in the East of England receive compassionate and dignified care at the end of life.

## Acknowledgements

Marie Curie thanks all the individuals who contributed to this study – patients, carers and those recently bereaved. Their voice is at the heart of this study – not just their experiences, but also what they felt should be priority areas for improvement. We are committed to ensuring that their valuable input shared does not go unnoticed. Our hope is that this report will provide renewed impetus for all organisations to continue to work together towards a more consistent and equitable experience of palliative and end of life care for all in the East of England.

## Full Report

Visit the Marie Curie website to access the full report.

## More information

Call 0121 752 9305* to find out how we can help in the East of England

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*Your calls may be recorded for training and monitoring purposes

### About Marie Curie

Marie Curie is the UK's leading end of life charity.

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end. We bring 75 years of experience and leading research to the care we give you at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system. Marie Curie is a charity working across the UK and we need your support to do our vital work.

### References

[1] National Palliative and End of Life Care Partnership. (2021) Ambitions for Palliative and End of Life Care: A National Framework for Local Action (2021–2026), **https://www.england.nhs.uk/wp-content/uploads/2022/02/ ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf**

[2] See: **beol-2024-report-england-commentary.pdf**