



End of life care in
Suffolk and north
east Essex

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1. Introduction

The Suffolk and North East Essex Integrated Care System's (SNEE ICS) 'Higher Ambitions' states:

“Everyone in Suffolk and North East Essex has flexibility, choice and control over their care, and support for those closest to them, at the end of their life.”

Specifically, this means that:

- People approaching end of life and their families are prepared, informed, and able to make early decisions and choices about their care and treatment.
- People at end of life and their families receive the best quality care and support.
- People bereaved have the support they need to cope with trauma and loss.

Furthermore, the SNEE ICS is committed to helping to build “compassionate communities that understand end of life and can provide mutual support for its members”.

This research aims to support these ambitions by helping local services and commissioners to understand more about people's experiences. That includes how things could be different in the future to ensure people receive the best possible care when they need it most.

There has never been a more important time to hear from people about how care and support has changed.

In the last year, there has been a significant increase in the numbers of people that have died across Suffolk and NE Essex, and this has been due to the coronavirus pandemic.

It is estimated that there have been approximately 2,000 excess deaths in the 12 months from March 2020 in Suffolk, Colchester, and Tendring areas combined¹.

This has therefore been a critical time for services that have been coping with increased demand, and for the families left with the effects of grief and bereavement.

However, this has also been a time when COVID-19 regulations have meant that:

- Access to primary and secondary health and care services has been disrupted
- Relatives have been unable to visit their loved ones in hospitals and care homes
- Social distancing regulations, no touch policies, and the use of Personal Protective Equipment (PPE) have meant relatives have felt separated and disconnected from their loved one

1. Note that this figure includes deaths within Waveney and parts of Colchester and Tendring that are not part of the SNEE ICS area.

- Limitations have been placed on social gatherings that may have offered people comfort and closure at their time of loss – specifically funerals

These restrictions have presented significant difficulties for people who are dying, and also for the people that have been supporting them (e.g. family members, friends, neighbours and carers).

The aims of this project have been to listen to people's experiences of end of life care, to find out what has worked and what could be improved, and to understand the impact that the pandemic has had on the delivery of end of life care and support. Additionally, this information will be used by the three alliance areas (West Suffolk, Ipswich and East Suffolk, and North East Essex) for planning and learning purposes, and to influence the design and delivery of end of life services in the future.

Healthwatch Suffolk would especially like to thank each and every person, as well as all organisations involved in this project, for contributing their insights on end of life care in Suffolk.

2. Methodology

In order to meet the objectives of the project, a dual method approach to data collection was adopted. This included:

- An online survey to provide quantitative data
- Semi-structured interviews to gather qualitative information and to hear more detail about people's experiences

The participants for this project were self-selecting members of the public who met these categories:

- People who had experiences of deaths that had occurred within the SNEE ICS area - this covers West Suffolk, East Suffolk, and North East Essex.
- Any adult (aged 18+) who had experienced the death of an adult relative or friend since the beginning of January 2020.
- Death could be from any cause e.g. it may have been sudden or unexpected, or the individual and their family may have expected and planned for the death to occur.
- Death could have occurred in any setting (e.g. hospital, hospice, care home or in their own home).

The online survey

To ensure that the content of the survey would align well with current SNEE ICS priorities for end of life care, and the wants and needs of service users, a working group was convened to co-produce the online survey. The group consisted of:

- Service users
- East Suffolk and North Essex Foundation Trust - End of Life Care Facilitator
- Community Services, including District Nurses from West Suffolk and East Suffolk and a Senior Matron at West Suffolk Community services
- West Suffolk Clinical Commissioning Group Transformation Lead for End of Life Care
- Suffolk County Council Head of Service Development and Contracts
- Representatives of the North East Essex Alliance
- Representatives of Healthwatch Suffolk and Essex
- Representatives from ACE - ANP Palliative and EOL Care and End of Life Champion for Clacton PCN

Although not all organisations were able to attend each meeting of the group, all members had an opportunity to contribute and comment on the final survey design.

The final questionnaire, which was agreed and signed off by the SNEE ICS End of Life Board in August 2020, included questions on the following topic areas:

- Respondent demographics and relationship to the deceased person.
- Place and month of death.
- How people were given the news that they or their relative or friend were at the end of life.

- Provision of care and support in last year of life, and also in the last days or hours of life.
- Provision and access to support, including ongoing bereavement support.
- Direct email to GP practice Managers.
- Direct email to all Parish Clerks.
- Social media activity by Healthwatch Suffolk (including paid for promotion) and also by local partners and stakeholders (e.g. Clinical Commissioning Groups).

The survey was hosted online using the SurveyMonkey online platform and was launched in September 2020.

To assist with the promotion of the project, a communications pack was developed and distributed alongside the survey. It was sent to VCSE partners and other relevant organisations across Suffolk and North East Essex (see list below).

The communications pack provided information about the project and included a press release, sample website and newsletter articles, graphics, supporting imagery and suggested content for social media posts.

Promotional activity

- Information was sent to all members of Healthwatch Suffolk in hard copy (printed newsletter) and digital (Mailchimp) formats.
- A press release was distributed to local media with local coverage achieved.
- Information was sent to communication leads for local NHS and social care providers and commissioners, who subsequently promoted the opportunity to take part across their respective networks.
- Communications were distributed to partners and stakeholders across the SNEE ICS by email and within the ICS newsletter.

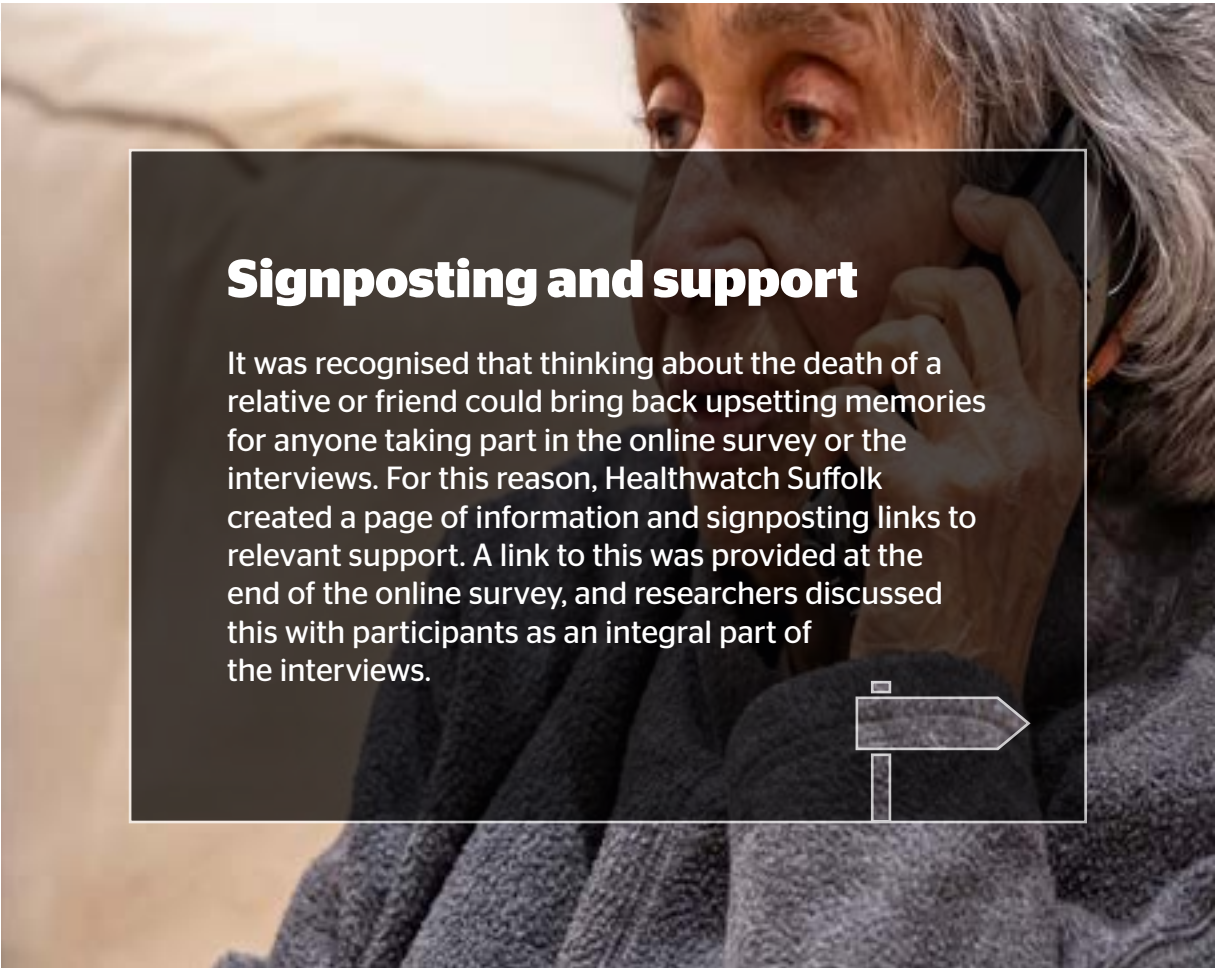
- Promotional activity and direct invitation by the three local hospices (St Nicholas Hospice, St Elizabeth Hospice and St Helena hospice).
- Direct email to all Healthwatch Suffolk partner organisations and other local Voluntary Community and Social Enterprise (VCSE) groups.
- Word of mouth within professional and personal networks.

Semi-structured interviews

In addition to the online survey, people were offered the opportunity to take part in an interview with a member of the Healthwatch Suffolk research team.

Those who registered were sent an information sheet outlining the purpose of the project. The information also detailed how participant information would be used and securely stored by Healthwatch Suffolk.

The interviews were semi-structured in design to allow for a more 'natural' conversation, in which the respondent could dictate the pace and narrative flow. Interviewers had a list of broad topic areas, mirroring the online survey, to cover during the interview.



Signposting and support

It was recognised that thinking about the death of a relative or friend could bring back upsetting memories for anyone taking part in the online survey or the interviews. For this reason, Healthwatch Suffolk created a page of information and signposting links to relevant support. A link to this was provided at the end of the online survey, and researchers discussed this with participants as an integral part of the interviews.

Table: Month of death, including those who did not say where their relative or friend had died.

	Total	I&E Suffolk	West Suffolk	NE Essex
January '20	16	3	6	1
February '20	8	4	4	0
March '20	12	7	3	1
April '20	10	2	4	2
May '20	8	2	0	2
June '20	10	2	1	1
July '20	10	5	2	0
August '20	6	2	3	0
September '20	15	5	3	3
October '20	9	6	1	1
November '20	5	1	0	1
December '20	9	5	2	2
January '20	13	5	2	3
Total	131	49	31	17

3. What people told us - survey results

The sample - who we heard from or about

A total of 153 people started the online survey. Unfortunately, only 138 respondents answered enough of the questionnaire to be included within this report. The following analysis is based on these 138 responses.

For the purposes of this report, the results herein are generally presented by SNEE ICS Alliance areas and also by the total response (based on the location of the person's death).

The total response is inclusive of people who died outside of the SNEE ICS footprint, or for whom it had not been possible to determine the location of death. These responses have been included because the experiences reported offer learning opportunities for the SNEE ICS, regardless of whether the death could be determined as having occurred within the local SNEE health and care system.

Twenty-two percent (38) of respondents did not provide any demographic information about themselves (e.g. their gender, age or ethnicity). Amongst those who did respond:

- Eighty-seven percent (91) were female, 12% (13) were male and 1% (1) preferred to describe their gender in a different way.
- Seventy-two percent (77) of the sample were aged between 45 and 64.
- Two thirds (67% or 61) described their ethnicity as White British. A further 18% (16) said they were 'White' and 11% (10) said they were 'British'. Only four people described themselves in any other way.

Their responses were 'Muslim', 'British Indian', 'Pashto' and 'Arabic'.

Fifty-two percent (71) of the sample were responding about the death of a parent or parent-in-law, 18% (26) were responding about the death of a spouse, partner or ex-partner, and 18% (25) were responding about the death of another relative (e.g. grandparent, sibling, son or daughter, aunt etc.). The remaining 13% (16) were responding about a friend or client or service user (e.g. through the provision of domiciliary care).

Thirty-seven percent (51) of responses were about someone who had died in the Ipswich and East Suffolk area, 24% (33) from West Suffolk, and 12% (17) from North East Essex. Sixteen percent (23) of respondents did not specify where their friend or relative died. Ten percent (14) were responding about someone living outside of the SNEE ICS patch:

- Three were from Cambridgeshire
- Four were living in Essex but outside the SNEE area
- Six were from Norfolk or Waveney
- One person was living in Stockport

It should be noted that throughout this report, total figures relate to all 138 respondents i.e., they will include those who did not specify where their relative or friend died, or whether they died outside of the SNEE ICS area. Wherever possible, data for the three alliance areas has been presented alongside the total figures. Care should be taken in drawing any comparisons between the alliance areas, particularly because the sample sizes are quite small.

Table:
Place of death.

Response numbers	Total (124)	I&E Suffolk (51)	West Suffolk (33)	NE Essex (17)
At home	31%	35%	27%	18%
Hospital	28%	29%	27%	35%
Hospice	21%	16%	30%	24%
Care home	19%	20%	15%	24%

Seven people did not specify when their friend or relative died. Amongst those who did respond (131), 27% (36) said their relative or friend had died between January and March 2020 prior to the first COVID-19 lockdown period. This means that 73% (95) of the responses related to a death that took place during the coronavirus pandemic.

The survey did not ask people to specify the cause of death. It is therefore not possible to determine how many deaths were caused by a COVID-19 infection. However, it is clear from respondent's comments that people's experiences were significantly impacted by the COVID-19 restrictions in place throughout much of 2020 and into 2021.

Twelve people did not answer the question about where their relative or friend had died. Amongst those who did answer (124), around a third (31% or 39) said their relative or friend had died at home, just over a quarter (28% or 35) had died in hospital, a fifth had died in a hospice, (21% or 26) and a fifth in a care home (19% or 24). There were

some slight differences across the three alliance areas:

- Amongst those whose relative or friend had died in Ipswich and East Suffolk, a higher percentage had died at home than in any other setting.
- Amongst those whose relative or friend had died in West Suffolk, a higher percentage experienced a death in a hospice than in any other setting.
- And amongst those whose relative or friend had died in North East Essex, a higher percentage experienced a death within a hospital than anywhere else.

Awareness, planning and preparation for end of life

The deceased

Respondents were asked whether their relative or friend was aware that they were

Table: *Did a health or care professional explain to your relative or friend that they were likely to die?*

Response numbers	Total (138)	I&E Suffolk (51)	West Suffolk (33)	NE Essex (17)
Yes	59%	57%	67%	53%
No	28%	29%	21%	41%
Don't know / They may have been told	13%	14%	12%	6%

Table: Did the person break the news to your relative or friend in a timely, sensitive and caring way?

Response numbers	Total (82)	I&E Suffolk (29)	West Suffolk (22)	NE Essex (9)
Yes, definitely	51%	55%	55%	67%
Yes, to some extent	38%	31%	41%	33%
Don't know	7%	10%	5%	0%
No	4%	3%	0%	0%

Table: Did your relative or friend understand that they were dying?

Response numbers	Total (82)	I&E Suffolk (29)	West Suffolk (22)	NE Essex (9)
Yes	79%	72%	77%	100%
I'm not sure / Don't know	13%	17%	18%	0%
No	7%	10%	5%	0%

likely to die and about how that information had been shared with them.

Overall, 59% (82) of the total sample said their relative or friend had been made aware that they were likely to die, however a fifth (16) of these qualified their comment by saying they had only been informed because they had 'asked'.

Twenty-eight percent (38) of the sample said their relative or friend had not been made aware. Of these, over half (21) said this was because they were too unwell or unconscious to understand what was happening, a third (14) simply said it was not discussed with them, and three people said the death had been sudden or unexpected.

Thirteen percent (18) of the total sample were not aware of whether their relative or friend had been informed. People who

were responding about a friend or service user were least likely to know whether the person had been informed or not. Spouses and partners were the most likely to know whether end of life had been discussed with their relative.

Of the 82 respondents who said their relative or friend had been informed about end of life, 89% (73) felt that this had been done in a timely, sensitive, and caring way. The majority (42) stated 'yes' definitely and the remaining 31 indicated that this had happened 'to some extent'. Only three people across the total sample felt they had not been told about the end of life in a sensitive and timely manner. Respondents generally felt that their relative or friend had been informed in a manner that meant they had understood they were going to die, with 79% of the sample agreeing to this statement.

Table: Had your relative or friend registered their care wishes?

Response numbers	Total (47)	I&E Suffolk (18)	West Suffolk (11)	NE Essex (5)
Registered with My Care Wishes (yellow folder) - Suffolk	49%	67%	73%	0%
Registered with My Care Choices - Essex	11%	0%	0%	80%
They had told family or friends	28%	17%	18%	20%
Told a health professional or other member of their care team	13%	17%	9%	0%

Despite the fact that 82 people said their relative or friend had been told they were likely to die, and 65 of these said their relative or friend had understood what they were being told, only 47 (57%) respondents were aware that their relative or friend had told someone about their preferences for end of life care.

There may be many reasons why respondents were not aware that their

relative or friend had made any end of life plans. This does, however, highlight the ongoing need to encourage those who are reaching end of life, and those who are supporting them, to have open conversations about their care wishes.

Amongst those who had made their care wishes known, 60% (28) had 'formally' registered with My Care Wishes (Suffolk) or My Care Choices (Essex). A further 13% (6)

Table: Analysis of whether people had shared their care wishes by place of death.

Response numbers	Died at home (39)	Died in a care home (24)	Died in a hospice (26)	Died in a hospital (35)
Registered with My Care Wishes or My Care Choice	36%	21%	23%	6%
Told family	13%	0%	8%	9%
Told a professional	10%	4%	4%	0%
No	13%	13%	19%	20%
Don't know	8%	8%	15%	9%
Blank	21%	54%	31%	57%

of respondents said their relative or friend had informed a health or care professional, while 28% (13) had spoken to family or friends.

Further analysis of the data reveals that:

- Those who died at home were more likely to have shared their care preferences with someone else - 59% (23) had spoken to either a professional, a family member, or had registered with My Care Wishes or Choices.
- Amongst those who died in a hospice around a third (35%) of people had made their end of life care wishes known to someone else
- Amongst those who died in a care home, only a quarter of people said their relative or friend had made end of life care preferences known - either through the My Care Wishes or Choices registers, by telling a professional, or sharing that information with a family member.
- Those who died in hospital were least likely to have discussed their end of life care preferences with someone else.

In addition to asking whether the deceased had been made aware they were dying; respondents were also asked about how

they had been informed of their relative or friends' prognosis.

Respondents

Eighty percent (93) of respondents said they had been informed that their relative or friend was reaching end of life. Of these 93, 13 people said they had to ask for this information.

Ninety-two percent (85) of respondents felt they were told in a timely, sensitive, and caring manner. The majority (58) answered 'Yes definitely' and the remaining 27 said 'Yes to some extent'. Only five people said 'No, not at all'.

Ninety-four percent of the sample felt they had been given the news in a way that meant they had understood that their relative or friend was reaching end of life.

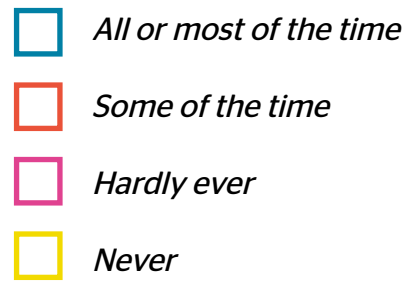
Respondents were also asked whether they had been told what to expect when their relative or friend died (e.g. symptoms that may arise). Ninety-three people answered this question. While 75% (69) of respondents felt that they had been informed of what to expect, only 40% (37) said 'Definitely', while 12% (11) of respondents said they had to actively ask for the information. A quarter of respondents (23) said they were not prepared for what might happen.

Table: Were you told what to expect?

Response numbers	Total (93)	I&E Suffolk (39)	West Suffolk (28)	NE Essex (10)
Yes, definitely	40%	36%	50%	50%
Yes, to some extent	23%	23%	14%	40%
Yes, but only when asked	12%	15%	18%	0%
No	25%	23%	18%	10%
Can't remember or don't know	1%	3%	0%	0%

Chart: Aspects of care in the last year.

When asking about care in the last year of life, the emotive or subjective statements were only asked of those who had indicated their relative or friend had been told that they were likely to die.



Adequate pain relief
(109)
62% / 28% / 7% / 2%



Help managing symptoms
(112)
54% / 38% / 6% / 1%



Treated with dignity and respect
(123)
60% / 34% / 5% / 1%



Made comfortable
(122)
57% / 34% / 6% / 2%



Involved in decisions
(107)
47% / 29% / 18% / 7%



Wishes taken into account
(70)
53% / 29% / 16% / 3%



Faith and culture supported
(47)
53% / 26% / 13% / 9%



Emotional support
(69)
43% / 28% / 20% / 9%



Asked what's important to them
(70)
36% / 40% / 17% / 7%

Care at end of life

Respondents were presented with nine statements about the care their relative or friend had received and asked to indicate the frequency with which each statement applied ('All of the time', 'Some of the time', 'Hardly ever', 'Never').

The statements were presented twice within the survey. Once asking about experiences of care in the last year of life, and again asking about experiences in the last few days and hours of life.

The statements were split between practical aspects of care (such as pain relief and management of symptoms) and more subjective and emotive issues (such as being asked about what was important to them and the provision of emotional support).

A number of people chose not to answer the statements or responded with 'Don't know/not applicable'. This means that respondent numbers for some statements are quite low. For clarity, sample totals have been provided on the graphs to the left, in brackets, after each statement.

Over 70% of those responding to each statement said they had occurred 'all' or 'some' of the time. However, less than two thirds of respondents felt they had happened 'all of the time'.

Respondents were more positive in their responses regarding the practical (and visible) aspects of care, such as provision of pain relief, being made comfortable, and symptom management. In contrast, they were less likely to be positive about subjective aspects of care (such as adequate provision of emotional support and understanding of what was important to the patient). By their very nature, these subjective issues are difficult to judge on

behalf of someone else. This may therefore account for the higher percentages of people reporting they 'hardly ever' or 'never' happened.

- A quarter (25%) of respondents said their relative or friend was hardly ever, or never, involved in decision making to the extent they would have wanted.
- Twenty-nine percent felt that their relative or friend was not given adequate emotional, or spiritual, support.
- Twenty-four percent said their relative friend was hardly ever, or never, asked what was important to them.

Analysing the statements (see table on page 16) according to whether the patient had made their care wishes known (and to whom) reveals the following findings.

When compared with those whose friend or relative had shared their preferences with a family member, a professional, or had not spoken to anyone at all, those who had registered with My Care Wishes or My Care Choices were more likely to say that their friend or relative:

- Had their faith and cultural wishes understood and supported
- Had preferences that were taken into account
- Were asked what was important to them
- Were given adequate emotional support

Those whose friend or relative had told a professional of their wishes were more likely to say they had received help with symptom management 'all of the time', that they were involved in decisions 'all of the time' and that they were treated with dignity and respect 'all of the time'.

Those whose friend or relative had shared their care preferences with a family member scored lowest on all of the statements, with the exception of 'being involved in decisions as much as they would have wanted'. This data underlines the importance of sharing end of life plans as broadly as possible, so that everyone involved in the provision of care and support understands what is important to the patient.

Last days or hours



When asked about care in the last days or hours of life a similar pattern of response emerged, with the practical aspects of care being more positively rated than the subjective or emotive aspects.

Interestingly, each statement was rated more positively when answered in relation to care received in the last days and hours

Table: Analysis of care statements according to whether the patient had made their care wishes known.

'Occurred all of the time'	My care wishes or my care choices	Told professional	Told family	Not told anyone
Their faith and cultural wishes were understood and supported	81%	60%	14%	31%
Their preferences and wishes were taken into account by the Health and Care professionals that were supporting them	73%	67%	25%	35%
They were asked what was important to them	58%	33%	8%	22%
They were given adequate emotional or spiritual support	58%	50%	11%	35%
They were given adequate pain relief	81%	50%	44%	68%
They were given help to manage symptoms	63%	83%	50%	32%
They were involved in decisions as much as they wanted to be	73%	83%	50%	32%
They were made as comfortable as possible	65%	67%	56%	60%
They were treated with dignity and respect	67%	83%	45%	55%

Chart: Percentage of respondents saying statement around compassion of care occurred all or most of the time in last year versus last days or hours.

 Last days or hours of life
 Last year



Made comfortable
 (108)
 81% / 57%



Adequate pain relief
 (96)
 80% / 62%



Treated with dignity and respect
 (108)
 75% / 60%



Help managing symptoms
 (98)
 68% / 54%



Involved in decisions
 (76)
 61% / 47%



Faith and culture supported
 (73)
 59% / 53%



Wishes taken into account
 (96)
 57% / 53%



Emotional support
 (90)
 56% / 43%



Asked what's important to them
 (88)
 47% / 36%

Table: Analysis of statements by the location where the person had died and response was marked as 'All of the time'.

'All of the time'	At home	Care home	Hospice	Hospital
Their faith and cultural wishes were understood and supported	65%	50%	67%	47%
Their preferences and wishes were taken into account by the Health and Care professionals that were supporting them	63%	64%	72%	27%
They were asked what was important to them	55%	50%	67%	14%
They were given adequate emotional or spiritual support	58%	79%	63%	32%
They were given adequate pain relief	87%	83%	88%	65%
They were given help to manage symptoms	63%	83%	79%	57%
They were involved in decisions as much as they wanted to be	59%	50%	77%	47%
They were made as comfortable as possible	83%	90%	88%	67%
They were treated with dignity and respect	78%	94%	75%	62%

of life, than they were for care received during the last year of life (see chart on page 17).

With the exception of 'They were asked what was important to them', over 50% of respondents felt that each of the statements applied 'all of the time' during the last days or hours of life. Analysing the data by the location where the person had died reveals that:

- Those whose relative or friend died in a hospital were least likely to say each aspect of care had occurred 'all of the time'.
- Those whose relative died in a care home rated 'awareness of cultural or faith wishes', 'being asked what was important' and 'being involved in decisions' as least likely to occur 'all of the time'.
- Those whose relative or friend died in a hospice were most likely to say they were asked about their preferences, what was important to them, and were involved in decisions compared to those who died in other settings.

Chart: Did your relative receive unnecessary medical treatment?

- Yes
- No
- Don't know



Last year
15% / 71% / 14%



Last day or hours
9% / 72% / 19%

Unnecessary medical treatment

Respondents were asked if they felt their relative or friend had received unnecessary medical treatment, both in the last year of life and during the last days or hours of life. Over 70% of the sample felt that their relative friend had not been subjected to unnecessary medical treatment.

However, 15% (20) of people felt their relative had received unnecessary treatment in the last year of life and 9% said the same about care received in the last days or hours prior to death.

Where people wanted to die

While 64% (89) of respondents said that their relative or friend had indicated where they would prefer to die, this had not been possible in 38% (32) cases.

Of the 32 people who said that their relative or friend had not died where they would have preferred, 30 had wanted to die at home and two had wanted to spend their last days in a hospice.

Reasons why people were unable to die in their place of choice

Amongst those who wanted to die in a hospice, one said that they had been unable to be admitted due to COVID-19 restrictions and had therefore died at home. The other case indicated their relative or friend had died at home, but did not specify why they were unable to access hospice care.

Amongst the 30 people who had wanted to die at home, six died in a hospice, eight in a care home and 16 in a hospital. The main reasons why people were unable to return home were:

They were too unwell or medically unfit for discharge (10 mentions)

“After a bad fall she got taken into hospital and could not return home.”

“The hospice said he was too unwell and kept putting us off until it was too late.”

“Too unwell - fast tracked out of hospital for palliative care.”

There was no appropriate care available to support them, and or their family, at home (seven mentions)

“Too difficult for their family to deal with.”

“Need dementia care that could not be provided at home.”

“A diagnosis of dementia prevented my mother from remaining at home.”

“We had to transfer my aunt to the care home due to increased falls and her not being safe at home.”

“Was in residential care which could not meet his needs.”

The COVID-19 pandemic was given as a reason in two cases

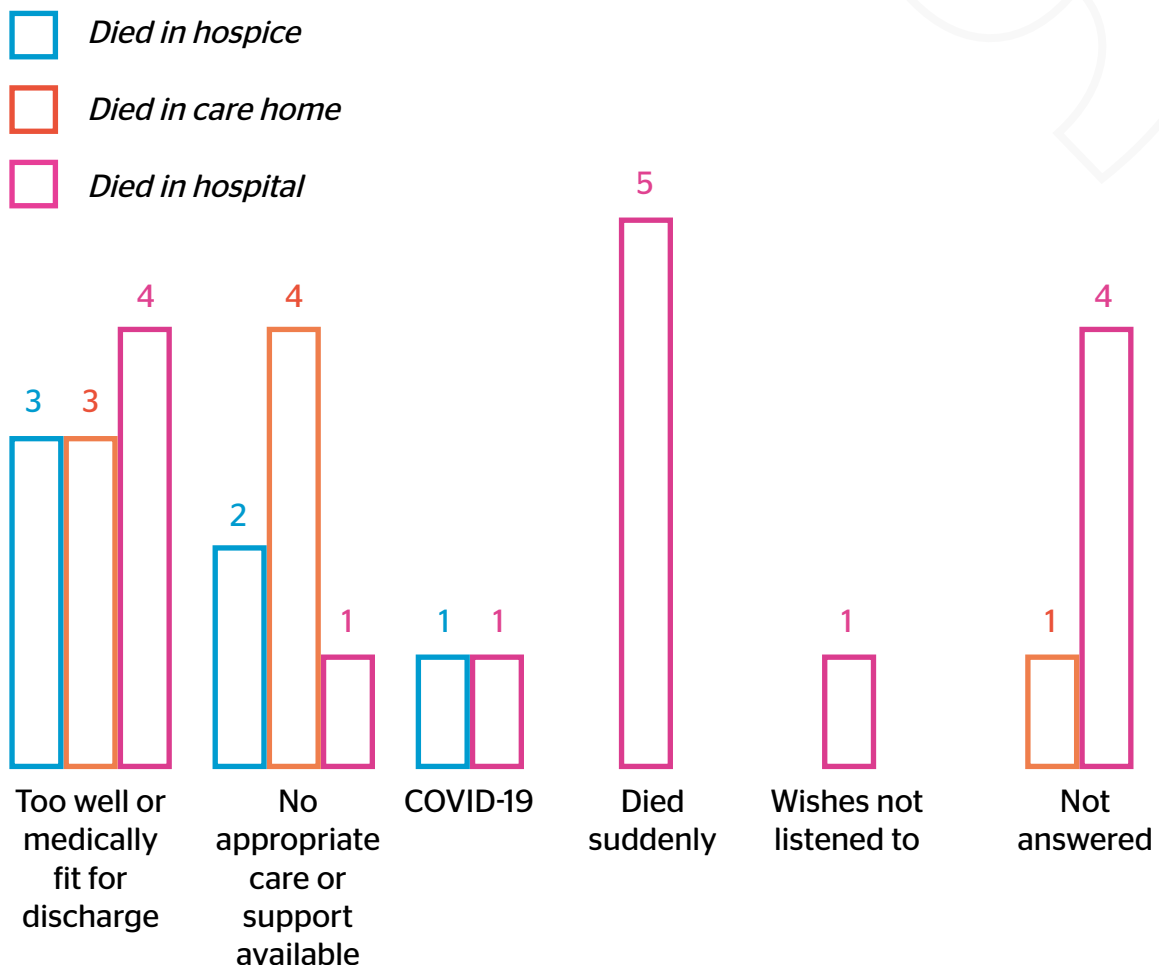
“COVID - it wasn't even considered how she could die at home - just we're in COVID lockdown so it's a no!”

“Coronavirus lockdown meant I couldn't go to look after him at home.”

One person said their wishes had not been listened to

“Wishes ignored as too difficult for hospital staff to care about!”

Table: Reasons why people were unable to die at home.



Support

Respondents were asked whether they had access to all of the support they needed in the last year and months prior to death and at the time of their relative or friend's death.

Table: Support people found helpful in the last months and year.

Support	Mentions
Hospice	15
Carers	9
Friends and family	6
District nursing team	5
Church	4
Specialist oncology unit at hospital	3
GP	3
Marie Curie	2
Condition-specific charity	2

More people responded to the question about support at the time of death (115)

than for the last year and months before death (93). Overall, the responses were quite similar, with just over half of the sample saying they did have access to all of the support they needed in each case.

Support people found helpful

Thirty-six people commented on the support they had found most helpful in the months or year prior to death. In around half of these cases (17), death had occurred at home. A further 10 respondents relative or friend had died in a hospice, four in a care home and four in a hospital.

Top of the list for support, with 15 mentions, were hospices. In nine instances, the respondent's relative or friend had died at home, showing the benefit of the outreach support that all three of the hospices within the SNEE ICS patch offer. The following hospice services were mentioned:

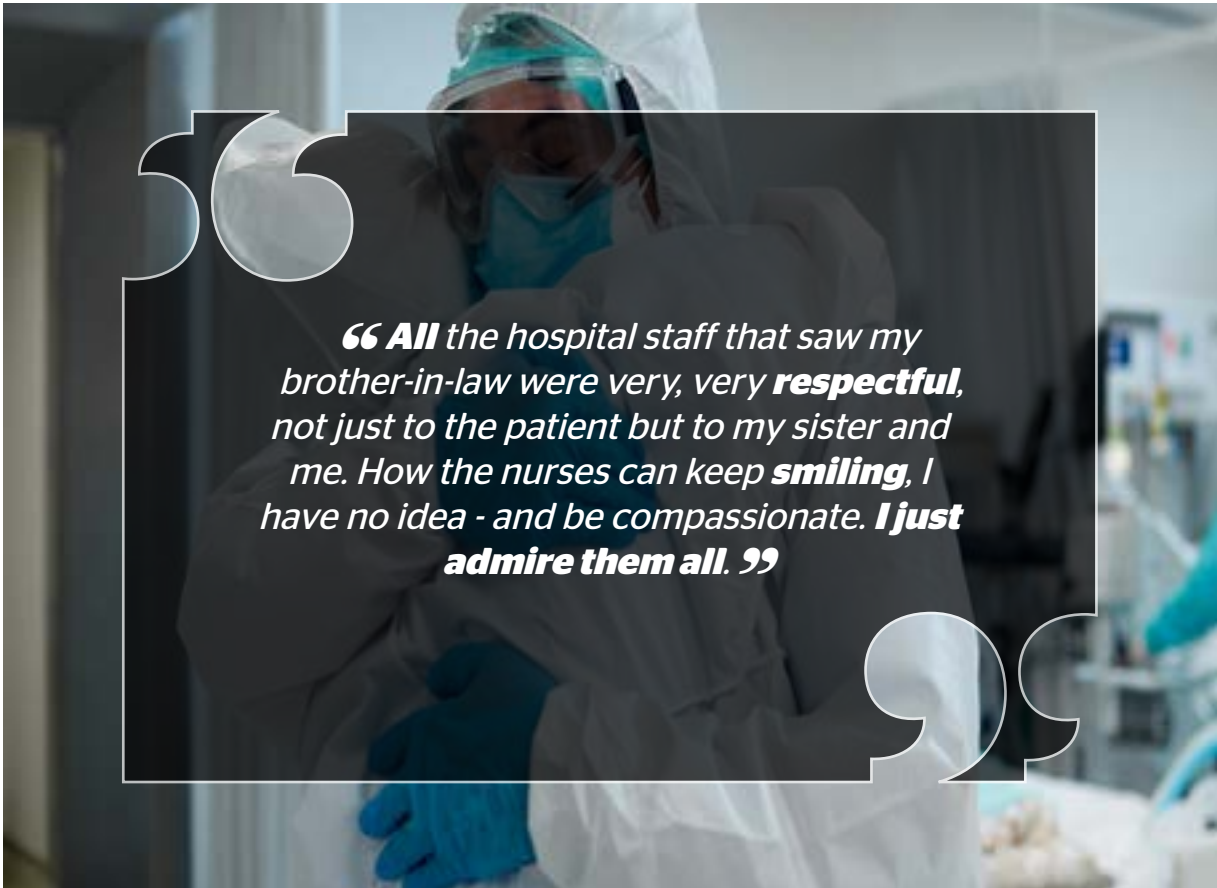
- The spiritual team, Hospice Neighbours, family support, the open house team, the home care team, the out of hours one call service, 565 service, the

Table: Did you have access to all of the support you needed in the last months or year?

Response numbers	Total (93)	I&E Suffolk (39)	West Suffolk (28)	NE Essex (10)
Yes	55%	56%	57%	40%
No	45%	44%	43%	60%

Table: Did you have access to all of the support you needed at the time of death?

Response numbers	Total (93)	I&E Suffolk (39)	West Suffolk (28)	NE Essex (10)
Yes	55%	56%	57%	40%
No	45%	44%	43%	60%



“All the hospital staff that saw my brother-in-law were very, very respectful, not just to the patient but to my sister and me. How the nurses can keep smiling, I have no idea - and be compassionate. I just admire them all.”

bereavement team, the day unit at St Nicholas Hospice, the virtual ward, and SinglePoint.

Of the nine people who mentioned the support they had received from carers, four related to carers within a care home, four referenced domiciliary care workers and one mentioned the support they had received from a live-in carer.

With the exception of the hospice (which provides both inpatient and outreach support), four of the top five sources of support mentioned were community based (e.g. carers, family, district nursing teams and churches).

“Day unit was invaluable support, very special team of people enabled patients to live to their full potential. Patients always treated as humans, as important and were cherished.”

“The whole hospice team was amazing. Their virtual ward team were so helpful and are a wonderful bunch of people who really care which made so much difference in a critical period whilst the necessary care was being put in place.”

“The staff at the care home were brilliant, very kind and understanding and explained all we as a family needed to know.”

“The carers my wife had were absolutely magnificent, something for which I will always be grateful.”

“This is difficult, because everyone was worried about COVID-19. But all the hospital staff that saw my brother-in-law were very, very respectful, not just to the patient but to my sister and

me. How the nurses can keep smiling, I have no idea - and be compassionate. I just admire them all. We were allowed to stay with him, which was comforting. Doctors and consultant were just the same. Even after his final breath, I went to tell the nurse and she came along and said 'Would you like me to take all the pipes and things out, so that you can see him without all the medical things?' Of course, we thanked her, and we were very touched by this. We asked if we could stay a little while and she said we could stay as long as we liked, then asked if we would like a cup of tea or coffee. I will always remember this because we were with our father when he died. We were literally told to go home, no sorry or niceness about it. That was worse than anything else, we were not even allowed to kiss him or hold his hand. I am referring to several years ago, things are very different now, thank goodness. Someone dying isn't a good experience, but the way the medical staff treated my brother-in-law made it so much better with all the compassion they showed. ”

Support at time of death

Thirty-six people commented on the support they had received at the time of death. Support from the hospice was again top of the list, with 21 mentions.

Table: Support people found helpful at time of death.

Support	Mentions
Hospice	21
Friends and family	5
Church	4
Marie Curie	2
GP	2
Hospital staff	2

While 10 of these respondents had a relative or friend who had died in a hospice, the remaining comments were made by those where death had occurred at home (nine mentions) or in a care home (one mention). One respondent did not specify where their relative had died. 'Friends', 'family' and 'Church' were the next most frequently mentioned sources of support.

Healthcare professionals (e.g. GPs and hospital staff) received two mentions each, alongside the specialist end of life support from Marie Curie.

“Family have been my main support, however, with COVID everyone has their own problems staying well, keeping their families well and recovering from COVID etc. ”

“Family are still watching out for me, ring me almost daily. My step-daughter has been fantastic, but is now back at work full-time. ”

“ [The Canon] visited and prayed with Mum for at least 30 minutes per day in the last few weeks of Mum's life. She brought her a palm cross made out of olive wood from the Holy Land and helped her hold it in her hand as she prayed. At that point, Mum was not able to respond. [The Canon] arrived just as Mum passed away so was immediately able to respond to the situation. I am not religious, but Mum was, and I'm grateful for the love and care she showed her. ”

Support people would have liked

In the last months or year

Forty-one people responded to the question asking about the support they would have liked in the last months or year prior to death.

Table: Support would have liked in last months or year.

Support	Mentions
Being able to visit or spend time with relative or friend	9
Better explanation or more information about what to expect at end of life	7
More support from GP	5
Access to specialist care and support	4
Integration or better communication between services	4
Felt abandoned or alone	4

Being able to visit or spend time with their relative or friend was mentioned by nine people. This is not particularly surprising given that the COVID-19 restrictions were in place.

“To have been allowed into the hospital to support my father at the time he was given his end of life diagnosis. I was told I couldn't visit because he was being fast tracked out to the nursing home (although other relatives of patients with end of life diagnoses were allowed in). When he went to hospital, he was feeling unwell but was completely lucid. He could not communicate at all with me when he arrived eight days later at the nursing home (a shock to me and the nursing home staff) and died 48 hours later. I do not know what he understood about what was happening to him. The nursing home let me spend time with him - I am very grateful for that.”

“Because of COVID, my mother and I had only seen my father once in six months prior to his final days. This is tragic and has affected us deeply

especially as he had advanced dementia and would have benefitted greatly from family contact in his final months. But this is not the fault of the care home.”

Seven people said they would have liked more information or a better explanation about what to expect at end of life.

“Should have been told what to look for in my dad's final couple of days whilst he was in hospital. Symptoms of his system closing down would not have been so traumatic had I known this was how my dad would pass. I'm not a medic and some of the terminology used was quite baffling to us. We didn't want to spend time away from Dad looking up or asking what things meant. It felt disrespectful talking about such things in front of Dad as we knew he would be able to hear us. Dad was very calm and reassured after the very kind consultant told Dad that he was going to die. I just needed to know the process and what I should be expecting. For example, Dad's skin was leaking on his arms and legs, and I didn't know why, and it wasn't explained even when the nursing staff kept changing his covers. Staff were lovely when Dad had slipped away though.”

Five people would have liked more support from their GP.

“My mother-in-law needed better GP care in the community - with a number of underlying health conditions, she and her husband became increasingly unable to manage appointments, tests and to keep up with call backs etc.”

Four people said they would have liked more access to specialist care to help them understand their relative's health conditions better. More help with dementia support was mentioned by a couple of respondents.

And four people mentioned that there had been a lack of joint working across the health and care system.

“ Before Mum was admitted to the hospice, she became very unwell. We had a perpetual cycle of the GP surgery, district nurse, and hospice, all trying their best not to come out to my mother. Each blaming the other. In desperation, I rang the hospice and had to plead with them to admit my mother, which was very distressing. No one took ownership of her care. Once in the hospice, the care and communication could not be faulted. We could finally enjoy seeing my mum for the last two weeks of her life. ”

Four people commented on the lack of support that left them feeling abandoned and alone at a very difficult time.

“ Apart from the district nurses coming in I felt we were quite alone. ”

At the time of death

Thirty-six people answered the question about support they would have liked at the time of death. Several of the themes are similar to those mentioned in the section above.

Again, being able to visit and spend time with their relative or friend was the most frequently raised issue (nine mentions).

Most of the comments were made by people whose relative or friend had died in either a care home or hospital. One person, however, mentioned the impact on visiting his father at home in the last weeks of life.

“ My father died three weeks after lockdown in April 2020. So I was unable to visit my father from lockdown in March until the day before he died, when he was unconscious. He lived with

dementia, and I feel that not being able to have visitors hastened the end of his life. I know he would have thought he had been abandoned by his family. To not be able to see your loved one in the final days and weeks of their life, was and will remain unbearable for me. ”

Table: Support would have liked at time of death.

Support	Mentions
Being able to visit or spend time with relative or friend	9
Information or better communication	9
Support at night or out of hours	3
More support from GP	2
Someone to look out for me	2
Access to end of life medication	2

The consequence of not being able to see relatives or friends meant that respondents wanted better, and more regular, communication with carers and health professionals about their relative or friend (nine mentions).

“ Having a named contact and regular and full feedback on how she was. I fully understand the difficulties of that time, but offered support and clear information on what was happening would have been better, rather than being told that my aunt had stopped eating and drinking, GP had been called and morphine given, expected her to die within days. ”

“ To talk with someone who was caring for her - someone actually there. We all know there is a pandemic, and we have to be careful but please - show us some respect too. ”

Three people mentioned the lack of support at night time. All of these comments were made by people whose relative or friend died in the Ipswich and East Suffolk Alliance area. And two people said they needed more support from their friend or relative's GP practice or doctor.

“The local hospice never answered the phone during the night - we called them three times during crisis situations and when we needed support, but we ended up sorting it out as a family or by dialling 999.”

Two people said they needed more support from their friend or relative's GP practice or doctor. Two people mentioned that they would have liked more support for themselves, and their family, at the time of death. Additionally, access to end of life medication had been an issue that caused concern for two respondents.

Whether respondent had been present at death

Respondents were asked whether they had been with their relative or friend when they had died. Overall, just under half the sample (46%) had been present at death. Twenty-three percent had been prevented from being with their relative or friend due to COVID-19 restrictions.

The graph (next page) provides a breakdown of whether the respondent was present at the time of death by place of death. Not surprisingly, it highlights that more people were able to be with their relative when death had occurred at home.

COVID-19 regulations restricted people being together most when death took place in hospitals or within a residential care or nursing home setting.

Table: Respondent present at death.

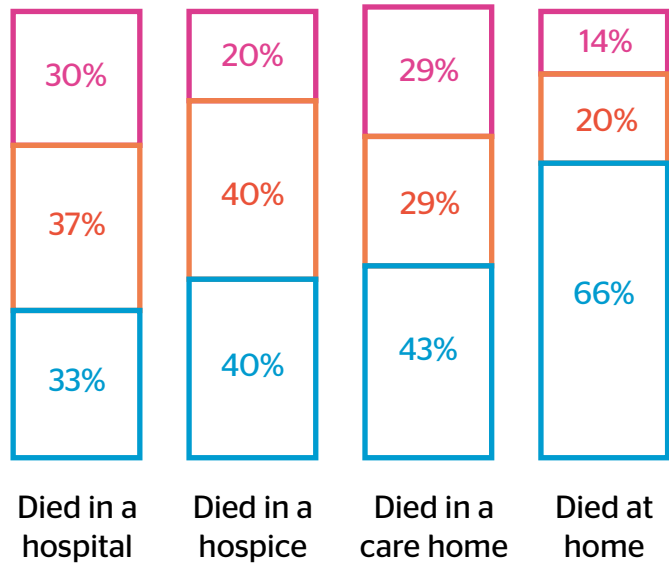
	Total (113)	I&E Suffolk (46)	West Suffolk (33)	NE Essex (13)
Yes	46%	57%	36%	38%
No	31%	26%	36%	38%
No, due to COVID restrictions (e.g. shielding, visiting restrictions, lockdown)	23%	17%	27%	23%

Table: Were you supported in a sensitive manner at time of death?

Response numbers	Total (76)	I&E Suffolk (34)	West Suffolk (20)	NE Essex (8)
Yes	72%	74%	80%	75%
No	12%	12%	10%	0%
Don't know	3%	6%	0%	0%
Does not apply, I didn't have contact with the staff	13%	9%	10%	25%

Chart: Whether respondent was present at death, by place of death.

- Yes
- No
- No, due to COVID restrictions



Seventy-six people responded to the question asking whether they had been supported in a sensitive manner at the time of their relative or friend's death.

Seventy-two percent (55 people) agreed that they had been supported and nine people said they had not felt sensitively

supported. In four cases, their relative or friend had died at home. In two cases, they had died in a hospice.

A further two cases had died in a hospital, and one had died in a residential care or nursing home.

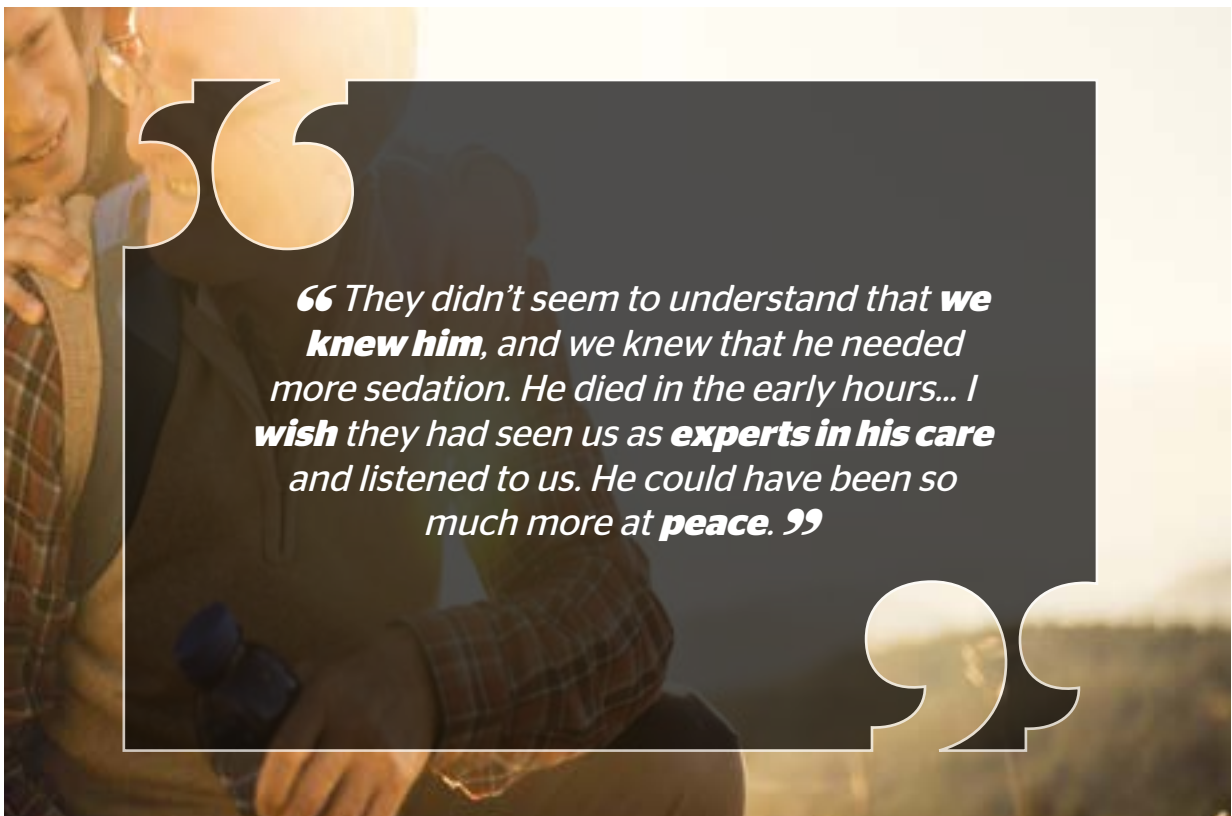


Table: Offered bereavement support.

Response numbers	Total (110)	I&E Suffolk (46)	West Suffolk (31)	NE Essex (13)
Yes	37%	39%	42%	31%
No	48%	46%	45%	46%
Don't know or can't recall	15%	15%	13%	23%

Bereavement Support

One hundred and ten people gave a response to the question 'Were you offered any bereavement support?'

Only 37% (41) of respondents indicated that they had been offered bereavement support following the death of their relative or friend. Support was most likely to be offered to those whose relative or friend had died in a hospice (63% or 15) and least likely to be offered to those where death had occurred in a residential care or nursing home (14% or three) or a hospital (17% or five) setting.

When asked whether they had received any bereavement support, only 17% said 'Yes'. Twenty-eight people said that they had been offered, but had not received, any bereavement support. Reasons given were:

- Fifteen people said they did not need it at the moment but might in the future.
- Seven said they had plenty of support from their friends and family.

- Six said they did not want any bereavement support or did not feel it was for them.
- One said they had been unable to access support at a time that was convenient for them.
- Three people gave other reasons. These included:

"I have support professionally."

"COVID arrived and that took over my life."

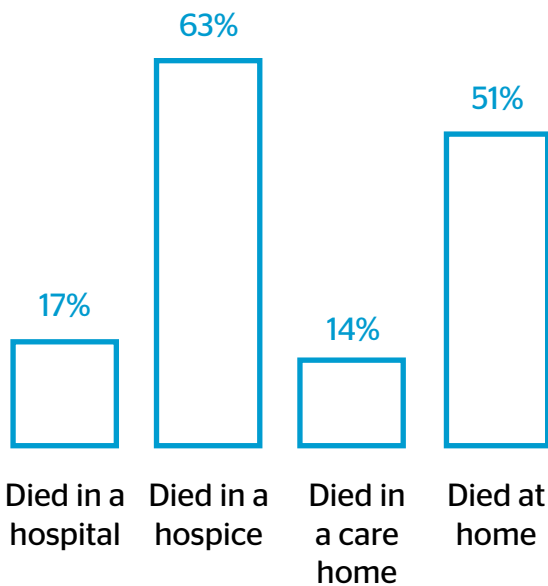
"They only wanted me to do family support and when my children couldn't do it, they said it was too late."

Respondents were asked whether there was anything they would change about the support they or their relative or friend had received. Seventy-one people left a comment. Twelve people said they would have liked to have been able to visit their

Table: Respondents who had received bereavement support.

Response numbers	Total (100)	I&E Suffolk (46)	West Suffolk (31)	NE Essex (13)
Yes	17%	20%	13%	15%
No	83%	80%	87%	85%

Chart: Offered bereavement support by place of death.



relative and to spend more time with them at the end.

“Even though hospital knew they were dying, they didn't allow anyone to visit. That's not care or compassion.”

“I don't know how we could have prepared for the effects of the pandemic and how that affected not being able to see our loved one in a care home. If I had had the power to take him out of the care home and bring him home for the last days or weeks of his life, I would have.”

Eight people felt they could have been offered more support from their GP practice.

“The local GP was particularly insensitive in discussions with my mum about Dad's care, and used COVID-19 as an excuse not to attend on a regular basis in the months leading up to Dad's passing - relying on district nurses to relay details.”

Seven people said they would change 'nothing' about the support they received. Five of these responses were made by people whose relative or friend had died in a hospice.

“My experience was great. My mum was happy being at home and the carers she had were fantastic. It was as perfect as it could possibly be.”

Six people said they wished they had been listened to more and that the family had been involved in end of life discussions.

“The day before he died, we knew he was restless and we as a family knew that time was short and he was dying but the district nurses didn't think he was near to death, so they told us to wait 'til Monday to speak to the GP about increasing his medication to help him relax. They didn't seem to understand that we knew him, and we knew that he needed more sedation. He died in the early hours the day after the nurses left (Sunday morning). I wish they had seen us as experts in his care and listened to us. He could have been so much more at peace those last hours.”

Five people would have liked better information about the treatment their relative or friend received and what to expect at end of life.

“It would have been helpful to have known what to expect at the end.”

“More idea about caring for a loved one at home - no-one ever described to me what it would be like. The signs of imminent death gone through - I used the internet to find out about imminent death signs.”

Five people would have liked better information about the treatment their

relative or friend received and what to expect at end of life. Three people said that having access to end of life medication and pain relief would have been of benefit.

“The end of life medication being available would have made the process easier. We had to pester the staff of the nursing home and call the local hospice to try to get them to help. The staff in the nursing home were second guessing when to administer pain relief and how much.”

Three people wished they had been offered bereavement support. Two people felt that being able to speak to a medical professional would have helped them come to terms with what had happened to their relative or friend. Two people mentioned that they had experienced problems accessing support ‘out of hours’.

“Someone to be with him at night for the last few weeks of his life. My dad had sundowners syndrome. He became very confused and tearful at night (particularly in the last few weeks) and didn't want to be by himself. The care home often let him sleep in a recliner in the lounge so he could see the night staff moving around so he knew he wasn't alone.”

Two people said they had wished that they had accessed support earlier. Other comments suggested:

“Somewhere we could have sat after the death and had a tea or coffee. To be able to take in the death initially without having to leave the hospital.”

Other comments

At the end of the survey, respondents were asked whether they had anything else they wanted to feedback.

Sixty-nine people took the opportunity to share more detail about their experiences, covering a number of different aspects of end of life care. The strength of these comments is in their narrative flow and the way they highlight the relationship of one event to another. This includes how one aspect of care could be outstanding, whilst another caused families pain (both physical and emotional) and distress.

Breaking these comments into individual themes would weaken the impact of these experiences. As such, they are presented on the next section in full and as they were written by the respondent.

One key theme that does emerge from these comments is the lack of integration and joint working across the SNEE system, which often made a difficult time even harder for families.



East

“The care home was amazing and did everything they could to support me and my dad. I stayed at the care home for the last week of my dad's life. I will be forever grateful to them for this. To be there to hold his hand and to try and comfort him and get help when he was in pain and see him treated with such care and kindness has given me some peace. The NHS system is disjointed - by the time mental health, social services and the nursing team had met and written their reports, it was too late for my dad. End of life care often seems poor for the elderly - it felt like he didn't matter. There doesn't seem to be any flexibility in the support system, whilst I appreciate it is difficult to assess someone's needs without some kind of framework, the tick list used for the assessment is too generic. I wished I'd just paid for help. It was only because a consultant at West Suffolk Hospital said my dad would be eligible for Fast Track Continuing Healthcare Funding in October 2019 when her prognosis was that he was end of life that we took that path. There was nothing 'fast' about the process that took place. I watched my dad have fall after fall and further hospital admissions. He wanted to die because he was so confused and in so much pain. My dad had myself and my sister to help fight for him - it shouldn't be a fight.”

“Once on the ward at the hospital, the care and compassion shown by the nurses was exemplary - and they tried to be as flexible as possible during visiting restrictions (there are three daughters). Junior doctor did not seem to realise that Dad was end of life although we were clear he was - we were sent home as he thought Dad could be treated and had only got down the road when we got the phone call to come back as some blood results came back to indicate high levels of carbon dioxide. We were left to sit with Dad at the end and when my sister approached a male nurse or HCA to say he had died, she was told she could get Dad's things ready and leave which felt very uncaring. We had a phone call from a lovely doctor in the afternoon, before we were called in, who had excellent skills in explaining the situation and probable outcome. We have also had great help from the bereavement team who got a doctor to phone me a few months after to go through what had happened in relation to concerns, we have about lack of care from GP.”

“He had an excellent GP who knew him well - and that gave him so much comfort. His GP couldn't visit in those last few days due to his workload - it would have helped enormously if he had been called by the district nurses. If the district nurses had asked more about who we were - they would have found out that we knew quite a bit about end of life care, so when we asked for help, we needed them to listen to us as we were best placed to know the person was dying. The hospice needs to know that if you ring in the middle of the night, an answerphone is not helpful - and if you could have a way to call people back who have attempted to ring, it may go a long way to relieving the distress. I know they have a ward with people dying, but more people die in the community without that support, and it is scary at 4am when you can't get through to someone and you don't want the person admitted to hospital at any cost. The East of England Ambulance staff were the kindest compassionate staff - and they were a great support to the family at a distressing time. Maybe they need an end of life team that can focus on the support at home to prevent admission to hospital?”

“Staff on the ward didn't know what to say or do. We really wanted someone in the room with us at the end, but all the staff stayed out of the room. I was offered food and drinks and allowed to stay on the ward with Mum. Staff found me a recliner chair to be more comfortable. The ward moved patients around to enable Mum to be in a single room. I would have liked to have seen an investigation as to how my mother became so ill in the nursing home before she was admitted to hospital. The medical examiner had said he would report to the CCG but in the end, it was left to me to complain. It was a horrendous death and I have not yet felt able to put together the complaint.”

“Due to COVID, I feel treatments were delayed. We were very much left to fend for ourselves. I got the impression GPs didn't actually want to come out to see him. Getting him admitted to hospital was difficult even though he had sepsis. The last weeks of his life he had infections that required IV antibiotics, yet no one wanted to refer him to hospital. Looking back, it was so wrong.”

North east Essex

“As my father was medically sectioned, the lack of communication between medical teams was extremely hard on the family. When being sent between the secure unit and general hospital the receiving teams didn't seem to have all the details of his condition and as a family, we were not offered explanations or any support at such a traumatic time.”

“The support we received throughout the final year was good. Essex community supplied some very useful appliances which helped ease the load. The only issue I had was it took over three weeks to collect the bed and commode which was a somewhat painful experience as it was a constant reminder every time I entered the bedroom. The hospice was amazing.”

“Couldn't fault anything at all. They were very considerate of everything when he had passed away. They let the family come and be with him when he had passed and gave us as much time as we needed - it was during the pandemic, but they did everything they could to accommodate our needs. The last few times he was admitted to the hospice they rang regularly to update us as he was unable to tell us much. St Helena was such a warm and friendly place, and all the staff are amazing at what they do. As we were stood outside even the catering lady came and gave her condolences and gave us a lovely memory of him. Even though we didn't use them much we knew and still know the services are available if we need them.”

West

“Hospice team I believe were supportive but need the whole system to pull together and work to one plan.”

“ I felt COVID took over and was regarded as more important than their death. ”

“ My mother didn't die from COVID, but she died because of it, we were unable to see her for four months until she became end of life. The fact that we couldn't see her all of this time in my mind was what caused her death, she just gave up as she couldn't understand why my sister and I couldn't see her every day like before. ”

“ My aunt died in the hospice, after I requested a referral, and this was a positive experience for the family. In the hospital, however, it had not been recognised that she was dying, despite jaundiced, not eating, variable conscious level. She has food in her mouth when I visited - when she was unresponsive. It was very difficult to alert all the family that she was dying, when they felt she was still for active treatment and therefore missed opportunity to plan with her. My uncle's referral to palliative care services did not happen until my aunt had died and this referral was also requested by myself. It did not feel all services were working together. ”

“ The care home was very supportive of us and tried very hard to enable us to see our father, within the restrictions imposed by government and the district nurse. I was shocked that the end of life process deprived the person of fluids and really did not understand the explanation that this was because of risk of choking. I do realise that a person's life must end at some point and that I was desperate for my father to continue to live so that I might be able to see him again and life would continue for him after COVID. But sadly, this was not to be. ”

Others

“ I think the communication between hospital and the local surgery was appalling. It is as if the two are not part of the same NHS. And so confusing that each hospital and department has no common uniforms, guidelines or aims. It's like going to 10 different shops all selling the same thing in 10 different ways but none of them actually selling what you want or need. Oh, they all carry on about pandemics (how many more times do we have to be informed) but we wonder what the excuse will be when this is all done? The most sensitive and kindly people we encountered were the least qualified - the cleaners, the porters, the volunteers. The grander their titles, the more they seemed distant and unhelpful. ”

“ The nursing at the home was outstanding and empathetic ...everyone was so so kind and understanding. The GP was terrible, and we had to fight for everything including the correct medicine to ensure our mother was comfortable in her last days or hours... we had to go and get it from the pharmacy! There needs to be more seamless support for those dealing with these situations. More training for GPs regarding dealing with older people at end of life and their loved ones. He even held back the death certificate because we had challenged him and his approach to our mother. Appalling behaviour. ”

4. What people told us - interviews

The semi-structured interviews provided an opportunity to explore some of the issues about death, dying and bereavement in more depth.

Thirteen people agreed to be interviewed and to share more detail about their experiences. One respondent was able to provide feedback regarding the death of two of her relatives, both of which had

occurred within the specified timescale for this project.

This analysis is therefore based on 14 experiences of end of life care and support in Suffolk. Despite attempts to promote the survey extensively within the North East Essex alliance area, no individuals came forward for interview.

Table: Relationship of the person to the deceased.

Father	Mother	Brother	Husband	Wife	Father-in-law	Friend
5	4	1	1	1	1	1

Table: Location where the death occurred.

Care home residence	Home	Hospital (including community hospital)	Hospice
6	4	3	1

Table: Month that the death occurred.

Jan	Feb	March	April	May	June	Jul	Aug	Sept	Oct	Nov	Dec	2021
2	0	2	0	1	1	1	0	4	1	1	0	1

Table: Suffolk and North East Essex Integrated Care System (SNEE ICS) Alliance area.

I&E Suffolk	West Suffolk
10	4

“People approaching end of life and their families are prepared and informed, and able to make early decisions and choices about their care and treatment.”

- SNEE ICS Higher Ambition

People preparing for their end of life

Receiving the news that you, or your loved one, is reaching “end of life” is devastating.

Understanding the prognosis of health conditions and having the chance to discuss treatment and care options, provides an opportunity for people to prepare for death. Full and frank discussions between patients, family members and health and care professionals offers the opportunity to develop a shared understanding about what is important to the patient and to shape the way in which end of life care is delivered.

The process of preparing for death, however, can be complex. The need for clear, and honest, communication between everyone is vital to avoid misunderstanding, unnecessary distress and emotional trauma.

Preparing for end of life

Preparing for end of life can start with the diagnosis of significant life limiting conditions. For several respondents, the time between diagnosis of health problems and the final stages of the end of life occurred many months, or sometimes years, apart.

They had, therefore, been living with the knowledge of their relative’s poor health for some time. This meant that, whilst there was an acknowledgement that ‘end of life’ was nearing, death still happened

suddenly; sometimes under unexpected circumstances (e.g. precipitated by a fall or development of an unexpected infection etc).

“She had vascular dementia. She was in a state of delirium for a lot of the last year of her life. She was physically very fit. It was the dementia that got her. For the last six months of her life, she was eating less and drinking less, and it was a real battle to get her to eat or drink anything. She was losing weight, she was spitting her tablets out and she was distressed quite a lot of the time. I have a rational head and an emotional head, and my rational head knew that she couldn’t continue this way.”

“I told Mum when she was first diagnosed three years ago that this was not going to go, but that she would have to fight it when it kept coming back. It was cancer. She understood that, but we were still believing, but at the beginning of December 2019 she was diagnosed with a kink in the small bowel as it was blocked. It happened all of a sudden... we were told eight days before death. It was a sudden turn around.”

“My mother’s death was sudden although she had had a stroke five months previously and had to move into a care home. The stroke took away her ability to walk, feed herself, speak properly and swallow liquids. Before this she was fully mobile and could drive, sing in a choir, play the piano. She was 82. Stroke was something we had



never thought about as she was on blood thinners with low blood pressure if anything. It came totally out of the blue..... three weeks before her death, she was getting weaker and weaker, and I raised my concerns [with the care home] that she was losing weight and becoming less communicative. She was eventually taken into hospital where blood tests showed that her kidneys were failing. She was severely dehydrated and the sodium levels in her blood were extremely high. ”

End of life prognosis

There comes a point, however, when it becomes apparent that a patient has exhausted all possible treatment options and a health professional will need to make an end of life prognosis.

It is important this information is delivered in a timely, sensitive and caring manner. It is also fundamentally important that the news is provided to people in a way that is clear, for everyone concerned, to understand.

Both the patient, and their family, need to be adequately supported during this process. This includes being provided with the information and emotional support to help them 'come to terms with' what they are being told. People should also be provided with the information to help them understand what might, or will, happen and what to expect.

The feedback received from respondents highlighted the variable experiences they had in receiving end of life prognoses and the support that was offered to them and their relative or friend at the time.

Four respondents were positive about the way in which they had been informed. However, one person said they had not been offered any support.

“ I asked to see a doctor and asked exactly that question. And he said, yes, he thought Dad was entering the end of life stage. And he did say to me that he would be very surprised if my father was still with us four weeks later.... And he talked to me very sensitively and he was only a young doctor, but he was very kind. He said the family needs to look after themselves and their own mental wellbeing as well as, obviously, looking after my father. So, yes, he was both helpful and sensitive. ”

“ [Interviewer: Was the news broken to you sympathetically?] Yes, very the consultant was amazing. The family weren't offered support, but I have a nursing background, so I felt I had enough information going forwards. It was just explained to us what effects the tumour would have. ”

“ They talked to myself and my husband when [my father-in-law] was diagnosed in September. Twelve years previously [my mother-in-law] died of bowel cancer. So [my husband] knew the signs and asked the surgeon questions. They were brilliant, you couldn't say anything else. Basically, we went in and the consultant shook our hands and he handed us over to Macmillan cancer care. It was done in a caring way, very sympathetically. Macmillan talked through things, and they said they were here for us but as we weren't at the stage [when my father-in-law] needed their care yet, it was up to the hospice. [My father-in-law] did not realise he was terminal then as we thought if he knew he would give up. I think he picked up on it though and when we were handed over to Macmillan, we then had the conversation. ”

“On the Thursday, it sounded quite hopeful. On the Friday at 5pm, I got a phone call from one of the doctors to say that this was what was happening, and this was what the concerns are and explained there was some strain on the right side of the heart. I said to him were we talking about end of life, and he said not at the minute, but the next 24 hours were quite crucial - if we don't see an improvement in the next 24 hours yes, we are then saying it was end of life. [The consultant] was lovely. It was really good.”

In six instances, respondents were not happy with the way in which they and their relative had been given the news.

The specific issues that these cases raised were:

- That information was not communicated clearly
- That the information was not given in a sensitive and caring manner
- That the patient was not offered support when being given the news

“I couldn't tell he was dying but I could tell he was dramatically more ill than he was when I had seen him a couple of days before. The doctor came to talk to me, and I was sitting holding my brother's hand completely traumatised. He came to talk to me but was talking in front of my brother, so I wasn't comfortable and asked if we could talk somewhere else and he took me to this little side room. And basically, used this expression again, 'He had aspirated earlier this evening.' and he said we have had the ICU team up to assess whether he should be moved and put on a ventilator, but they decided his chances of survival aren't good enough

- so basically they left him on the ward to die. When I think about it in hindsight, he seemed incredibly uncomfortable. He was very young, I doubt he was 30.. he was not comfortable talking to me.”

“When he left hospital, it was the beginning of the end. We were called because they didn't think he was going to live. And after they moved him into the home, I had a call from the home and the GP had been in and he said he had taken a turn for the worse. And that he didn't expect him to live and I said 'Do I have time to get my daughter?' and he said 'I am not saying it's imminent' so I asked how long did he think and he said 'I never was much good at guessing when people were going to die' and laughed....The girls at the home kept him going and after three weeks I got to speak to the doctor again and I said 'You obviously haven't been in to see [my husband] because you are not doing visits but obviously he didn't die.' And again, he laughed and said, 'I told you I wasn't very good at guessing when people died in fact, I feel an idiot.' ... My remark was 'I am saying nothing doctor.' and put the phone down.... I was upset because of his attitude.”

“[The GP] was the only person who was willing to have a genuine and frank conversation with me about Mum dying and what was happening and what was going on. I know what happens when someone dies, I know all that, but actually, for someone to be willing to talk about it in very, erm, not direct exactly, but very factual but also compassionately knowing that Mum is lying there in the other room and knowing that I am going to be really upset as well. She was just wonderful, and I am very grateful to her. A number of people came in the last couple or three weeks of Mum's life

and I said to them how difficult it was to watch Mum die like that and as I said the GP was the only one who was able to have a conversation with me really and reassure me. I just needed them to be a bit braver and to have a difficult conversation with me because it would have been difficult for them, I appreciate that, but it was hell for me and actually if they had been brave enough to have that conversation with me then maybe that would have helped. ”

Finally one respondent reflected that, whilst they had understood what was happening, no-one had actually “said the words”. Their comment highlights why clarity of information is so important in helping people to come to terms with what they might face.

“ I think when they were talking about her options, coming towards the end of the time in the hospital, when there wasn't too much they could do, and she chose the option to go to the hospice - they didn't actually say the words, but it is fairly obvious when you're going to go from the hospital to the hospice what's going to happen. My other son, and I were called in to see a consultant. And he broke the... it was the first time we sort of... he put it in black and white to us. [Interviewer: But you feel he told you sensitively?] Well, to be honest, I mean, you're sort of in a daze, really. You're not really sort of- it's not real, you know? I don't know. It's a bit odd to describe... ”

It was evident from the interviews that people had different views and perspectives about the concept of ‘planning’ for death. Three respondents did not mention whether they had discussed end of life care plans with their relative or friend.

In five cases, the deceased person and their family had discussed and documented

a formal end of life plan. Four of them specifically mentioned using the My Care Wishes Folder. In one instance, a family felt that they were not consulted about their relative’s care preferences when death occurred, despite having made and shared the plan with the care home in advance. In their words ‘they just did their own thing’. Conversely, another respondent found that the constant re-checking of her parent’s wishes was causing her unnecessary distress and anxiety every time her mother became ill.

“ [When we were first given the prognosis some years ago] there was time for my father to plan about end of life. It was spoken about and planned with the family, and it was all documented at the care home. [When the tumour started to grow again] we were in lockdown... and we were doing video calls [with the home] but at no point in time did the manager contact me to say Dad was getting worse and they didn't talk about how we wanted [end of life] to happen or discuss it with us. They didn't discuss what my father's wishes were, or ours. They just did their own thing... We weren't asked what his wishes were, and neither was he. They were playing music when I arrived. I stopped this because it wasn't the type of music he would have liked I then put on the music I knew he would like. In looking through his care plan, I can't remember seeing anything about his end of life, who he would like to be there, the type of music. They didn't discuss his wishes or needs with him or us. I have complained to the care home. ”

“ We had planned and said we would keep her at home as this was what she wanted... [In relation to her funeral] She planned it all, she wrote at the beginning her own eulogy, what she wanted. ”

“ [We had completed an end of life plan – a yellow folder] The end-of-care, I was consistently asked until I said in the end ‘Can you stop this. It’s causing me extreme and deep stress. And I’ve given the instructions of what I want to happen.’ My mum had pneumonia twice. And her chest is very bad. And every time, they had to call- I mean, we had the conversation the first time, when I actually thought she was going to die several years ago. And we had an end of life plan in place. And to me, nothing changed in that, in this plan. And then she had another bout of illness. And they asked again, and we had to go through this yet again. I think I did it four times. And it made me quite ill with pain. And the fourth time, I just said, ‘You need to stop this because I can’t deal with it anymore. I’ve dealt with it, as far as I’m concerned. Stop asking me what I want to happen. I’ve said it. I’m not going to change my mind.’ [Interviewer: Did the care home follow what was asked for in the plan.] Yes. They did. ”

In one case, the respondent was aware of her mother’s wish to die at home. For her, the “promise” she had made was the “end of life plan”.

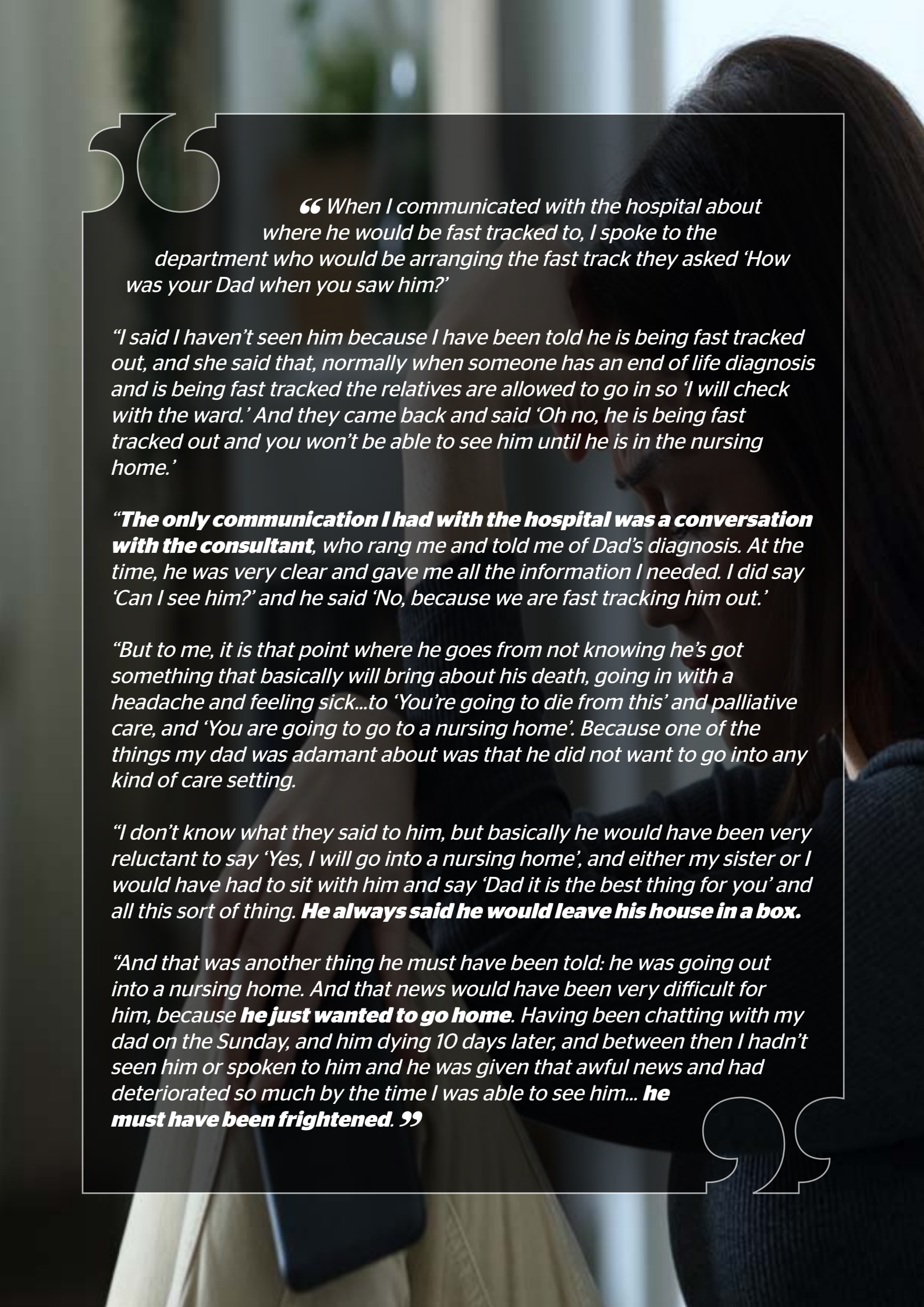
“ We did discuss end of life with her, but she wouldn’t have understood [because of her dementia] I looked after my father when he died five years ago. After Dad died, Mum carried on living with us. It was a promise I made to them that I would make sure that they didn’t die in hospital but that they would stay at home, so that is what we did. ”

In three cases, death occurred suddenly. This had left the family little or no time to discuss end of life care wishes. In the first case, the respondent knew where her father would have wanted to be buried but, beyond that, they had not had time

to discuss end of life care preferences. This was because it had all happened too suddenly (the patient was admitted to hospital on the Wednesday and died Saturday). She felt angry about the delay there had been in diagnosing her father’s heart condition, which had robbed them of the time that they could have spent supporting him during the lockdown.

“ I think we knew when obviously Mum died (two and a half years ago) that his wish was to be buried with her. I don’t necessarily think he would have wished to die in hospital, but I don’t think there was much choice really..... For us, the difficulty is if we had been aware that he was end of life we would have made arrangements for him to move in with one of us or us to move in with him because it was lockdown. So obviously he was on his own during lock down which we think finished him off really. He was still grieving for our Mum and was getting more ill and more ill and losing significant amounts of weight and not really feeding himself. And we think that’s where we feel we have missed out, had we known it was end of life and had a plan in place in March we could perhaps have cared for him. ”

Another respondent spoke about her brother who had sustained broken ribs as a result of a fall. The care he received in hospital had exacerbated his injuries and he subsequently died. There had been no discussion about end of life care wishes as this was a totally unexpected death. In the third case, the respondent’s father was taken into hospital where he was diagnosed with a tumour on his lungs that had metastasised to his brain. The family were told they were unable to visit their relative as he was due to be ‘fast-tracked’ out of the hospital to a care home. This took 10 days, during which time the family were unable to visit or speak with him. He was



“ When I communicated with the hospital about where he would be fast tracked to, I spoke to the department who would be arranging the fast track they asked ‘How was your Dad when you saw him?’

“I said I haven’t seen him because I have been told he is being fast tracked out, and she said that, normally when someone has an end of life diagnosis and is being fast tracked the relatives are allowed to go in so ‘I will check with the ward.’ And they came back and said ‘Oh no, he is being fast tracked out and you won’t be able to see him until he is in the nursing home.’

*“**The only communication I had with the hospital was a conversation with the consultant**, who rang me and told me of Dad’s diagnosis. At the time, he was very clear and gave me all the information I needed. I did say ‘Can I see him?’ and he said ‘No, because we are fast tracking him out.’*

“But to me, it is that point where he goes from not knowing he’s got something that basically will bring about his death, going in with a headache and feeling sick...to ‘You’re going to die from this’ and palliative care, and ‘You are going to go to a nursing home’. Because one of the things my dad was adamant about was that he did not want to go into any kind of care setting.

*“I don’t know what they said to him, but basically he would have been very reluctant to say ‘Yes, I will go into a nursing home’, and either my sister or I would have had to sit with him and say ‘Dad it is the best thing for you’ and all this sort of thing. **He always said he would leave his house in a box.***

*“And that was another thing he must have been told: he was going out into a nursing home. And that news would have been very difficult for him, because **he just wanted to go home.** Having been chatting with my dad on the Sunday, and him dying 10 days later, and between then I hadn’t seen him or spoken to him and he was given that awful news and had deteriorated so much by the time I was able to see him... **he must have been frightened.**”*

finally moved to the care home where he died less than 48 hours later. The son had only been able to see his father for one hour, during which time his father was non-communicative (see page 41).

One respondent reflected that their relative would not have been able to state his end of life care wishes due to his advanced dementia.

“ He had advanced dementia. He had been in a care home because of his dementia, for two and a half years. He had had a fall 10 days prior to his death, at the care home. Which at the time didn't seem particularly serious, although they took him to hospital. And it became clear at that point that he was nearing end of life. When you say, 'Could he prepare?' The answer is no, because he didn't have the mental capacity to prepare. But the family were told to prepare, basically. ”

A further respondent recalled being present when her friend's GP had discussed end of life care, but as far as she was aware, no 'formal' plan had been made. It was not clear whether her friend's wishes were noted down and whether they could have been shared with those providing care for her at the end.

“ [Interviewer asks about My Care Wishes:] No, I haven't seen anything like that, and I've just cleared her house. So I never found anything like that but- I was with her when her GP sort of- several times she sort of talked to her. What would you like for your end of life? And she always said she wanted to die at home because she had a little dog. The dog was her life, basically..... she also had a red bag that was provided by the hospice which I think it was- I don't know. It had drugs in it, and it said if there was an issue or something

an ambulance came, and they'd have stuff there that they could give her straightaway to help. ”

Knowing what to expect at the 'end of life'

Responses to the online survey indicated that families felt there was a lack of information about the dying process and what to expect as death occurs. This issue was raised in two of the interviews, where the respondents felt they would have been more prepared to deal with the situation had they been better informed.

“ What I didn't have from the care home - and I would have quite liked well in advance, was an open conversation about what the actual process of death would be like. I'd never witnessed a death before. I didn't know about these final end of life issues with the driver and all this sort of things. It was my daughter-in-law who talked me through all this. It had been mentioned to me by the home that this may happen. And I think if I had not had that conversation with my daughter-in-law, I would've been quite shocked and would've found that difficult to process. So I know sometimes these things happen suddenly, and I know it's very hard for people to talk about but personally, I needed to know, what was going to happen, what the process was going to be, what support he was going to be given medically, in particular, and during those last few days. But I don't know what information they give to other relatives which is just sort of a [inaudible]. 'This is what will be happening next.' ”

“ I asked the hospice if there was a leaflet you could give to people to explain what would happen when they were dying because we would have wanted to know more about the terminal agitation. We knew it could

happen but not in real detail. We feel we could not understand how a body could be so cold and still alive. It felt as if she had come out of a fridge and as if she was gone. It would have been really good to have had that knowledge. And also the catheter bag one morning had blood in it. The nurse had to explain that this was natural and that it was about the body closing down. The next morning it was blue, and the carers left it until the nurse came in. She said it was part of the process of the organs closing down. It was deoxygenated blood. It would have helped to know this and that the feet and legs would go purple and motley and that it would go up to the hands and the knuckles would go deep purple and we would like to have known all that. We didn't know all this We had been told about terminal agitation, but they don't tell you how violent and nasty it can be. I said I would write a leaflet but they said they were in the process of writing a new pamphlet called 'Caring to die or dying to care' and front liners would be involved as it was intended for frontliners but we said when you are caring for someone at home you are the front liners. They said someone would be in touch but we haven't heard anything. ”

In addition to a lack of information, two respondents highlighted the distress they had experienced when their relative became unable to eat or drink towards the end of their life. Providing sustenance to others is a basic human instinct and both felt traumatized by seeing their relative “starving to death”. Neither felt they had been prepared for what they experienced.

“ Because of the vascular dementia she'd had little TIAs, and on Boxing Day night she had a small stroke and she lost the ability to swallow, so was unable to eat or drink from then on. For the last

two and a half weeks of her life she ate and drank nothing. For those two and a half weeks, we received no support. When the 111 doctors came, they offered IV fluids, which I accepted. I didn't realise at the time it was only one bag, that was all they were going to give her, I found that very distressing and upsetting. The speech and language therapist gave me some gel to put inside her mouth which rehydrated her mouth which helped and was quite a relief to me really. Beyond that... nothing. My rational head knew that they weren't actually going to do anything, but the emotional trauma from that, watching my mum starve to death was the most horrific thing... You could argue that you are just delaying the inevitable but I have spent the last 10 years doing as much as possible for my parents and then to suddenly at the end not be able to do anything to help her. I knew I couldn't make her better, I knew I couldn't make her live, but I just needed to be doing something. ”

“ The saddest part was we had to watch her starve to death. She couldn't eat or drink and the worst part was that she had to force food down, but it tasted awful because of the chemo, but she would try to eat but it would come back because of the blockage. ”

Similar issues, around the provision of food and drink at the end of life, were also raised by a signposting caller who contacted Healthwatch Suffolk about the care their relative had received in one of the community hospitals.

“ On the Wednesday, the head doctor called me at work and said that they felt they could do no more for him. She felt that once the IVs were removed, he would be unlikely to eat and drink and would, most likely, submit to multiple infections. After having seen and heard him so distressed

the previous Sunday, I agreed to no more invasive procedures. Following this phone call, his IV line was removed. When I was visiting the hospital at lunchtime the next day, I managed to get (my husband) to have some sips of Ribena, and the nurse said that I shouldn't give him any drink as 'it would take him longer [to die]'. Another nurse then put NBM on his board, I questioned

this, as I did not agree to have food and drink withdrawn. In my opinion, this does not form part of palliative care. That same afternoon he opened his eyes, joked with the tea lady and thanked the two attending nurses, saying that they were 'wonderful people'. At this point the nurse added 'whilst asleep' under the NBM on his board."

“People at end of life and their families receive the best quality care and support.”

- SNEE ICS Higher Ambition

Best quality care and support

Unnecessary medical treatment

Whilst most interviewees felt that their relative or friend did not receive unnecessary medical treatment at the end of their life, three respondents disagreed and expressed dissatisfaction with elements of the care and support that had been provided.

- One respondent felt that carers were trying to give unnecessary medication to sedate their relative, in order to “make life easier for themselves”.
- Another respondent felt that the care home had not taken enough steps to understand her father’s medical condition and had therefore continued to issue medication that was no longer appropriate for him.
- One respondent was informed by the doctor that her dying relative would still receive active treatment for his asthma.

“‘You will not inject him with anything until you speak to me first.’ ‘Well, he’s

distressed.’ I said, ‘I’m sorry,’ very sarcastically. I walked into the room, I said, ‘He’s asleep. He’s sleeping like a baby. How can you possibly say he’s distressed?’ ‘Well, he caused us a bit of aggravation while we were trying to get him changed.’ I said, ‘So you want to drug him up? Do you? Well, you’re not going to.’ That was the only time I intervened and put my foot down. ”

Quality of care in different settings

Care homes

Seven respondents were able to provide feedback on the care their relative or friend had received in a care home. Of the six cases where the resident died in the home:

- Four were generally positive about the quality of care their relative had received. This was particularly evident at the time of death, when staff went that extra mile to ensure the resident was made as comfortable as possible and that the family was supported. In one case, a senior nurse had recognised that the individual was close to the end of life and had ensured that the relative

had been able to spend some important time with them before they died the next morning. One respondent had an overall positive experience of care for their relative, including that the home had kept them fully informed during the pandemic and provided excellent care. However, they mentioned that there had been a delay in the receipt of pain medication because the syringe driver at the home had expired.

- Two respondents were less satisfied. In one instance, despite describing the carers as lovely and kind, the respondent also mentioned that her friend was left alone in her room with no television on, no glasses and unable to move or do anything for herself. The home had also failed to pass on a photo of the residents' dog, who had been a very important part of her life prior to moving into the home. In the final case, the relative described the care at the home as 'overall quite good', however, the home had failed to discuss end of life support wishes with the family, or to consult his end of life plan.

“I have to say they were absolutely excellent. I cannot fault them.... They were absolutely marvellous. They really took great care of her. [Interviewer: You felt that she was treated with dignity and respect and that she was given all the adequate pain relief?] Yes. Yes, I do, and they deliberately went in and made sure they got pain relief, just in case but they didn't have to use it. She died of old age, which again, was great.”

“The deputy manager who has responsibility for end of life care was superb. I mean, she was very clear and very, very helpful. Communicated well with us in those last few days. And I mean, she loved my father to bits as well, and she made sure that the end

of life care that he had was the best that they could possibly provide there. I can't fault them for that and for her communication with us in those days before and in the weeks afterwards.”

A further respondent was able to feedback about the care her mother had received in a care home, prior to being admitted to hospital, where she subsequently died. Her experience of care in the home was less than satisfactory and has led to her raising a safeguarding concern due to the neglect that she feels occurred.

“In the nursing home she was neglected. Her newspaper was out of reach, the food was as bad, they didn't put the TV on, the bell was out of reach, the table was on the wrong side. I went every day bar four for three months and felt I if I said something I was complaining every day. She expressed she was not getting things to meet her needs and she expressed herself through frustration. She stopped eating and lost weight. She couldn't speak by this time and although I complained nothing happened. The problem is that there is a change of staff all the time and despite the handover people don't have time to read care plans they go off to their area and get stuck in. In the three weeks before her death she was getting weaker and weaker, and I raised my concerns that she was losing weight and becoming less communicative beginning to sleep more when before she would be up in the morning and might have a nap but then would be up and doing things. But here she just wanted to sleep. If the appropriate action had been taken, she would not have died when she did.”

Where dissatisfaction arose, the main concern was the general lack of communication relatives received from

“ It was just really sad. I mean, I was frustrated. She didn't have a television in there. She didn't have her glasses on, but I think they did have her glasses. But she didn't have them on. And so **she was just sort of laying in her bed.**

"She had a single room. She couldn't do anything herself anyway, but I just thought, 'Oh, that's really sad.' So **I took a photo of the dog and stuck it outside--** yeah, I gave it to the staff. But I posted it, and when I was talking to them, and I said, 'Have you got the picture?' And they said, 'No.' And then she went, 'Oh, is it in a big, brown envelope?' I said, 'Yes.' 'Oh, nobody opened it.' So she can't open it, could she? Yeah.

"I said, 'Look. It's a picture of a dog. It's laminated. You can wipe it down. Just stick it on the wall in front of her so she can see it.' **Her dog was the most important thing to her.** But generally, the home seemed ever so nice.

"All the staff I spoke to - and I spoke to quite a few over the time - they were all ever so nice and really kind. Well, they were to me, as far as I could tell. She died at night and they phoned me in the morning. I think it was 7:30 in the morning, I think. They were lovely, all of them. **They were lovely. And the person that phoned me was actually with her when she died.**

"She said, 'I was there. And someone else was there. So she didn't die on her own.' I said, 'Oh, that's really nice.' I was glad about that. But yes, she said that it was just over very quickly. And I just said, 'Well, I'm pleased that it was quick, and it wasn't too painful for her.' Just, you know. ”

care homes about their relative. The changes to care home visiting policies during the coronavirus pandemic, and the inability for families to see and talk to their relative themselves, placed an even greater emphasis on the need for good, regular and honest communication between the care home and families. Many respondents found this to be severely lacking.

“I think the home themselves could have done a little bit more, even if it was only once a week, to say, ‘Oh, this is how Mum is’, to prepare you a bit more.”

“I hadn't seen my father since the middle of March, until I saw him in the hospital. Apart from on one occasion on his birthday in July. I was very shocked when I saw him. I've got a lot of good things to say about the care home but also some things that where I think, particularly during this pandemic, that they could have handled better. I think communication with the family about resident's health and welfare could have been better. We were getting information about lovely things that were going on in the home but unless we were really proactive, we weren't getting information about the health and welfare of the resident. And that was why it was such a shock to me when I went to the hospital and saw my father there.”

Hospices

While only one respondent was able to feedback about their experience of end of life care within a hospice, several others had been supported by a hospice whilst caring for their relative at home (see section below on quality of care at home).

Comments about support from hospices were highly complementary. The positive role they played in supporting the dying

and their family within the community was clearly evident in the interviews.

“I can't fault the hospice at all in any way, shape, or form. Yeah. In the last few days, she was needing quite a lot of morphine and it was literally on demand. She'd only have to press her buzzer and they was there. There were offers of support all the time from all levels of the staff. I can't really think of anything that went amiss at all.”

Care at home

Caring for someone who is reaching the end of life at home can be incredibly comforting and rewarding, however, families rely on being well supported. This must encompass practical matters (such as having the correct equipment and medication available) and emotional support. Accessing and co-ordinating all of the support required can sometimes feel like a battle, leaving families tired and disheartened.

Six respondents had cared for their relative or friend at home. Four eventually died at home, while of the remaining two, one died in hospital and the other in a care home. Some of the challenges faced by these six respondents whilst caring for their relative at home included:

- Accessing specialist dementia support, particularly help with managing challenging behaviours
- Frequent changes of carers resulting in lack of continuity of care
- Not being able to access care when required (e.g. night sitting services) to allow family carers to have a break

“And over the last sort of year, he was incontinent at times. So, I would say - I

love my dad dearly, but he's a stubborn, old bugger, and he didn't want to think he needed anything. So, I scrolled the internet, and found what we called 'man pants' which were pants for men, but they were dark blue and man-like. And he put those on. He'd wear one of those at night. And I said to all the carers that came in, 'He wears these.' 'Well, we've got these. They're much better.' I said, 'No. They're nappies. You're not putting my dad in a nappy.' 'Oh, this is silly. He'll be absolutely fine.' I said, 'You're not doing it.' 'Well, those ones are difficult to put on.' I said, 'I don't care how difficult they are. They're just a pull-up pant. You're a carer. Surely.' And they huff and they puff, and they put one on. But this was every day. And I thought, 'My father should have some dignity for goodness' sake... the constant fighting with the NHS carers was a real drain. It was a constant fight to be able to get Dad the care he wanted. There was one day when the last carers came at six o'clock in the evening, and my son (who lived with my dad and provided care for him) was having a couple of days off. He basically hadn't had a full day off for two years. And all this was just too much. He couldn't cope. He needed to just get out. And I lived with my family and my disabled daughter, so I cannot just drop things. And Dad was left from six o'clock one evening until 10:00 AM the next morning. [Interviewer: They were aware your son was having some time off?] Yes. 'No, if you want any more care he has to go into a home.' Those are their exact words. I said, 'Thank you so much for your empathy.' And I just put the phone down. ”

Hospice Outreach support

Described by one respondent as the "catalyst for change", the hospice was invaluable in resolving issues for families

caring for their relative at home. Two respondents reflected that they could not have managed to care for their relative without the support of the hospice and that, without it, they would not have been able to fulfil their relatives wish to die at home.


“ So, I had a look round, and I found the hospice. And I spoke to a lovely lady there, explained the situation, and she said, 'I will sort something out. Don't panic. I will get someone round there tomorrow morning.' And about 10 o'clock on a Saturday morning, a district nurse arrived with a carer who was fantastic. Couldn't have faulted the lady. I said, 'Right', because he didn't get out of bed on Saturday morning. And they got a hospital bed in within four hours. I was completely gobsmacked... I could ring the hospice up at any time, and they rang me up to see how things were going. If it wasn't for the hospice, I couldn't have made it through. They were very good. ”

“ When the hospice nurses came in after she came home, they had a bed and commode there in an hour. They also arranged for ladies from a home care team to come in and a lovely lady came in and we sat and talked and laughed. We had a lovely meeting. The humour was there. There was care three times a day. It gave us a chance to chill, and they were brilliant... ”

Support from GP

When caring for someone at home, it is important that the relationship between family and GP is a supportive one. Unfortunately, several respondents felt let down by their GP, or GP practice, because:

- A GP would not attend the patient when requested



*“ The saddest part was we had to watch her **starve to death**. She couldn't eat or drink and the worst part was that she had to force food down, but it tasted awful because of the chemo, but **she would try to eat** but it would come back. ”*

- A GP had failed to diagnose significant health conditions, and this had delayed vital treatment
- A GP had not understood their relatives' medical conditions, which were clearly recorded in their medical notes

“ The other paramedic wanted to get him checked over by his GP. The GP didn't want to come out and the paramedic was quite angry, and he said 'We are the ones that are here, and we get this all the time.' The patients need to see the GP, but they just walk away from it. The GP must have been still there, because when he rang back five minutes later, he said that he thought my father-in-law had an infection and 'I think he just sent some antibiotics.'... We felt let down by the surgery and GP. For instance, we needed something, and I kept ringing them, and no answer! So

I went in there and they said I should ring them. I said I had rung them six times and can't get through. 'I need this because my father in law is dying.' The paramedics and the district nurses got up close and personal when changing dressings and seeing to him. The doctor clearly didn't want to come out and didn't go near him, but just said 'Is there anything else you want?' The surgery was just over the road, but were the only ones who weren't caring about the situation we were in. ”

One respondent, however, had a good relationship with her mother's GP, and felt able to contact her for support and advice at any time. She was grateful for the trust the GP had in her ability to care for her mother at home, and felt that the GP had helped to facilitate her in being able to carry out her mother's wish to die at home.

“ I had a really good relationship with the GP, Mum’s GP. She trusted me to look after Mum, I am forever grateful to her because she supported me and enabled me to look after Mum at home. I could phone her up and say ‘Look I’m thinking of doing this, what do you think?’, and she would say ‘Yes’ or ‘No’, or ‘Have you tried this, or thought of that?’ She just left... not just left me to it, but I knew she was at the end of the phone, and she was just wonderful. And when Mum died, I went to her and thanked her very much, and she said ‘I didn’t really do anything.’ And I said ‘Well, you were there, you were there for me.’ I know that GPs these days don’t generally do home visits anymore, but in Mum’s last week she did come and see her. ”

Hospital

Three respondents had relatives or friends who died in hospital and could therefore comment on the care provided. Four further respondents were also able to share their experiences of the care received in hospital in the weeks or months prior to their relative or friend’s death. In five cases, respondents felt that the care received in the hospital had shortened their relatives life because it was of such a low standard. They attributed this to:

- A lack of awareness and understanding of issues relating to dementia and learning disabilities
- A lack of assistance for patients with eating and drinking that had resulted in significant weight loss
- A lack of dignity and respect given to patients
- A lack of communication between health professionals

“ With that, he was taken to hospital. I explained he had dementia. I explained he gets very confused. He was taken into a cubicle before I arrived, then taken out the cubicle and put back in the corridor. Then, he was moved from the corridor into another cubicle where they were trying to take blood. And I said, ‘Look. It’s like getting blood out of stone. You just can’t get it. Do you have to have blood?’ ‘Well, we can’t get blood because he’s dehydrated.’ I said, ‘He’s not dehydrated.’ But no, they wouldn’t listen to anything I said. By then, I think it was five nurses plus doctors and two ultrasound machines to get blood out of my dad... He asked if he could get to the loo. I went to get a nurse. ‘I’ll be there in a minute.’ I said, ‘No. He really needs to go.’ ‘I’ll be there in a minute.’ And five minutes later, they came, and it was too late. I could go on, but it was ten hours from hell. And by the time Dad got out of that hospital, he didn’t know who he was or where he was. And he never really recovered from that. And with lockdown and everything else, he just didn’t want to be here anymore. ”

“ He was very easy to neglect. He would be very undemanding, and I couldn’t be there fighting his corner for him, which I have done his entire life. He had a fantastic life, and the one time we hand him over to someone else’s care, they fail him. ”

However, one relative was grateful for the quality time she had been able to spend with her father in hospital.

She had found the dementia care he received on a general ward to be exemplary.

“ It was a no-touch policy at the care home. I spoke to the ward’s sister, and she said, ‘You know you can come and see him.’ And I jumped at it, and I made



Case study - "Mr R"

Mr R had an accident in the home, and was taken to hospital with concussion.

*He was due to be discharged, but the care home would not take him back as **he had not been tested** for COVID-19. He ended up in hospital for 10 days, where discussion took place between the hospital and care home, as the care home was reluctant to take him back until special arrangements were made in writing to pay for his care.*

*He was then tested twice; both proved negative. During his hospital stay, **he lost 13lbs and was skeletal.***

Mrs R believes that, as he was not in a dementia ward, he was not helped to eat or drink, was not moved or washed, and his meals were just taken away from him, uneaten. He was eventually sent back into isolation in the home, where he was put onto end of life treatment. Wearing PPE, Mrs R and her daughter were allowed to see him, as he appeared to be dying.

*“ He’d had such **a traumatic experience** in the hospital, and I think he’d **given up**. He couldn’t face it any more every day, as he was not talking, not speaking, not eating... Just laying in a bed, because - by that time - he was laying in bed most of the time. ”*

“ Communication between the SALT (speech & language therapy) team and the ward staff was **appalling**. The SALT team deal with food and liquid intake, and they look at what the patient can have and the diet, depending on how they can swallow. The nursing staff could never get it right about what food she could have, despite it being written on the board above the bed. Once they found the level of food she could tolerate, she worked her way up from pureed to solid and chewable food.

“ It was the hostess trolley staff who took the orders for the morning, and often Mum was receiving personal care in the morning, so was unable to place an order. So, they were **picking food for her and making inappropriate decisions**, and not the food Mum like to eat... which she called ‘slop’. She needed to be encouraged to chew and swallow, as that was how the muscles would get stronger. **She then refused to eat.**

“ We got to the point that **I had to then take time off work**, prepare the food, and get on a bus with my mum’s food, and - in my wheelchair - get across the hospital, [while not being] allowed to heat it up in the microwave....We would talk to her main consultant about her needs and where we wanted to be, but when he went off, the other would ‘blow it out of the water’.

“ The care plan was to get her home in the middle of January, but not before Christmas, as she wouldn’t be able to go home on her feet with a walker. I arrived when the other consultant came in, and he looked at her notes, said she wasn’t making much progress, and the best thing would be to send her home. My response was ‘That will be interesting’. Mum lives in a little village (not even a shop), miles out of Ipswich. I pointed out the difficulties of arranging for care over Christmas... He said **‘I am a consultant and I think I know better than you...’**

“ When a meeting was held between the physio and this consultant before Christmas, the physio said she wasn’t happy for her to go home, and she shouldn’t be discharged. She pointed out that there was a plan already in place. **He changed her feeding routine**, and the consequence of that is she got **pneumonia**. There was a disagreement over liquids, and some of the liquid went into her lungs. She was put onto nil by mouth on Christmas Eve, and **that was really the end for her**. There was obviously a lack of communication. ”

an appointment because this is what you have to do. And she told me about PPE. And I said, 'Presumably, it's a no-touch policy.' And she said, 'My dear, if you want to hold his hand, nobody here is going to stop you,' which was lovely for me. And I was able to have time with my father that was more meaningful than either of my sisters' or my mother's were - they weren't able to come to the hospital. I went two consecutive days, and I was able to sit there, hold his hand, give him that physical comfort, and my sisters and my mother were never able to. So, it was the same person, with the same risk, in a medical environment, and yet there were different standards. It meant so much to me that I was able to do that. He actually kept saying to me - he'd very little language left, but he kept saying to me, 'That's lovely.' And he was calm. The staff were fabulous with him. I've got no criticism of the care he had in the hospital at all. They asked me to bring some photographs in, because I had got some photographs on my phone, and although he'd no language, he was awake when I saw him, particularly on the second day. And I was showing him and reminding him, showing him pictures of Mum in particular, and old ones. Their old wedding photos, that sort of thing, which I'd got on my phone. And he was responding to it. So, they asked me to take the photographs in, and I did a little folder, and I think the staff did sit with him and show him again, and I labelled them up into who they were. And I thought that was quite exceptional. ”

A further respondent spoke positively about the care her mother had received in hospital at the time of death, although she felt that improvements could be made if families were allocated a nominated member of staff for all enquiries.

“ The ward Mum died on were absolutely amazing and they moved her bed into the corner of a six-bedded side ward, and then, when they could, they moved the ward around so they could move her into a side room and I was allowed to stay with her (although I didn't actually give them a lot of choice). And they very kindly found me a reclining chair with blankets and pillows and provided me with tea or coffee and toast. So many beds moved to get her into a side room. They left us in the side room as Mum was dying, and because she was so very distressed they gave her medication, but it didn't work. So that distressed us, and we would have liked to have someone to say that was OK. They hovered outside and the door was shut, but when we opened the door to ask for more help, there seemed to be a crowd out there. Nobody wanted to ask the question and we didn't feel we could ask. The situation would be improved if there had been someone whose role it is that the family's needs are listened to and acted upon. I cannot stress how important communication is as on a public ward - everyone is very busy and you can't interrupt people in the middle of something else. There should be someone there in support of family and patient. Afterwards, it was bizarre we were told we could stay with Mum as long as possible, but nobody offered us the visitor's room or teas and coffees, although they had before. They didn't even tell us where the chapel was. We were actually given a bereavement leaflet about things like getting a death certificate, but no one offered us a quiet space or support. I left in tears and went on public transport. One nominated person should be given training on bereavement and end of life. ”

The application of COVID regulations within the hospital prevented families from being

able to spend quality time with their relative in two cases.

- In one case, although three members of the family had been spending time with their relative on the ward, when the patient was moved to a side room, for end of life care, only one member of the family was allowed to stay with them.
- In the other case, the family were informed by the hospital that their relative was being 'fast-tracked' into nursing care and they would be unable to visit him in hospital because of this (despite him being end of life). It took 10 days before he was discharged to the care home, during which time he had become non-communicative.

“People bereaved have the support they need to cope with trauma and loss.”

- SNEE ICS Higher Ambition

Support

Respondents were asked about the support they had been offered while caring for their relative at the end of life, and after their death.

At the point of interview, many of the respondents were still coming to terms with the loss of their relative. Many were still dealing with the practical issues that arise once someone has died (e.g. clearing rooms in care homes or social housing, chasing up death certificates, sorting loans and paperwork associated with the deceased) and had not had time to consider their own feelings of loss. Others were in the process of pursuing complaints with the care home, GP practice, or hospital.

On the whole, people said they felt they knew where to go if they wanted help, or they would “simply look it up on the internet.” Most people mentioned that they would turn to the hospices for advice.

Only two respondents had actually taken up the offer of bereavement counselling. One from the hospice and one from their workplace wellbeing service. Another person planned to take up a referral from her doctor.

In terms of support from within their own community, most respondents felt well supported by their family and friends.

One respondent, however, reflected that while she felt she could speak to her daughter about her grief, she also had to be mindful that the deceased person was her 'grandmother' and this meant she needed to be careful about how much she shared.

Other sources of support mentioned by respondents included:

- Macmillan Cancer Care
- John Le Vay Cancer Support and Information Centre
- Funeral directors or undertakers

- Hospital chaplain
- Suffolk Family Carers

“It was nobody’s fault, but it would have been nice if the home or the head office had sort of said ‘Do you want to talk to somebody about how you feel?’ I think that is what I have missed - being able to talk about my feelings and my fears. But I don’t think the home could have done much more. No, they couldn’t. But they couldn’t...I won’t see anybody now until, I don’t know, Wednesday or Thursday? Unless I go out, and then people have masks on. It’s a difficult time. It’s not normal with all the restrictions, but if I could go out and have a cup of coffee with someone and chat about it and get my feelings across... because you don’t know if how you feel is normal. When it happened, I was so in control of everything. And now, I think I was on automatic pilot. I said to my daughter ‘Should I be crying my eyes out? Should I be really really sad?’ but she said no, because for so long he wasn’t Dad anymore. And we had hoped he would go to sleep, but I feel guilty about my feelings. But at the time, I did cry at night on my own, but I could have a conversation as I am with you without bursting into tears. It just comes and goes. I do worry that I feel sometimes that I am suppressing it, but I am not because I think I did my crying a long, long time ago.”

Support from the hospice

“The hospice send letters every now and again that say if you need us you know where we are.”

“[They] offered support and said they were here if we wanted anything.”

To conclude, respondents were asked how they were feeling now. Some of their final reflections are presented below.

“So, obviously, he was on his own during lockdown, which we think finished him off really. He was still grieving for our Mum, and was getting more ill and more ill, and losing significant amounts of weight and not really feeding himself. And we think that’s where we feel we have missed out. Had we known it was end of life and had a plan in place in March, we could perhaps have cared for him.”

“If I hadn’t seen him, then the last time I would have seen him was when I waved him off to the hospital. My sister was not able to see him because she had arranged to see him the next day in the nursing home, but he died at 5am that morning. I have this raw wound in my heart about my mum, and it happened to my dad. I just hope it doesn’t happen to everyone. I just want it to be better for others. I just hope my experience will make it better for someone else.”

Impact of COVID-19

Although none of the respondent’s relatives had died directly from coronavirus, COVID-19 lockdown regulations had an impact on almost every experience shared with us. The effects were perhaps most obviously felt by those who were unable to visit their relative or friend in hospitals or care homes:

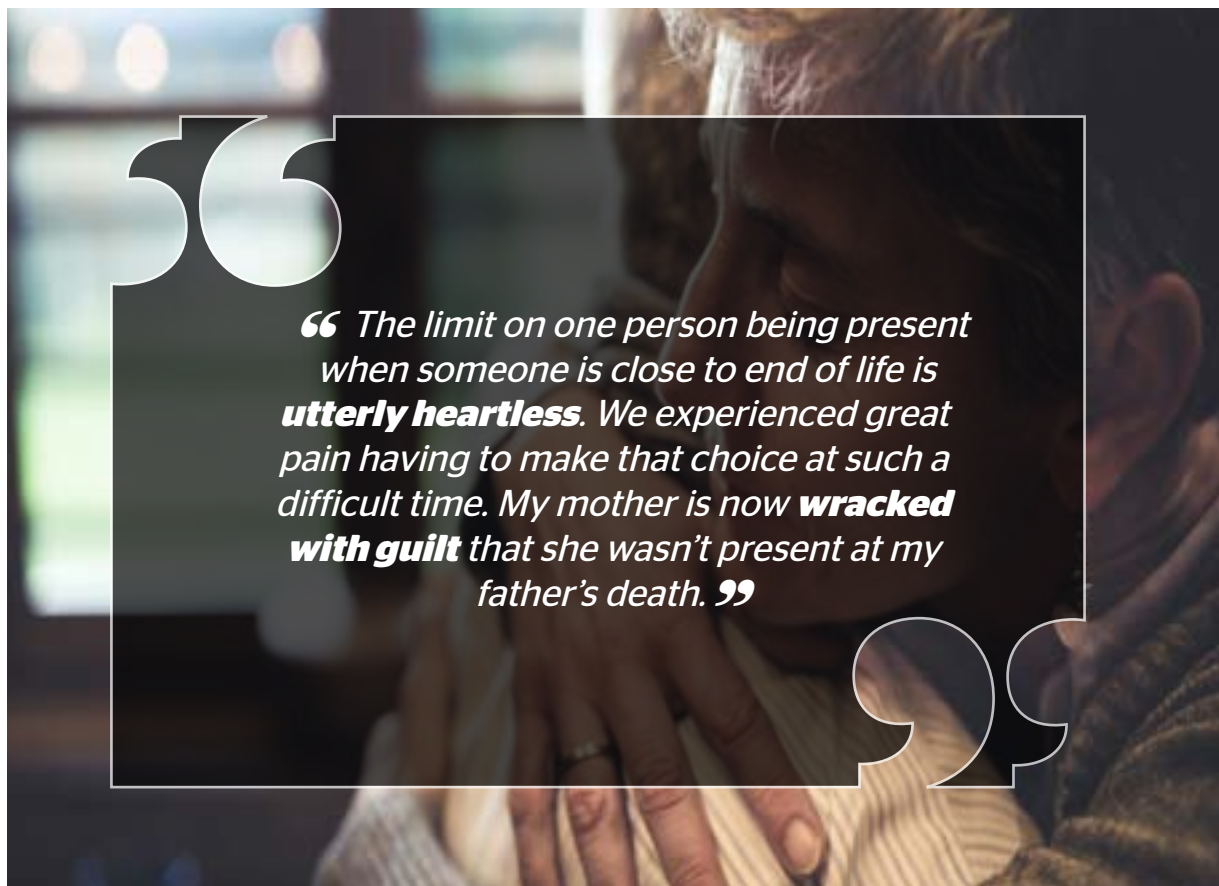
- Some felt that the lack of contact and social stimulation had accelerated the decline in their relative’s health and wellbeing.

- One respondent reflected on how the lockdown in her father's care home had impacted on her mother's wellbeing because it cut off her social life too.
- Some families felt that the homes did not do enough to keep them informed about their relative's health and wellbeing.
- One respondent reflected that the home had not been proactive in applying the 'exceptional circumstances' visiting policy once her father had been recognised as 'end of life' and that the family had needed to push for this to happen.

“One of the very good things about my father's care home, they included (my mother) in their family if you like. And two days a week, prior to the pandemic, she was spending at the

home with him, and they treated her just like another resident. She was part of the family. So she had lunch there, she took part in any activities, and she was with him for those two days. And it was her social life as well. And of course, with the pandemic, she's lost that.”

“From late August, you were only allowed to go on a Tuesday or a Friday, and if you didn't get a slot booked, you didn't get in. It was only from-- I think it was about 11 o'clock to three o'clock. And of course, if you have anybody who's working, they are stuffed completely. So it was quite restrictive, and I understood and appreciated the COVID regulations. But I felt pushed out in a way, it's my honest reaction, a little bit pushed out. And I was her daughter. [Interviewer: Did the home make allowances for the fact that she was end of life and to enable you to spend more time with your



Mum?] No. I mean, with COVID, I know it's there. I know we've got to be vigilant and very careful. But I think there's a time when you've got to be a little bit more relaxed, and help the people that are suffering outside. ”

For some, COVID-19 had affected the support they were able to access in the community. This affected both specialist services (e.g. mental health assessments and community heart failure teams), more generic services provided by their GP and bereavement services. This caused enormous frustration for families and, in some cases, had led to a delay in patients receiving vital medical treatment.

“ We felt let down by the surgery and GP. For instance, we needed something, and I kept ringing them. And no answer. So, I went in there and they said I should ring them. I said I had rung them 'six times and can't get through. I need this because my father-in-law is dying.' The paramedics and the district nurses got up close and personal when changing dressings and seeing to him. The doctor clearly didn't want to come out and didn't go near him, but just said 'Is there anything else you want?' ”

Others had felt the impact of the limitations placed on funeral gatherings and reflected on the added stress this had placed on the bereaved who were left to choose who could attend.

“ It was a nightmare because they changed the restrictions after we'd started making the arrangements. It was 30 at the funeral and 30 at a wake. And then, a week before the funeral... the restrictions were changed to 15 at the wake, so we had to uninvite people. So my mother had to choose which members of the family wouldn't be able to come to the wake. They were still able

to come to the funeral. It's heartbreaking. It's all been absolutely heartbreaking. ”

The impact of the coronavirus lockdown(s) on the emotional wellbeing of our communities should not be underestimated. This has been particularly hard for those who have experienced a bereavement during the pandemic. Respondents expressed feelings of guilt about letting their relative down, deep sadness that they had missed out on time spent with their loved one, anger that they were unable to provide the care they would have liked, and loneliness at not being able to access the support of friends.

“ [In the home] it was a no-touch policy. So, my mother couldn't hold his hand. But actually, it's tragic, it really is. I mean, my parents had their 70th wedding anniversary in July. They weren't able to be together. And my mother, she's still got all her faculties, all right? She's physically very, very frail. But the impact that this has had on her has been enormous. It's massive, and I do think that the emotional impact of the end of his life and - she's just so sad that she hasn't been able to be with him during his decline, and I'm sure that that emotional impact is part of the reason she's gone downhill so suddenly. I'm sure it is. And there's also a great deal of guilt there that she hasn't been able to be there with him. She feels she's let him down. ”

“ There is a lot of anger there around that, and a lot of guilt, as you couldn't provide the care you wanted to. But we all feel it was inevitable. It was going to happen. because he was so heartbroken about Mum, he had just given up. Mum was just 70, and Dad 72, and we had expected to have Dad for at least another 10 years and lockdown was the last thing for him. ”

5. Ensuring equality of access

In 2016, in response to an independent review of choice in end of life care, the government made a commitment to making sure everyone has access to the right end of life care, regardless of geography, age, diagnosis, background or means. However, a report by Macmillan in December 2017, entitled *Final Injustice Variation in end of life care in England* highlighted the continued variations and inequality of access to end of life care for some communities.

Evidence from national research indicates that people from Black, Asian and other ethnic minority communities access palliative services less delay access for longer than other patients, are more likely to die in hospital, and are more likely to receive more intensive treatments at the end of life. (Calanzani N, Koffman J and Higginson I. *Palliative and end of life care for BAME groups in the UK*. King's College London: Cecily Saunders Institute; 2013). Despite this evidence, little is known on a population-wide level about the experiences and satisfaction of end of life care amongst patients and families from ethnic minority communities.

The disproportionate impact that COVID-19 has had on people from ethnic minority communities has further amplified the need to listen to and learn from their experiences, and to help improve end of life care provision both in the event of a further spike in COVID-19 cases and for future service planning.

Methodology

Experience from national surveys, such as the National Bereavement Survey (VOICES), has shown that the proportion of people

from ethnic minority groups responding to surveys about end of life care is low. In 2015, only 2.4% of those responding to the VOICES survey were from an ethnic minority group.

To address this issue within the project, local VCSE groups working with ethnic minority communities were asked to help promote the Healthwatch Suffolk survey and support individuals to participate (an extract from the service specification is given below).

“ We are seeking organisations who will:

- **Actively promote the end of life survey amongst their community group.**
- **Encourage individuals to complete the online survey, and where necessary support them to do this e.g. if an individual is not able to access the online survey themselves or they need assistance with translating the questionnaire.**
- **Identify individuals to take part in an interview and where necessary to support those individuals during the interview e.g. through the provision of translation.**
- **See the importance of this project and value the benefits it could bring to their community groups.**

We are looking for a minimum of 15 people, from a Black Asian and other minority ethnic communities, to complete the online survey and at least five people to take part in a telephone interview. We are looking for organisations to commit three days of engagement activity to this project. ”

Healthwatch Suffolk asked the commissioner of the project to make funding available, from the SNEE ICS, to recompense organisations and community groups for their time and effort in supporting this project.

VCSE groups were able to apply for funding by submitting a brief 'expression of interest' application. An evaluation panel was established to review and award the applications for funding. In the event, only one organisation applied, and was sadly unable to receive funding because their legal status as a community interest company was not registered at the time.

It was decided that repeating the same offer would not achieve any different response, and therefore in early 2021, a different approach was adopted. Instead of requiring formal expressions of interest for funding, a more informal approach was taken. VCSE groups and interfaith groups were asked to continue to promote the project and to actively encourage discussion amongst their members.

Where possible, they were asked to link a member of the research team into these discussions, otherwise they were asked to provide informal feedback on the issues raised. VCSEs were offered funding to cover any expenses they incurred in supporting the project.

As a result of this activity, one individual came forward for interview. While her experience dated back to March 2019 (outside of the original timescales set for this project and well before the impacts of COVID-19), her feedback highlights some important themes, many of which mirror the issues raised at the #WhatAreWeMissing end of life workshop event (see on page 60).

Visiting restrictions within hospitals

“So on the day, it was a case of my dad clearly did not want to go to hospital. It was easier for the whole family. And to be honest, if he had gone to hospital, none of the grandchildren or my grandbaby would've been able to see him.”

“I think people dealt with my dad's death better than my mum's.... So, she was living in Barbados, but she died in England on a visit and she was put straight in hospital where nobody could see her.”

“We kind of had a room full of people saying goodbye, and I think that's what helped everybody deal with it. Because like I said, the minute people go to hospital, that's when all the barriers come up. You can't see. You can't visit. You can only have one person. I think that's another reason why lots of people don't want to include the NHS.”

Importance of family

“We just called everybody. My brother called every child whether they were in London, wherever. My son was in college, and I told him, 'When you come out of college, get your friends straight to your grandad's house.' We had the whole family.”

“We had the family take turns, so we said to grandchildren, 'Go in there. Go say your prayers. Go cry. Just get it off your chest.”

#WAWM End of Life Workshop

In May 2020, a community-led initiative (#WhatAreWeMissing) brought Suffolk's faith representatives and people from Black, Asian, and other minority ethnic groups together with senior leaders from the NHS, council, and voluntary sectors, to talk about their experiences and to discuss the issue of inequalities and injustices within health and social care.

Following this initial event, further workshops have taken place, including one about end of life in April 2021. Feedback from this end of life workshop highlighted the following issues:

What does “good” look like in end of life services?

Community expectations of what is a good service may differ significantly to what commissioners and service providers think is a good service. There is often talk about under-representation of ethnic minorities accessing end of life services, however, people may not engage if they do not recognise the service offer as “good” from their perspective.

Trust that services can deliver what they promise

The My Care Wishes folder speaks of personalised care but do the staff within hospitals, hospices, or care homes really understand people's cultural, religious, and spiritual needs e.g. what food they are able to eat, when and how they should pray etc.? This is especially important when the patient has dementia or memory loss, which means they are unable to provide guidance and prompts themselves.

Some families derive satisfaction and blessings from supporting their relatives at end of life

They do not want to or feel that they can delegate this responsibility to others. Some individuals expressed the honour they felt at being present as their relative took their last breath. It is not necessarily that services do not do enough, it is simply that the family want to provide that care themselves.

Can people grieve in ways that fit with their culture?

Communities express grief in many different ways e.g. through dance, song or loud crying. How is this perceived or accommodated in a hospital, hospice, or care home setting?

Importance of family

Limitation on visitor numbers, particularly in hospitals and hospices, can present difficulties for people who are dying and simply want to have their family around them. Examples were given of pastors being made to feel unwelcome in the hospital because they increased the number of visitors at the patient's bedside. Recognition needs to be given of a pastor's role in administering last rites, and the importance of personal touch at these times.

Fear of not being looked after as well in hospital, particularly at night

At home, the family can ensure someone is available 24/7, but this cannot be guaranteed or accommodated within a hospital setting.

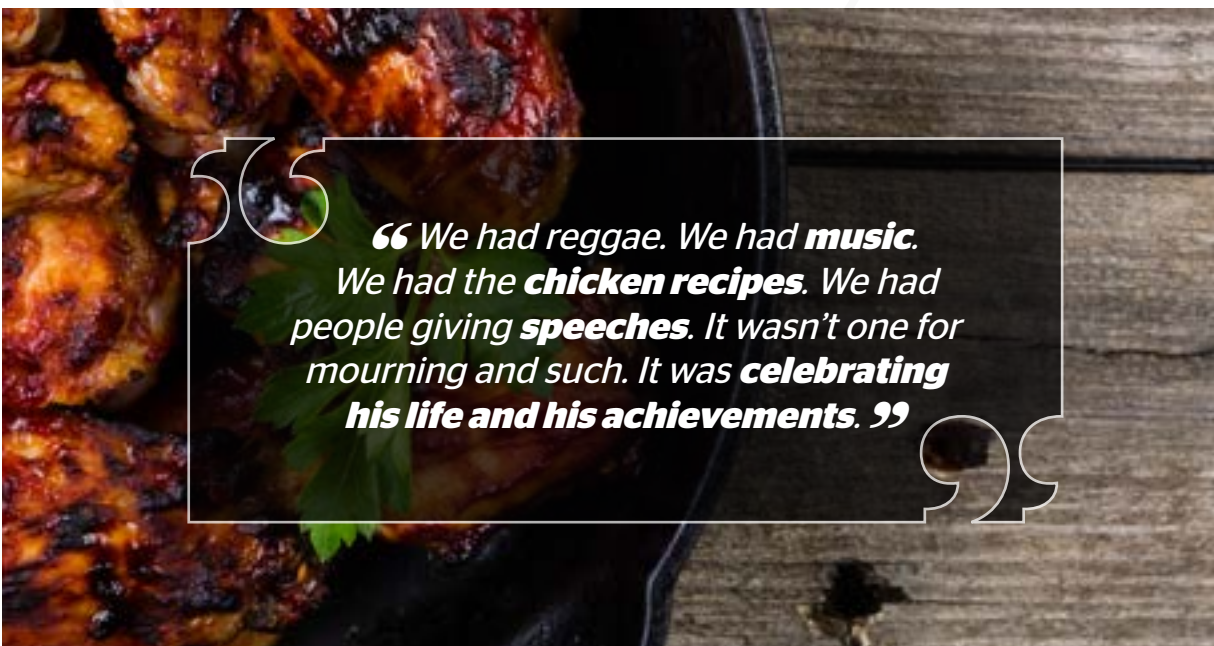
Supporting or caring for the dying

“ I cleaned him up. I picked him up off the floor. I said, ‘Look, this is my way of grieving by taking part.’ So [the paramedics] helped me pick my dad up off the floor, put him on the bed, and I tidied him up so the family could come in.... they put him on a stretcher. I asked if I could cover him, put him in the body bag. So, I helped put him in the body bag. They had that lovely burgundy-type velvet robe - like a big blanket, they cover the body bag with. I asked if they would let me put that on, so I covered him. [Interviewer: It sounds like the ambulance people allowed you to do what you needed to do?]. Yeah. Well, I just said, ‘Look. This is my way. I’m the one that deals with everything.’ I’m the organiser of the family, right? And I just dealt with it. And I knew that was part of my grieving process. ”

Attitudes to grief or funerals

“ [We had hundreds of people at the funeral] We had people fly in from Barbados, America, Canada. We don’t do this one-hour ceremony and just have a cup of tea. The polite, British way. We had reggae. We had music. We had the chicken recipes. We had people giving speeches. It wasn’t one for mourning and such. It was celebrating his life and his achievements. ”

While we recognise that minority ethnic communities are not homogenous, (everyone is an individual regardless of what community they belong to) and that person-centred care is essential, there is clearly further work to do in understanding the end of life experiences of people from ethnic minority communities - what are the needs of those who are dying, what support would families welcome, what does a “good” end of life service look and feel like? Involving community leaders and VCSE organisations in shaping this work from the outset is vital to gaining trust and engagement from members of these communities.



6. Summary and conclusions

The aim of this project has been to help support local services and commissioners in achieving the SNEE ICS ambition for “everyone in Suffolk and North East Essex to have flexibility, choice and control over their care, and support for those closest to them, at the end of their life”.

The aim has been to assist the three alliance areas (Ipswich and East Suffolk, West Suffolk and North East Essex) in the future design and delivery of end of life services by listening to, and learning from, people’s experiences. This research has sought to find out what has worked, what could be improved and understand more about the impact that the COVID-19 pandemic has had on people’s access to care and support at such a critical time.

Using a dual method approach to data collection (online survey and semi-structured interviews) supported with a programme of promotional activity, Healthwatch Suffolk has collected experiences from 138 survey respondents and 14 interviews.

Around three quarters of the survey responses, and all of the interviews, related to someone who died within the SNEE ICS area. Experiences of deaths that had occurred outside of the SNEE ICS patch have been included within the survey results because they still offer valuable learning opportunities, regardless of where the death had occurred.

Preparing and planning for end of life

The process of preparing for the end of life can be complex. The need for clear

and honest communication, between everyone concerned (e.g. the individual, their family, their health professionals and their carers) at every step, is vital to avoid misunderstanding and unnecessary distress. For some the process starts at the point when significant and life limiting health conditions are diagnosed. Others may only become aware when an end of life prognosis is given.

Whatever the circumstances, people appreciate having the chance to discuss treatment and care options to help them to prepare for death. Through these discussions, patients, family members, and health and care professionals can develop a plan that reflects what is important to them. Ultimately, this plan can, and must, be used to shape the way in which end of life care is delivered when the appropriate time arises.

Whilst survey respondents were generally positive about the way in which they and their relative had been given an end of life prognosis (89% agreed their relative had been told in a timely, sensitive and caring manner, and 92% reported they had been informed sensitively), around 10% of respondents were not satisfied.

Feedback from the interviews also highlighted the variable experiences people had of receiving an end of life prognosis. The main concerns, for those who were not happy, were:

- That information was not communicated clearly enough
- That the information was not given in a sensitive and caring manner
- That the patient was not offered support when being given the news

Planning

It was evident from the interviews that people viewed the concept of planning for end of life in different ways. For some, it was a promise to care for their relative at home. For others, it was about knowing where someone wanted to be buried or processing legal aspects of care (e.g. arranging power of attorney, knowing who the executor of a will was, or understanding whether a DNAR had been signed).

Only six of the 14 interview respondents were aware that their relative had created a 'formal' plan in a format that could be shared with others. Findings from the survey showed that only 47 respondents were aware that their relative or friend had told someone about their preferences for end of life care. Twenty-eight had registered with My Care Wishes or My Care Choices, and the remainder had simply told a health professional or a family member. The survey results revealed that:

- Those who died at home were more likely to have shared their care preferences with someone else
- Amongst those who died in a hospice, around a third (35%) of people had made their end of life care wishes known to someone else
- Only a quarter of people who died in a care home had made their end of life care preferences known
- Those who died in hospital were least likely to have discussed their end of life care preferences with someone else

The analysis of the care quality statements within the survey revealed:

- Those who had registered with My Care Wishes or My Care Choices were

more likely to say that their friend or relative had their faith and cultural wishes understood and supported, had preferences that were taken into account, were asked what was important to them, and were given adequate emotional support

- Those whose friend or relative had told a professional of their wishes were more likely to say they had received help with symptom management 'all of the time', that they were involved in decisions 'all of the time' and that they were treated with dignity and respect 'all of the time'
- Those whose friend or relative had shared their care preferences with a family member scored lowest on all of the statements, with the exception of 'being involved in decisions as much as they would have wanted'

These findings not only highlight the ongoing need to encourage those who are dying to have open conversations about their care wishes as early as possible, but they also serve as a reminder about the importance of sharing end of life plans as broadly as possible. This is so that everyone involved in the provision of care and support understands what is important to the patient.

Knowing what to expect

Survey respondents, and those who took part in an interview, indicated that families felt there was a lack of information about what to expect at the end of life. Respondents felt they would have been better prepared to deal with the practical and emotional aspects of seeing their loved one die if they had been better informed. Specific issues mentioned included:

- Terminal agitation

- Changes in body temperatures
- Changes in skin colour
- Symptoms of systems closing down or organ failure

Issues around the provision of food and drink at the end of life were raised by three respondents. The emotional trauma of watching her mother “starve to death” over the course of a fortnight was described by one respondent as “horrific”. More information is required to help relatives understand what options are available to support them both practically and emotionally in these situations.

Quality of care

The findings from the survey are helpful in providing an overall indication of quality of care at the end of life, and the interviews provided more detail about different care settings.

The survey results indicated that respondents were generally quite positive about the quality of the care their relative had received, both in the last few months of life and in the last few days or hours of life. Respondents were more likely to say the practical or visible aspects of care (such as pain medication and being made comfortable) occurred ‘all of the time’, compared to the more subjective or emotive issues (such as being provided with enough emotional support). The analysis of the care quality statements by where death occurred revealed that:

- Those whose relative died in a care home rated ‘awareness of cultural or faith wishes’, ‘being asked what was important’ and ‘being involved in decisions’ as least likely to occur ‘all of the time’

- Those whose relative or friend died in a hospice were most likely to say they were asked about their preferences, what was important to them and were involved in decisions compared to those who died in other settings

- Those whose relative or friend died in a hospital were least likely to say each aspect of care had occurred ‘all of the time’

The interview respondents were able to provide more detail about the different care settings that had been involved in the care and support of their friend or relative. Their feedback was as follows:

Care homes

Respondents had variable experiences of care within care homes. Some had found the care to be good, particularly in the last few hours or days of life when staff would go the extra mile to ensure the resident was made as comfortable as possible and relatives were accommodated and supported. There were, however, examples where care was less than satisfactory and one case where a safeguarding concern had been raised due to issues of neglect. One of the main areas of criticism about care homes was the lack of communication with relatives, and while this was particularly important during the lockdown, it was not an issue that was exclusive to the pandemic.

Hospices

Comments about the care provided by the hospices, both within the hospice itself and in the community, were highly complimentary. For those caring for a relative in the community, the hospice was often seen as a catalyst to unlock access to much needed support.

At home

The predominant message arising from the feedback from those who were caring for a relative at home, was that people felt they had fought constant battles to get the help or support they needed.

Accessing hospice services within the community often resulted in the unlocking of support that families desperately required. Two of the respondents felt that, without the support of the hospice, they would not have been able to fulfil their relatives wish to die at home. Some of the challenges people faced when caring for a relative at home were:

- Accessing specialist dementia support, particularly help with managing challenging behaviours
- Frequent changes of carers resulting in lack of continuity of care
- Not being able to access care when required e.g. night sitting services or to allow family carers to have a break
- Lack of support from GPs

Care in hospitals

Whilst respondents experiences of care in hospitals was variable, most people expressed dissatisfaction about how their relative had been looked after, with some people expressing the view that poor standards had actually shortened their relative's life. These concerns included:

- Staff lacking awareness and understanding of issues relating to dementia and learning disabilities
- A lack of assistance for patients with eating and drinking, resulting in significant weight loss and dehydration

- A lack of dignity and respect given to patients
- A lack of communication between health and care professionals (e.g communication between hospitals and care homes regarding the health of the patient)
- Insufficient staff capacity on wards to cope with the needs of the dying in a caring and supportive way

Summary

The experiences reveal that there is a considerable amount of variation in the quality of care provided at end of life across the sector. There is therefore a need to review how this might be addressed to ensure that people feel well supported, in a compassionate way, irrespective of where they, or their friend or relative dies. This is particularly important for those whose death might occur in a place they had not expected.

Providing opportunities for continuous reflective learning about death amongst staff delivering end of life care and support (whether in a hospital, hospice, care home or community), may help to address some of the issues raised by participants.

Communication and joint working

One of the key issues that arose from both the survey comments and the interviews was the lack of joint working and communication across the health and care sector. At best, this had frustrated families, and, at worst, this had led to delays in accessing vital treatment and support at critical moments. For some, these issues were exasperated when there was a lack of clarity over who, or which service, was responsible for the delivery of care (or decision making) at specific moments.

“Where several departments were involved, there was often conflicting information.”

“Unfortunately, although good elements of care, no one took ownership of the matter. GP said hospice was dealing. Hospice said GP. District nurse was too busy and so the cycle went on.”

“Did it feel like everyone was working together to support you and your relative or friend. Not at all.”

Unnecessary medical treatment

While the majority of respondents were satisfied that their relative had only received treatment that was necessary at the end of life, 20 survey respondents felt their relative had been given unnecessary medical treatment in the last year of life, and a further nine respondents said their relative had unnecessary treatment in the last few hours or days of life. Unfortunately, survey respondents did not provide details about the types of treatment that were being administered.

Support for families

Only around 50% of survey respondents agreed they had access to all of the support they needed, both at the time of death and in the last year or months prior to death. The hospices were the most frequently mentioned sources of support, regardless of where the person had died. This demonstrates the benefits of the outreach support that the hospices provide across the SNEE ICS area.

When asked what support they would have liked, respondents mentioned:

- More support from GPs

- Better explanation or more information on what to expect at end of life
- Access to specialist support
- Better joined up working across the system
- Access to out of hours or night sit services

Only 37% of survey respondents said they had been offered bereavement counselling. The majority of those who had been offered support did not feel that they needed it at the moment, though they might in the future. This mirrored the attitudes expressed by the interview respondents, many of whom were still too busy with the practical tasks associated with the death of a friend or relative (e.g. sorting belongings, dealing with admin etc.) to have had time to consider their own feelings and sense of loss.

While many people felt that they would know where to find support should they need it, some respondents were struggling to process their sense of grief. For many, the impact of the COVID-19 restrictions added further pressure on their emotional wellbeing. Respondents expressed:

- Anger at having missed quality time with their loved ones due to the lockdown
- Guilt at having let their relative down when they needed them most
- Loneliness and isolation from their social networks



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7. Recommendations

The following series of recommendations has been determined from analysis of the things people said could have been better about end of life care and support in Suffolk and north east Essex.

They have been co-created with SNEE ICS health and care system leaders to ensure that they can be implemented and used to shape the future of support across the footprint. The term 'families' is used to mean a person close to a patient and may include friend.

1. Communicate clearly - make sure people have understood what they have been told.

When giving an end of life prognosis, health professionals should ensure that patients, and their families, have understood what they are being told, are given time (in the moment or at a later date) to ask or clarify any questions, and are provided with appropriate support or given information about how to access support or more information.

2. Compassion and understanding are important to people - think about communication style.

Some people felt that the language professionals used was too clinical, lacked compassion, or had been inappropriate. Services must ensure that all professionals, who may have contact with someone experiencing a loss, understand the need to always communicate with people in a compassionate manner to prevent unnecessary distress. This message must

be repeated regularly within services that have a high turnover of staff.

3. Offer the choice to be supported at key moments.

Patients should be able to choose whether they would like to have a family member, friend or trained professional available to support them when being given a diagnosis of terminal illness or an end of life prognosis. People must be made aware that this is an option available to them, or have their preference noted as part of a care plan, in advance.

4. The system must continue to encourage community conversations about death and dying.

Patients and their families should be encouraged to have conversations about end of life wishes as early as possible (i.e. not just when an end of life prognosis is given). There is an opportunity to build upon much of the excellent work by local hospices to encourage community conversations and for this work to be supported fully by the wider health and care system.

5. Give people access to the tools they need to prepare for death, or the death of someone close to them.

People should have ready access to information and tools to help them

prepare and plan for death and grief. This information should be reviewed regularly and co-produced with people that have experienced a loss.

6. Make it easier to share and access end of life preferences.

Mechanisms should be made available to allow people to record and share their end of life preferences in an easily accessible format.

People should be made aware of the benefits of sharing their wishes as widely as possible.

7. Co-produce information for patients and families about what to expect when a person is dying.

Patients and families should have access to more information about what to expect when a person is dying. Such information should be consistent across the SNEE system to ensure that everyone has access to the same standard of materials (with local variation about services or support where necessary).

This information should be co-produced with people who are facing death or have been bereaved because that is the best way to ensure the information is reflective of things people would have valued as a part of their experiences.

8. Make sure people know what to expect when supporting someone who is dying at home, including what services are

available and when to access them.

Families should have access to more information about what to expect when caring for a dying relative at home (both physical or digital copy information) and as a part of conversations with professionals. This must include information about what support services are available, when they could be accessed and who to contact. Encouraging families to engage with services early, rather than waiting until a crisis occurs, may ensure that the right support is available when needed and will help to reduce the numbers of inappropriate hospital or hospice admissions that result from carer breakdown or fatigue.

Information should be co-produced with people that have recently cared for a dying relative at home and also hospital or hospice staff with an understanding about how the care and support 'system' works. This information must be marked for review regularly to ensure it is kept up-to-date.

9. Consider the opportunities new digital innovations bring for information sharing with patients and families.

The SNEE system should consider the opportunity that new digital tools and innovations (e.g. care planning apps and websites) bring to sharing information and signposting with those who are dying and their families. This includes how they can raise a concern about their care, feedback directly or independently for continuous service development and how they can find information (e.g. what to expect if caring for someone at home and who to contact and when etc.).

Please note, services are required in law to provide information, and to communicate with people, in a fully accessible format (see the NHS Accessible Information Standard). Information and digital tools should be tested and co-produced with users and carers. Developers, commissioners and providers of new digital tools should also refer to Healthwatch Suffolk's Guiding principles for health and social care providers and commissioners planning or delivering digital care in Suffolk and north east Essex (available from www.healthwatchsuffolk.co.uk/digitalhealthandcare). The document aims to ensure local services are accessible to all who need them now and in the future.

10. Make sure all professionals can access the information they need about patients with specific long-term conditions.

All documentation relating to patients living with dementia, or a physical or mental issue, should be held centrally so that patients can be immediately identified if they enter hospital or any other form of care. Specially trained professionals should ensure that any treatment they are given is appropriate and that relatives are consulted and informed at all points of treatment in line with their wishes.

11. Consider how information sharing and communication between professionals can be improved at all levels.

While communication, in general, needs to be improved, the communication between services needs particular attention (e.g.

between staff in hospital, care homes, surgeries and patients and their families), there are specific issues concerning the storing and sharing of information for patients who are near death. Thinking in terms of levels of information will help to determine who needs what type of information, and how it will be accessed. For example, emergency services and out of hours services will need access to one level of information, some professionals may need access to summary information only, whilst those involved in end of life care will need access to more detailed care plans and end of life preferences.

12. Be clear about who, or which services, are responsible for the delivery of care and decision making. Don't let families be passed between services.

There needs to be greater clarity about roles, responsibilities and appropriate referral processes amongst professionals and services working with patients who are dying. This includes better communication with patients and carers about which services and contacts are responsible for different aspects of end of life care provision.

There should be better communication and joint working across the sector to ensure patients and their families receive a cohesive response, rather than the fragmented response they currently receive. Where possible, services should seek to take responsibility for a person's care to avoid unnecessary delays in treatment and people being passed between services. If there is a disagreement between services about a particular aspect of care, professionals should work together to find a clear way forward.

13. Ensure information about support is available to all, even if they may not benefit from formal therapeutic intervention at the time of death.

Grief comes in many different forms and affects people in different ways. For those who require formal therapeutic intervention, following the death of a relative or friend, there should be better information, signposting and access to support. GPs have a key role in identifying those who require specialist support and helping them gain access to the help they need.

Many people will not require such formal interventions, but will value having easy access to information about normal responses to grief and support online if needed and having this made available to them.

14. Help people to talk about grief within families and communities.

Not everyone, however, will require formal grief or bereavement counselling but would benefit from the informal support of friends or relatives and others within their local communities. People should be encouraged to talk openly and honestly about death, bereavement and grief without feeling awkward. Again, there is an opportunity to build upon the recent work of the local hospices in encouraging compassionate conversations.

15. Encourage continuous reflective learning for all professionals delivering end

of life care through formal and informal support systems.

The coronavirus pandemic has seen services develop new ways of working and supporting staff who have experienced difficult circumstances at work (e.g. loss of life during the pandemic). This includes opportunities to de-brief or reflect with other professionals in their environment. Services must ensure that this learning from the pandemic is not lost by continuing to find opportunities (both formal and informal) for continuous reflective learning about deaths and dying amongst all staff working in primary care, hospitals, hospices and care homes.

Reflective learning can often be more effective in improving quality of care than simply offering training courses where skill fade can be high. Furthermore, staff who feel supported are better able to do their jobs effectively. Staff across the whole care sector should therefore be supported and encouraged to reflect on their practice in relation to end of life care. This could be done both formally (e.g. through individual or team debriefings after a death has occurred) and through informal opportunities to discuss issues with colleagues. This might be as simple as encouraging people to reach out and to have conversations with each other or making it a part of a themed conversation within team meetings or learning environments.

16. Ensure a continued review of people's experiences using this report as a baseline of experiences.

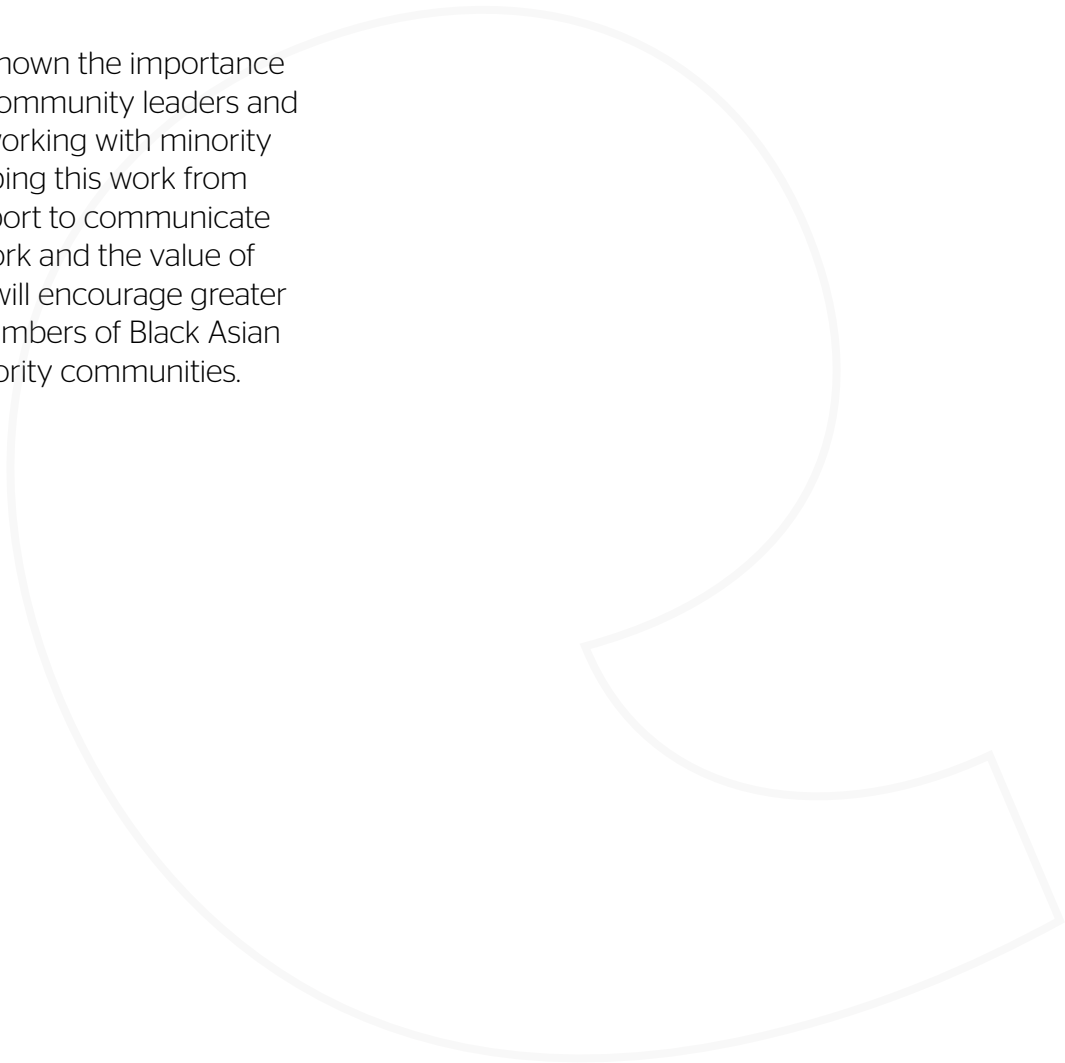
A continuous review of people's experiences of end of life support should

be implemented to check whether the above recommendations have been realised and whether people's experiences are improving post the impact of the coronavirus pandemic.

17. Undertake further work with Black Asian and other Ethnic Minority groups.

Building on work already started within the SNEE ICS area around inequalities (e.g. #WhatAreWeMissing and initiatives around the COVID-19 vaccination programme), further work needs to be undertaken to understand the end of life experiences of people from Black Asian and other Ethnic Minority groups.

Our experience has shown the importance of directly involving community leaders and VCSE organisations working with minority ethnic groups, in shaping this work from the outset. Their support to communicate the benefits of this work and the value of sharing experiences will encourage greater participation from members of Black Asian and other ethnic minority communities.



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