End-of-life care in Cornwall: Perceptions and experience

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Healthwatch Cornwall commissioned a piece of independent research with local people.

This research supports the End of Life Strategy Board's work towards Priority One in the work plan by building a picture of public understanding and experience of end of life, as well as preferences for support.







665 people in Cornwall

Recruitment took place online through a local panel, social media, and Healthwatch's own promotional channels in April 2018

9 (1%) with a terminal illness
385 (58%) with a family member with a terminal illness
285 (43%) carers of someone with a terminal illness
361 (54%) supporters of someone with a terminal illness
205 (31%) people who had experienced a recent bereavement

159 (25%) people with no experience of bereavement or terminal illness

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This presentation covers four different groups of people

The public

Terminal illness

All people who took part in the survey (including those with terminal illness and bereavement experience) People with a terminal diagnosis and family of people who have had a terminal diagnosis

Carers and supporters

People who consider themselves a carer (paid or unpaid) or a 'supporter'

Bereaved

People who have experienced a bereavement in their immediate family in the last two years

Section 1: Perceptions of endof-life care Section 2: Experience of terminal illness and end of life care Section 3: Experience of caring and supporting those with terminal illness Section 4: Experience of bereavement



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1. Perceptions of end-of-life care





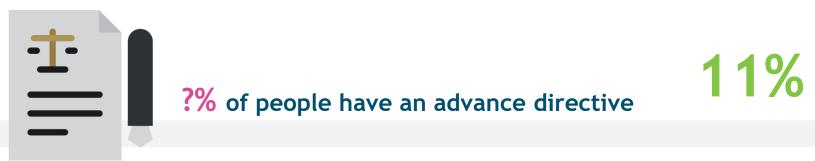


?% of people have spoken to their family and friends about their preferences for end-of-life care

4% ?% of people have an end-of-life care plan



41%



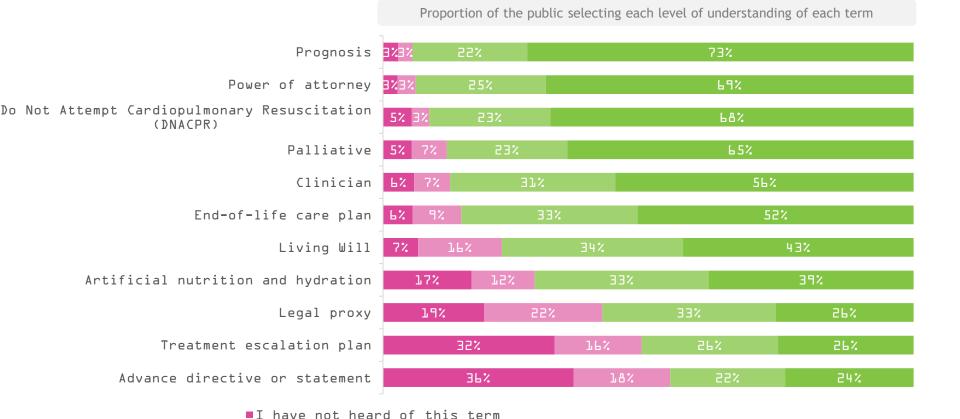


Do you have an Advance Directive? Have you ever spoken to your family and friends about your preferences for your end-of-life care? Do you have an end-of-life care plan? Base: **665** (all participants)



The public

Understanding of many of the terms used in EOL care varies: particularly low for technical terms



I have heard of this term but do not know what it means

I have heard this term and have a general idea of what it means

We would like you to think about how well you understand some of the words and terms that are used in end-of-life care. Base: 665

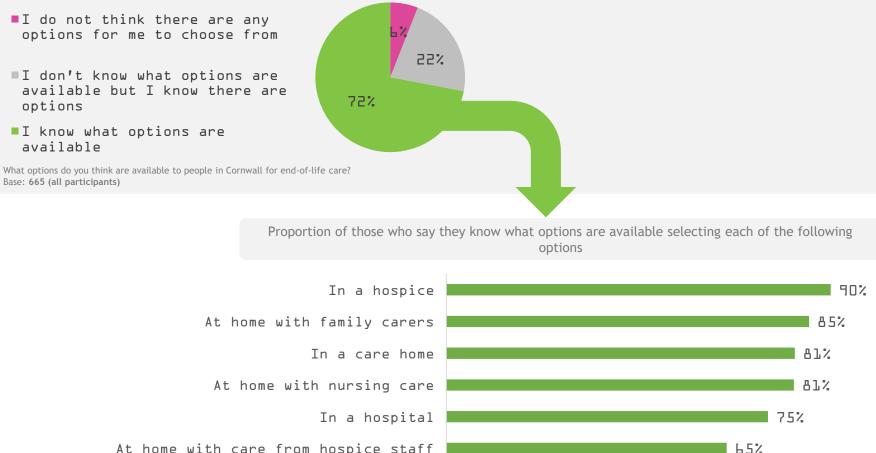
I have heard this term and have a good understanding of what it means

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(all participants)

Most of the public know there are options available to choose from...

Proportion of the public with knowledge of end of life care options



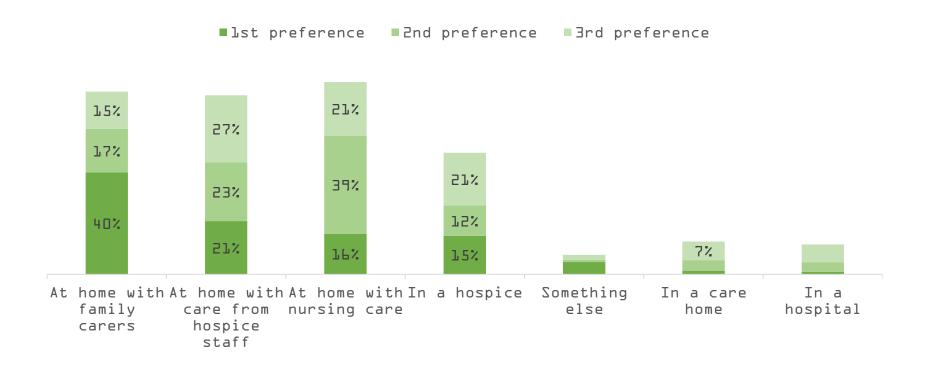
At home with care from hospice staff



What options do you think are available to people in Cornwall for end-of-life care? Base: 478 (all participants who stated they knew which options are available for end of life care)

The clear preference for end-of-life care is to be at home

Proportion of the public selecting each end-of-life care option as their first, second, or third preference



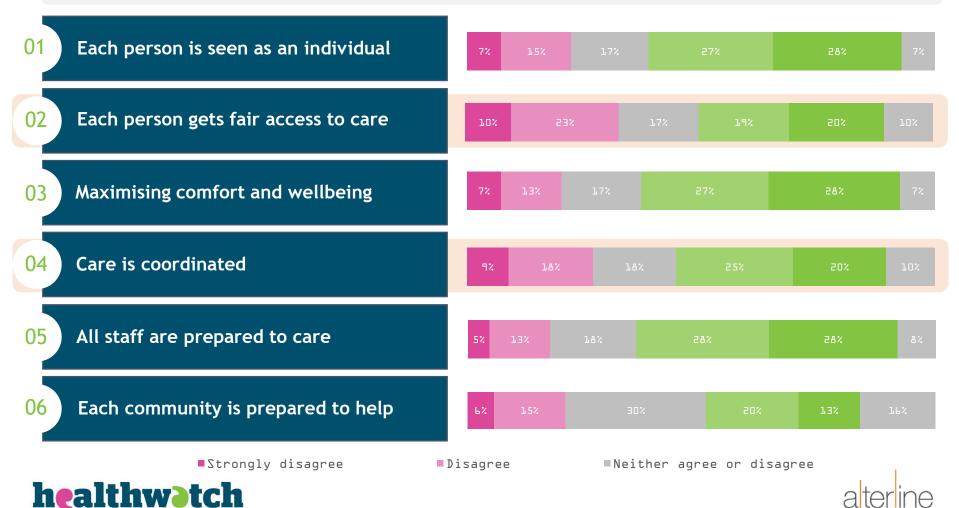




The public

Alignment with Ambitions for Palliative and End of life Care: access and coordination appear to be areas for improvements

Proportion of the public who agree or disagree that their expectations or experience of care is reflected in each ambition statement



The best possible end-of-life care is dignified and pain-free

People in Cornwall are most likely to say use words like 'dignity' (172), 'pain-free' (156), 'peace' (132), and 'care' (117) to describe their best possible end-of-life care.

Words used by the public to describe the best possible end of life care (word size is proportional to the number of mentions)





If you were to think about what the best possible end-of-life care looks like, what 3 words would you use to describe it? Base: 620 (all participants who provided an answer) The words shown received 3 or more mentions and are proportional in size to the number of mentions



Words used to describe the reality of end-of-life care by **those with experience** are mixed

Terminal illness

Bereaved

People in Cornwall most often describe their experience of end-of-life care with words like 'care' (45 mentions), 'dignity' (40), and 'peace (36). However, there are large numbers of more negative words, such as 'pain' (35), 'sad' (32), and 'stress' (27).

Words used by those with experience of end-of-life care or bereavement to describe personal experience of end of life care (word size is proportional to the number of mentions)





Thinking about your personal experience of end-of-life care, what 3 words would you use to describe it? Base: **392** (all participants with experience of terminal illness or bereavement) The words shown received 3 or more mentions and are proportional in size to the number of mentions

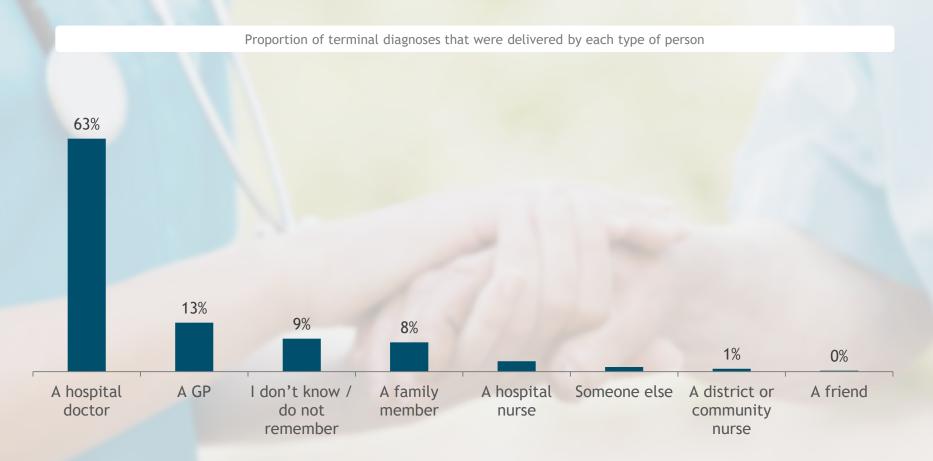


2. Experience of terminal illness





Diagnosis is most often delivered by a hospital doctor



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Thinking back, who told you/your family member that your/their illness is terminal? Base: 392 (People with a terminal diagnosis or family members of someone who has had a terminal diagnosis)



'Satisfaction' with diagnosis is variable: 21% dissatisfied - but only 40% satisfied

Proportion of those with experience of terminal illness who are satisfied or dissatisfied with how their/their family members' diagnosis was delivered

15%	9% ጌ7%	27%	73%	17%
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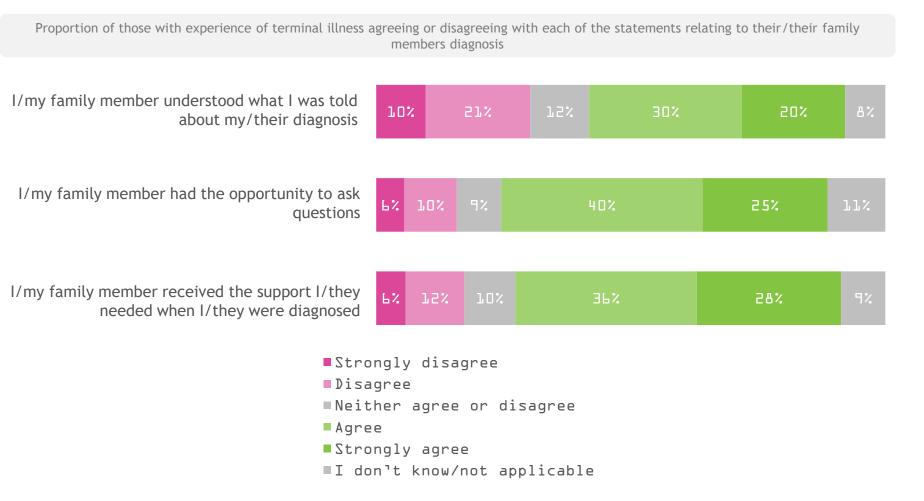
Very dissatisfied
Dissatisfied
Neither satisfied or dissatisfied
Satisfied
Very satisfied
I don't know / do not remember



On a scale of 1 to 5, how satisfied or dissatisfied are you with the way your/your family members' diagnosis was delivered? Base: 392 (People with a terminal diagnosis or family members of someone who has had a terminal diagnosis)



Almost a third of those with a terminal illness disagreed that they understood what they were told about their diagnosis





On a scale of 1 to 5, how satisfied or dissatisfied are you with the way your/your family members' diagnosis was delivered? Base: 392 (People with a terminal diagnosis or family members of someone who has had a terminal diagnosis)



A 'good' diagnosis is delivered...

- With compassion, kindness and sympathy
- Straightforwardly and honestly
- At an appropriate time and place
- Clearly and informatively, with expectations of a timeframe
- With guidance on next steps, options, and accessing care, and reassurance about comfort and pain
- By someone familiar and trusted
- By someone who has time and can answer questions
- With appropriate preparation (not abruptly)

"She was very straightforward about it, gave a possible time frame, didn't treat it as a drama, just an unfortunate reality, was encouraging about the time left to my mother."



"Care home staff were very honest and sympathetic."

"The doctor was kind, but straight to the point. He did not shy away from the truth of the matter."

"Because I knew everything possible was being done to make my family member's last days as comfortable as possible and pain free."

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Why did you feel this way? (How satisfied or dissatisfied are you with the way the diagnosis was delivered?) Base: 392 (People with a terminal diagnosis or family members of someone who has had a terminal diagnosis)



A 'bad' diagnosis is delivered...

- Blunt and without compassion
- In a rushed manner, without opportunities to ask questions
- In an inappropriate setting (e.g. on a ward)
- Without family present
- When it is not necessary or asked for
- Without advice on next steps or options for care
- 'Too late'

"It was delivered in a cold and matter of fact way with no compassion. The doctor might have easily been saying she had an in growing toenail!"



"Not upfront about how much time and no advice on next steps."

"They treated my father like an idiot. They didn't listen or use respect."

"It wasn't explained fully or in a comfortable setting. I was told in a doorway to an office very briefly and very rushed. I wasn't asked if I fully understood what I was told."

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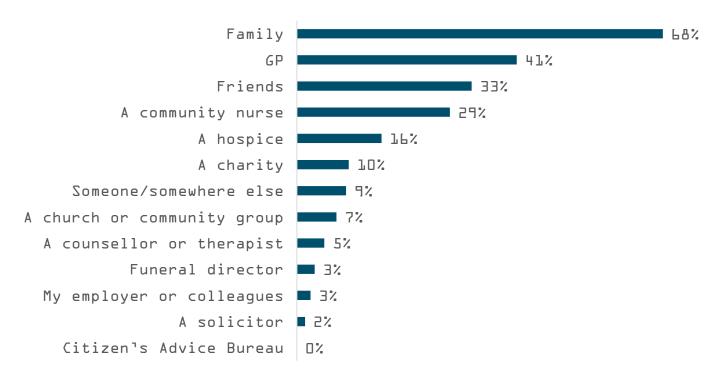
Why did you feel this way? (How satisfied or dissatisfied are you with the way the diagnosis was delivered?) Base: 392 (People with a terminal diagnosis or family members of someone who has had a terminal diagnosis)

Terminal illness

Family, GPs, and friends are the most common sources of support in dealing with a terminal diagnosis

Proportion of those with experience of terminal illness reporting that they/their family member received support in dealing with their diagnosis from each source







Where did you receive support from in dealing with your diagnosis? / Where did your family member receive support from when dealing with their diagnosis? Base: 392 (People with a terminal diagnosis or family members of someone who has had a terminal diagnosis)



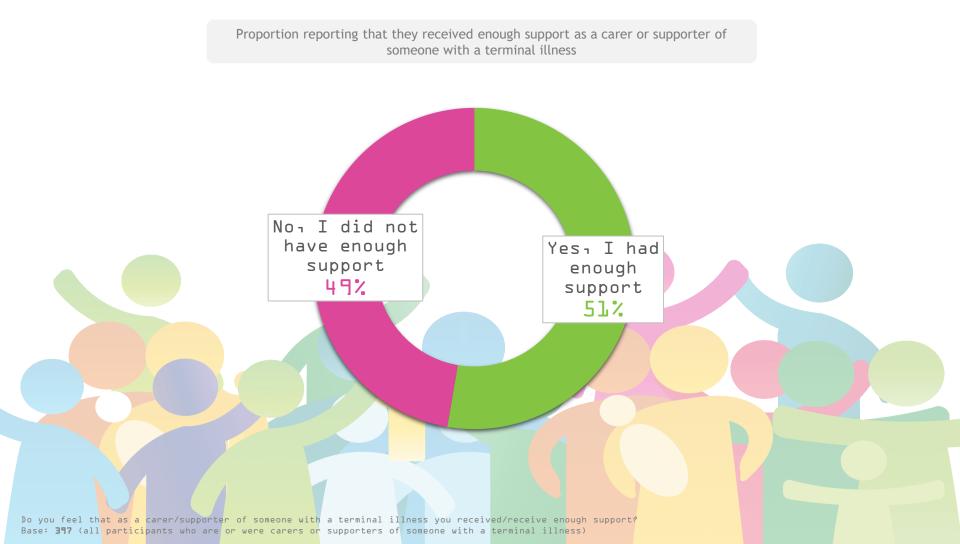
3. Carers and supporters of those with terminal illness





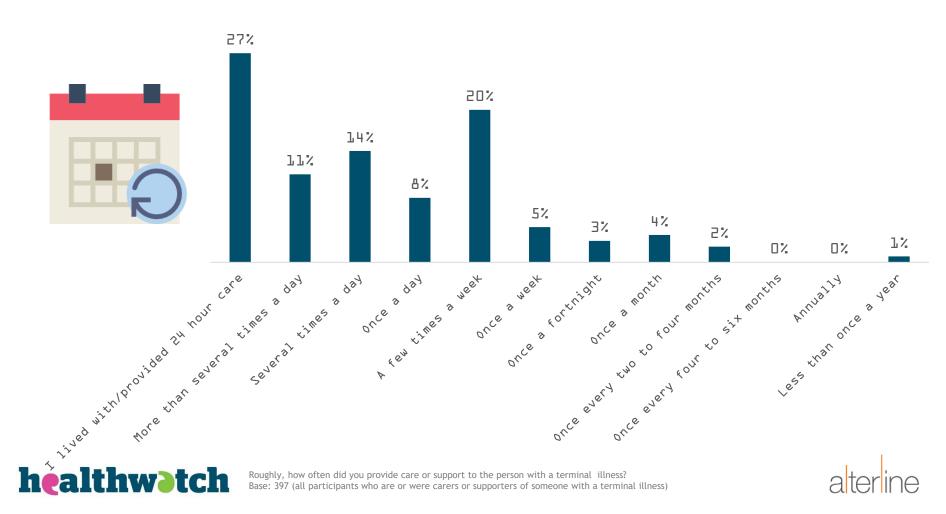
Carers and supporters

Almost half of carers or supporters of someone with a terminal illness do not feel they had enough support



Almost all carers and supporters are providing care or support more than once a week

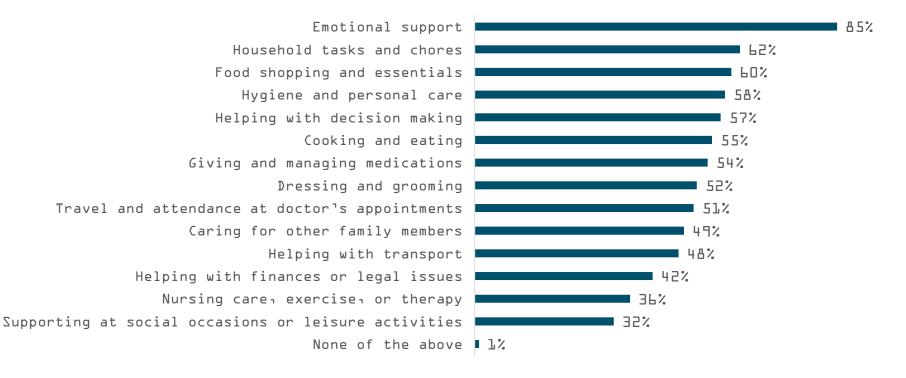
Proportion of carers and supporters providing care or support at each time frequency



Carers and supporters

Carers and supporters are providing a variety of tasks, most commonly emotional support

Proportion of carers and supporters providing care or support with each task





Which of the following tasks did you provide help and support with in your role as a carer or supporter of someone with a terminal illness?

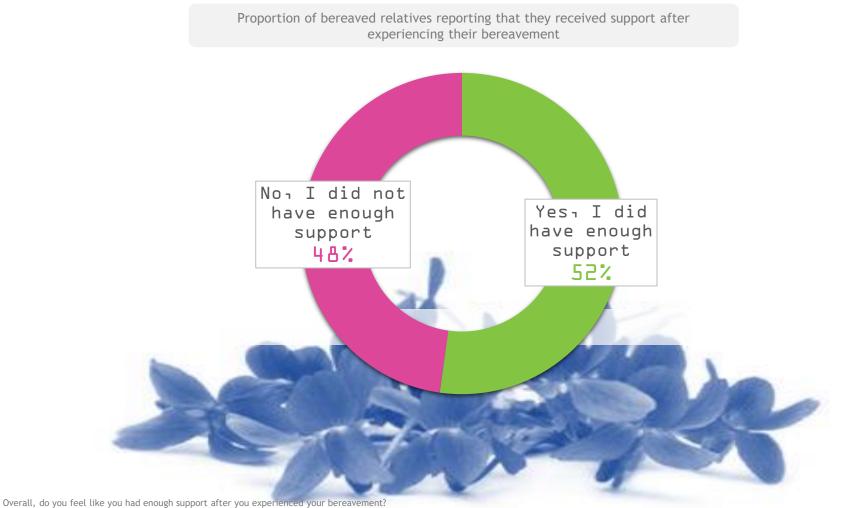
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4. Experience of bereavement





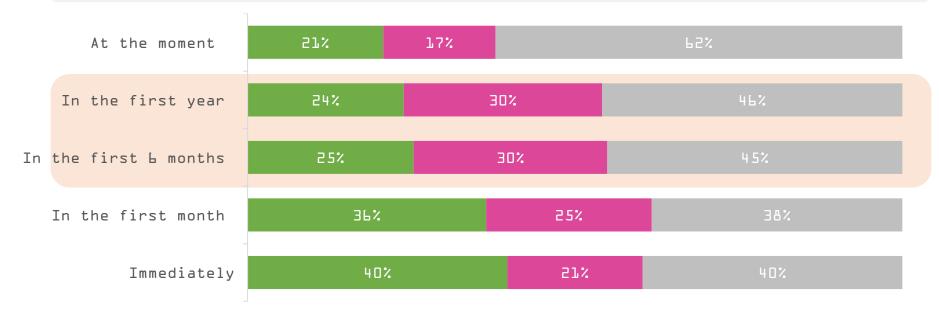
Almost half of those who were bereaved did not feel they had enough support



Base: 186 (all participants who have experienced a recent bereavement who chose to answer this question)

There appears to be an unmet need for support following the immediate bereavement period

Proportion of bereaved relatives who needed help or support at different time periods following their bereavement



I had help and support at this time
I did not have help and support at this time, but I wanted it
I did not have or want help or support at this time



After your bereavement, in which time periods did you have or want help and support? Base: **186** (all participants who have experienced a recent bereavement who chose to answer this guestion)



Around a third of people would have liked help with private, legal or financial affairs, more information, and support for carers

Proportion of bereaved relatives who wanted each different type of support following their bereavement							
Funeral arrangements		46%		20%	34%		
Help with private, legal, or financial affairs	28	3%	27%		45%		
More information	22%		30%		48%		
Counselling	16%	18%		66%			
Online support (e.g. forums, online chat)	14%	11%		75%			
Peer support groups	75%	14%		73%			
Support for carers	5%	27%		68%			
Telephone helplines	5% 12%			83%			

- I had this type of support
- I did/do not have this type of support but wanted it
- I did/do not have or want this type of support



Did you have or want the following type of support following the bereavement? Base: **186** (all participants who have experienced a recent bereavement who chose to answer this question)

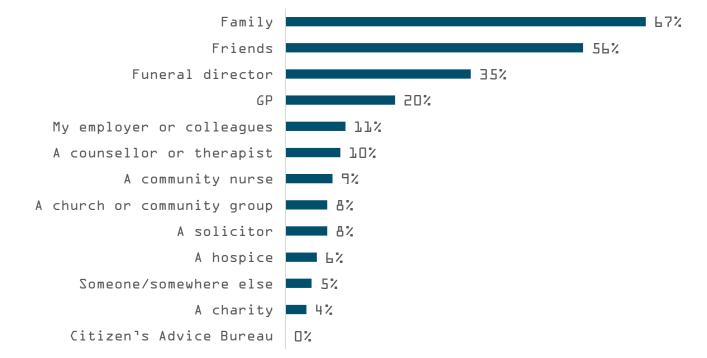


Bereaved

Friends and family are the main sources of support following bereavement

Proportion of bereaved relatives receiving support from each different source of support









Bereaved

While 50% were satisfied with the end-oflife care their family member received, 29% were not

Proportion of bereaved relatives who were satisfied or dissatisfied with the quality of care that their family member received during the end of their life 16% 13% 22% Very dissatisfied Dissatisfied Neither satisfied or dissatisfied Satisfied Very satisfied I don't know / do not remember



How satisfied or dissatisfied were you with the quality of care and support that your family member received during the end of their life?



Base: 205 (all participants who have experienced a recent bereavement who chose to answer this question)

5. Conclusions and initial reflections





This research will feed into Healthwatch's strategy for end of life care in Cornwall, and be used for public education, service improvement, and meeting unmet needs. Our recommendations may include:

- **Public education measures** on the importance of talking about what care would be preferred at their end-of-life
 - Ensure the public know they have **choices** on what happens to them
 - Education on the language and terms needed to talk about end of life care
- Support **provision of end-of-life care at home** where possible, whether with family, nurses, or hospice staff
 - Ensure care is **dignified**, as **pain-free** as possible, and provides **peace** and **comfort**
 - Target the key ambitions that performed less well in Cornwall; **'each person gets fair access to care'** and **'that care is coordinated'**
- Improve the experience of diagnosis with a terminal illness
 - Hospital doctors most often deliver diagnosis and hospitals often the location of unsatisfactory diagnosis: stress importance of: tone, care and comfort, give timeframe; right: place, people, and appropriate time next steps
 - Understanding the diagnosis: an area where the experience could be improved
 - Diagnosis: Provide families and GPs with the **tools** and **skills** needed to provide support
- **Recognise and support carers and supporters**; they are common in the community, providing very frequent care and many types of care, but **not getting enough support**
- Increase the support for those who are bereaved, particularly at the 'middle' of their journey and with private, legal, financial affairs, information provision, and support for carers
 - Give family, friends, and funeral directors tools and support needed to support those who are bereaved





"It's all been such a muddle of financial and emotional turmoil. It's like a bomb exploded in our midst and we were all flung apart never to really find our way back together again. It's the aloneness of all the choices and decisions, coping with breakdowns of people, homes, appliances, with only yourself to refer to. The absence of that lifelong partner and father to, is a huge emotional hole in our lives to this day"

"I believe that we should all be able to choose how and when we die if there is no chance of a recovery to the point of enjoying life. I never want to be a burden to my family or the health and care services. It seems to be that there is a consistent lack of joined up thinking about end of life care mainly because we don't discuss it often enough in the public domain.

Hopefully, this will be the beginning of a change."





Thank you. Any questions, please contact:

Natalie Swann Research Manager

Amanda Stratford Chief Executive Officer







5. Appendix





Those with experience have a better understanding of terms

	Living will	4% 33% 33%		49%	
	Clinician	4%6% 28	2	63%	
Those with	Advance directive or statement	31%	18%	22%	29%
experience of	Power of attorney	21%		75%	
	Legal proxy	18%	21%	32%	29%
terminal	Artificial nutrition and hydration	13% 10%	31%		46%
illness of	Do Not Attempt Cardiopulmonary Resuscitation			77%	
bereavement	End-of-life care plan	4% 7%	31%	58	5%.
(n=496)	Treatment escalation plan	26%	16%	27%	31%
(11-490)	Prognosis	27. 177.		79%	
	Palliative	37.57. 167.		75%	

	Living will	1.3% 22%		8%	27%
	Clinician	15% 10%	41%		37%
Those without	Advance directive or statement	50%		20%	50% 71%
experience of terminal	Power of attorney	67.57 3	5%	53	2
	Legal proxy	24%	25%	34%	18%
	Artificial nutrition and hydration	28%	18%	38%	17%
illness of	Do Not Attempt Cardiopulmonary Resuscitation	117 57	41%		42%
bereavement (n=169)	End-of-life care plan	10% 17%	39%		34%
	Treatment escalation plan	51%		18%	51% 70%
	Prognosis	57 57 347		563	
	Palliative	15% 10%	41%		37%

I have not heard of this term

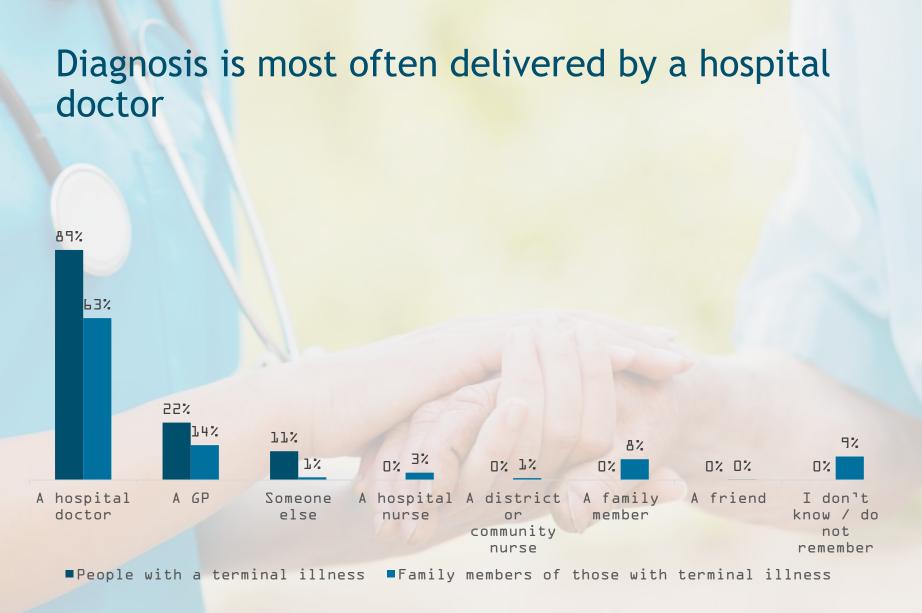
■I have heard of this term but do not know what it means

■I have heard this term and have a general idea of what it means

I have heard this term and have a good understanding of what it means

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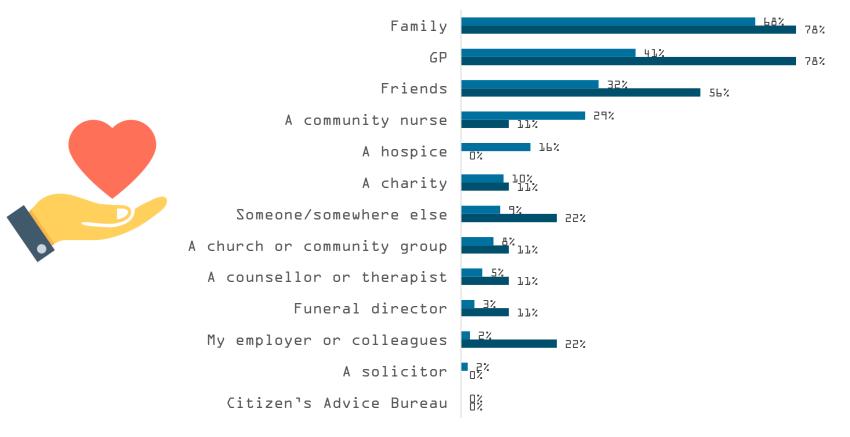


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Thinking back, who told you/your family member that your/their illness is terminal? Base: People with a terminal diagnosis (n=9) or family members of someone who has had a terminal diagnosis (n=385)



Family, GPs, and friends are the most common sources of support in dealing with a terminal diagnosis



Family members of those with a terminal diagnosis

Those with a terminal diagnosis



Where did you receive support from in dealing with your diagnosis? / Where did your family member receive support from when dealing with their diagnosis?

Base: People with a terminal diagnosis or family members of someone who has had a terminal diagnosis (n=392)



Demographic data of survey respondents

Gender	
Male	25%
Female	74%
Non-binary	0%
Prefer to specify	0%
Prefer not to say	0%

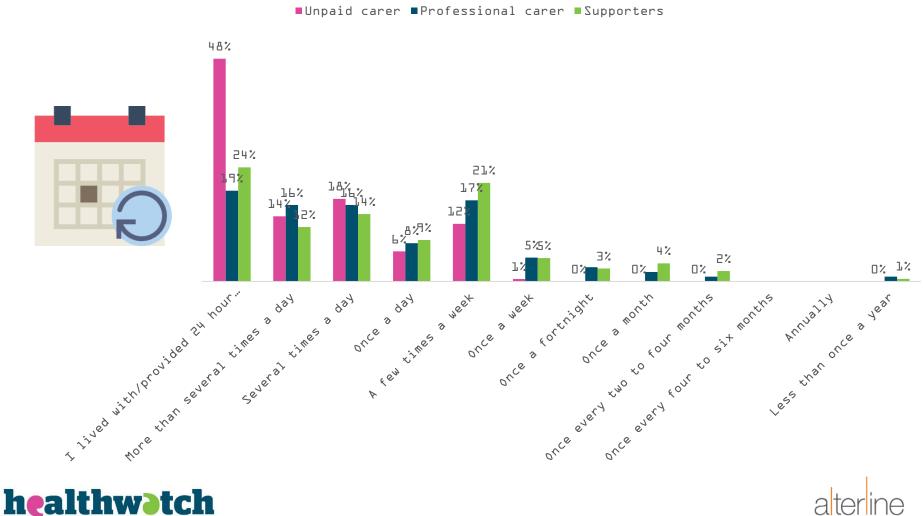
Yesı I have a physical	
disability	16%
Yes, I have a mental	
disability	5%
Yesı I have a learning	
disability	6%
Noı I do not have a	
disability	72%
Prefer not to say	
Fielei not to say	3%

Age			
Under	18	years	0%
18 to	24	years	3%
25 to	34	years	7%
35 to	44	years	14%
45 to	54	years	22%
55 to	64	years	26%
65 to	74	years	25%
75 to	84	years	3%
85 to	94	years	0%
0ver 9	4 у	vears	0%
Prefer	nc	ot to say	0%

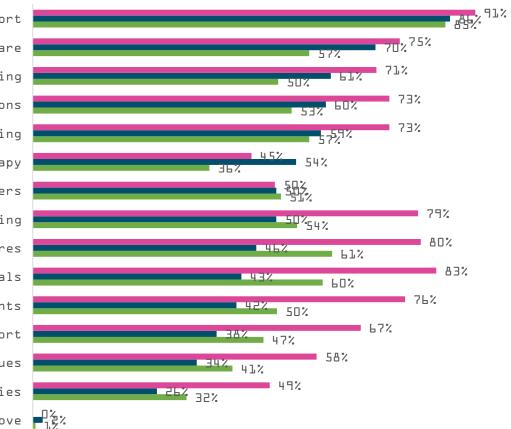




Unpaid carers are more likely to be delivering 24-hour care



Carers and supports are providing a variety of tasks, most commonly emotional support



Emotional support Hygiene and personal care Dressing and grooming Giving and managing medications Helping with decision making Nursing care, exercise, or therapy Caring for other family members Cooking and eating Household tasks and chores Food shopping and essentials Travel and attendance at doctor's appointments Helping with transport Helping with finances or legal issues Supporting at social occasions or leisure activities None of the above

Unpaid carers Professional carers Supporters



