

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

Natalie Swann  
Research Manager

Amanda Stratford  
Chief Executive Officer

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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

# This presentation covers four different groups of people

## The public

All people who took part in the survey (including those with terminal illness and bereavement experience)

**Section 1:**  
Perceptions of end-of-life care

## Terminal illness

People with a terminal diagnosis and family of people who have had a terminal diagnosis

**Section 2:**  
Experience of terminal illness and end of life care

## Carers and supporters

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

**Section 3:**  
Experience of caring and supporting those with terminal illness

## Bereaved

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

**Section 4:**  
Experience of bereavement

# 1. Perceptions of end-of-life care



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

41%

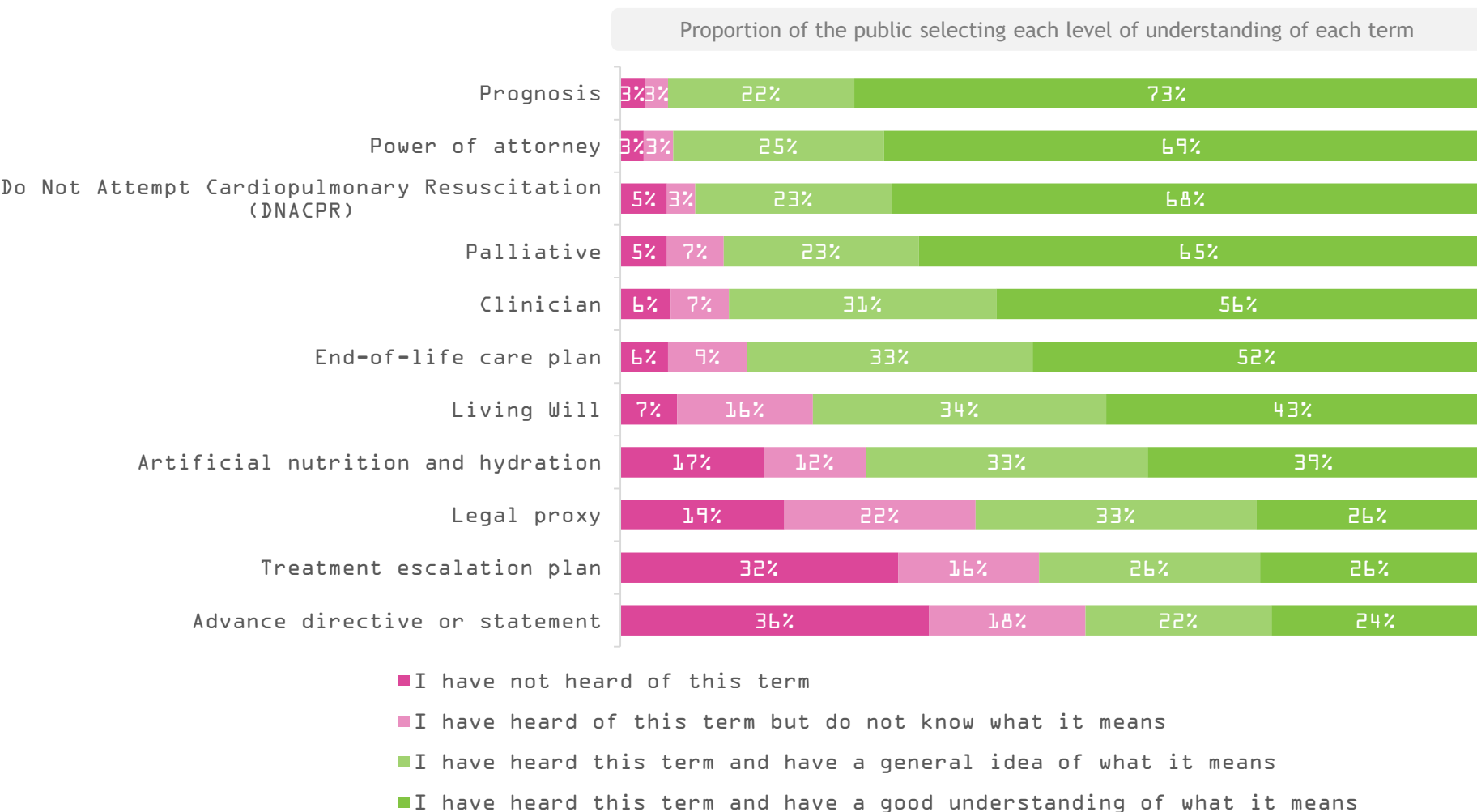
4% ?% of people have an end-of-life care plan



?% of people have an advance directive

11%

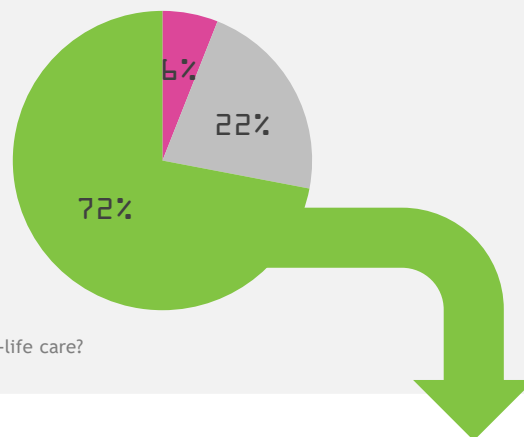
# Understanding of many of the terms used in EOL care varies: particularly low for technical terms



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

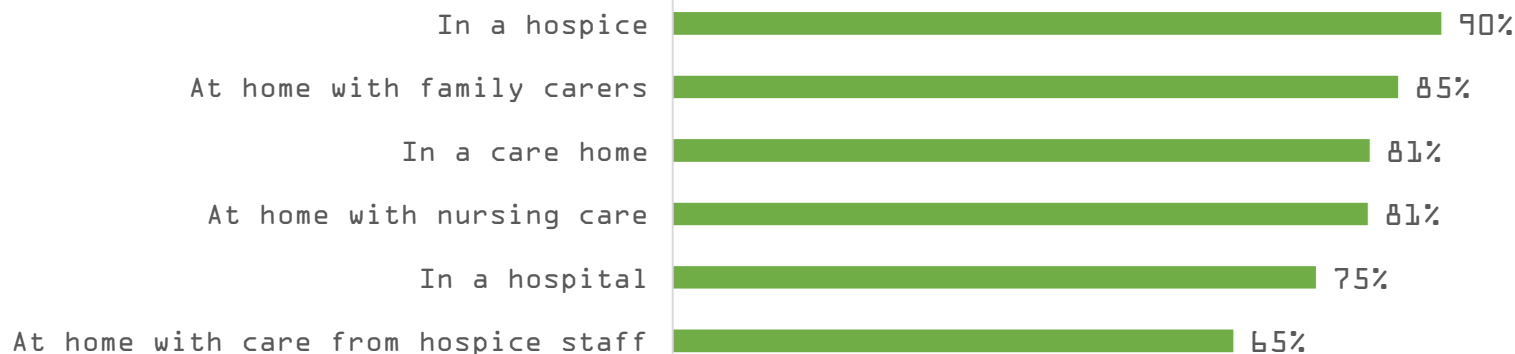
Proportion of the public with knowledge of end of life care options

- I do not think there are any options for me to choose from
- I don't know what options are available but I know there are options
- I know what options are available



What options do you think are available to people in Cornwall for end-of-life care?  
Base: 665 (all participants)

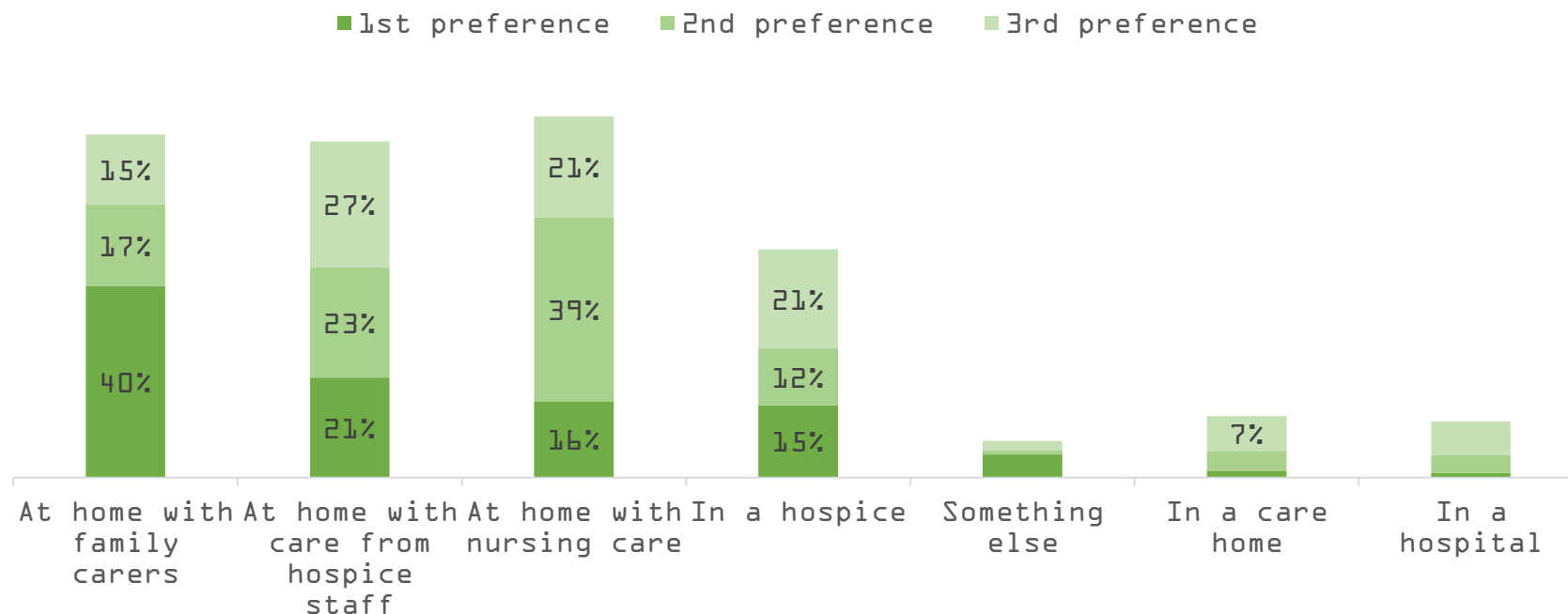
Proportion of those who say they know what options are available selecting each of the following options





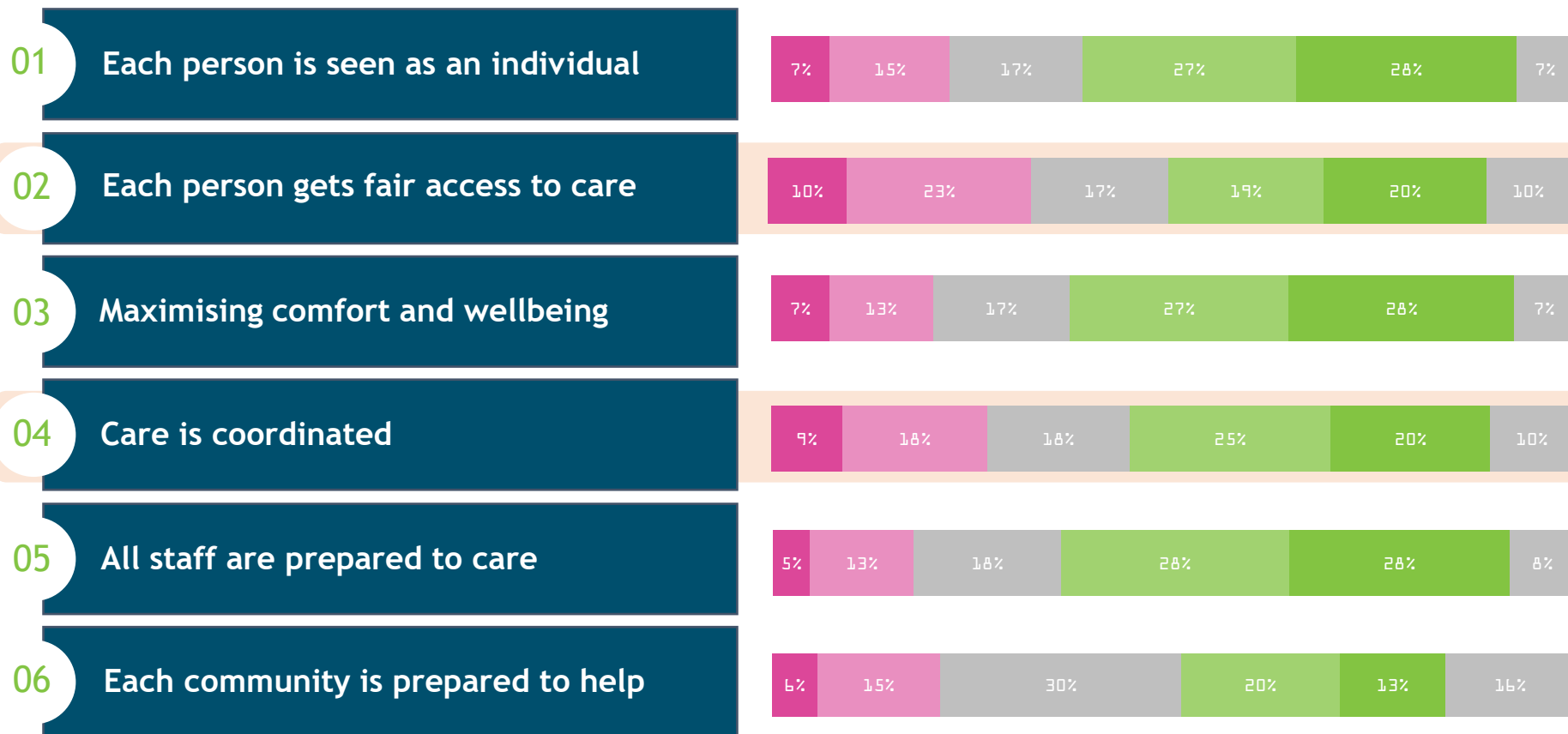
# The clear preference for end-of-life care is to be at home

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



# 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



Strongly disagree

Disagree

Neither agree or disagree

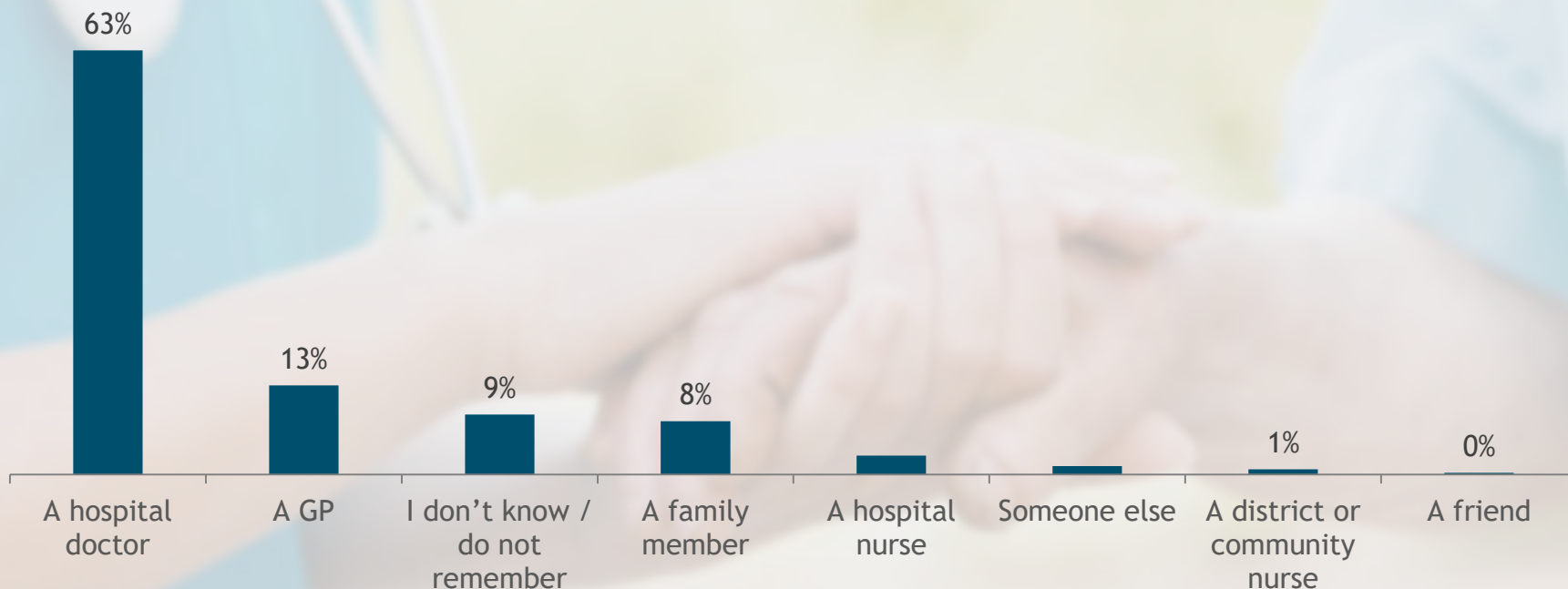




## 2. Experience of terminal illness

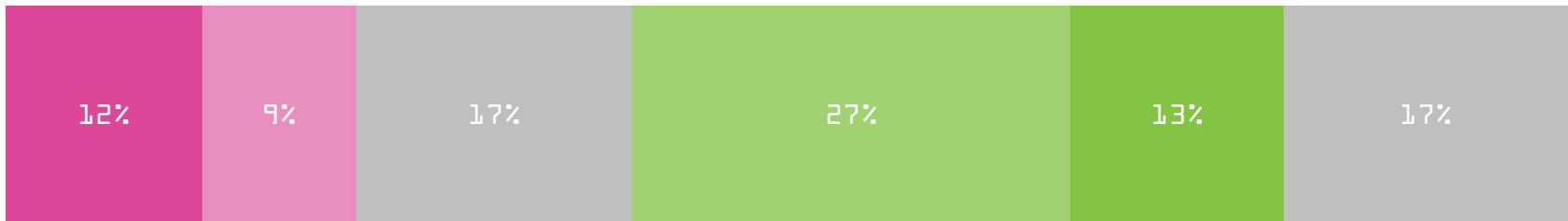
# Diagnosis is most often delivered by a hospital doctor

Proportion of terminal diagnoses that were delivered by each type of person



# ‘Satisfaction’ with diagnosis is variable: 21% dissatisfied - but only 40% satisfied

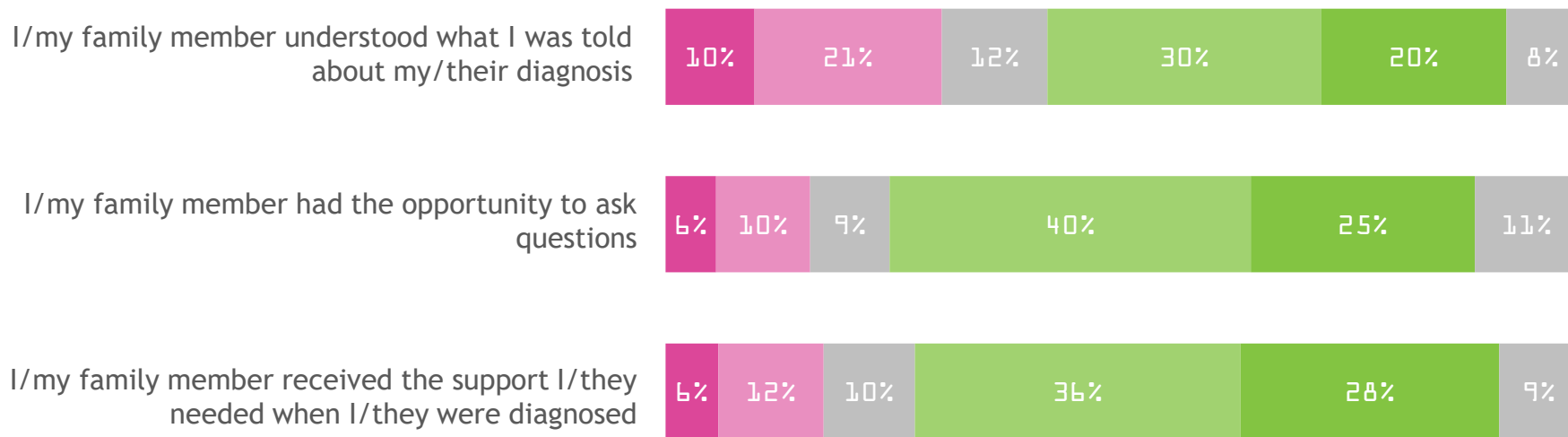
Proportion of those with experience of terminal illness who are satisfied or dissatisfied with how their/their family members’ diagnosis was delivered



- Very dissatisfied
- Dissatisfied
- Neither satisfied or dissatisfied
- Satisfied
- Very satisfied
- I don't know / do not remember

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

Proportion of those with experience of terminal illness agreeing or disagreeing with each of the statements relating to their/their family members diagnosis



- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree
- I don't know/not applicable



# 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.”*

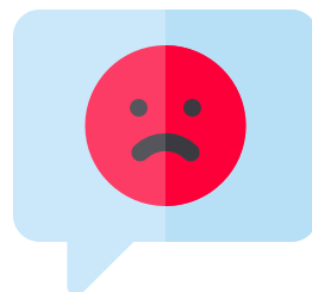
*“The doctor was kind, but straight to the point. He did not shy away from the truth of the matter.”*

*“Because I knew everything possible was being done to make my family member’s last days as comfortable as possible and pain free.”*

# 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!”*



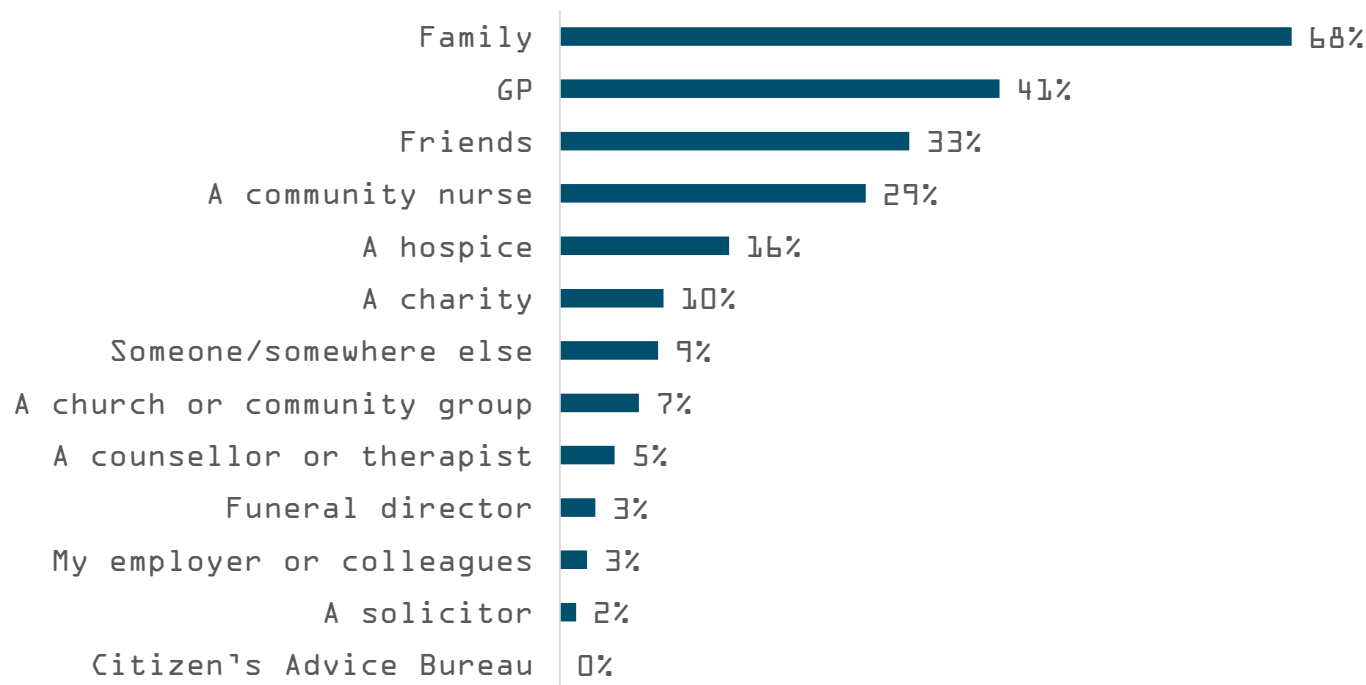
*“Not upfront about how much time and no advice on next steps.”*

*“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.”*

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

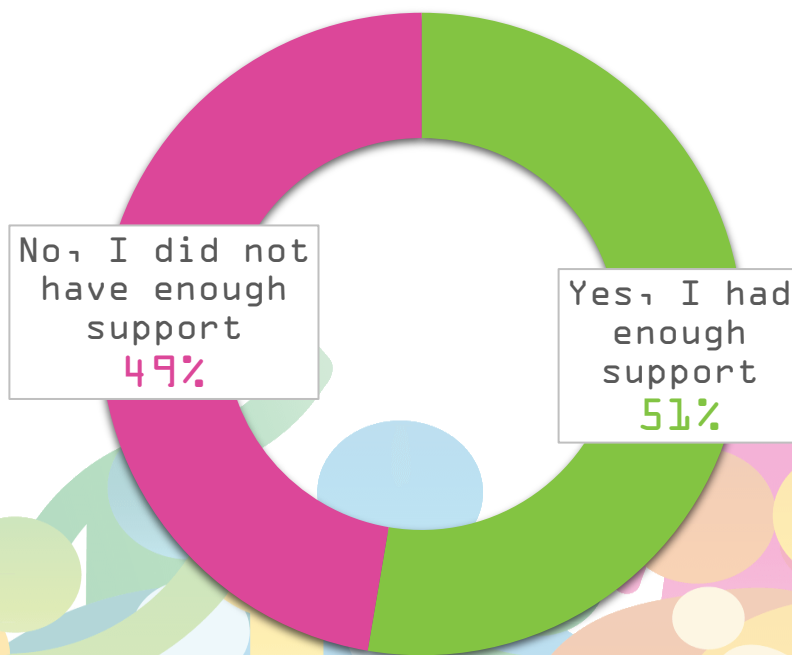
Proportion of those with experience of terminal illness reporting that they/their family member received support in dealing with their diagnosis from each source



### 3. Carers and supporters of those with terminal illness

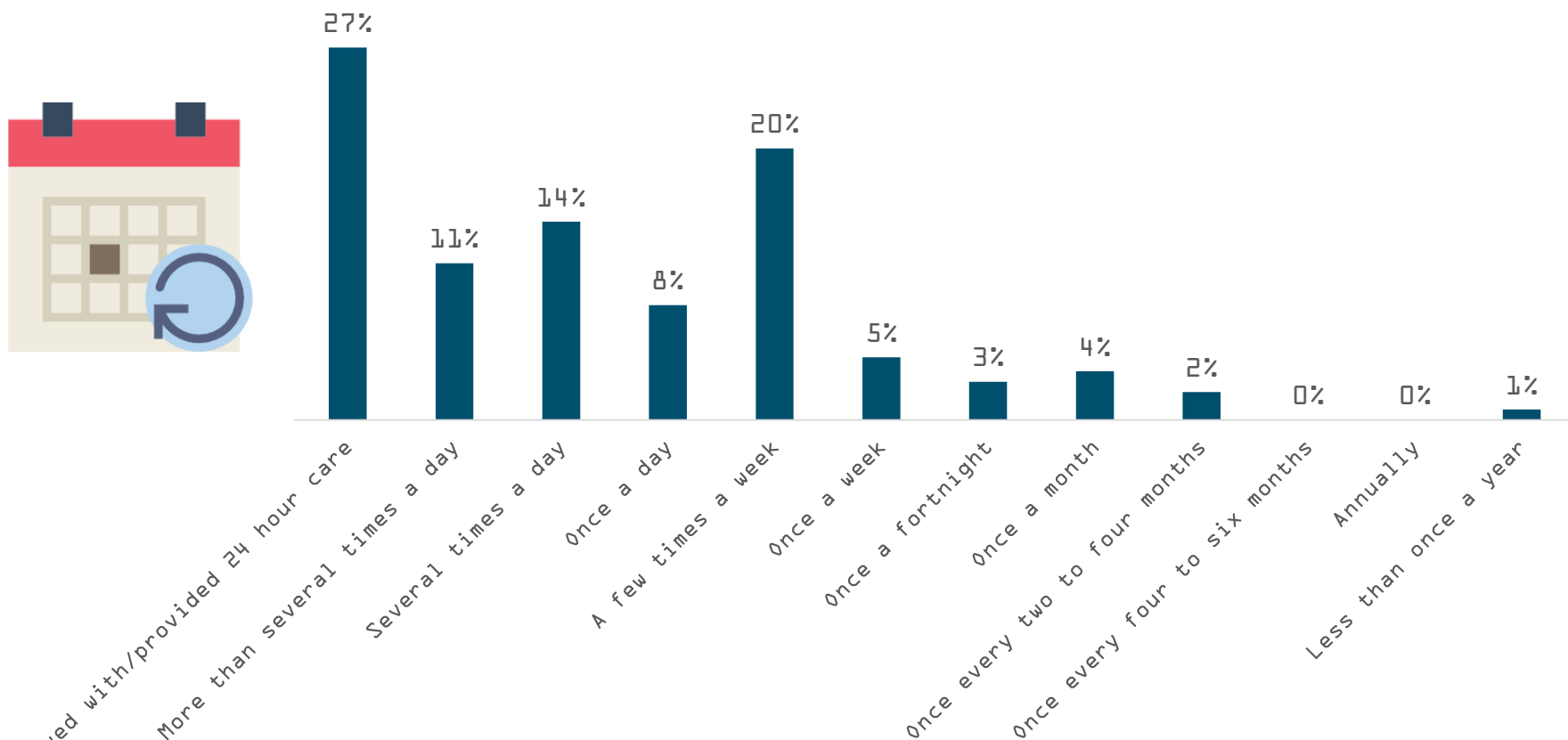
# Almost half of carers or supporters of someone with a terminal illness do not feel they had enough support

Proportion reporting that they received enough support as a carer or supporter of someone with a terminal illness



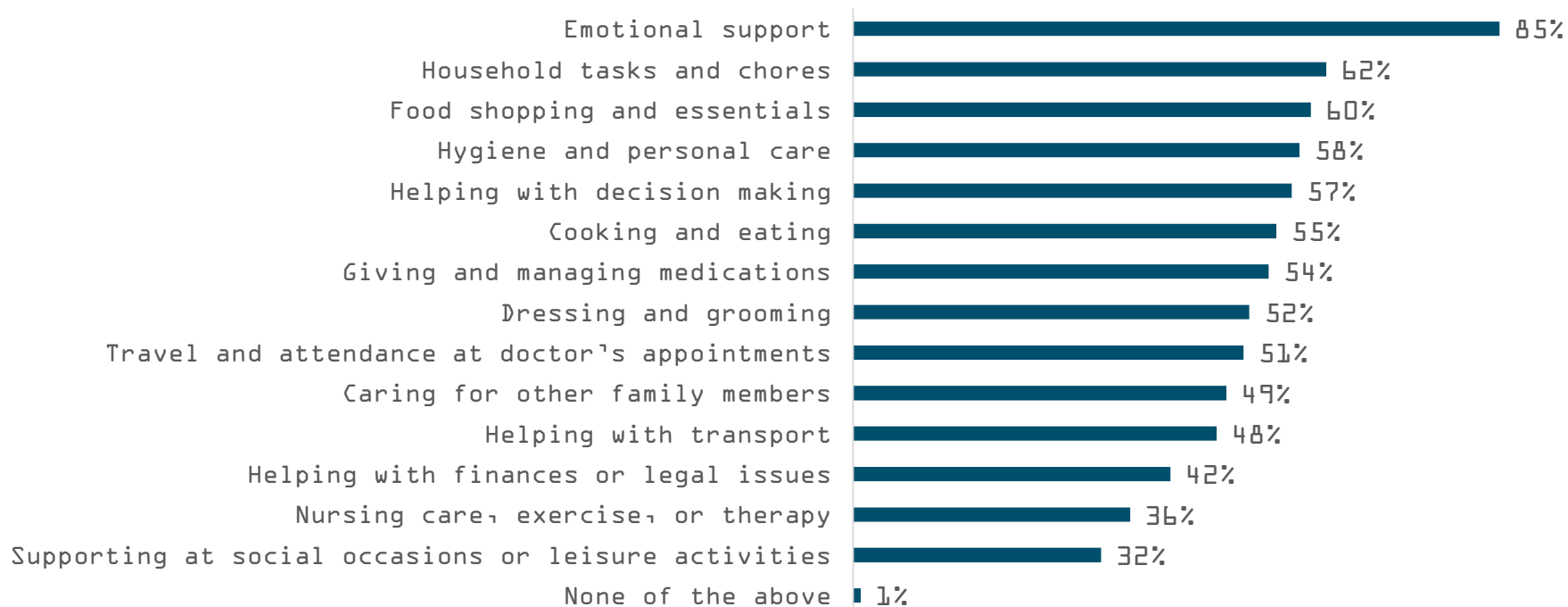
# Almost all carers and supporters are providing care or support more than once a week

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



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

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

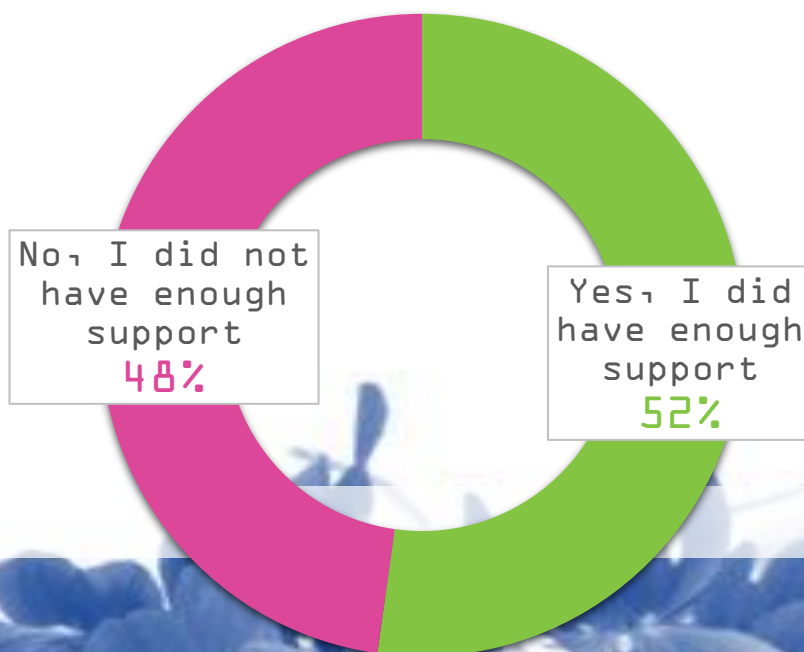


# 4. Experience of bereavement



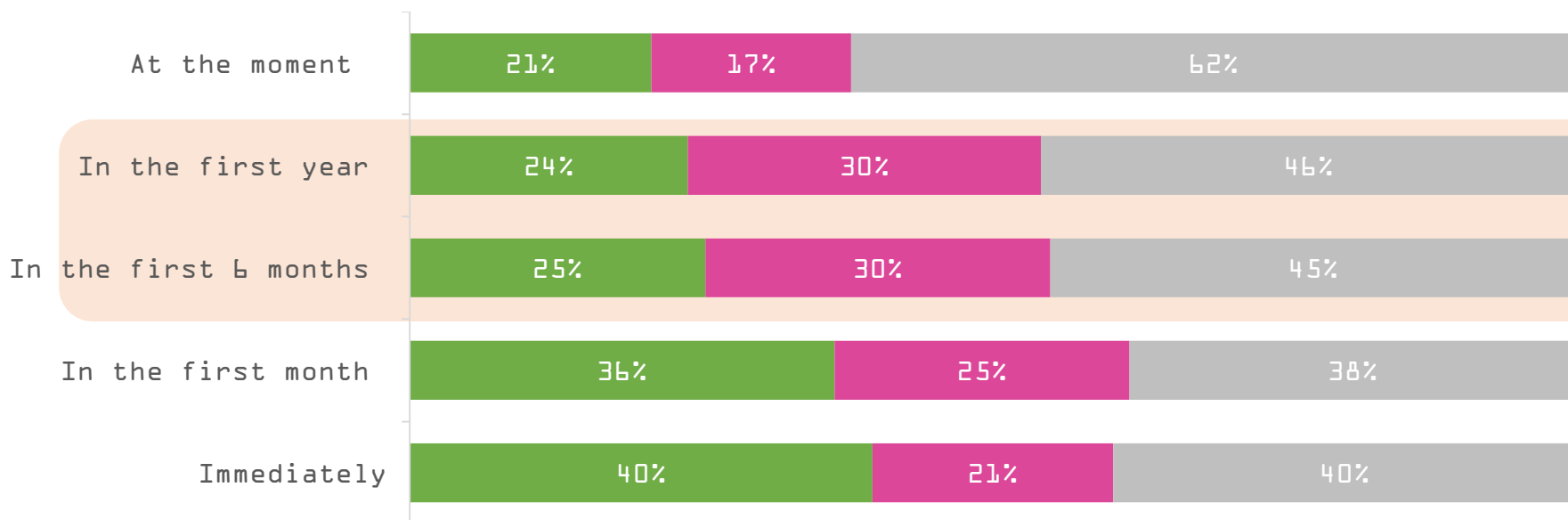
# Almost half of those who were bereaved did not feel they had enough support

Proportion of bereaved relatives reporting that they received support after experiencing their bereavement



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

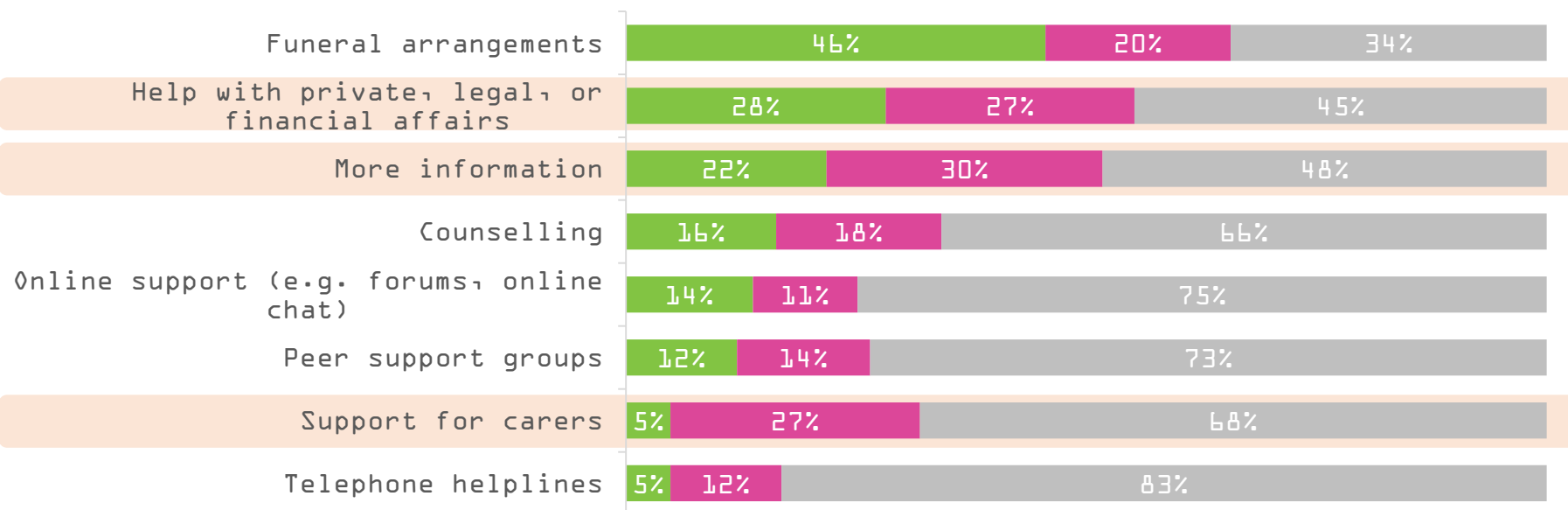
Proportion of bereaved relatives who needed help or support at different time periods following their bereavement



- 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

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

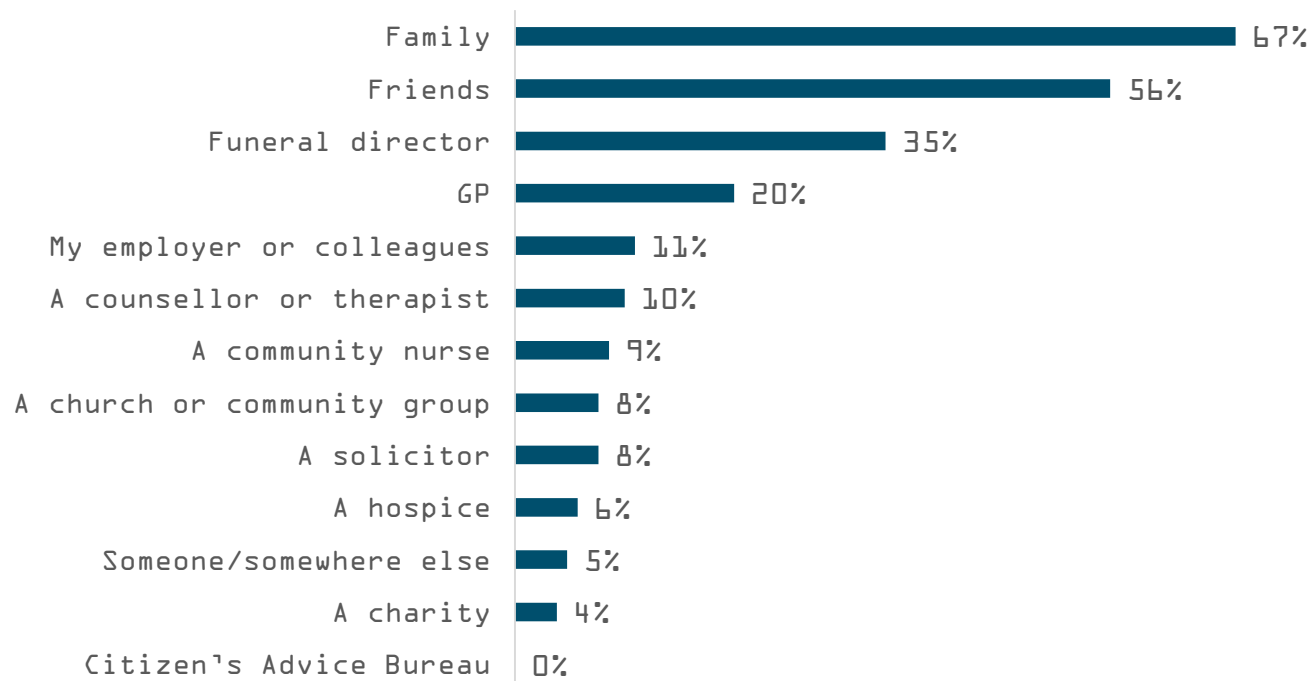
Proportion of bereaved relatives who wanted each different type of support following their bereavement



- 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

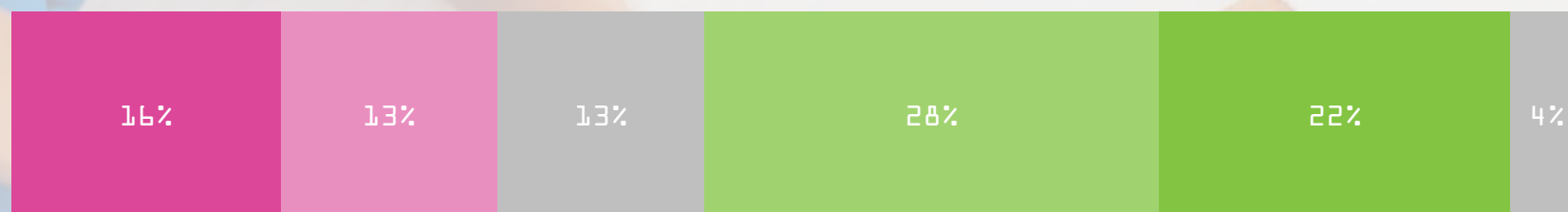
# Friends and family are the main sources of support following bereavement

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



# While 50% were satisfied with the end-of-life 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



- Very dissatisfied
- Dissatisfied
- Neither satisfied or dissatisfied
- Satisfied
- Very satisfied
- I don't know / do not remember

# 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

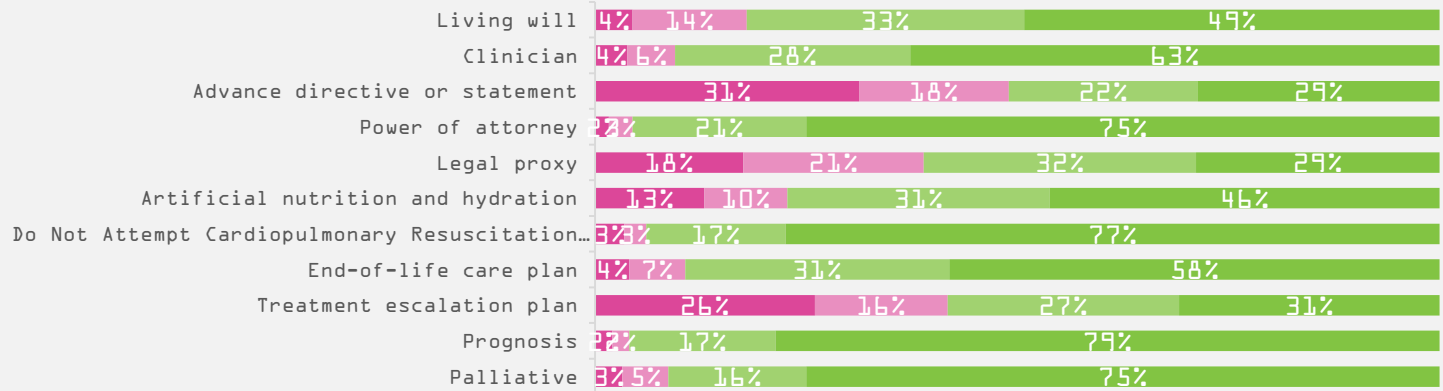
Amanda Stratford  
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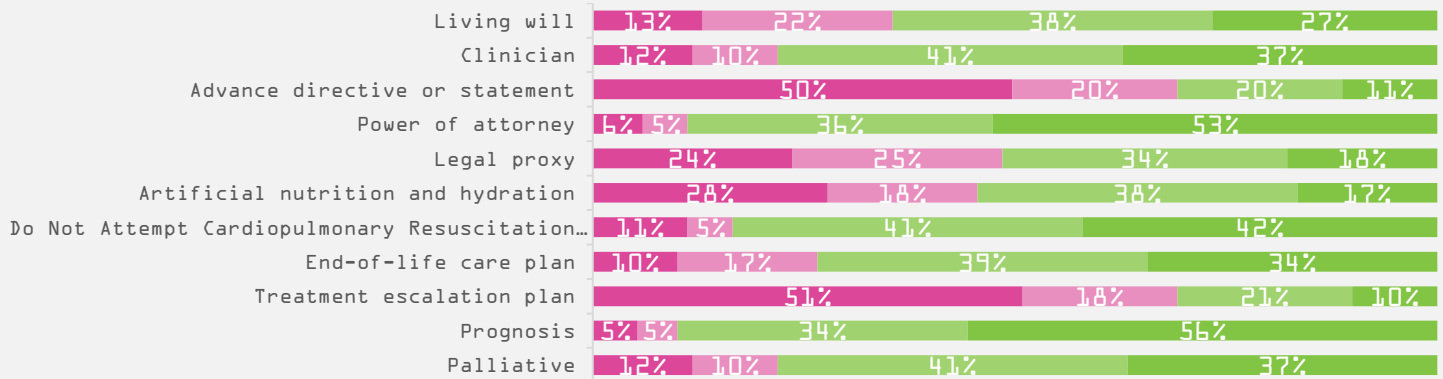
# 5. Appendix

# Those with experience have a better understanding of terms

Those with experience of terminal illness of bereavement (n=496)

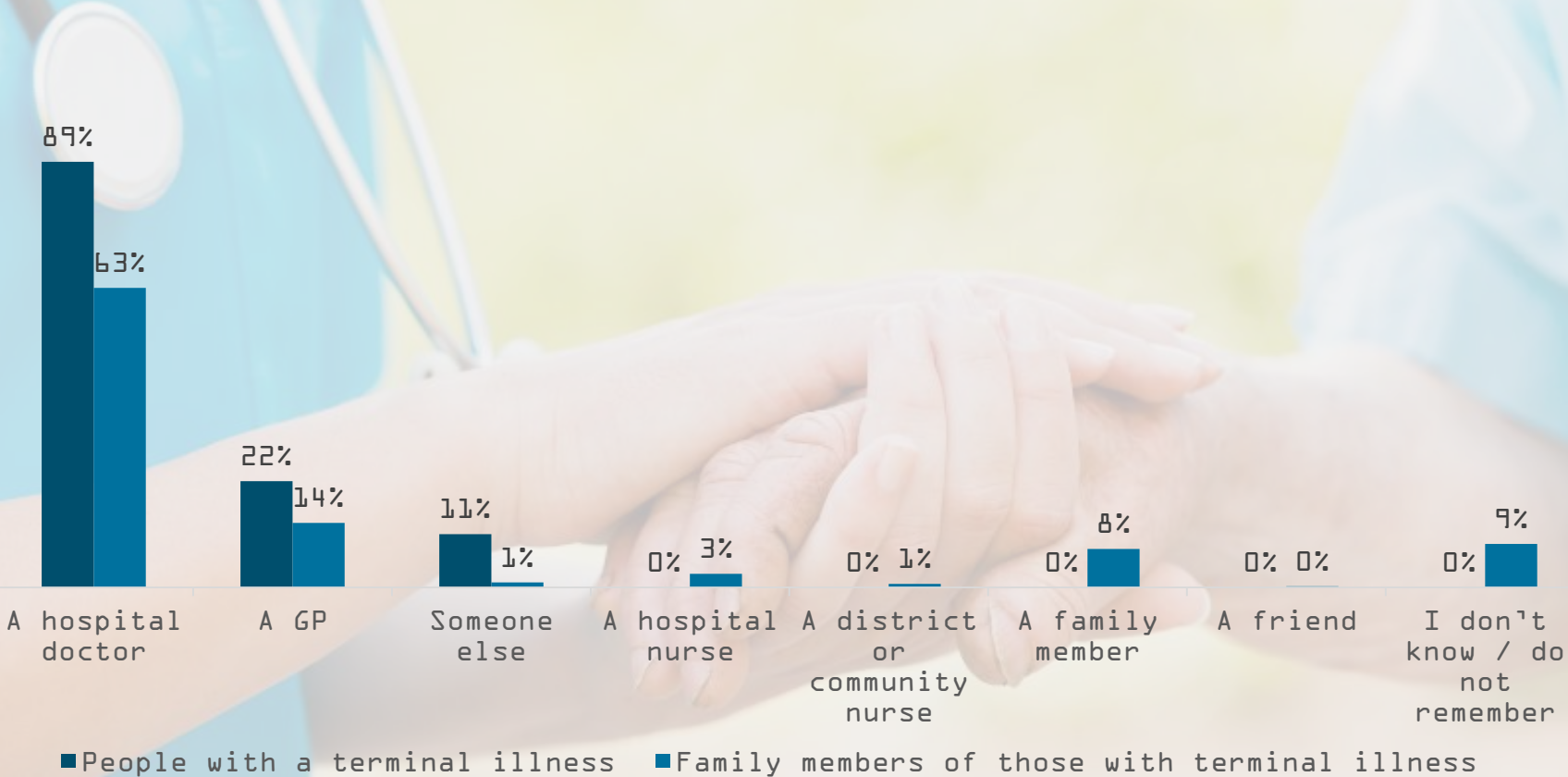


Those without experience of terminal illness of bereavement (n=169)

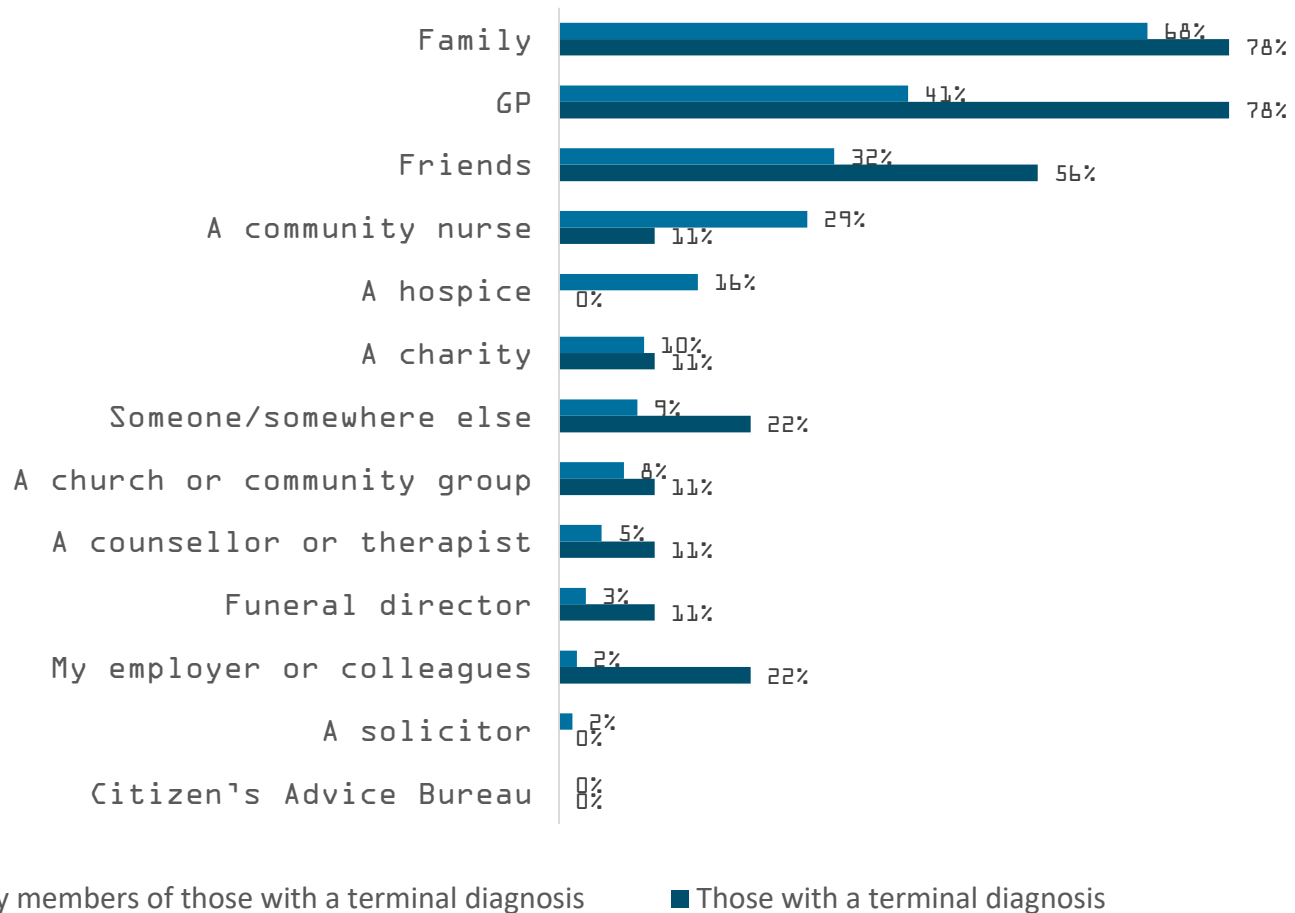


- I have not heard of this term
- I have heard of this term but do not know what it means
- I have heard this term and have a general idea of what it means
- I have heard this term and have a good understanding of what it means

# Diagnosis is most often delivered by a hospital doctor



# Family, GPs, and friends are the most common sources of support in dealing 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)

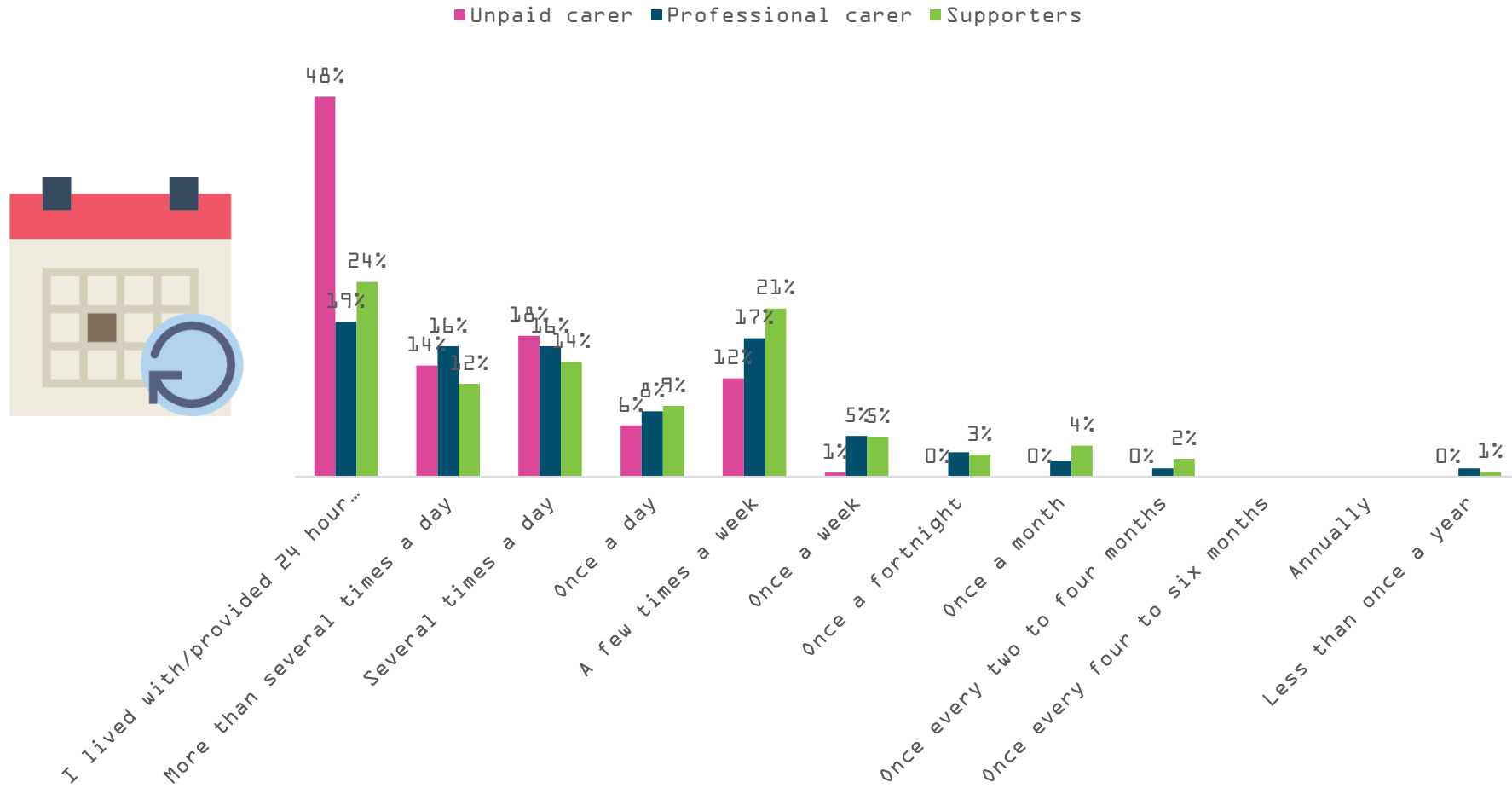
# Demographic data of survey respondents

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

Gender	
Yes, I have a physical disability	16%
Yes, I have a mental disability	5%
Yes, I have a learning disability	6%
No, I do not have a disability	72%
Prefer 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%
Over 94 years	0%
Prefer not 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

