



The experiences of informal carers of people at the end of life

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*On behalf of the
Carers Working Group*

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Background



- People are living longer with chronic and life limiting conditions¹
- Carers are essential for the delivery of sustainable person-centred care
- 55% of care required at end of life provided by informal carers²
- Caring can impact on physical and mental health³
- Support for carers remains inconsistent⁴

¹ Harrop et al., 2014, ²Jansma et al., 2005, ³Kelley et al., 2013, ⁴Harding and Higginson, 2001

Aim of Hospice survey



Carers Working Group launched the survey to:

1. Understand the experience of carers of Hospice patients
2. Identify carer needs and gaps in services
3. Inform Hospice strategy

Methods



- Mixed methods study design
- Purposive sampling between 11/2017- 2/2018

Eligibility:

- Carers of patients on staff caseload

Exclusions:

- Potential distress and/or lack of capacity

Survey domains of caring situation



Demographics

Activities

Support

Assistance

Physical health

**Emotional
health**

Meeting needs

**Sense of
control**

Fulfillment

Analyses



Quantitative :

- Descriptive statistics
- Tests of association (meeting needs, years caring)
- Significance $p < 0.05$

Qualitative:

- Thematic analysis (Braun and Clarke, 2006)

Carer and patient demographics

(n=44)



68% Female

29% 4+ years

Carer **60** years

54% 1-3 years caring

7% < 1 year

Patient **65** years

52% retired

25% working

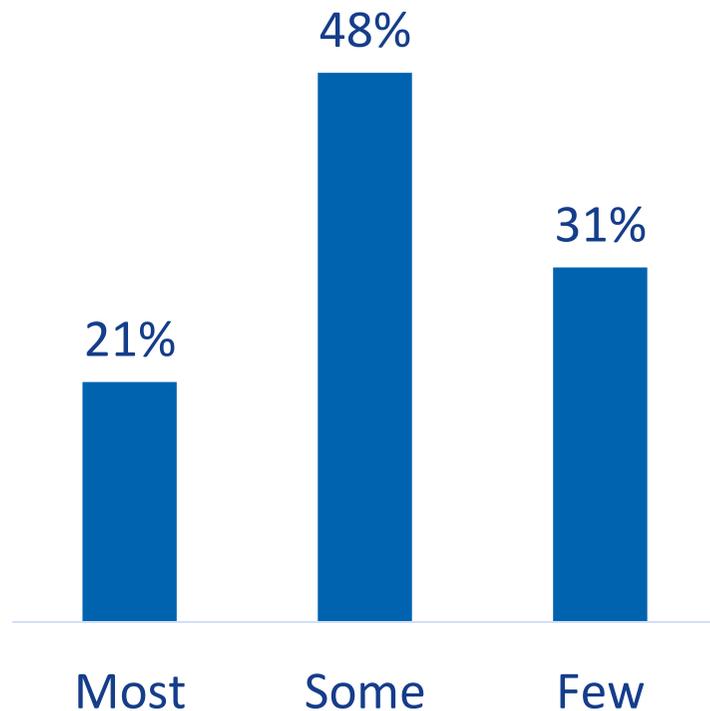
70% spouse

57% Need some assistance

36% Dependent for all care

89% live with patient

Ability to maintain activities outside caring



Unable to leave

There is an expectation to put them first

Not enough hours in a day

Duration of caring and activities

67% <1 could do a few things vs
8% of 4+ years

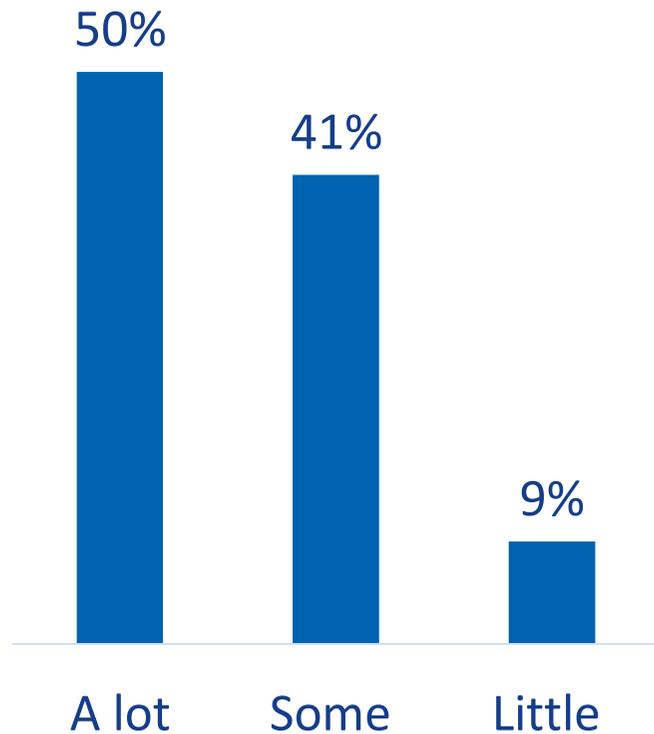
Support from family and friends



I am happy with the support I receive

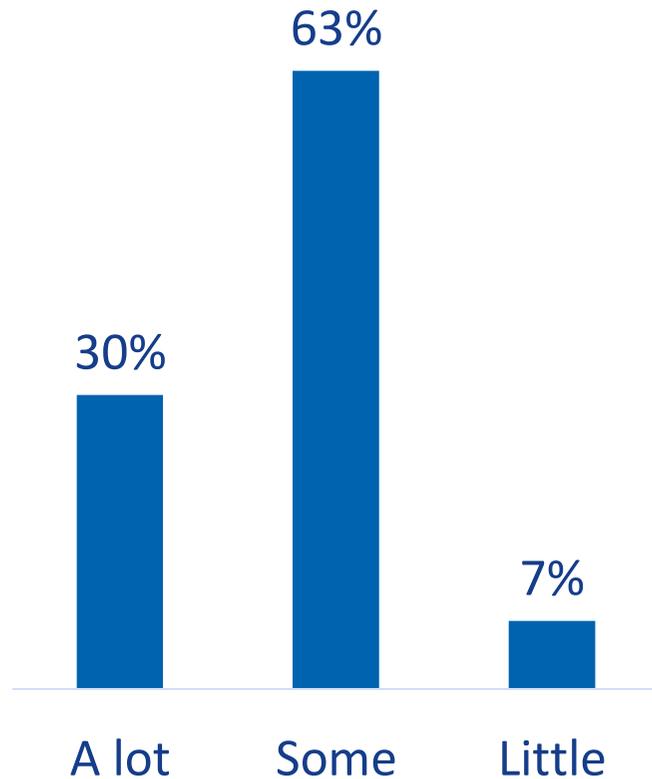
I wouldn't feel comfortable asking

Feelings of guilt asking for help



"All of our family live in the UK. They help on visits over but there are only a certain amount of times they can come because they have work or family commitments" (1/3/10)"

Assistance from Hospice and other organisations



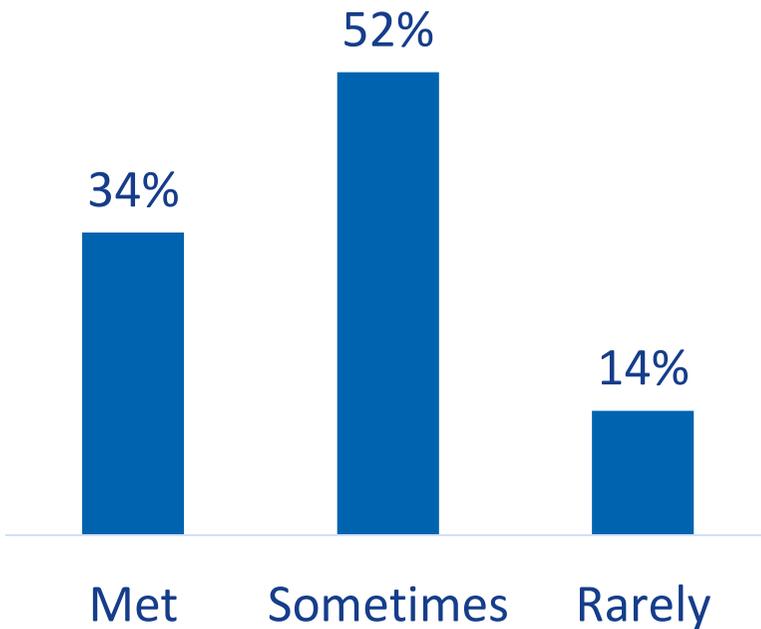
Valued ability to talk

Availability in times of crisis

Unaware of availability of support

“Would wait until [loved one] deteriorated”

Self-care and awareness of their own needs



Difficulty allowing themselves permission to meet own needs

Priority of the cared-for person

What would help?

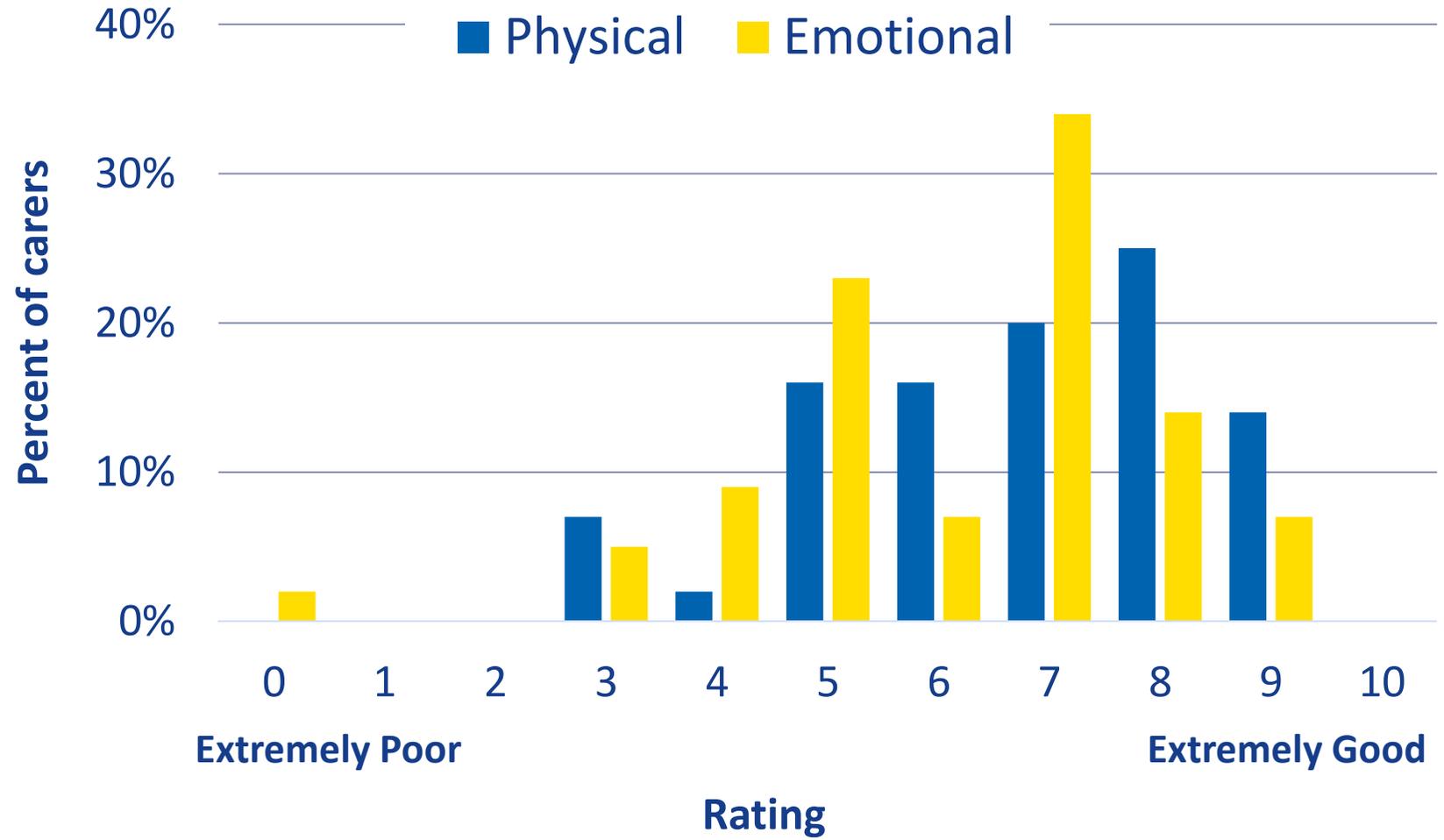
- *Respite*
- *Self-care activities*
- *Social support*

If rarely more likely to report:

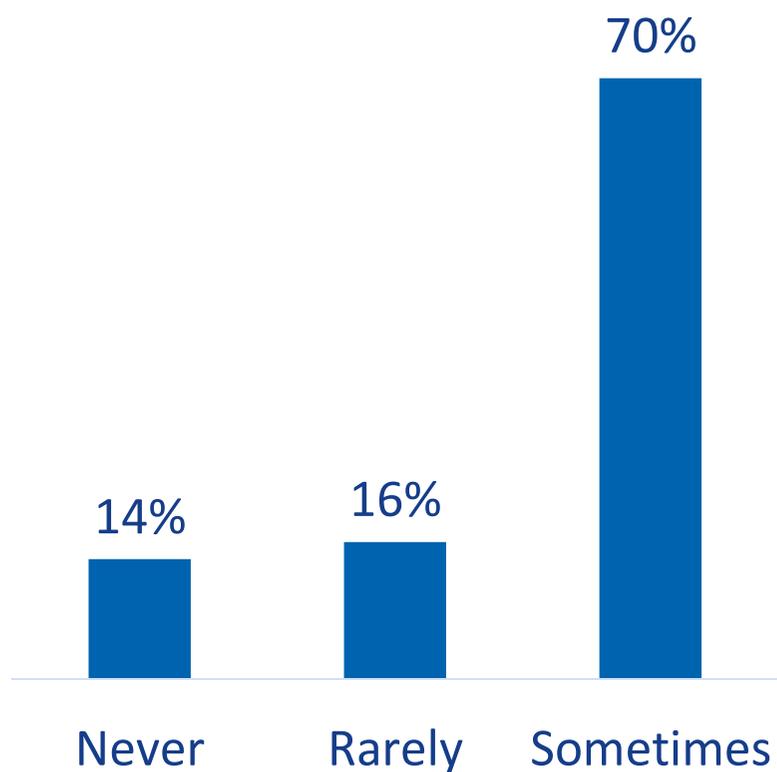
Poor physical health

Fully dependent patient

Self-rated physical and emotional health



Feelings of loss of control



I don't have enough time to myself

I feel housebound

Emotional consequences of caring:

- *Being exhausted*
- *Worry and guilt*
- *Dictated by illness*
- *Loss*



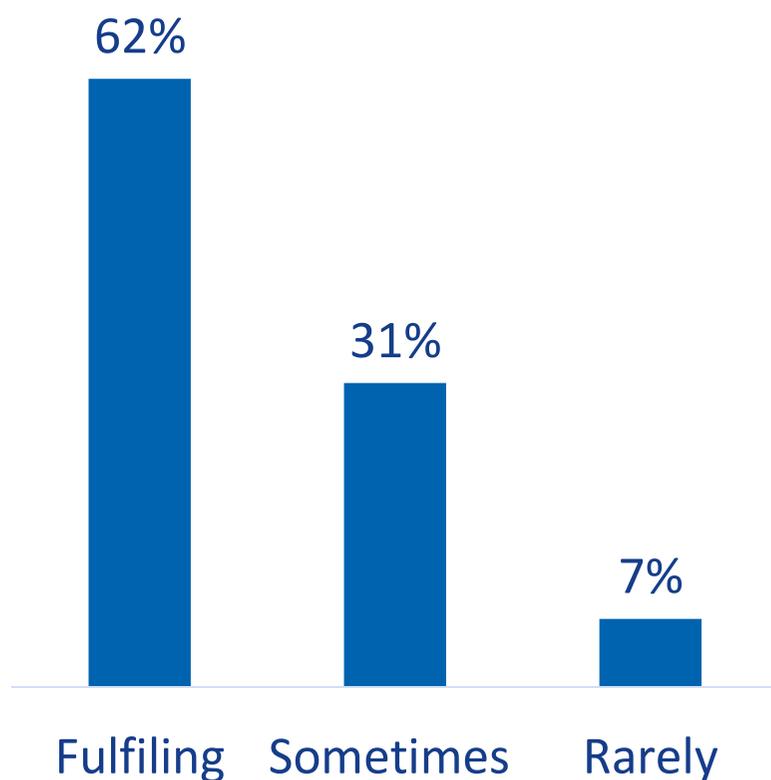
***“As I’m writing this it’s a beautiful and sunny (cold) day. I would love to put my coat on and go out for a walk, for a couple of hours. But I can’t. Sometimes it feels like I’m under house arrest”
(2/2/26).***

What is associated with loss of control?



- Female
- Younger age
- Working or unemployed
- Parent or child of the patient
- < 1 year or 4+ years caring
- Rarely taking time to meet own needs
- Less likely to report fulfilment from caring

Fulfilment from caring



Not fulfilling

Fulfilling when...

- *Person is doing well*
- *Feeling capable*
- *Problems are solved*
- *If not feeling guilty leaving tasks to others*

Difficulty with carer identity

*Associations with relationship

What did we learn?



- Stage of caring matters
- Greater awareness of needs might improve wellbeing
- Reluctance to ask for help from family and friends
- Groups to target for early intervention:
 - New carers
 - Carers who are children or parents of the patient
 - Younger carers, working age
- Information and training may improve fulfilment and sense of control

Carers Working Group





CARER SUPPORT SERVICES





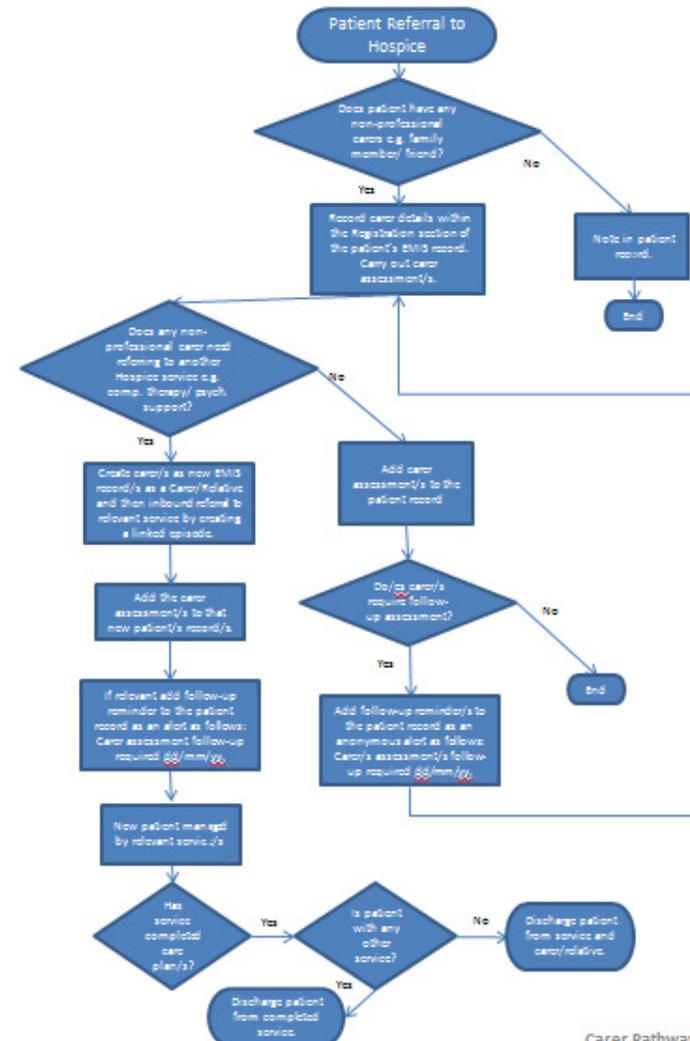







www.hospice.org.im

Hospice Isle of Man Carer Pathways





Thank you

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