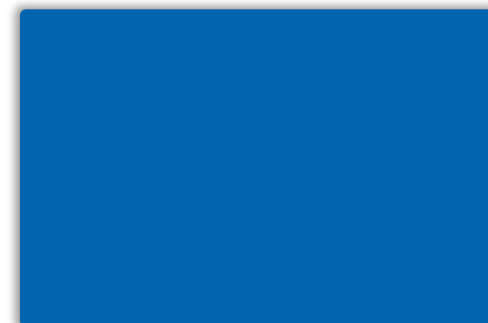


# “Feeling loss of control”: The experiences of informal carers of people at the end of life

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# Background



- People are living longer with chronic and life limiting conditions<sup>1</sup>
- Carers are essential for the delivery of sustainable person-centred care
- 55% of care required at end of life provided by informal carers<sup>2</sup>
- Caring can impact on physical and mental health<sup>3</sup>
- Support for carers remains inconsistent<sup>4</sup>

<sup>1</sup> Harrop et al., 2014, <sup>2</sup>Jansma et al., 2005, <sup>3</sup>Kelley et al., 2013, <sup>4</sup>Harding 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**

**Fulfilment**

# 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

**54%** 1-3 years caring

Carer **60** years

**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

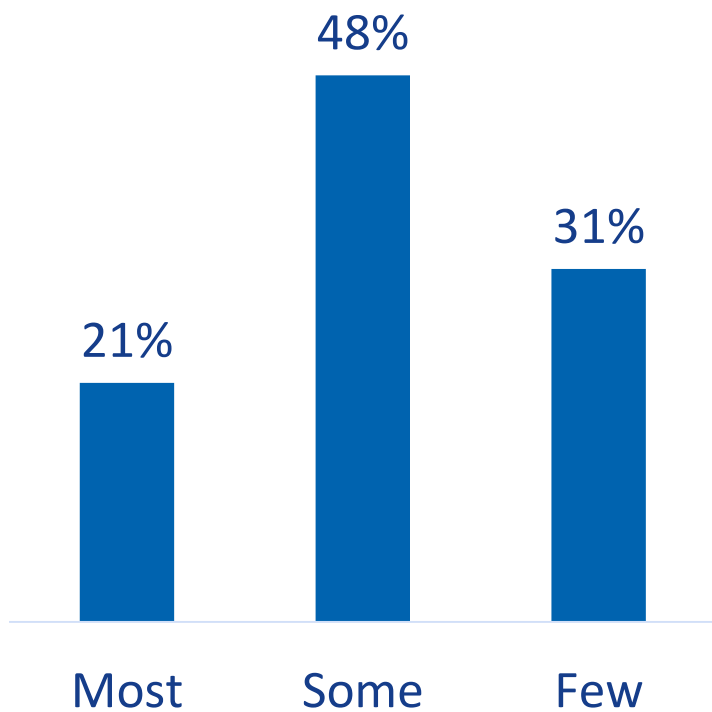
*Unable to leave*

*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





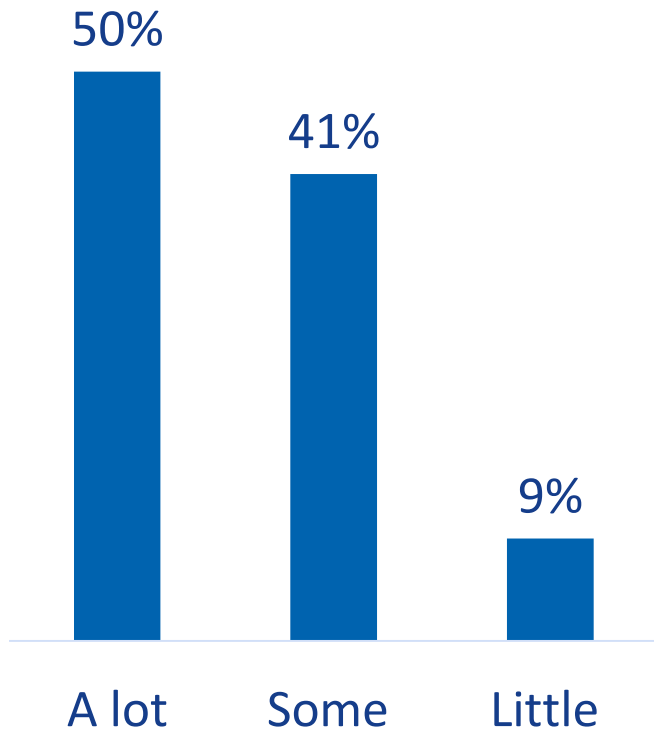
# Support from family and friends



*Happy with the support received*

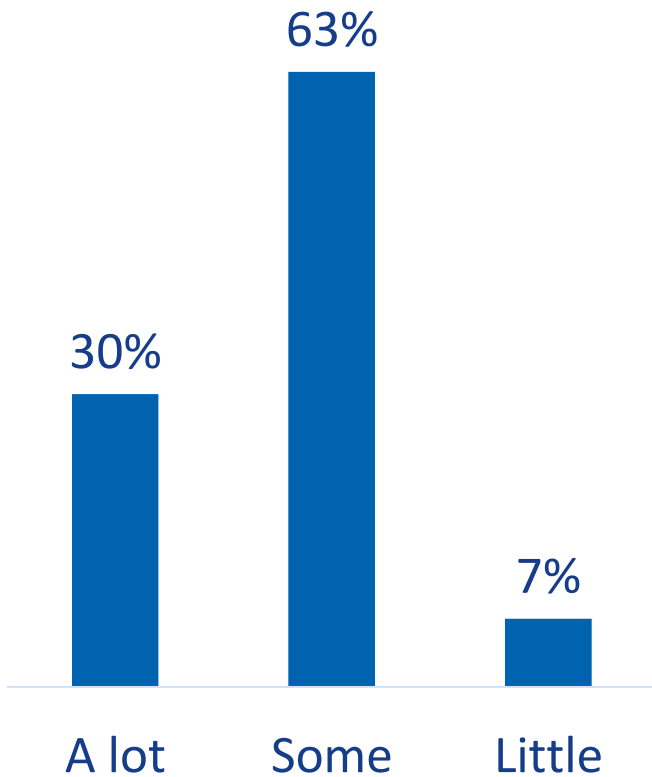
*Do not feel comfortable asking*

*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



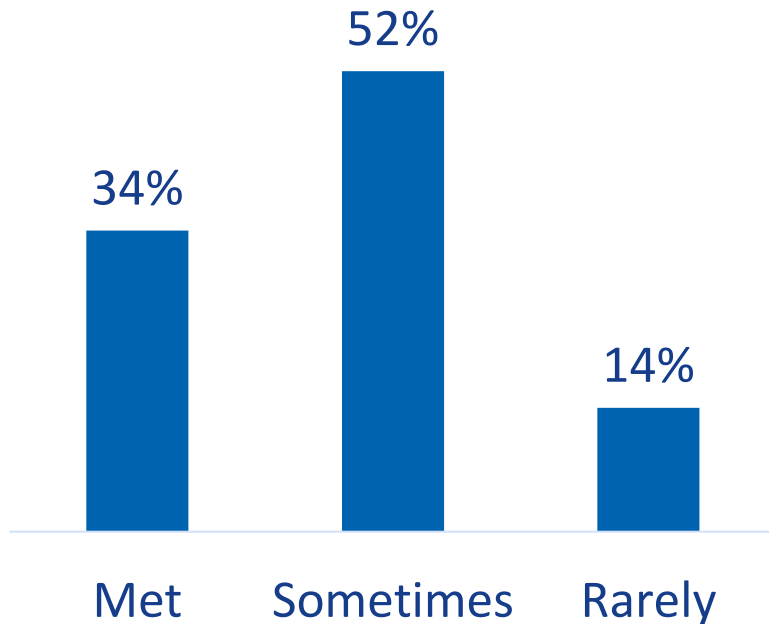
*Valued ability to talk*

*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?*

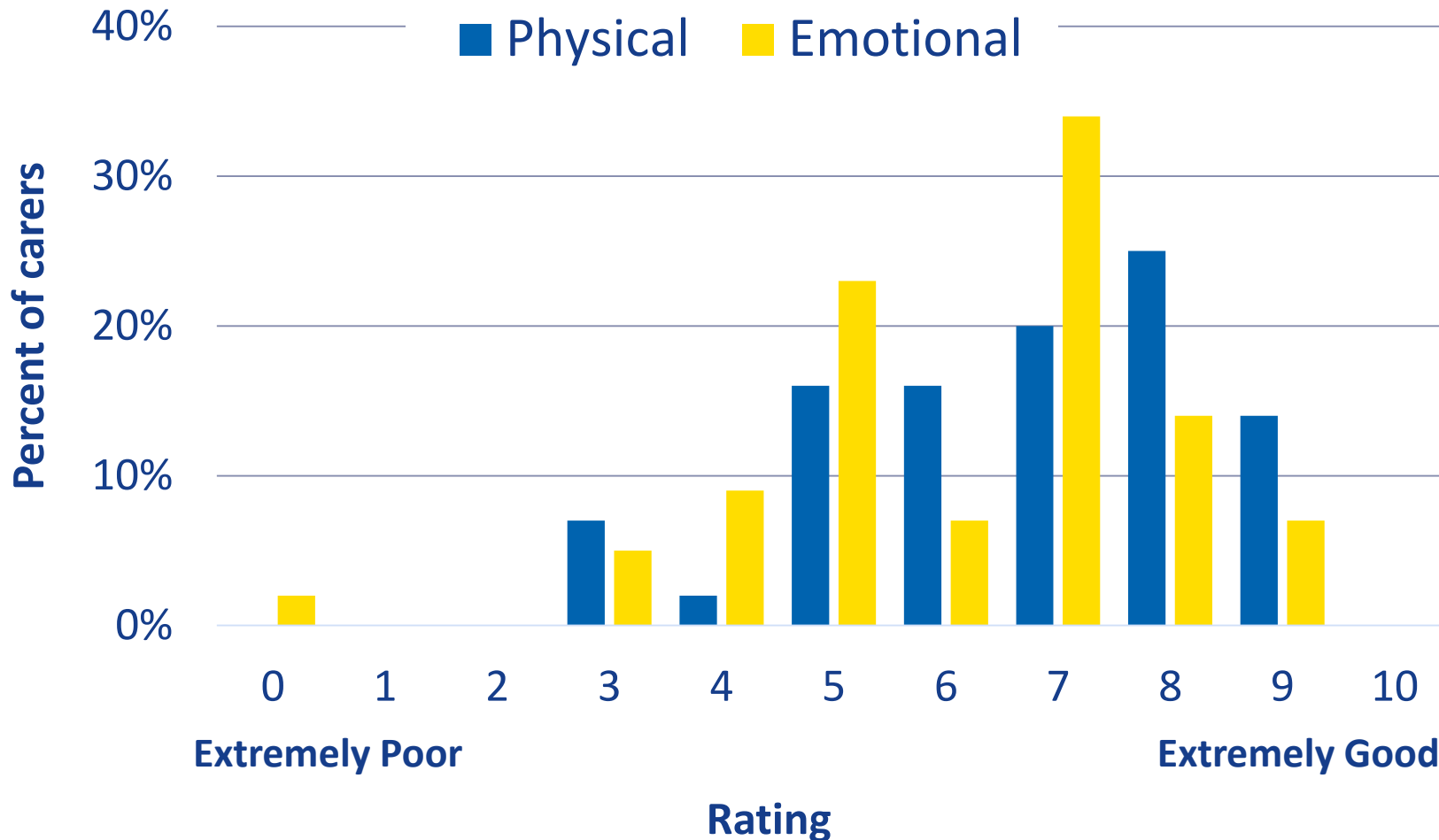
- *Respite*
- *Self-care activities*
- *Social support*

If rarely more likely to report:

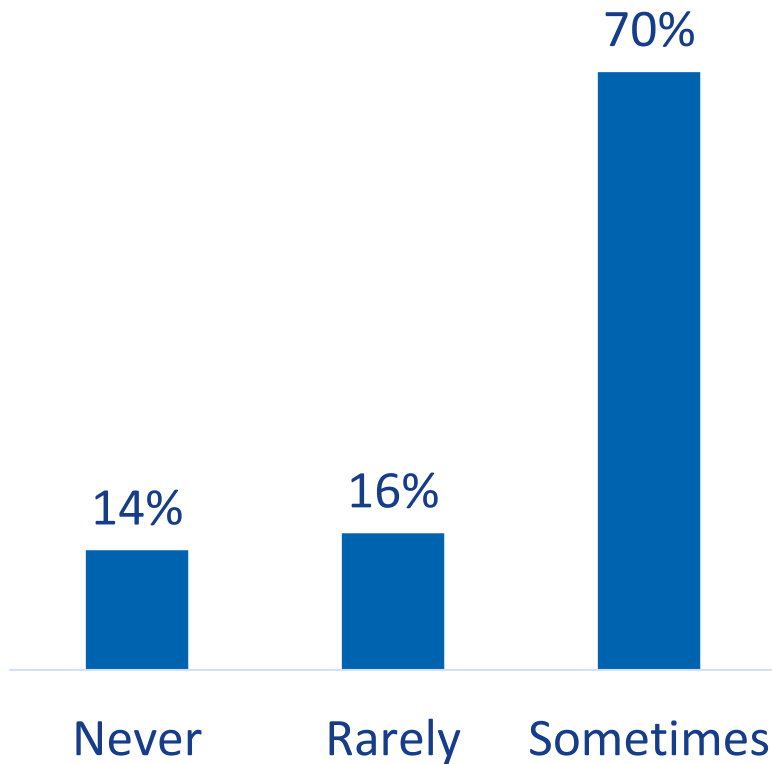
Poor physical health

Fully dependent patient

# Self-rated physical and emotional health



# Feelings of loss of control



*Not enough time to myself*

*Feeling 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 fulfillment from caring

# Fulfilment from caring



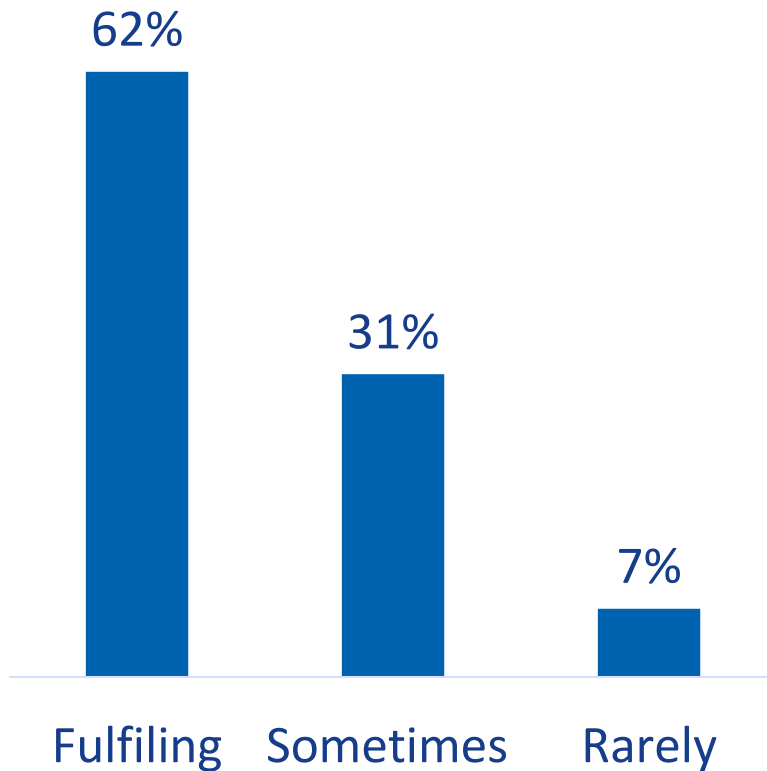
## *Not fulfilling*

## *Fulfilling when...*

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

## *Difficulty with carer identity*

Associated 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

# Conclusions and recommendations



- Informal carers are an integral partner in care
- Reluctant to ask family – rely on services for help
- Support should be tailored to the stage of caring
- Carers face challenges but also find fulfillment
- Carer Pathway for *systematic*:
  - Identification, Assessment, Care plan
- Working in partnership with statutory services and Third Sector organisations to support carers
  - *Isle of Man's Carers' Charter*



# Thank you

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