

## Background

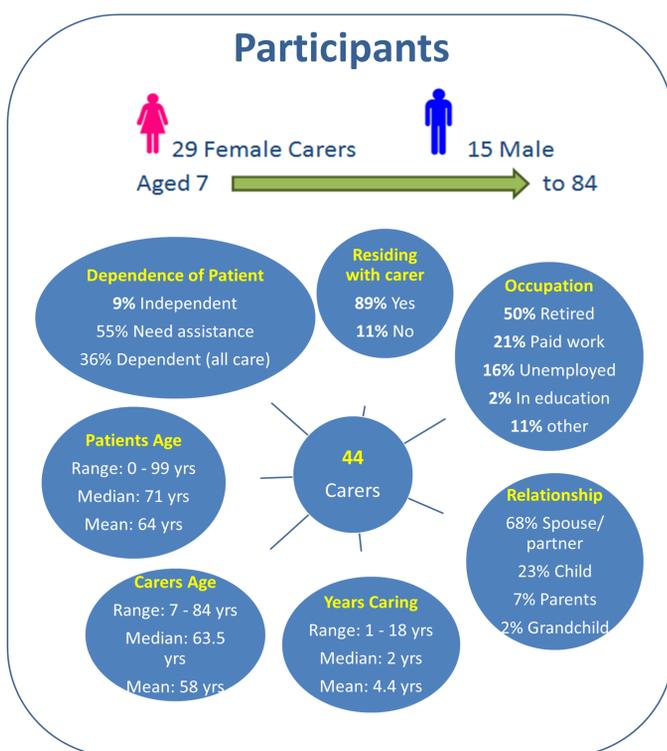
- ❖ Hospice Isle of Man is reviewing and developing the services that are available to carers.
- ❖ Hospice UK has recently published 10 recommendations to improve the way healthcare providers support carers' needs<sup>1</sup>
- ❖ Informal carers provide around 55% of the care required at the end of life<sup>2</sup>
- ❖ The significant demands of caring can have a detrimental impact on the physical and mental well-being of carers<sup>3</sup>

**Aims:** 1) To identify the support carers access and value, alongside the factors that assist or hinder accessing support; 2) To understand carer well-being and the carer experience.

## Methods

- ❖ A Carer Experience Survey was designed based on carer reported outcome measures<sup>4</sup> and the Carer Experience Scale.<sup>5</sup>
- ❖ The survey was distributed by clinical staff to carers of patients on their case loads between 1<sup>st</sup> November 2017 to 28<sup>th</sup> February 2018.
- ❖ Data were collected on demographics and domains of the carer experience.
- ❖ Frequencies were calculated for multiple-choice questions. Differences in proportions were tested using a Chi-square test.
- ❖ Open-ended questions were analysed using thematic analysis.

## Results



### Support from family and friends

- The majority (91%) reported they had 'a lot' or 'some' support.
- Themes:** "I am happy with the support I receive", "I wouldn't feel comfortable asking"

### Carer well-being and self-care

- 64% of participants indicated some difficulty in making time to meet their emotional and physical needs.
- Physical health rated higher than emotional health

### Activities outside of caring

- 30% reported they were able to do few of the things they wanted.
- Significant differences by years of caring: 57% for < 1 year vs. 8% of those caring for 4+ years (p=0.02).

**Themes:** "Unable to leave", "There is an expectation to put them first", "Not enough hours in a day"

### Assistance from services

- 93% of carers said they receive 'a lot' or 'some' assistance from services.
- Themes:** Carers value "being able to talk".

### Sense of control

- 68% of carers stated that they 'sometimes' felt they had lost control of their own lives. This impacted emotional health.
- Themes:** "I don't have enough time", "I feel housebound". Emotional consequences of "being exhausted", "worry and guilt", "loss", "interpersonal", "dictated by illness"

### Fulfilment from caring

- 89% indicated that caring gives them a sense of fulfilment. Many felt that it depended on contingent factors, including the well-being of their loved one.

## Findings and recommendations

- 1. Stage of caring** is important: continuous assessment, individual plans, peer support, information to meet needs by stage.
- 2. Education and training:** Information on the carer role, diet, hygiene, manual handling, respite opportunities delivered in a variety of formats.
- 3. Emotional support and connectedness:** Psychological support service, education packages on role of supporting, adjustment, identity, Social networks.
- 4. Service Delivery:** Flexible, out of hours, reassuring, timely. Practical support with transport, meals, household. Respite is key. Options.

## What would help?

### Respite

"Put things in place so we can choose!  
District care finishes at 6pm and Hospice at Home could be a bigger service" (1/2/7).

### Talking

"Counselling support" (1/1/4)  
"To talk to someone" (2/4/35)

### Being connected

"That my family all support each other in helping my wife they have created a WhatsApp group to send messages, advice and love" (1/2/17)

## Conclusions

- ❖ The carer experience varies depending on the stage of the caring journey and perhaps on the trajectory of their loved one's illness. This study's findings have highlighted important recommendations to ensure that future service delivery legitimises and meets the needs of carers.

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### References

- <sup>1</sup>EWING, G. & GRANDE, G.E. *Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change*. London: Hospice UK, 2018.
- <sup>2</sup>JANSMA, F. F., SCHURE, L. M. & DE JONG, B. M. 2005. Support requirements for caregivers of patients with palliative cancer. *Patient Education and Counselling*, 58, 182-186.
- <sup>3</sup>KELLEY, M., DEMIRIS, G., NGUYEN, H., OLIVER, D. P. & WITTENBERG-LYLES, E. 2013. Informal hospice caregiver pain management concerns: a qualitative study. *Palliative medicine*, 27, 673-682.
- <sup>4</sup>MICHELS, C. T., BOULTON, M., ADAMS, A., WEE, B. & PETERS, M. 2016. Psychometric properties of carer-reported outcome measures in palliative care: a systematic review. *Palliative medicine*, 30, 23-44.
- <sup>5</sup>GORANITIS, I., COAST, J. & AL-JANABI, H. 2014. An investigation into the construct validity of the Carer Experience Scale (CES). *Quality of life research*, 23, 1743-1752.

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## Next Steps

- ❖ Develop a carer's strategy and adapt service delivery to ensure carer's needs are addressed.
- ❖ Further research to explore other aspects of the caring experience.