



# "Your Time, Your Place" Setting up a hub and spoke model

to support people with dementia and their carers.

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# Background

- Approximately 1400 people living with a dementia diagnosis on the Isle of Man.<sup>1</sup>
- Caring for people living with dementia can be an overwhelming experience for carers who often have unmet needs and experience physical and emotional pressures.<sup>2,3</sup>
- Hospice Isle of Man in partnership with Dementia UK and the Forget Me Not Trust, have recognised the need to support people living with dementia and their carers to live well and die well.

#### Aim: To develop and evaluate a hub and spoke model to support people with dementia and their carers throughout key

#### transition points of the disease trajectory

## Methods



#### "Your Time, Your Place" hub

- Starting January 2022. 8 x 3 hour sessions for the person living with dementia and their carers.
- ✤ 20 people at any one time
- Person living with dementia can take part in reminiscence, music therapy and art therapy
- Carers will receive bespoke training from Admiral Nurses to enable them to manage their caring role

#### Spokes for people living with dementia

- To enable them to remain at home
- To avoid unnecessary hospital admissions
- To plan for a good death in a place of their choosing

#### Spokes for carers

- To reduce carer burnout and stress
- To provide tools to manage their anticipatory grief and loss
- To support them to reconnect to society and move forward post bereavement (to start March 2022)
- Clinics to start in November 2021

### Results

"It gave me and my family all the information we needed to prepare for (name) dying" Wife / Carer *"It was a relief to have someone who could actually tell me what is happening and not skirt around the subject" Wife / Carer* 





12<sup>th</sup> July – 30<sup>th</sup> Sept 2021

"You supported us and went beyond to give us peace in a difficult time" Daughter / Carer

*"I'm in a better place now, feel more positive since [Admiral Nurse] came along" Daughter / Carer* 

### Conclusions

Any support model should promote open, honest, two-way dialogue to facilitate patient choice at the end of life and anticipatory care planning to enable the person living with dementia and their carers to achieve a good death in a place of their choosing.

The hub and spoke model should help to reduce inequalities of access for people living with dementia and their carers by providing appropriate and timely support.

**References:** 

1. Alzheimer's Society, (2019), Alzheimer's Society, (Isle of Man) Conference and Report;

2. National Institute for Health and Care Excellence. End of Life care for adults: Service Delivery [internet]. [London]: NICE; 2019 [cited 2021 Oct 5]. (NICE guideline [NG142]). Available from: <a href="http://www.nice.org.uk/guidance/ng142">www.nice.org.uk/guidance/ng142</a>

3. World Health Organization. 10 Facts on Dementia [Internet]. 2019 [cited 2021 Oct 5]. Available from: https://www.who.int/features/factfiles/dementia/dementia facts/en/

