
The Dementia Carers Campaign Network

'Towards a Refreshed National Carers Strategy'

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@DCCNIRL



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The Dementia Carers Campaign Network

- **An advocacy group** that presents a vital opportunity for **family carers** to raise awareness of issues affecting **families living with dementia** in Ireland.
- **48 members** within our Leinster and Munster based groups.



Overview of our presentation

Part One:

Research by the Dementia Carers Campaign Network (DCCN)

Part Two:

Recommendations for the National Carers' Strategy

Part Three:

The *lived experience* presented by Aisling Harmon

What is Carer Resilience?

The 'bounce back ability' of a carer to continue caring following hardship.



Part One: Research into Carer Resilience by the DCCN

How informed and supported do carers feel as their person being cared for engages with long-term residential care or hospice care?

PPI Research



Survey of Carers



The Carer Voice

Results

*Our carers felt more informed and supported when their person being cared for engaged with **hospice care** than long-term residential care.*

Long-term residential care:

Susan explained that “whilst there is some appreciation that a carer needs help when a loved one is living with them – we are not taken into account when our loved one is in full time care”.

Hospice care:

Martin said that his hospice nurse “was an angel, she explained all that was going to happen. She removed our panic and we got all 10 grand children in to say goodbye to Nana and then we spent the next day with Brigid letting her know all was ok and she was free to go.”



Results

*Our carers felt more informed and supported when their person being cared for engaged with **hospice care** than long-term residential care.*

Long-term residential care:

Bernadette wishes there had been “somebody to discuss the huge transition into residential care. The adjustments, the sadness, the feelings and struggles that the transition brought for me personally.”

Hospice care:

Annie said that “Hospice care in the community was wonderful. They were always available, day or night, and they worked with me accepting I was the expert in my husband’s care.”



The impact on Carer Resilience

- Carers don't feel properly informed and supported as their person being cared for engages with long term residential care.
- Carers feel more informed and supported as their person being cared for engages with hospice care.

IMPACT



Hospice care
on Carer Resilience



Long-term
residential care
on Carer Resilience

How can a refreshed National Carers' Strategy enable carers to be better informed and supported as their loved one engages in long-term residential care?



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Part Two: The National Carers' Strategy

- The aim is to support people **to live in dignity and independence in their own homes and communities** for as long as possible.

Does the strategy include all carers?

- This Strategy **focuses on carers in the community** who can be caring for family members or for neighbours or friends in some cases.
- Some aspects of the Strategy will address the needs of carers who do not fit the primary definition. For example, carers who provide care for a limited number of hours or for a short period may still need some support, including information.

The DCCN recommends an amendment of the definition of 'Carer'

Currently the National Carers' Strategy "focuses on carers in the community".

The strategy identified that up to 80,891 (43%) provide up to 2 hours of care per day.

A carer supporting their loved one in long term residential care may provide a similar amount of care.

The Dementia Carers Campaign Network proposes an amendment to the National Carers' Strategy to specifically include and offer provision for family carers whose person being cared for engages with long-term residential care. The caring role doesn't end when their loved one no longer lives at home.

The DCCN recommends an amendment of the definition of 'Carer'

The DCCN proposes that research is undertaken to create proper policy provision for carers whose person being cared for engages with long-term residential care.

Specific policies and measures targeting carers can promote their recognition and inclusion as partners with care teams in long-term residential care.

Learnings may be made from the engagement of carers in the Hospice model.

These specific policies and measures may positively impact carer resilience.

Amendment of the definition would allow carers to be better informed and supported through the ‘Four National Goals for Carers’:

- 1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for**
- 2. Support carers to manage their physical, mental and emotional health and well-being**
- 3. Support carers to care with confidence through the provision of adequate information, training, services and supports**
- 4. Empower carers to participate as fully as possible in economic and social life**



Through inclusion in the National Carers' Strategy Vision Statement these Carers would:

'Be recognised and respected as key care partners. They would be supported to maintain their own health and well-being and to care with confidence. They would be empowered to participate as fully as possible in economic and social life.' This would have a **positive impact on Carer Resilience.**



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Part Three:

The Lived experience of Carer Resilience presented by Aisling Harmon



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FINANCIAL

EMOTIONAL

RESILIENCE
.....has many domains

INTELLECTUAL

PHYSICAL

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Thank You

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