

# Adapting to support patients and their families living with a diagnosis of dementia in challenging times- the role of the Dementia Support Nurse.

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Dementia Support Nurse

# Dementia

“It affects memory, thinking ,orientation ,comprehension , calculation ,learning capacity and judgement.

Dementia has physical ,psychological , social and economic impacts , not only for people living with dementia ,but also for their carers , families and society at large.”

(WHO 2021)

# Statistics

2021 – 64,000 people living with dementia.

By 2045 – 150,000



180,000 in Ireland are carers for a family member with dementia

1 in

**10**

Under the age of 65



63% of people living with dementia are at home



Dublin 2016 – male 6,191

female 10,776



# What is Dementia Support ?

“ Following a diagnosis, the person with dementia will need considerable emotional and practical support.

Local, well coordinated support services are needed to assist people and their families to cope with the choices and dilemmas confronting them at this often distressing and challenging time”

( National Dementia Strategy 2014)

## Post- diagnostic support definition

“Post –diagnostic support include intervention, therapeutic treatments and activities that build on strengths and abilities, helping to maintain and enhance quality of life...they enable and assist people with dementia and their families to live a life of their choice **throughout the continuum of dementia.**”

( Dementia post- diagnostic steering group 2018)

“A report from the Alzheimer's society of Ireland showed that people with a diagnosis of dementia are feeling lonely, trapped and family are struggling with a decline in cognition” (ASI 2020)

**Challenges:**

Covid pandemic

Cyber hacking

Closing of community services  
and resources

Increase in social isolation

Increase in Carer burden

Staff re-deployment

**Pre-Diagnosis:**

Assessment's ceased or stalled

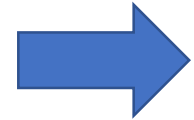
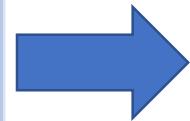
lack of continuity of care

Progression of disease without  
assessment

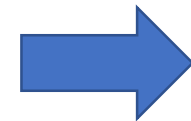
Lost opportunity due to time  
delay in diagnosis

# Development of role : 2020-2022

- Establishment of new service plan do study act, while meeting the challenge of running service immediately
- Provide post diagnostic dementia support sessions 4-8 weeks following diagnosis
- Introduction of phone service
- Development of dementia Support as point of contact to help with non cognitive symptoms of dementia a pathway to help prevent or manage concerns or crisis



- Carer support sessions
- Monitor care given to a person with diagnosis of dementia
- Identify and link a person and their family into local community resources
- Work as part of the MDT within the day hospital
- Act as a source of support for patients and families through the acute service with link to the FITT team and rehab MDT



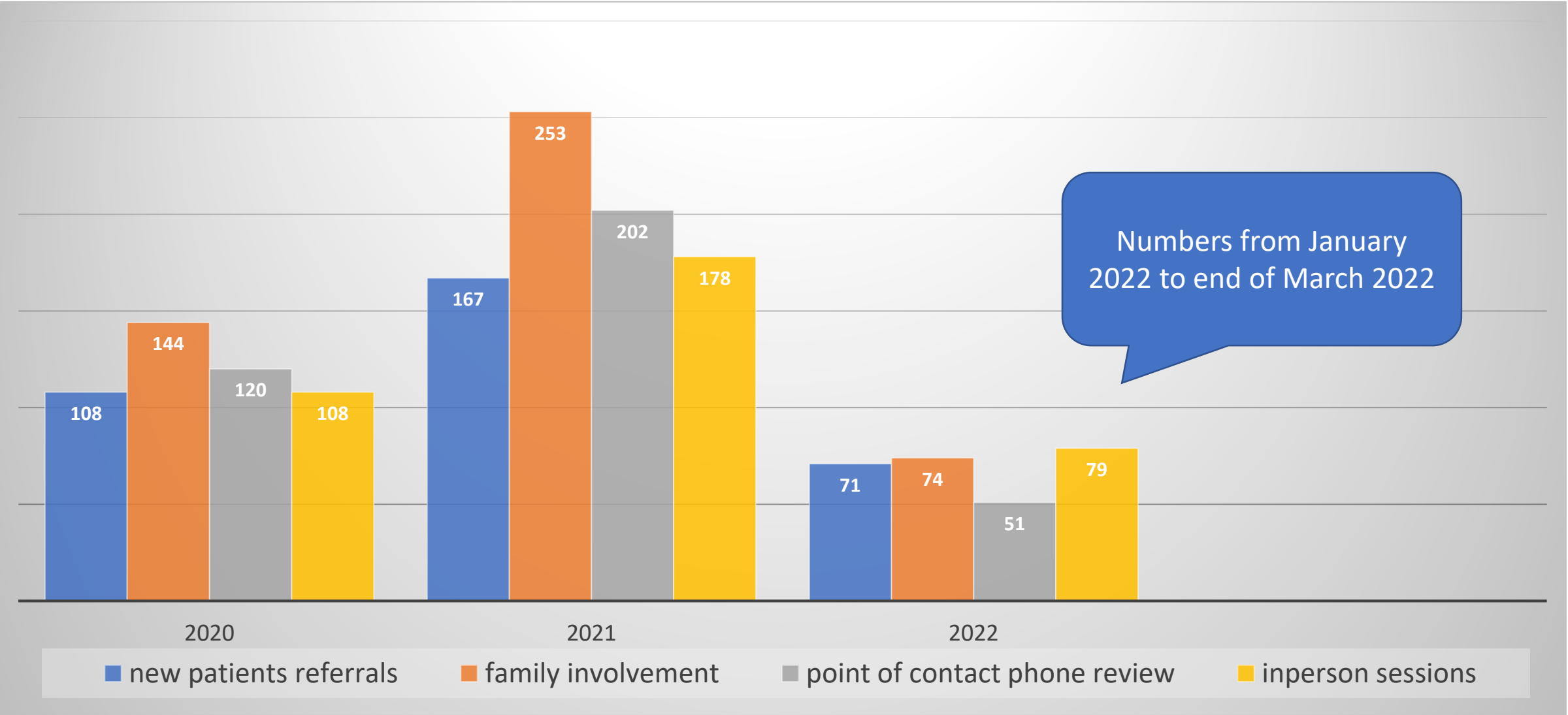
- Developing the role to be part of the referral pathway in Beaumont
- Point of access for community services dementia advisors PHN, day center managers
- Establishing a dementia support nurse EPR, important for patients notes and capturing statistics
- Role of education both for staff and at conferences



# Referral pathway

- Type of patients:
  - New diagnosis of dementia
  - Mild cognitive impairment
  - Management of non cognitive symptoms of dementia
  - Carer support
- Referral pathway:
  - Day hospital
  - OPD
  - FITT team
  - Multi-discipline team
  - Rehab ward

# Growth of Dementia Support Nurse Role



# Point of contact

- Referrals are by consultants, FITT team or self referral
- 25% need urgent link to consultants
- 20% carer stress / ill health concerns
- 55% management of 1 or more NCSD

(sleep disturbance, verbal aggression, walking (old term wandering) and 2-3 cases of physical aggression)



# Support Program

- Providing supports
- Processing and understanding the impact of dementia
- Daily routine advice
- Role of technology
- Community and social connection/support networks – hobbies
- Maintaining relationships
- Health and wellbeing
- Planning for the future
- Advice on Driving
- Carer support and wellbeing
- Expediating medical or psychosocial reviews via existing structures

# Non- Cognitive Symptoms of Dementia

## Mild NCSD 30%

Apathy, shadowing,  
Wandering, night-time  
Disturbance.

## Moderate NCSD 20%

Depression, verbal aggression,  
Sexual disinhibition, wandering.

## Severe NCSD 10%

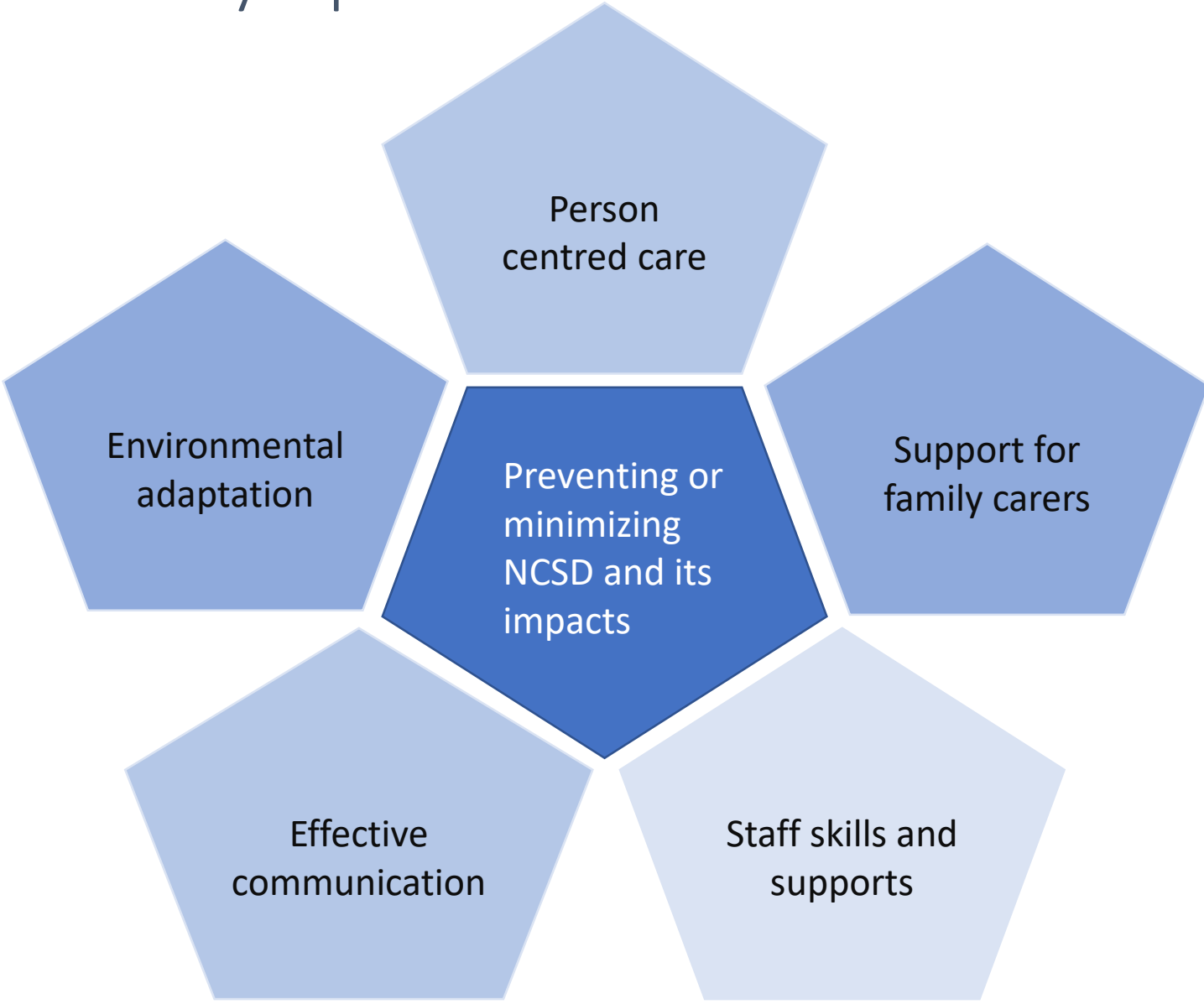
Severe depression, screaming,  
Agitation

## Very Severe NCSD 1%

Physical aggression

(Brodaty et al 2003)

# Non -Cognitive symptoms of Dementia



Non- cognitive symptoms of dementia (NCSD)

# Model of care for dementia in Ireland – draft summary 2021

## 4 key Elements

- A diagnostic model with pathway to diagnose
- Guidance on disclosure
- Personalised care planning that involves person with dementia and their family
- Post diagnostic support and treatment

Follow up 4-8 weeks

Named person

Post diagnostic support is intended to be delivered in order, but as relevant, recognizing that dementia is a progressive condition and a person's needs change

# Patient Survey-2021

- Feed back survey completed 2021
  - Included people with dementia and their family's
  - Sample of qualitative answers

“very pleasant and understanding to my needs delighted to meet Karen and express my feelings”

“very understanding of situation took extra time and attention to my father so he could explain himself”

“Mammy shared a lot with Karen that she would not normally discuss at all eg grieving my father “

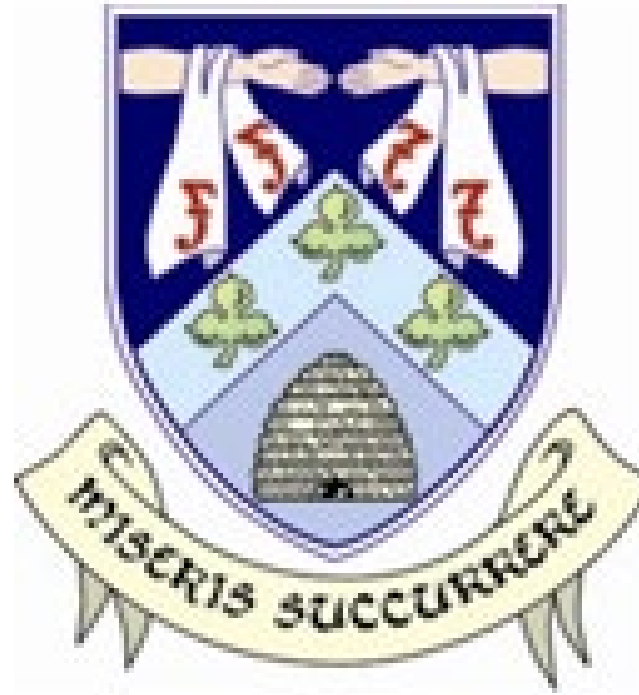
“Excellent advice –love how she spoke directly to my mam and not through me – give my mam control and personal autonomy”



# Next Steps

- Commencement of Memory Matters Carer Education programme ( May 2022)
- Part of Homecare Education programme ( May/ June 2022)
- Dementia register
- Automatic referral for all patients and families receiving a diagnosis of dementia.

**GOAL**  Dedicated post for Dementia Support Nurse role in Beaumont Hospital integrated pathway.



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Thank you

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