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Rationale

- Estimated 3,583 persons with early onset dementia in Ireland (Cahill, O' Shea & Pierce, 2012)- As of 2016 there may be as many as 5,000 (Haase, 2005)

- This group reports depression, changes to family relationships, & a gradual reduction in social contact with friends & community (Haase, 2005; Alzheimer's Australia, 2007).

- Approximately half of EOD caregivers will have symptoms akin to anxiety & depression (Bentham & La Fontaine, 2005)

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Early onset dementia:

Individual, family & professional perspectives on experiences and support strategies

Caroline Kilty, PhD
Alzheimer Society of Ireland

Rationale

- Children of persons with EOD are likely to be younger, and are also affected by the lack of the correct support (Svanberg, Stott & Spector, 2010)

- EOD faces an inverse ageism, with a lack of specific systems in place to address many varied needs (Chaston, 2011)

- While there are similarities, EOD differs from typical age dementia in many respects.

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Overview of the presentation

- Rationale
- Research gaps
- Literature review
- Research questions
- Research methods
- Findings
- Discussion
- Implications for future practice & research
- EOD today
- References

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Research Gap

- Majority of research centres on typical age dementia, and often particularly Alzheimer's disease.
- Literature is informative but little focus on current, lived experience.
- Past research often drew from just one group of stakeholders, i.e. caregivers
- Still some gaps remained as to preferences in terms of supportive strategies in EOD, from the perspective of those involved
- My clinical experience and anecdotal evidence

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Overview

- Qualitative design used over 4 studies

- Participants included persons with EOD, family caregivers and health care professionals

- This research aimed to explore the Irish context, by gathering perspectives & identifying what is most beneficial to the individual, their relatives and those who work in the field

  Quality of life, ability to cope and hope

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Research Questions

1. What is the current experience of EOD in Ireland? What are the main issues?

2. What interventions and strategies are currently available to persons with EOD in Ireland?

3. What do persons with EOD and their caregiver, perceive as beneficial?

4. What are the recommendations for future policy & practice in EOD in Ireland?

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Literature Review

- **Relevant literature:** Alzheimer's Australia (2007) Explored the needs of younger people with dementia, and identified unique issues, warranting unique responses.
  - Difficulty obtaining diagnosis
  - Family issues
  - Revision of current plans, and plans for the future
  - Added concern of genetic forms of dementia

- Haase (2005) in her needs analysis, contributed greatly to our understanding of the Irish experience, and this research aimed to build upon this knowledge, by introducing current qualitative data on the subject, from a psychosocial perspective.

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Research Methods

Study No.	Research Aims
Study 1 Postal Questionnaires	To explore the current experience of EOD in Ireland, exploring all research questions. To inform the development of a pilot intervention
Study 2 Qualitative interviews Family Carers	Qualitative interviews with family caregivers, exploring all research questions.
Study 3 Qualitative interviews Health Care Professionals	Qualitative interviews with health care professionals, setting out to explore research questions 3 & 4.
Study 4 Pilot group for persons with EOD & Caregivers	Pilot intervention for persons with EOD & caregivers, addressing research question 3.

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Theoretical framework

Psychosocial perspectives:
- Braudy Harris & Keady (2009) looked at the lived experience & selfhood in EOD, on transitions in identity.
- Enriched Model of dementia- acknowledges the place of an individual in life, with *"integrity, continuity & stability of the sense of self"* (Kitwood, 1997, p8)- respect for personhood throughout the trajectory of the dementia.
- Kitwood hypothesises that there are factors which are damaging to the individual's well-being, & factors which support the person.
- A psychosocial approach framed the current research

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"Something's not right"
Superordinate Theme- Diagnosis as problematic

Subordinate themes	Data from questionnaires and interviews
(a) Path to diagnosis long & uncertain	*"As a G.P, I know these people... their family... then they come in and it's like...someone has just thrown a grenade into the room .. I would feel devastated for them. I often feel inadequate in terms of ...dealing with it ...it's not the diagnosis you make on the spot".*
(b) Misdiagnosis	*"..It literally took years,…I used to come away thinking then there's something wrong with me (family carer)"*
(c) Time after diagnosis	*"..It's just the case of complete shell shock. What do I do? There doesn't seem to be anywhere to turn to…"*

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"It's just devastating"
Superordinate Theme- The impact of the illness

Subordinate themes	Data from questionnaires and interviews
(a) Quality of Life poor	"He no longer feels part of a community. He was always very sociable"
(b) Losses, i.e. loss of place, roles	"Loss, at a time in one's life when they might have expected not to have lost these things for another 20 years"
(c) Loneliness	" ..It must have been horrendously lonely for him knowing something was wrong but not being able to grasp what it was"
(d) Impact upon the family	it does impact on the whole family. It impacts professionally, financially, socially, sexually, emotionally. It's devastating for the family & a huge financial implication for the family as well "

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"We need to have a serious re-think"
Superordinate Theme- Future recommendations

Subordinate Theme	Data from questionnaires and interviews
(a) Pro-active approach to diagnosis	"Big gap in the area is passing on that knowledge to people who need it. If you get that knowledge out there it would make a huge difference, G.P.s, community health professionals..."
(b) Lifting the barriers	"If there could be...loosening of the...the barriers in the statutory service on the age 65 cut off; people are being punished for getting a diagnosis before their time. Access to services should be based on need, not chronological age"
(d) Rethink our approach to current interventions	"If services could be tailored ...say a day just one day a week ...geared specifically towards younger people..." "To participate more", & to be part of a group in a similar situation, received emphasis throughout

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"They don't belong anywhere"
Superordinate Theme- Perception of current supports

Subordinate themes	Data from questionnaires and interviews
(a) Lack of services	"I though there'd be more...through him being a younger age. I got a bit of a shock when I heard there wasn't"
(b) Age-related barriers	"There shouldn't be any age bar; it is effectively discrimination by regulation...You can't say "Sorry, I know you're suffering but we can't deal with you until you're 65"
(c) The journey throughout	"There's very little...... services are very poor & practically non-existent", "One of the difficulties is that people are sort of given a diagnosis &... left to fend for themselves..."

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Discussion

- **Diagnosis** could benefit from increased awareness amongst professionals on early diagnosis & timely referrals (e.g. Memory Clinics for diagnosis & treatment, the ASI for the initialisation of early support strategies)
- **Care pathways**- There needs to be a clearly defined care plan structure for EOD, with nominated specialties responsible for assessment, diagnosis, treatment and ongoing support.
- **Services** should be based on need rather than age. An individualised approach to care planning, as per the Dept of Health (2012b) may help to address this.

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'A new paradigm with huge potential'
Superordinate Theme- Suggestions for future strategies

Subordinate themes	Data from questionnaires and interviews
(a)Social/ Supportive Interventions	"It would be great (to) come together, ...have a cup of coffee... People with other illnesses, they always have someone to talk to..."
(b) Coordinator/ framework	"A good co-ordinator to get things going, knowing that there is a system in place that will make the transition from each stage easier...."
(c) Inclusive strategies	"You are very much on your own...totally on your own" "Directly or indirectly the family are being affected...in their own way they need support..."

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Discussion

- Reassess **typical dementia approaches** in EOD- Social & supportive community interventions are a preferred option

- Existing structures should consider a **review or modification of services** in order to include younger persons (i.e. Day care)

- Need for the development & implementation of **supportive, collaborative strategies** that are inclusive of the family unit.

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Future research

- Future research should ideally include a greater number of individuals with EOD
- Caddell and Clare (2010) highlighted a need for future research on identity and self in dementia. The current study, with reports of losses, loneliness, changes to work life, & relationships, enhances the argument
- Through the piloting of a designated EOD group, the author explored feasibility, & identified strengths & limitations

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Conclusion- EOD Today

- **ELEVATOR** project (DCU/HSE)
  - Dementia awareness training for health & social care prof-
  - Psychosocial skills training for family caregivers
- **PREPARED** project
  - Upskill & support GPs to make timely diagnosis
  - Explore optimal & evidence based dementia care pathways
- **Crystal Project-** Alzheimer Society & HSE
  - Singing for the Brain
  - Café de Mentia
- **Alzheimer Society of Ireland**
  - Social Club
  - EOD carer support group
  - Plan for the development of an Early Onset Support Group/ Social group

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Implications for practice

- A strength of this study was the inclusion of persons with EOD, as persons with dementia have featured little in previous literature (Nolan *et al*., 2006).
- It is important that persons with dementia receive the support of peers, & the opportunity to maintain positive ways of living (Chaston, 2011). This research identified that this is something persons with EOD, & those who care for them, are actively interested in.
- This desire to be amongst others, as opposed to solitary interventions (i.e. counselling), is a finding which can guide future EOD intervention design.

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End of presentation

Thank you for listening

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EOD today

- While the Dementia strategy does not highlight EOD as an area for focus, there are initiatives that are in development & in progress which will have a role in EOD

- **Dementia Advisors**-Alzheimer Society of Ireland
  - This is a key point which emerged in Studies 3 & 4- the need for signposting, timely referrals, specific information

- **Dementia Friendly Communities** -Genio/ASI
  - From studies 1, 2 & 3 it was evident that isolation and reduced social outlets are an issue in EOD. The provision of community support could assist with this.

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