Psycho social interventions for younger people diagnosed with dementia

A focus on communities
Presentation Overview

- Evidence of ‘what people look for in psycho-social interventions’
- Current Guidance available
- Models and approaches
- Sustainability
Current estimates

• In the UK, approximately 42,000 people (approx. 5%) have been diagnosed with young onset dementia (<65 years of age)

• Diagnosis is often delayed
  ➢ Symptoms not dementia specific
  ➢ Atypical dementias
  ➢ Resistance to being diagnosed

• Average time to diagnosis: 4.5 years
What do younger people with dementia look for in psycho-social interventions?

What we already know
1. Undertook **scoping review**: >700 documents
   - 25 years descriptive research on the unchanging experience on the difficulties of people living with young onset dementia
   - Needs based

2. **Discussed findings** with ‘Experts by Experience’

3. **Focused systematic review on service provision** for younger people with dementia:

   Only 10 peer reviewed papers on service provision
In involving younger people with dementia

- Gap highlighted: Studies had not explored how agencies could mediate peer-to-peer support
- Pragmatic ideas of how to improve services (EbE)
Findings from discussions with Experts by Experience

• **Recognition**: Small numbers of people (works against sustained funding of service-led provision)

**Third sector**: focal point for advice and support

• Suggestions: To enable families in similar situations to meet / build networks of mutual support
• Introduction service?
• To overcome issues of data protection; unintended consequence of maintaining isolation
• Online service (local events / lift sharing)
• Third sector / local business, eg. clubs / restaurants……

**Anchored by a core**
GUIDANCE
Young onset
Guidelines at the systems level: NHS pathway through the system

This is for dementia more widely and includes younger onset

- Preventing well
- Diagnosing well
- Supporting well
- Living well
- Dying well

- Dementia management
- Support for carers
- Making services accessible
- Staff training and education

About dementia including young onset, but not young onset specific
Practitioner level: Young onset dementia

Decision making guide for GPs

Endorsed by the Royal College of GPs

https://www.youngdementiauk.org/gp-guide
• **Memory Services National Accreditation Programme**
  • Coordinated by: The Royal College of Psychiatrists

• **Adopted a new set of national standards for Young onset dementia (2016)**

• **Recommendations:**
  • **Service planning and commissioning:** “…specific pathway for people with young onset dementia, learning disabilities and rarer forms of dementia where diagnosis is more complex and more likely to be delayed” p11

  • **Staffing:** “A named lead within the team for people with young onset dementia” p17

Current models and approaches described in the literature

Young onset dementia
## Micro-level:
Wide range of psycho-social interventions...

...most frequently mentioned in our group discussions with Experts by Experience

<table>
<thead>
<tr>
<th>1. Dementia Advisors / signposting</th>
<th>5. Family support / bespoke / including respite options / assessment ASC</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Post diagnostic support</td>
<td>6. Day centres for younger people with dementia</td>
</tr>
<tr>
<td>3. Social connections / Peer support</td>
<td>7. DEEP social network</td>
</tr>
<tr>
<td>4. Third Sector organisations as ‘anchor’</td>
<td>8. TIDE carers support network</td>
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Targeted support: Specialist support groups

http://www.raredementiasupport.org/
https://www.ucl.ac.uk/drc/support-groups
Example from my NHS TRUST

- Encountering few people with young onset dementia
- One home visit; Alzheimer’s Support Worker or Dementia Advisor
- Signposting to local support e.g.: memory groups, befriender services
- Carer’s assessment offered;
- OT referral (if required)

Multi-disciplinary team meetings (once a week)

**Recommendations** (will also benefit younger people with dementia):
More integrated working between clinical services, ASC and Third Sector

❖ Standardising services that are sustainable
Community based support

- Main providers: family members
- Range of models; different providers, many rely on volunteers
- Locally available elements of support not joined up
- Frequent changes of staff / volunteers
- No continuity of care / support
- Unique journey of adjustment
Case management: For young people with dementia

**UK:** Tessa Gutteridge: Director of YoungDementiaUK
- Key workers; trained; long-term staff;
- Work with a family for as long as support is desired
- Key workers are not volunteers
- NOT linked to HC&SC system; relies on charitable funding

**UK:** Alzheimer’s Society:
- Side by Side model: service supporting individuals & families; volunteer led
- Currently +/- 60 locations in the UK
- Volunteer recruitment, retention, attrition

**AU:** Alzheimer’s Society:; case management; long term; linked to federal structure (H&SC)
Community based organisation

**AU:** Based on members’ abilities, interests

- A sense of ownership and belonging
- An anchor; ‘someone who is a constant presence’
Day-centre model: The ACE Club

<table>
<thead>
<tr>
<th>Clinical observations</th>
<th>Identified needs</th>
<th>ACE goals</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active disablement and loss of self esteem</td>
<td>Confidence building and raising self esteem</td>
<td><strong>Achievement:</strong> Adopt a culture of enablement and promote autonomy</td>
<td>Increase in self-esteem: diverse activities promoted <strong>confidence</strong> and independence</td>
</tr>
<tr>
<td>Socially isolated and excluded</td>
<td>Social activity; inclusion</td>
<td><strong>Belonging:</strong> foster development of supportive network</td>
<td>Identify with each other; found companionship and considerable support</td>
</tr>
<tr>
<td>Risk of depression; Mal-adaptation to life with dementia</td>
<td>Acceptance and positive adaptation to chronic and life-changing condition</td>
<td><strong>Continuity:</strong> Dynamic: response to natural ebb and flow of life and changing circumstances</td>
<td>Facilitated people’s abilities to <strong>come to terms</strong> with having dementia and enabled them to be more open about their difficulties</td>
</tr>
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Peer support, relationship centred day service

Based on ‘Senses Framework’ [linked to clinical observations] (Nolan et al 2006)

Promoting wellbeing and peer support for younger people with dementia (Davies-Quarrell, 2010)
Options for younger people with dementia within wider dementia provision
A local charity

- Run 40 support groups
- Reach +/- 300 people each month
- Younger people move between groups
- Merge according to interest
- This model is deliberately ‘loose and fluid’
- ‘Stage’ appropriate rather than ‘age’ appropriate
- +/- 70 volunteers
- Former social workers / dementia charities
- Former carers
- Succession planning?

Key points:

- Developed in NL 25 years ago to provide local community support to people living with dementia and their family carers.
- Emphasis on early support and intervention. i.e. applicable to YOD
Macro level: Dementia Friendly Communities (DFCs) (DEMCOM) study:

- Government target that by 2020 50% of the population will be living in a Dementia Friendly Community (DFC)
  - Varying compositions / configurations (DAA, LA, H&SC, business…)
  - **Remit**: to connect, campaign, raise awareness, share best practice, and take action on dementia;
  - Currently +/- 330 accredited DFCs in England

- DFCs are not Young Onset specific, yet much of the **PPI** (Patient and Public Engagement) and Community Engagement, is **carried out by younger people with dementia** who contribute, make suggestions, offer feedback

- Bottom-up working is effective, but for continuity the backing of an anchor institution like a LA or NHS Trust is needed
Networking model
Psycho-social support

Innovations in Dementia
-Dementia Engagement and Empowerment Project (DEEP) >120 groups in the UK

A social movement

- Group dynamics?
- Leadership?
- Support?
- Sustainability?
SUSTAINABILITY
What promotes sustainability?

- A positive dementia discourse [capacity & potential] (Dröes et al 2017)
- UK: Integration of HC&SC with designated dementia leads / professionals
- Population based initiatives that are bottom up
- Succession planning to optimise community based support
- Involvement of younger people with dementia
Future Research priorities
as highlighted in my research

We know what people affected by younger onset want and need:
The Q is: how can we deliver it?

1. To understand different models that sustain and support people living with young onset dementia and to understand how to support volunteers

2. Making explicit the role of Health Care, Social Care, Third sector organisations

3. The financial impact of Young Onset Dementia on families

4. Other priorities?
In conclusion
Thank you

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