Young Onset DeMEntia Service

“Focus on ME”

Simon O’Donovan MBE
Team Leader

YOD Conference, Sep 2018
Prevalence
Ref. UK Dementia Report (Second Edition), Alzheimer’s Society 2014

- 850,000 people with dementia in the UK
- 42,325 younger people with dementia in the UK (ages 35-64)
- 2,220 younger people with dementia in Wales
- 289 younger people with dementia in Cardiff and Vale
- 142 people with young onset dementia known to C&V service currently (43 between 66-70)
Referrals data

<table>
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<tr>
<th>Referrals received in year</th>
<th>21</th>
<th>27</th>
<th>93</th>
<th>39</th>
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<tr>
<td>Discharges in year</td>
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<td>6</td>
<td>39</td>
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<tr>
<td>Deaths in year</td>
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<td>4</td>
<td>9</td>
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<td>Overall caseload</td>
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<td>112</td>
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<td>Primary MH caseload</td>
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<td>43</td>
<td>65</td>
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<tr>
<td>Secondary MH caseload</td>
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<td>69</td>
<td>55</td>
<td>65</td>
<td>72</td>
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YOD Service Referral & Caseload Data
**A YEAR IN YOD**

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<tr>
<th></th>
<th>As at Oct 2017</th>
<th>As at Sept 2018</th>
<th>Discharges</th>
<th>Deaths</th>
<th>Referrals Received</th>
<th>Overall Picture</th>
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<tbody>
<tr>
<td>Primary Caseload</td>
<td>62</td>
<td>76</td>
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<tr>
<td>Secondary Caseload</td>
<td>66</td>
<td>63</td>
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<tr>
<td>Deaths</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Referrals Received</td>
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<td>Referrals Accepted</td>
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<tr>
<td>Totals</td>
<td>128</td>
<td>139</td>
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</table>

* 169 YOD clients and families supported in year *

* 128 Oct 1st 2017 clients + 24 new accepted referrals in year + 11 discharges + 6 deaths in year
Developing specialist services for younger onset dementia

- Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed. *(NICE CG42, reviewed in 2016)*

- There is a paucity of specialist services nationally to meet the needs of this group. Young Dementia UK has developed a database of YOD services.

- There appear to be only 10 specialist, dedicated Younger Onset Dementia multi-disciplinary teams within the NHS in the UK. Only 4 of these have dedicated Consultant Psychiatrist sessions or posts.

- The C&V service model appears to be the most fully formed, with dedicated sessions or posts across every discipline, a formal partnership with the Alzheimer’s Society and an inpatient unit.
Facts about younger people with dementia

- Dementia presents differently in younger age people.
- Problems with language, vision, personality or behaviour may feature as early symptoms, rather than memory problems.
- People are more likely to still be working, have significant financial responsibilities such as a mortgage and have children or parents to care for.
- Remaining physically and socially active is especially important to younger people with dementia.
- The rate of progression and decline may be faster than in older age people with dementia.
- Younger people with dementia more often survive to the end stage of the illness where a focus on palliative care is required.
Dementia subtypes in younger people

- Only 1/3 of all YOD cases have diagnosis of AD
- Greater representation of FTD affecting behaviour and speech
- Rare forms and inherited causes account for almost 1/5 of cases (links with Medical Genetics Clinic)
- Atypical presentations are common
- Diagnosis is often delayed.

Causes of Dementia in over 65s

- AD: 62%
- Vascular dementia: 17%
- FTD: 2%
- LBD/PD: 6%
- Mixed: 3%
- Other: 10%

Causes of YOD

- AD: 34%
- ARBD: 10%
- LBD: 7%
- FTD: 12%
- Vascular dementia: 18%
- Other: 19%
- Mixed: 3%
- Other: 10%
The National Dementia Vision for Wales (WAG, 2011) saw a sum allocated to Health Boards across Wales for starting up specialist younger onset dementia services.

Cardiff and Wales allocation was £69,200. This allowed for the appointment of a full time Dementia Care Advisor post and 1.6 Family Support Worker roles.

Some reallocated Directorate funds saw Team Leader and Consultant Psychiatrists sessions added to form a start up team, with the already existing Alzheimer’s Society half time post.

A Business Case followed to enable formation of a full multi-disciplinary team with dedicated inpatient beds for extended psychiatric assessment. (Based on repatriation of patients in high cost external CHC beds.)
YOD Multidisciplinary Team (Community)

Claire Hardcastle, Speech and Language Therapist (0.5 wte, Band 6); Jo Daunt, Community Mental Health Nurse (f/t Band 6); Karen Warlow, Medical Secretary (0.8 wte, Band 4); Mark Jones, Dementia Care Advisor (f/t, Band 6); Simon O’Donovan, Team Leader (0.5 wte, Band 7); Julie Rees, Physiotherapist (0.5 wte, Band 6); Phil Addicott, Dietician (0.5 wte, Band 6); Dr Dragana Turic, Consultant Psychiatrist (f/t); Tim Nicholls, Community Mental Health Nurse (8.4 wte, Band 6); Helen Cook, Alzheimer’s Society Support Officer (core team member - 5 sessions); Gafyn Blake & Sue Gallagher, Family Support Workers (both f/t, Band 3); Gail Pickford, Occupational Therapist (0.5 wte, Band 6); Jay Coakley, Therapy Technician (f/t, Band 4); Holly Davies, Clinical Psychologist (0.5 wte, Band 8a)
Admissions data

MHSOP Inpatient Admissions - Under age 65 *
(* Noting YOD Service criteria includes 65 and over, usually up to age 70 if still surviving)
(Also 2018 only first quarter)

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<td>Respite admissions</td>
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<td>15</td>
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<td>16</td>
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<td>4</td>
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<tr>
<td>MHA</td>
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<td>Total</td>
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<td>25</td>
<td>23</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>31</td>
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</table>
I feel frightened and alone

Shared themes of existential need

Are there other younger people with dementia?

How can I share my thoughts and feelings with people who will understand?

How do others manage?

- Post Diagnosis Support Groups – seven sessions
- Monthly Keeping In Touch Group
Cognitive Stimulation Therapy Groups

- **Share** – Community CST group (over 14 weeks)
- **The Friendship Group** - Hospital based CST group (weekly)
- **The Tuesday Club** - For inpatients cared for on a young onset dementia assessment ward (weekly)

*CST activities blog.* [www.simondementia.co.uk](http://www.simondementia.co.uk)
Taking Services Beyond the Hospital

- Using the **collective voice** to advocate for dementia appropriate services

- **Ty Hapus Day Service** – 10 places day service in Barry. Close working relationship

- **Individualised Gym Sessions** - supported by Therapy Technician staff (weekly)

- **Walk & Talk Group** – monthly walking/hiking group supported by YOD team (monthly)

- **Pedal Power supported Cycling Group** (monthly)

- **Table Tennis club** (monthly)

- **Working with Gofal** – developing **The DIAL** project and enabling access to **Volunteer Befrienders**

- **Chapter Arts Centre** – The development of **Dementia Friendly Cinema screenings**

- **The National Museum of Wales** – linking with dementia workshops

- **Re-Live** – engaging people with therapeutic theatre work
Supporting Carers

The Carers Support Group
Meeting in a public house/private space
Open forum for carers to discuss issues, concerns
Periodic input from professionals to address specific topics of interest
Monthly afternoon session

Carers Group for Adults with a parent with dementia
Located at Chapter Arts Centre
Participants typically in early twenties
Enables mutual support, counters isolation, forum for discussion, information sharing, learning together
Monthly evening session

‘Could not manage without Group contact’

‘Coming here allows me to depressurise’
Service satisfaction

- 2017 service evaluation demonstrated clear benefits to clients and carers, with a service satisfaction rating of 92.5% (response rate 40/120).

- Most highly valued aspects of service:
  - Ease of access
  - Continuity of support
  - High levels of person centredness
  - Rapid response to changing circumstances
  - Social and therapeutic opportunities
  - Support during transitions in care
  - Recognition of grief and loss
Tania is the wife of Nich, who has a diagnosis of early onset Dementia with Lewy Bodies and is currently an inpatient.

“The Young Onset Dementia Service has been life changing for us during the last few years. When my husband was first referred we only expected regular outpatient appointments. How wrong we were. The level of engagement across the various parts of the service has been outstanding. We are so grateful for the continuity of support, which works very effectively.

Staff have been friendly, informative and helpful. What I value most is the transparency with which things are done and the unique way in which staff treat both patient and carer. There is a true feeling of togetherness, rather than us and them. Everyone has gone the extra mile to enable us to cope with the challenges we have been faced with.”
Living with PCA: ‘just take everything by day’

Nazmoon Bajaji and Christina Maciejewski discuss the rare form of dementia known as posterior cortical atrophy (PCA). They draw on the experience of Linda Hall, who was diagnosed by Cardiff memory team at the age of 59.

Posterior cortical atrophy (PCA) is a rare progressive condition in which there is damage to the brain cells at the back of the brain, namely the parietal and occipital lobes and the occipitoparietal region. The vast majority of cases are thought to be caused by an atypical variant of Alzheimer’s disease.

PCA tends to affect people at an earlier age than Alzheimer’s disease normally does, with people experiencing symptoms such as visual problems and cognitive difficulties. Linda Hall, who lives in Cardiff with her husband Ken, is one of these. In 2011, she was diagnosed with PCA at the age of 59 by the Cardiff memory team and is now supported by Cardiff and Vale Older Adult Day Service.

People with PCA report a gradual decline in vision and visual-perceptual abilities, which can lead to changes in the way they see things, as well as changes in the way they interact with the world. This can result in difficulties with reading, writing, and drawing, which may be a concern in the early stages of the condition.

N: Tell us about the process of how you got a diagnosis at PCA.
L: They didn’t know what kind of Alzheimer’s I had. I had been in the consulting room and they said I had a brain tumour.
N: Ken, you’re a consultant, what did you think of that?
K: I think it’s a common worry when things have gone wrong with your brain, and it’s not necessarily something that’s going to happen.

N: How do you feel about being given this diagnosis?
L: For me, it was a revelation. I just didn’t know what was going on, and I was terrified.
N: Can you remember the day it happened?
L: The day before the diagnosis, I just remember being rushed to the hospital.
N: How has your life changed since the diagnosis?
L: I’m not in control of everything now. I have to be in control, always have.
N: What difficulties do you now face?
L: I find the pace of everyday life has slowed down, and I find it hard to keep up with things.
N: What adaptations have you tried and found useful in overcoming these difficulties?
L: I use my notebook and my phone all the time, and I find that’s been really helpful.

Life is good sometimes – it’s not all bad. We try to go out every day, even just for a cup of coffee or quick look at the shops.

Linda and her husband Ken

L: We had one day before the diagnosis. For two hours she was just looking at the window, and then she turned to me and said, “I want to go out.” And I said, “Okay, let’s go.” She was so happy.

N: You have to be in control all the time.
L: I think it’s important to have some control over what you’re doing.
N: We do have control over what we can do.

Further information
Linda and her family openly discuss the Rare Dementia Support website, where there is much useful information and a support group that can provide valuable insight into the experiences of people living with PCA. Go to: www.raredementiasupport.org.uk

The authors also recommend the memory clinics and dementia support groups in the local community.
First full year operations realised net cost savings of £133k and cost avoidance (external placements) of £457k. The total £590k saving was after staff costs of £258k.
The dementia specialist

Anyone who has seen a loved one with dementia will know how devastating it can be. About 850,000 people in the UK have been diagnosed with the condition, a figure that experts say will continue to increase as the population ages. But there is another side to the disease: about 42,000 people in the UK are living with younger onset dementia. Simon O’Donovan, the team leader of the younger onset dementia service in the Cardiff and Vale region, is one of those dedicated to helping them.

“There are some really important differences between younger people with dementia and older patients,” he says. “They are often in employment, they might have young families, they may have large financial commitments - there are massive implications about how they will live with their journey through dementia.”

O’Donovan chats over a cup of tea in the University Hospital of Wales in Cardiff, but most of his time is spent in his car, criss-crossing the region going to support groups for patients, to homes, or to act as an advocate for those who may be facing disciplinary action because of a lack of understanding of their condition.

The treatment of younger dementia patients has been revolutionised over the past decade, O’Donovan says, and the former consultant nurse’s contribution to that change was recognised this year when he was awarded an MBE. In Cardiff and Vale, younger dementia patients may go to a walking group, to musical therapy, play table tennis or take part in a mindfulness session. Their houses are visited, their families are consulted, and the painful emotional and psychological strain of living with dementia does not go unignored.

“We’ve been running for about five years, and the data suggests we are helping people to avoid crises; we are keeping them out of hospital and care homes and managing their condition in the community,” he says. “There was expenditure in bringing the team together, but the cost avoidance is huge, even in just bed days … and that’s before you count the emotional cost to patients and their families. We are a small service with big dividends.”

O’Donovan gives the example of one patient, a woman in her 40s. After he was called by her GP, he visited her house and found it in total disarray. Food was out of date, and tasks had been started and not finished. Thanks to the advocacy work of the team, she was diagnosed and has the support she needs.

“She has a personal assistant she sees every day, the local cafe gives her breakfast, a local pub gives her lunch,” he says. “When I visited her last week she was well-dressed, clean, happy. Five years ago she would have been in residential care by now, and the cost to the state and to her would have been huge. We can really turn people’s lives around.”

He says he is hopeful about the future, but the government and society has to face up to the real challenge of dementia. “There is no getting away from the issue of long-term care,” he says. “Its funding is going to have to be faced up to.”
Future directions

- Plan to develop St Barruc’s and Morfa units in Barry Hospital as a **Health & Wellbeing Centre For Young Onset Dementia**

- Bid in for refurbishment of 16 bedded ward (6 acute assessment beds; 10 extended assessment beds including 1 respite),

- … for YOD MDT base

- … and future development of YOD Day Hospital service

- Need to share our work to promote further YOD developments nationally.
Cardiff and Vale Young Onset Dementia Service

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