

Scotland's Dementia Strategies: a look at rights, education and diagnosis

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Our beliefs



At the Alzheimer Scotland Centre for Policy and Practice we believe that people affected by dementia deserve high quality care and support.

We know that this is possible when:

- Practitioners have enhanced dementia knowledge and practical skills
- When enlightened policies are put into practice
- When society respects the rights of people with dementia
- When we listen to what people with dementia and family carers are saying.
- When we work in partnership with people with dementia, their family and friends to develop care, caring interventions and education.

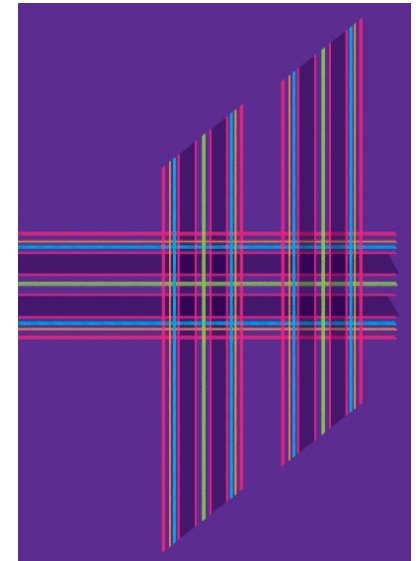


Talk Plan



Focus on 3 themes within all three strategies

- Rights
- Education
- Diagnosis and post diagnostic support





Rights – underpinning concept



Between 2003 and 2009 people living with dementia organised themselves.



Rights – underpinning concept



Website: www.sdwg.org.uk Email: sdwg@alzscot.org Twitter [@S D W G](https://twitter.com/SDWG)



Strategy 1 2010-13 Rights

Standards of Care for Dementia in Scotland

Action to support the change programme,
Scotland's National Dementia Strategy

June 2011

I have a right to

1. a diagnosis
2. be regarded as a unique individual and to be treated with dignity and respect
3. access a range of treatment, care and supports
4. be as independent as possible and be included in my community
5. have carers who are well supported and educated about dementia
6. end of life care that respects my wishes

Strategy 2 2013 -16 Rights



People with dementia & family caregivers report back

‘Moral imperative’ to improve Standards of Care - acute hospital settings

Big lottery funding – Life Changes Trust to support grassroots community initiatives



Strategy 3 2017-20 Rights

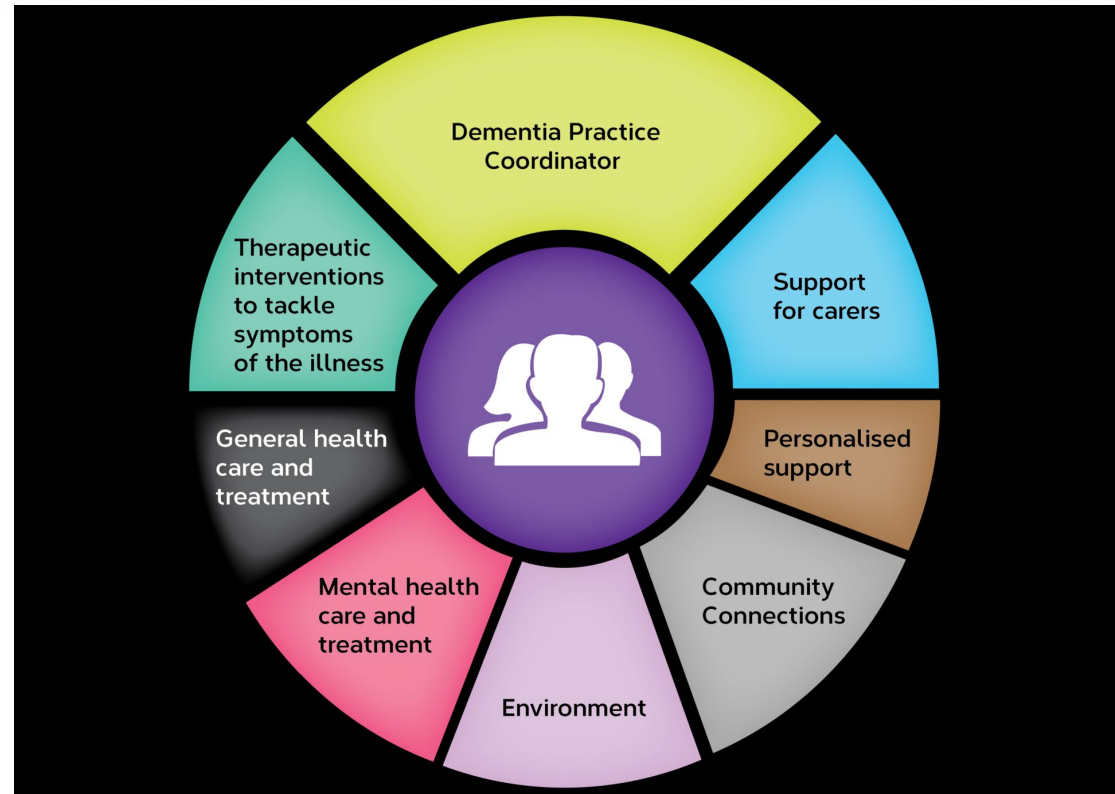


Dementia and equalities

Post diagnostic support

Communities

Fair Care



https://www.alzscot.org/assets/0001/9484/ADPM_Summary.pdf

<https://www.alzscot.org/fairdementiacare>



Strategy 1 2010-13 Education

Promoting Excellence:

A framework for all health and social services staff working with people with dementia, their families and carers

Educational response to change care practices –PE
framework for all staff working in health and social care
Not mandatory

Evidence based

Underpinned by Charter of rights

Supports delivery of Standards of Care

Strategy 1 2010-13 Education



Acute care - National Dementia champions Programme

Jack-Waugh A., MacRae R & Ritchie L. (2018) Assessing the educational impact of the dementia champions programme in Scotland: implications for evaluating professional dementia education. Nurse Education Today. Vol 71, Pp 205-210
<https://doi.org/10.1016/j.nedt.2018.09.019>



Strategy 2 2013 -16 Education



Continue programme to support workforce development –

- Educational resources
- Training programmes
- Develop infrastructures to ensure spread & sustainability
- Dementia education included nursing curricula



Strategy 3

2017-20

Education



Continue Promoting Excellence programme of work

Advanced Dementia care education – masters & Palliare

Palliative & end of life care education - DSILs

<https://www.uws.ac.uk/research/research-areas/health/alzheimer-scotland-centre-for-policy-and-practice/>

<https://www.uws.ac.uk/study/postgraduate/postgraduate-course-search/gerontology-with-dementia-care/>

<http://www.knowledge.scot.nhs.uk/dementia.aspx>

Strategy 1 2010-13 Diagnosis



2008 Target to increase diagnosis rates

2012 Target to increase diagnosis rates

2013 Target to provide PDS

The need for PDS higher than estimated and growing



By 2013 estimated 64% of people were getting diagnosed



Strategy 2

2013 -16

Diagnosis & PDS



Emphasis on timely & accurate diagnosis

Models of support developed

PDS needs very diverse

Recognition many getting diagnosed later

- PDS Target not being met
- Not enough Link workers
- CPNs being co-opted in

Dementia Estimated Diagnosed Incidence in Scotland 2014-20



Year	Total	Under 60	60-64	65-69	70-74	75-79	80-84	85-89	90+
2014	16,712	268	343	878	1742	3198	4336	3699	2246
2015	17,097	268	344	899	1766	3228	4430	3812	2349
2016	17,496	268	348	911	1818	3223	4516	3945	2466
2017	17,994	268	356	875	1972	3254	4590	4106	2572
2018	18,489	268	364	861	2058	3322	4708	4232	2675
2019	18,989	268	372	857	2117	3403	4807	4356	2809
2020	19,493	267	381	861	2170	4360	4876	4503	2954

Strategy 3

2017-20

Diagnosis & PDS



PDS needs to be more flexible, personalised.

2016/17 - PDS to 47% newly diagnosed

HEAT target for PDS removed

Campaign to improve PDS



Current Landscape: Integration



Integration of Health and Social Care – 31
Integrated Joint boards

Responsible for adult social, primary &
community care and some hospital services –
A&E, general, geriatric, rehab medicine, palliative
and mental health.

Dementia strategies and plans will be locally
developed & implemented, not nationally driven
and coordinated



Where are we now?



- World leading policies
- World leading educational resources
- Rights shifts thinking
- Stigma & discrimination
- Voice of people with dementia
- Skilled and educated workforce
- Care remains inequitable
- Poorer health outcomes
- Grassroots community work





Lillo-Crespo, M., Riquelme Galindo, J., Macrae, R., Abreu, W., Hanson, E., Holmerova, I., Cabanero, M.J., Ferrer, R and Tolson, D (2018) Experiences of Advanced Dementia Care in seven European countries: Implications for Educating the Workforce. Global Health Action. Vol 11 (1) DOI: <https://doi.org/10.1080/16549716.2018.1478686>

Hvalič-Touzery, S., Skela-Savič, B., MacRae, R., Waugh, A., Tolson, D., Hellström, A., Abreu, W. & Pesjak, K. (2018). The provision of accredited Higher Education on dementia in six European countries: an exploratory study. Nurse Education Today. 60, p. 161-169 DOI: 10.1016/j.nedt.2017.10.010. Epub 2017 Nov 6.

Tolson, D., Holmerova, I., MacRae, R., Waugh, A., Hvalič-Touzery, S., de Abreu, W., Lillo-Crespo, M., Merta, A. & Hanson, E. (2017). Improving Advanced Dementia Care: An Interprofessional Palliative Learning Framework. Journal of the American Medical Directors Association. Vol 18, Issue 7, pp 561-563. DOI: <https://doi.org/10.1016/j.jamda.2017.03.014>

Hanson, E. Hellstrom, A., Sandvide, A., Jackson, G., MacRae, R., Waugh, A., Abreu, W and Tolson, D. (2016). The extended palliative phase of dementia- an integrative literature review. Dementia: the International Journal of Social Research and Practice. 0 (0) 1-27 DOI: 10.1177/1471301216659797.



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