# Agenda - Health, Social Care and Sport Committee

Meeting Venue:

**Committee Room 2 - Senedd**

Meeting date: Wednesday, 25 January 2017

Meeting time: 09.00

For further information contact:

**Sian Thomas**

Committee Clerk

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## Informal pre-meeting (08.50 - 09.00)

## 1 Introductions, apologies, substitutions and declarations of interest

## 2 Inquiry into the Welsh Government's draft national dementia strategy - evidence session 1 - Alzheimer's Society

(09.00 - 09.45) (Pages 1 - 30)

Sue Phelps, Director of Alzheimer's Society in Wales
Dr Ed Bridges, External Affairs Manager for Alzheimer's Society in Wales

## 3 Inquiry into the Welsh Government's draft national dementia strategy - evidence session 2 - Age Cymru and Wales Carers Alliance

(09.45 - 10.30) (Pages 31 - 39)

Rachel Lewis, Policy Manager, Age Cymru
Kieron Rees, External Affairs Manager, Wales Carers Alliance

## Break (10.30 - 10.45)

## 4 Inquiry into the Welsh Government's draft national dementia strategy - evidence session 3 - Royal College of Psychiatrists and Royal College of General Practitioners

(10.45 - 11.30) (Pages 40 - 45)

Dr Victor Aziz, Chair of the Old Age Faculty of the Royal College of Psychiatrists in Wales and Old Age Consultant Psychiatrist in Cwm Taf University Health Board
Dr Jane Fenton May, Royal College of General Practitioners

## 5 Inquiry into the Welsh Government's draft national dementia strategy - evidence session 4 - Public Health Wales

(11.30 - 12.15) (Pages 46 - 134)

Dr Les Rudd, Mental Health Service Improvement Lead, Public Health Wales

## 6 Paper(s) to note

**Correspondence from the Chair of the Equality, Local Government and Communities Committee regarding the Public Services Ombudsman for Wales Annual Report for 2015-16**

(Pages 135 - 136)

## 7 Motion under Standing Order 17.42 to resolve to exclude the public from the remainder of the meeting

## 8 Inquiry into the Welsh Government's draft national dementia strategy - consideration of evidence

(12.15 - 12.30)

# 9 Correspondence from the Chair of the Constitutional and Legislative Affairs Committee regarding it's inquiry 'A stronger voice for Wales: engaging with Westminster'

By virtue of paragraph(s) vi of Standing Order 17.42

# Agenda Item 2

Document is Restricted

# Dementia Strategic Action Plan

## Alzheimer's Society briefing, January 2017

### Overview

The Welsh Government has launched for consultation a draft of Wales' first ever dementia strategy. It sets out actions over the next five years, and will be reviewed and refreshed after three years to ensure it remains relevant and appropriately targeted.

Alzheimer's Society in Wales views the draft strategy as a huge opportunity for Wales to set clear, ambitious targets to improve life for the 45,000 people in Wales living with dementia. There is a great deal in the strategy which we strongly welcome, and it is heartening to see dementia being recognised as "*one of the most significant health and social care issues we face*"[1], costing Wales in the region of £1.4bn per year[2].

Alzheimer's Society wants the draft strategy to be ambitious in its goals for dementia care, support and services in Wales, but also for it to be achievable – something that all sections of Welsh public services can work towards. We have consulted extensively with partner organisations, and have set out ten key areas where the draft strategy should aim to drive change. These can be read online at alzheimers.org.uk/walesstrategy

### Key points

Some of the key points from the draft Dementia Strategic Action Plan include:

1) The Dementia Strategic Action Plan will be overseen by the Older Persons' Delivery Assurance Group (DAG) within Welsh Government.
**Calls**: Alzheimer's Society wants to see involvement from people affected by dementia in this process, in particular during the refresh in three years. We must ensure the Older Persons' DAG properly reflects the needs of people with younger onset dementia (dementia developed younger than age 65) in its work.

2) A proposal for an annual increase of 3% per year from Wales' existing diagnosis rate of 51% - ie, 54% by 2018, 57% by 2019, 60% by 2020, 63% by 2021 and 66% by 2022.
**Calls**: Alzheimer's Society wants a more ambitious target for dementia diagnosis. Northern Ireland currently has a 64% diagnosis rate, which Wales would only match by 2021/2022 under the proposed target. In addition, the move to a different

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[1] Welsh Government (2017) *Together for a Dementia Friendly Wales 2017-22: consultation document*, Wales: Welsh Government: p9.

[2] Alzheimer's Society (2015) *The Hidden Cost of Dementia in Wales*, Cardiff: Alzheimer's Society.

method of calculating diagnosis rates by Welsh Government[3] means that the 2,000-3,000 people in Wales with young onset dementia would not be included in official figures. We must also ensure that there are sufficient services to support an increased number of people with a diagnosis of dementia.

3) A pledge that every newly-diagnosed person with dementia will have access to a Dementia Support Worker.
**Calls**: This is a very welcome proposal, as we know that a support worker is a valued and important first point of contact who can signpost and support people with dementia, as well as their family/carers. Alzheimer's Society wants to see funding provided to ensure enough support workers to meet demand. Currently, Welsh Government funds 32 DSWs – but with 18,000 people with a dementia diagnosis and an aspiration to increase this number, we will need significantly more of these support workers. This pledge also does not seem to support all those individuals with an existing diagnosis. The Government provided £1 million in 2010 for Dementia Support Worker posts – it would be useful to better understand how the £800,000 for 32 posts builds on this existing work.

4) A series of High Level Performance Measures by which progress will be gauged.
**Calls**: Alzheimer's Society wants these High Level Performance Measures to be measurable, accountable and time-limited in order that the impact of the strategy can be effectively measured.

5) Proposals to increase the number of primary care settings, hospitals and care homes that are dementia friendly, as well as targets for memory clinic waiting times for every person referred for an assessment of dementia to receive a first assessment by 28 days and a working/preliminary diagnosis within 12 weeks (when it is clinically possible to do so).
**Calls**: Alzheimer's Society want to see more detail in due course on how these excellent aspirations will be met.

6) Proposals to ensure 75% of NHS employed staff who come into contact with the public are trained in an appropriate level of dementia care (as specified in '*Good Work: Dementia Learning and Development Framework*') by the end of 2019.
**Calls**: Alzheimer's Society want to see commissioned staff appropriately trained as well. Training must ensure staff have adequate skills and understanding of dementia to respond to people's needs in an appropriate and sensitive manner that protects their dignity and respect and minimises distress. Training should also recognise the importance of mental and physical aspects of dementia and other health concerns of people living with dementia. Undergraduate health and social

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[3] Under the new strategy, Welsh Government will move from the Delphi consensus system of measurement to the CFAS prevalence estimate. Both approaches have their merits, but CFAS does not include data for under-65s living with dementia.

care courses should include dementia awareness and formal training pathways. People with dementia should be involved with training and developing training.

7) Monitoring the number and percentage of carers offered an assessment and for those with 'eligible needs' to be offered a support plan and a commitment for Welsh Government to examine a national approach to respite care.
**Calls**: Alzheimer's Society wants to see firmer targets for carers' assessments and a proper plan for respite care, to avoid this important area falling between different aspects of Welsh Government's ongoing policy development work. We must ensure that carers' assessments reflect the realities of living with dementia – for example, that dementia is a terminal condition that is degenerative, and may need regular review. All healthcare professionals should be able to access information on a patient's carer in order to provide support. There should be better recognition for and involvement of carers, supported by implementing the Triangle of Care in Dementia, which is a "therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing"[4], and introducing a national approach to involving carers, including training for health and care home staff in identifying, supporting and involving carers of people with dementia. We must recognise and value the carers journey and ensure a commitment to adequate respite, support, and training for carers.

8) Proposals for District General Hospitals to have a psychiatric liaison service / support worker team in place.
**Calls**: Alzheimer's Society wants to ensure this service is age-appropriate, in order to have the expertise necessary to identify and intervene as early as possible in the patient's experience in the hospital. It should also have an understanding of the distinct requirements of individuals with younger onset dementia. The pattern of substance misuse in older people, a key indicator and cause of some forms of dementia, can also be different in older people than in younger adults.[5]

9) An ambition to build a *Dementia Friendly Wales* by increasing the number of Dementia Friends, Dementia Friendly Communities, and dementia friendly corporate/public bodies in Wales, and to promote the *Creating a Dementia Friendly Generation* educational resources developed with Alzheimer's Society.[6]
**Calls:** Alzheimer's Society wants to better understand how Welsh Government will aim to underpin and support this work.

10) Proposals for a reduction in the percentage of people with a diagnosis of dementia prescribed antipsychotic medications and a reduction in duration of treatment. This

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[4] Carers Trust (2013) *The Triangle of Care - Carers Included: A Guide to Best Practice in Mental Health Care in England*, 2nd edition, London: Carers Trust, p.3.

[5] Connelly, P. & Perera, N. (2013) *Developing an ideal old age service*, London: Royal College of Psychiatrists.

[6] Alzheimer's Society (2016) *Dementia information for children, teenagers and young adults*.

is an area where the Older People's Commissioner for Wales, the Royal College of Psychiatrists Wales, and the Royal Pharmaceutical Society Wales have all been active in promoting the approach that antipsychotics should not be routinely prescribed to treat behavioural and psychological symptoms of dementia, and when necessary only the lowest dose should be prescribed for the shortest time.[7][8] **Calls**: Alzheimer's Society want to see more information on how this will be implemented and what will be reported to local mental health partnership boards by June 2018. We must ensure that people have a full explanation of the medication they may be prescribed and choice in their treatment. We should ensure that people with dementia prescribed antipsychotics have support from carers, loved ones, or advocates. Multidisciplinary support and regular reviews should be available to reduce over-use of antipsychotics.

**11)** Proposals for health boards, local authorities, primary care clusters and third sector providers support people to plan ahead for the end of life, identify professionals for training in initiating serious illness conversations, and work with bereavement services to recognise the differing needs of families and carers of those with dementia. We welcome the recognition that dementia is a terminal diagnosis "*which can lead to poor care, inconsistent quality of care and inadequate pain management*", that was highlighted in *Living and Dying with Dementia in Wales*[9], and that it is the explicit wish of most people, with dementia and without, to die at home, yet hospital often ends up being the 'default' option. **Calls**: Alzheimer's Society wants to see a national review of the current provision of palliative and end of life care. Where possible and desired, people should be enabled to die at their place of residence with support from professionals such as community nurses. Welsh Government should ensure that better dementia training is available for hospice staff, and all relevant health and social care staff are trained and supported to help people with dementia develop advanced care plans.

**12)** Ensuring that services are sensitive to the BAME community, the LGBT+ community, and individuals with learning disabilities or sensory loss. According to Welsh Government, "*services should take steps to address this locally to improve equity, such as developing different information resources and/or appointing outreach workers*". The draft calls for health boards and local authorities to develop actions to increase access for individuals with protected characteristics. **Calls**: Alzheimer's Society wants to see more specific actions that Welsh Government expect health boards and local authorities to meet. Wales has diverse communities and cultures, all of which may have distinct requirements for dementia care which need to be addressed. Families are reluctant to use services

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[7] Royal Pharmaceutical Society Wales (2016) *Improving Medicines use for Care Home Residents*, Cardiff: RPSW.

[8] Older People's Commissioner for Wales (2014) *A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales*, Cardiff: OPCW.

[9] Alzheimer's Society and Marie Curie (2015) *Living and Dying with Dementia in Wales: barriers to care*, Penarth: Marie Curie.

that do not meet cultural or religious needs and try to carry on alone. Services need to be co-designed with locally prevalent communities and families should be involved in delivering and designing care. Work should be done to reach out to BAME communities to increase awareness of dementia and to design culturally sensitive services. Services should work to lower barriers to the gypsy and traveller community accessing services. Services should be aim to be proactively friendly towards the LGBT+ community, and promote diversity inclusion and present the environment as non-discriminatory. Awareness of diverse sexual and gender identities (and the diversity within those) should be present throughout health and social care training, and should ensure staff do not make assumptions about sexuality and gender identity.

13) Proposals for health boards to improve access to a diagnosis and care in the Welsh language. These are very welcome, as people with dementia may revert to their first language as a result of their condition. The draft Dementia Strategic Action Plan recognises that this represents a clinical need. Additionally, there is a commitment from Welsh Government to engage with researchers to ensure there is a clinically validated dementia assessment tool for use in the Welsh language.
**Calls**: Alzheimer’s Society want to see more detail on how this excellent series of measures will be taken forward. Action is needed to mainstream the “Active Offer” principle into dementia services as they are designed and implemented.

14) An acknowledgement that rural areas face specific challenges in delivering dementia care – something which we have highlighted through our own research[10].
**Calls**: Alzheimer’s Society wants the final strategy to include a more detailed section on dementia in rural Wales, setting out how Welsh Government will develop a better understanding of the extent, impact and growth of dementia in rural Wales. We must ensure current services are accessible to people in rural areas and are designed with rural areas taken into account, as well as ensuring those responsible for designing services are accountable for this.

## Conclusion

Wales’ first dementia strategy is a historic step forward and an enormous opportunity to drastically improve the lives and wellbeing of people affected by dementia in Wales. We have come a very long way in developing such a strong and comprehensive draft strategy, and the calls above hopefully identify some of the areas where the Health, Social Care & Sport Committee can raise questions during the inquiry and the ongoing Welsh Government consultation.

As always, we are happy to provide further information or tailored briefings to committee Members if they require any further detail.

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[10] Alzheimer’s Society (2016) *Dementia in Rural Wales: the three challenges*, Cardiff: Alzheimer’s Society.

**Dr. Ed Bridges**
External Affairs Manager
[redacted]

Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-03-17 Papur 2 / Paper 2

# Consultation Response

## Draft Strategy – 'Together for a Dementia Friendly Wales' 2017 - 22

**Health, Social Care and Sport Committee**

**January 2017**

## Introduction

Age Cymru is the leading national charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.

We are pleased to respond to the Health, Social Care and Sports Inquiry into the Draft Dementia Strategic Action Plan. Age Cymru welcomes the Welsh Government's commitment to creating a dementia friendly nation and to promoting the rights, dignity and autonomy of people living with dementia.

## Dementia support workers

We welcome the action on p26 that states that '*every newly diagnosed person with dementia is offered access to a dementia support worker or equivalent*.' Last year, Age Cymru was commissioned by the Older People's Commission to carry out interviews with people living with dementia and their carers across Wales[i]. Interviewees told us that they would value access to a single point of contact to support them to navigate the often complex interface between health, social services and community based third sector provision. Daily contact with so many agencies can prove extremely stressful. A dementia support worker can provide the extra support needed to reduce the pressure on people living with dementia and their carers and families.

Although we welcome the role of the dementia support worker, it is important to note that this post can only be effective in areas where there are services in place to signpost people with dementia and their carers to. P24 states that a key role of the dementia support worker will be to signpost people with dementia onto '*appropriate information and local facilities*.' However, access to activity groups or dementia cafes is becoming increasingly scarce.

In response to this, the document does state that *'health boards and local authorities will work with local communities and third sector organisations to encourage them to open up their* *services so that people with dementia, their families and carers can participate*' (p30). We would like to clarify the intent on this point. For example, is there evidence that people with dementia are being turned away from community and third sector services? Training would need to recognise the needs and behaviours of two people with dementia are never the same.

**Access to services**
People living with dementia and their carers have told Age Cymru that there is a need for more befriending and respite services that respond to the needs of individuals[ii]. However access to befriending projects in Wales is already scarce and evidence shows the situation is likely to get worse. For example, In Swansea a volunteer led befriending project that has been funded by the LA for over 10 years, is due to close by the end March of 2018 if not before.

Long standing issues with the short term funding of dementia services can leave people feeling vulnerable and isolated when a service is withdrawn. There is a pressing need to develop a national strategic approach to the funding of dementia services. For people with dementia, their families and carers, the lack of access to community based support services can have a devastating impact on their quality of life. Additionally, health boards and local authorities need to ensure that the knowledge and expertise of third sector organisations and people living with dementia are utilised in the design and planning of any new service to ensure it is suited to individual need.

**Training for carers**
P26 mentions '*opportunities for carers' education about dementia should also be taken via formal courses run by organisations such as Carers Trust, Crossroads or Alzheimer's Society*.' Given the points raised in the section above, we would welcome more information on how these courses will be funded and rolled out nationally to ensure all carers have equal access to the service.

**Engagement**
There is a lack of reference throughout the strategy of the importance of involving people living with dementia in the design and planning of services that affect them. Without this engagement people living with dementia will continue to feel that they are expected to fit in with the delivery patterns of formal services rather than the services being designed to meet their individual needs.'[iii] One of the performance measures (p52) is that '*all memory services to involve people with dementia and carers in feedback and service development.*' This should be extended to include services delivered by local authorities and the third and private sectors.

**People with protected characteristics**
The draft strategy states that people from the Black African-Caribbean and South Asian UK population have a higher risk of developing both dementia and early onset dementia (p21 and p23). Although the document does propose an action for '*health boards and local authorities to develop actions to increase access for individuals who have protected characteristics' (p28),* there is no performance measure to monitor the effectiveness of any new initiatives. Given the documented evidence that shows that BME people with dementia present to dementia services later when their condition is more severe[iv], increasing uptake of services to BME populations should be viewed as a priority and allocated a performance measure.

Furthermore, the proposed review of Population Assessments (p21) should ensure that it includes an assessment of levels of need (including dementia) amongst BME communities.

**End of life care**

The document states although dying at home is the wish of most people, hospital often ends up being the 'default option.' As many people with dementia end their lives in care homes, the strategy should include a section on the need to ensure that care homes have policies and protocols in place that allow people to die in their place of residence.

## High level performance measures

- It is important to note that none of the performance measures listed on pages 51 – 52 require local authorities or health boards to monitor or measure how the strategy will impact on the lives of people living with dementia, their families and carers. We believe it is important to measure outcomes as well as inputs.

- Also, point 7, p51states the strategy with measure the numbers of carers being offered a support plan, but with no mechanism in place to monitor the impact and delivery of the plan, an increase in the number of plans is meaningless.

- We question whether the target of a 3% per annum increase in the number of people formally diagnosed with dementia is sufficiently ambitious, but welcome the measure relating to the receipt of a diagnosis within 12 weeks**.**

- Age Cymru is pleased to note the reference to the need to ensure access to independent advocates on p43, but believe access to advocates should be included as a performance measure.

- Performance measure 5, p51, relates to '*staff who come into contact with the public being trained in an appropriate level of dementia care.'* Age Cymru would like clarification that this will include all clinical staff working in within environments where people receive care, treatment or support.

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[i] Older People's Commission for Wales (2015) *Dementia – more than just memory loss.*

[ii] Older People's Commission for Wales (2015) *Dementia – more than just memory loss.*

[iii] Older People's Commission for Wales (2015) *Dementia – more than just memory loss.*

[iv] By Jo Moriarty, Nadira Sharif and Julie Robinson Black and Minority Ethnic People with Dementia and their Access to Services. (Review date 2014) Available online: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf

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Cynghrair
**Cynhalwyr** Cymru
Cymdeithasau gwirfoddol yng Nghymru yn ymwneud â Chynhalwyr

Wales
**Carers** Alliance
Voluntary organisations in Wales concerned with Carers

## Response to Health, Social Care and Sport Committee’s inquiry into the Welsh Government’s draft national dementia strategy

19 January 2017

### About Wales Carers Alliance

Wales Carers Alliance exists to represent the concerns and further the interests of carers in Wales. There are over 370,000 carers across Wales providing unpaid care to friends and family, together the 18 member organisations of Wales Carers Alliance work with and for carers to promote the well-being of all carers.

### Key Points

### Key Points

- Wales Carers Alliance broadly welcomes the draft strategy and many of the actions proposed within it. We also welcome the consistent reference to the work of unpaid carers of people with dementia.

- There are around 37,000 people caring for a person with dementia in Wales, the contribution of this care is worth £622 million a year.

- Carers play a critical role in preventing or delaying residential care admissions.

- Although reference is made to carers of people with dementia throughout the strategy, we feel the draft strategy could better reflect the role carers by demonstrating an understanding of the issues they face and by including proposed actions that would support them. For example, by including commitments around providing out-of-hours access to hospital wards for carers or local health boards adopting the ‘Triangle of Care for Dementia’ model developed by the Royal College for Nursing and Carers Trust.

- We believe there needs to be a bigger focus on the role played by short breaks and replacement care in improving the well-being of both the carer and the individual with dementia, enabling the person with dementia to stay at home for longer. We welcome the commitment to exploring a national respite scheme, but believe the draft strategy would benefit from looking at further ways breaks and replacement care could be improved.

- Wales Carers Alliance believes that the high level performance measures could be more ambitious and include more carer-focused measures that look at the impact actions have on carers of people with dementia (ie. improved well-being) rather than the actions themselves (ie. number of carers assessments offered).

## Background

1. Wales Carers Alliance welcomes the opportunity to provide evidence to the Health, Social Care and Sport committee's inquiry into the Welsh government's draft national dementia strategy.

2. There are at least 370,000 people caring unpaid for a friend or family member in Wales. Of those, it is estimated that around 10%, 37,000, care for a person with dementia. The contribution of unpaid carers in Wales is worth £622 million a year[1].

3. The presence of an unpaid carer brings important benefits to both the person with dementia and health and social care services in Wales. A longitudinal study of 100 people with dementia found a 20-fold protective effect of having a co-resident carer when it comes to preventing or delaying residential care admissions[2].

4. A recent study by Carers Trust in partnership with the Social Policy Research Unit (SPRU), The University of York and Firefly Research found that there are 10 critical points when information, support and services for unpaid carers of people with dementia are essential, including:

    - When dementia is diagnosed

    - When the carer takes on an 'active' caring role

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[1] https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=3051

[2] https://carers.org/sites/files/carerstrust/media/commissioning_wales_finallo.pdf

- When the capacity of the person with dementia declines

- When the carer needs emotional support and/or a break from caring

- When the person with dementia loses their mobility

- When the carer's own circumstances change

5. There needs to be a fundamental shift in health services in Wales in how the carers of people with dementia are supported, recognised and involved. This includes involvement and support during diagnosis, information and advice around difficult areas such as power of attorney and managing medications and carer-friendly policies in place in hospitals, for example allowing carers out of hours access.

6. Although the role of carers is represented throughout the draft document, we do not feel it is adequately recognised or that the document demonstrates an adequate commitment to put in place the support that carers of people with dementia need.

**Raising Awareness and Understanding**

7. On page 17 it would be beneficial if the strategy also committed to raising awareness of the role played by carers among health staff. A lack of understanding of the role of the carer can negatively impact the well-being of the carer and the individual with dementia. This was the reason for the 'Triangle of Care for Dementia' jointly developed by Carers Trust and the Royal College of Nursing. The Royal College of Nursing project Dignity in Dementia; Transforming General Hospital Care (2011) highlighted that involving carers was highly instrumental in supporting improvements in care and will lead to better outcomes for patients, carers and ultimately the professionals supporting them[3]. The key standards that form the Triangle of Care are:

    - Carers and the essential role they play are identified at first contact or as soon as possible thereafter
    - Staff are 'carer aware' and trained in carer engagement strategies

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[3] http://www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013%20reports%20page.pdf

- Policy and practice protocols regarding confidentiality and sharing information are in place
- Defined posts(s) responsible for carers are in place
- A carer introduction to the service and staff is available, with a relevant range of information across the care pathway
- A range of carer support services is available

## Recognition and Identification

8. Over half (52%) of carers of people with dementia reported difficulties in obtaining a diagnosis of dementia for the person they cared for in Carers Trust's Road Less Rocky research[4]. Professionals should be educated in properly supporting and involving carers to help improve the diagnosis process.

9. Wales Carers Alliance welcomes the commitment in the document to provide 'all individuals' with access to a dementia support worker. However, we feel that the role of this worker in supporting/working with carers should be clarified.

10. We welcome on page 25 of the draft strategy the recognition of the needs of carers and the emphasis placed on carer support provided by the Carers Trust Network (which includes Crossroads services) and Alzheimer's Society. However, we feel that there needs to be a stronger commitment, in health settings, to providing information and advice to carers of people with dementia. More than half of carers (56%) had not been given information non legal issues, such as lasting power of attorney, and 55% had not been given information on managing money[5].

## Living as well as possible for as long as possible

11. We believe that the document should address the important role played by replacement care and short breaks in supporting the well-being of both the person with dementia and the carer. When a carer is supported, they are more likely to remain healthy themselves, 35%

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[4] https://professionals.carers.org/sites/default/files/dementia_report_road_less_rocky_final_low.pdf

[5] Ibid.

of carers without good support experienced ill health compared to 15% of those with good support[6]. Providing information, support and services to carers of people with dementia can help the person with dementia to stay at home and both to live as well as possible for as long as possible.

12. We welcome the recognition that taking a ‘team around the carer’ approach with the carer as part of the team is desirable (P. 37) and the recognition that it is important to avoid carer breakdown or hospital admission.

13. Wales Carers Alliances welcomes the commitment in the draft strategy to ‘examine a national approach to respite care’. The pressure on replacement care and breaks services means it is becoming increasingly difficult for all carers, including those of people with dementia, to access the support that they need. Wales Carers Alliance strongly believes that a national scheme should be put in place that meets the needs of carers and takes into account lessons learned elsewhere, for example with the long-running and successful Short Breaks Fund in Scotland.

### Good Care in Hospitals

14. We believe that this section should also recognise the importance that hospitals are not only ‘dementia supportive’ but also carer-friendly and that a proposed action would be to improve staff awareness of the role of carers of people with dementia and to put in place carer-friendly policies such as out-of-hours access to wards.

### High level performance measures

15. High-level performance measures could include more carer-focused commitments, for example number of local health boards implementing a ‘Triangle of Care for Dementia’ model or the number of hospitals signed up to the principles of the carer-friendly campaign ‘John’s Campaign’[7] which calls for the right of people with dementia to be supported by their carers.

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[6] https://carers.org/sites/files/carerstrust/media/commissioning_wales_finallo.pdf

[7] http://johnscampaign.org.uk/#/

16. We care concerned that the high level measure around carers assessments only measures the number of carers being offered assessments and support plans. This measure does not take into account with the quality of the assessments or the support plans, whether the carer was suitably involved in developing the assessments or support plans, or whether the actions included in the assessments or support plans were delivered.

**Contact**

Kieron Rees

[redacted]

Agenda Item 4

Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-03-17 Papur 4 / Paper 4

# Royal College of Psychiatrists
## Consultation Response

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| **DATE:** | **16 January 2017** |
| **RESPONSE OF:** | **THE ROYAL COLLEGE OF PSYCHIATRISTS in WALES** |
| **RESPONSE TO:** | **Dementia Strategy** |

The Royal College of Psychiatrists is the professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and in setting and raising standards of psychiatry in the United Kingdom.

The College aims to improve the outcomes of people with mental illness, and the mental health of individuals, their families and communities. In order to achieve this, the College sets standards and promotes excellence in psychiatry; leads, represents and supports psychiatrists; improves the scientific understanding of mental illness; works with and advocates for patients, carers and their organisations. Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies.

RCPsych in Wales is an arm of the Central College, representing over 550 Consultant and Trainee Psychiatrists working in Wales.

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**The Health, Social Care and Sports Committee Work on Welsh Government's draft Dementia Strategic Action Plan**

The Royal College of Psychiatrists welcomes the Committee's work on the draft Dementia Strategy and is pleased to be invited to respond. We were happy to learn at the beginning of last year Welsh Government had plans to introduce a Strategy, which was then set out in the *Together for Mental Health Delivery Plan 2016 – 2019*. Unlike Scotland and England, there is currently no Dementia Strategy for Wales. The driver for improvements in dementia services has come from *The Dementia Vision* report that was published in 2011, which is laudable document, however lacks specific targets. The College feels that a strategy is long overdue.

1. The Strategy is an important document that requires a significant amount of time and expertise to develop. We are concerned that the initial deadline for completion by end of 2016 was unrealistically short. The extended deadline of end April 2017 is welcomed but we still feel that more time should have been afforded to this important piece of work. This document must be able meet the challenges we face now and into the future.

2. We think the title of the strategy document 'Together for a Dementia Friendly Wales' is misleading and actually does not reflect the content. The title could be revised to 'Together for Dementia'.

3. The consultation strategy meets most of the areas in a joint signed letter sent to the Health Secretary (attached) apart from meeting the needs of living with dementia in rural settings. We are also concerned about the strategy meeting the needs of minority groups residing in Wales.

4. The Strategy is a national pathway from diagnosis to end of life care. It covers the area of: 1. recognition and identification; and 2. assessment and diagnosis of dementia, which are clinical components that cannot be avoided since dementia is caused by disease. An overarching clinical strategy and management of dementia plan would complement the dementia strategy.

5. To ensure workable dementia strategy in Wales robust integration of health and social care will need to be implemented first.

6. We are pleased that the document stresses the importance of *timely diagnosis.* What *is* crucial is the provision of support services once a diagnosis has been made. This is addressed in the strategy.

7. The Strategy is fairly generic with no specific outcomes. The Actions at this stage are ambiguous. We must wait until a delivery or implementation plan is developed to see if outcomes are SMART. The College would be most willing to participate in this.

8. The English and Scottish Strategies could have been modified to fit the Welsh Context. We are cross referencing these strategies against the Wales consultation documents. We need to learn lessons from the other devolved Nations that already have dementia strategies in place.

9. We are concerned that more emphasis should be placed on the following areas:

- Young/early onset
- LD and cognitive impairment
- Palliative care
- Traumatic brain injury
- Alcohol
- Sensory impairment
- BME community.
- Prison population
- Supporting primary care services

# Appendix

Cabinet Secretary for Health, Wellbeing & Sport,
Welsh Government,
Tŷ Hywel,
Cardiff, CF99 1NA
*Correspondence.Vaughan.Gething@gov.wales*

8th December 2016

Dear Cabinet Secretary,

As organisations representing a wide spectrum of people living with dementia, as well as carers and health & social care professions, we welcome the Welsh Government's work to date on developing Wales' first Dementia Strategy.

We want to ensure that the vision for dementia care for Wales is ambitious and achievable, and as such are writing to you to make ten recommendations which we believe must be included if the Strategy is to be seen as sufficiently ambitious for people living in Wales with dementia.

We are aware that the Welsh Government has commissioned a series of engagement and consultation events to involve people affected by dementia in the development of the Dementia Strategy. The voices of those affected by dementia should always be central in Welsh Government's concerns, and we hope that those meetings are fruitful and give the Welsh Government a strong steer for the direction of Wales' first Dementia Strategy. The proposals below are the views of a range of organisations which work with people affected by dementia in a variety of capacities.

We believe that the Dementia Strategy should:

1. **Set out clear targets for increasing dementia diagnosis rates in Wales**. We believe that by 2021, each Local Health Board (LHB) should attain a diagnosis rate of at least 75%. As an interim measure, by 2019 we believe Wales should learn from good practice to match the diagnosis rate in Northern Ireland (currently 64%). As a step towards this this, LHBs should immediately commence routinely recording the number of people newly-diagnosed with dementia. Welsh Government should also aim to ensure early and timely diagnoses. A national minimum waiting time standard for time from referral to first contact of 4 weeks and from referral to diagnosis of 12 weeks for all memory clinic services should be introduced.

2. **Ensure that by the end of the Strategy's lifetime, every person with dementia can access support from a Dementia Support Worker**. A DSW can provide vital support and signposting to people with dementia, and can help support follow-up with people with dementia, and vastly improve an individual's well-being. We recognise the high level of qualifications of Dementia Specialist Nurses and believe that both DSNs and DSWs have a role to play in providing support for people affected by dementia. Evaluations of a variety of Dementia Support Worker and Dementia Adviser roles have found there is scope to ensure provision is cost-neutral after just four years.

3. **Ensure that all hospitals and primary care settings achieve dementia friendly status by 2021** – this should be supported by spreading accepted best practice such as John's Campaign, the Butterfly Scheme, and "This is Me" type leaflets to all Local Health Boards. There are many models for adapting care settings to better suit the needs of people with dementia.

4. **Ensure appropriate dementia training and dementia awareness is taken up in all settings**. By 2018, there must be higher levels of training for NHS and care staff including all nursing staff in particular practice nurses and nurses working in the independent sector, social workers, social care workers, domiciliary care staff, and others who are working within environments where people with dementia receive care, treatment or support. This training must ensure staff have the skills to ensure they have sufficient knowledge and understanding of dementia to respond to their needs in an appropriate and sensitive manner that protects their dignity and respect and minimises distress. The *Good Work* Framework should form the basis of this training, complimented by specific training in outcome focused/what matters conversations. Training should recognise the importance of mental and physical aspects of dementia and other health concerns of people living with dementia. This should include NHS employed staff and, wherever possible, commissioned staff. It should also ensure that all undergraduate health and social care courses include dementia awareness and more formal training pathways.

5. **Support carers and family of people with dementia**, including by ensuring appropriate information is available at the right time and the right place including at diagnosis, ensuring access to a carers assessment, and ensuring people with dementia and their carers are involved with clinical professionals as equal partners in care supported by a multi-disciplinary team with professionals from different specialities. All healthcare professionals should be able to access information on a patient's carer in order to provide support. There should be better recognition for and involvement of carers, supported by implementing the Triangle of Care in Dementia, and introducing a national approach to involving carers, including training for health and care home staff in identifying, supporting and involving carers of people with dementia. We must recognise and value the carers journey and ensure a commitment to adequate respite, support, and training for carers.

6. **Prevent the over-use and inappropriate use of antipsychotics, and support people with prescriptions**. Antipsychotics should not be routinely prescribed to treat behavioural and psychological symptoms of dementia, and when necessary only the lowest dose should be prescribed for the shortest time. Multidisciplinary support and regular reviews should be available to reduce over-use of antipsychotics. People with dementia may need more support with their prescriptions such as receiving weekly prescriptions - care home residents should receive regular reviews to optimise their medication regimen. With patient consent, all pharmacists directly involved in care should have full read and write access to a patient's health record in the interest of high quality, safe and effective care.

7. **Meet the challenges of living with dementia in rural Wales**. Too often, services are designed for urban areas, and the needs of those in rural Wales are forgotten. Lack of access to appropriate services is a particular problem for people living with dementia in rural areas. The Welsh Government should develop a better understanding of the extent, impact and potential growth of dementia in rural Wales and commit to working with the Rural Dementia Taskforce and other stakeholders to address these challenges.

8. **Support people living with dementia right to the end of life**, including by establishing a national review of the current provision of palliative and end of life care. The explicit wish of most people – with dementia and without – is to die at home, yet hospital often ends up being the "default option" for many people. Where possible and desired, people should be enabled to die at their place of residence with support from professionals such as community nurses. As people live longer, they die with more complex and often multiple conditions. Statistics show that more and more people are dying with dementia. Welsh Government should ensure that better dementia training is available for hospice staff, and all relevant health and social care staff are trained and supported to help people with dementia develop advanced care plans.

9. **Ensure that dementia services meet the needs of Welsh language speakers.** For many Welsh speakers, language is an integral element of their care – as dementia progresses, they may lose use of their second

language. The Dementia Strategy should work to spread best practice. Action is needed to mainstream the "Active Offer" principle into dementia services as they are designed and implemented. A more proactive approach to language need and choice is needed, with responsibility placed on providers to offer their services in Welsh thereby eliminating the unfair burden on patients to request services in Welsh. There is also a need for data on dementia in Welsh language communities in Wales, so there can be a better understanding of the relationship between rural dementia and Welsh language, as well as data on the numbers of Welsh speakers suffering dementia in each health Board as a basis for the planning of Welsh language services.

10. **Ensure that dementia services meet the needs of BAME, LGBT+, and other minority communities**. Wales has diverse communities and cultures, all of which may have distinct requirements for dementia care which need to be addressed. Families are reluctant to use services that do not meet cultural or religious needs and try to carry on alone. Services need to be co-designed with locally prevalent communities and families should be involved in delivering and designing care. Work should be done to reach out to BAME communities to increase awareness of dementia and to design culturally sensitive services. Services should work to lower barriers to the gypsy and traveller community accessing services. Services should be aim to be proactively friendly towards the LGBT+ community, and promote diversity inclusion and present the environment as non-discriminatory. Awareness of diverse sexual and gender identities (and the diversity within those) should be present throughout health and social care training, and should ensure staff do not make assumptions about sexuality and gender identity.

We would be very happy to discuss these points with you further if it would be helpful to do so. We will also, of course, be submitting individual consultation responses on behalf of our own individual organisations.

Yours sincerely,

*Signatories*

age Cymru
Alzheimer's Society Leading the fight against dementia
BASW CYMRU BRITISH ASSOCIATION OF SOCIAL WORKERS CYMRU
BGS
carers trust Wales action · help · advice

Care & Repair Cymru
CHARTERED SOCIETY OF PHYSIOTHERAPY CYMDEITHAS SIARTREDIG FFISIOTHERAPI
Marie Curie Gofal a chefnogaeth drwy salwch terfynol Care and support through terminal illness
Coleg Nyrsio Brenhinol Cymru Royal College of Nursing Wales
RC PSYCH ROYAL COLLEGE OF PSYCHIATRISTS

ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS
Royal College of Physicians | Coleg Brenhinol y Meddygon (Cymru)
Comisiynydd y Gymraeg Welsh Language Commissioner

Agenda Item 5

Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-03-17 Papur 5 / Paper 5

GIG CYMRU
NHS WALES
Iechyd Cyhoeddus Cymru
Public Health Wales

# Response to the Health, Social Care and Sport Committee on the Dementia Inquiry, to inform the oral evidence session on the 25th January

| | |
|---|---|
| **Date:** 18 January 2017 | **Version:** 1 |

Thank you for the opportunity to provide information in advance of the evidence session to the Health, Social Care and Sport Committee's scrutiny of the Welsh Government's draft Strategy 'Together for a Dementia Friendly Wales'. Public Health Wales welcomes this opportunity to contribute to this important agenda.

Due to the short timescale for responding, we have given our general views on the draft strategy, with additional detail being given in some specific areas.

We will be providing a more detailed response to the Welsh Government consultation of the Strategy (due by April 3rd), and would be happy to send the Committee a copy of this response in due course.

We would like to highlight that we have only provided a limited response due to having less than 4 working days to respond to this important inquiry and would like this to be considered by the Committee when launching future inquiries.

1. In general, the document would benefit from more specificity regarding delivery – both in relation to *who* will be delivering and *what* they will be delivering. There are also two specific omissions as follows;

   **1.1 Case identification, assessment & diagnosis**. On page 22 it is not made explicit that a diagnosis rate of 51% (compared with those expected to have the condition) is the lowest rate in the UK, far lower than Northern Ireland and Scotland (c 90%). Subsequently there should be a commitment to specific annual targets to improve the rate of case identification and diagnosis.

   On page 20 *'Health Boards and Local Authorities to ensure appropriate case finding'* should be explicitly linked to page 44 'the Welsh Government Directed Enhanced Service (DES)' to better incentivise GPs. The DES incentive is for GPs to better support people in nursing and care homes and in doing so they are more likely to identify cases.

   **1.2 The provision of psychological / behavioural training to staff to improve management of behaviours that staff find 'challenging'**. This is particularly in managing behaviour in the provision of personal care – which is a core nursing skill. Current training is patchy, very limited and not systematic. There is a need for an all Wales approach that follows an evidenced based training approach.

2. On page 39 the proposed key action is '*to increase the number of hospital settings that are dementia supportive'*...... and on page 40 '*Acute hospital pathways should reflect the growing proportion of people with dementia accessing acute care'.* The central issue that is not referenced is that staff need regular specialist training in how to reduce distress and aggression in older people's services generally, and inpatient services & nursing homes specifically.

3. Dementia Services consistently have the highest incidence of aggressive incidents of any clinical population and there is a wealth of clinical evidence about reducing challenging behaviour in dementia that is specific to this condition. The presentation in **Appendix 1**, will form the main content of British Psychological Society (BPS) guidance (pending publication summer 2017) and includes some of the evidence and references.

4. The recommendation of an all Wales approach, to Bradford University Dementia Care Mapping, for both Physical and Mental Health inpatient wards. Only one Health Board (Betsi Cadwaladr) has capacity for this in Mental Health Services at present.

5. There is a need to support the population to adopt healthy lifestyles, particularly in midlife. This includes risk factors to dementia including smoking, obesity (risk for diabetes in particular), poor nutrition, and alcohol and other substances. There is also some evidence of the impact of social isolation on cognitive functioning, and on mental wellbeing more generally, which will impact on dementia risk. There should be a systems approach to minimising the risk factors, which at a population level will help to avoid (or at least delay) the onset of dementia, as well as a range of other chronic conditions.

6. **Appendix 2** shows a paper 'Dementia – Early Intervention and Prevention' produced by North Wales Public Health Team; this includes recommendations and provides further evidence on the points in paragraph 5 above, as well as on the following:
    - groups in the population which are at a higher risk of developing dementia e.g. people with a learning disability – particularly Down's Syndrome - or people who have existing mild cognitive impairment
    - the importance of early diagnosis and support, but in the context of ethical considerations for each individual
    - the importance of supporting informal carers
    - wider determinants and community action e.g. supporting dementia friendly communities, lifelong housing etc.

## 7. Appendices

### Appendix 1

Bespoke Training Presentation

Appendix 1 Dementia
Inquiry.pptx

### Appendix 2

Public Health Improvement and Dementia

Appendix 2
Dementia Inquiry v1 (

# Bespoke Training

## Reducing Distress and Aggression in Older People's Services

Written by Kate Ross and Gary Firkins

A combination of psychological approaches to challenging behaviour in dementia and best practice in the use of holding skills

# WHY?

- Combining knowledge bases to achieve highly specialised skills training

- **Because … dementia care nursing is the most demanding nursing there is – we demand a combination of general nursing skills and psychiatric nursing skills and knowledge and understanding of neurological impairment**

Novice
Advanced Beginner
Competent
Proficient
Expert

# Is This a Problem?

- For us, it was a major problem. We were having regular psychiatric emergencies and injury to staff and patients. On one 12-bedded unit, we had more than **150** incidents of physical aggression reported in a single year.

- Dementia Services consistently have the highest incidence of aggressive incidents of any clinical population
- There is a wealth of clinical evidence about reducing challenging behaviour in dementia that is specific to this condition

# Why is dementia different?

- It is extremely stressful to have dementia. Challenging behaviour in dementia is about people having to problem solve on their feet and trying to escape fearful situations

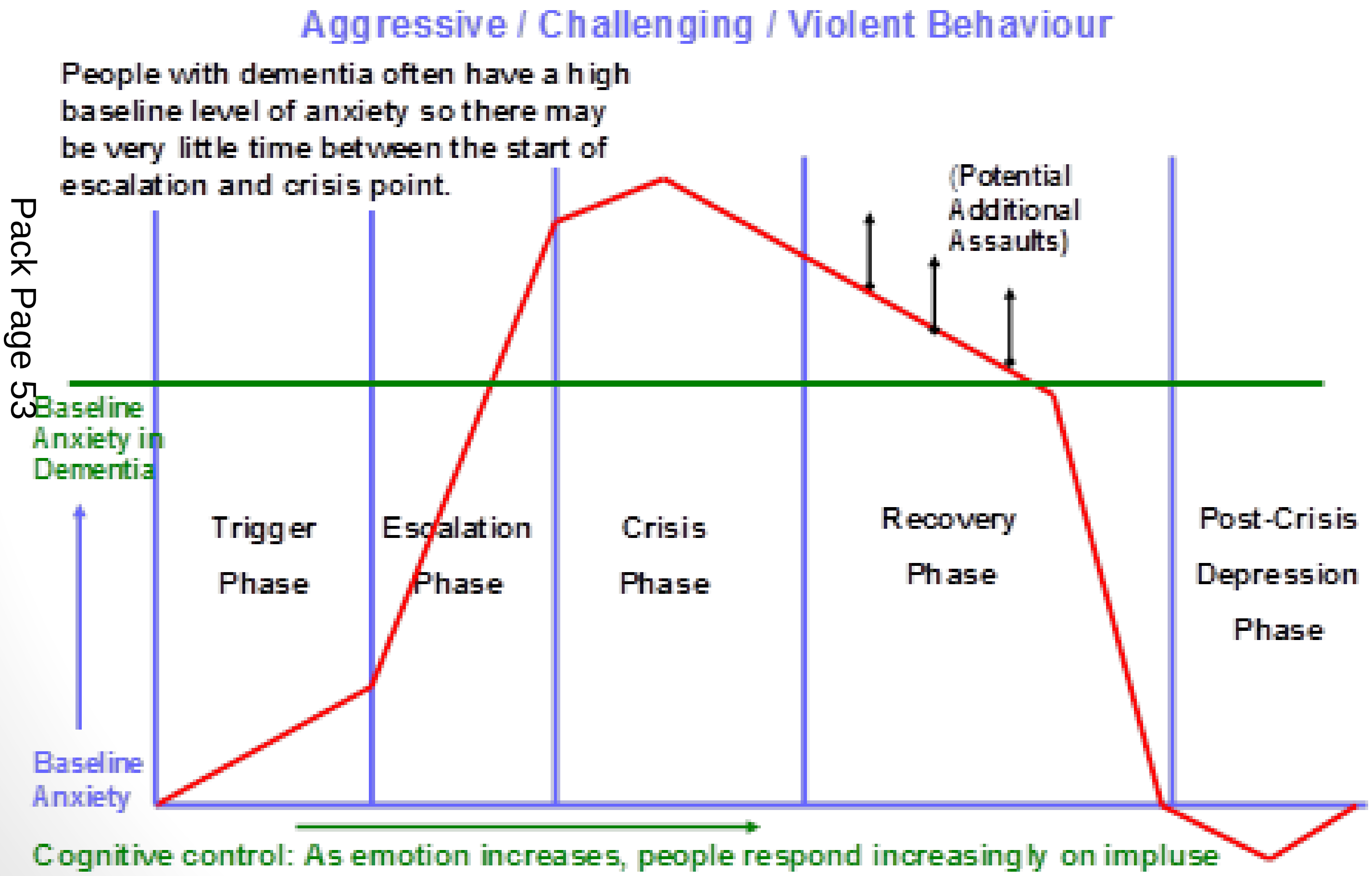
- Constant Insecurity - always being caught unawares and having to think on your feet, always having to make the best sense you can of the information you've got before you without any background to it, always being anxious that you might get separated from the people who are most important to you, living on your wits, not being able to put emotional hurt into perspective, being at a disadvantage

*"When you know your history, then you know where you're coming from. Then you wouldn't have to ask me, who the heck do you think I am?"*

Bob Marley

# Challenging Behaviour is Ordinary Behaviour in Trying Circumstances

Typical Assault Cycle
(Adapted from Kaplan and Wheeler 1983)



People with dementia often have a high baseline level of anxiety so there may be very little time between the start of escalation and crisis point.

Pack Page 53

# Risk Factors for Aggression

- Poor communication skills
- Misinterpretation of others’ behaviour/ feeling threatened by others
- Noisy and over-crowded or chaotic environments
- Need for help with intimate personal care
- Disorientation and confusion
- Disinhibition
- Over sedation

- People with dementia often find others’ behaviour challenging. What are WE doing that could be seen as out of character or unusual?
- By far the highest incidence of aggression in Older People’s Services occurs during personal care

# How to Reduce Aggression?

- Improve reporting – identify the hotspots, both in terms of clinical areas and in terms of function and place within each clinical area

- Improve aggression management – training targeted at personal care and for use with people who are frail, hotspot training, individual consultancy

- Train staff in **PREVENTION**

# Dealing with Aggression

- Very often predictable
- Most medication is fairly ineffective and carries significant risks
- The recommended and most effective form of intervention is functional analysis – identifying and adapting to the individual triggers

Pack Page 56

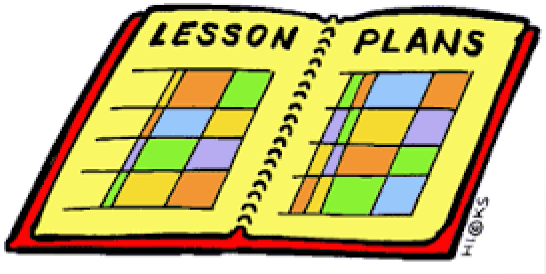
# Staff

- Staff perception of own ability to cope much more critical than actual severity of challenging behaviour being presented
- Possible to enhance staff coping (relationship with patient's family, opportunity to relate to patients as individuals, knowledge of life history, opportunity to deliver person-centred care, perception of behaviour as related to the dementia not a personality trait, encouragement to take time to engage with the patient rather than complete the task, optimism, sympathy)
- Good evidence for efficacy of staff training
- Lets smile!

# What?

- National guidelines on dementia and challenging behaviour
- Information on strategies to reduce the risk of aggression
- Skills training around approaching and communicating with people with different types of neurological damage
- Experiential learning about being a care recipient
- Training in the non-abusive application of learning theory
- Skills training on holding people safely who have stiff joints and low bone density
- A focus on managing behaviour during personal care which is the most high risk activity

Pack Page 58

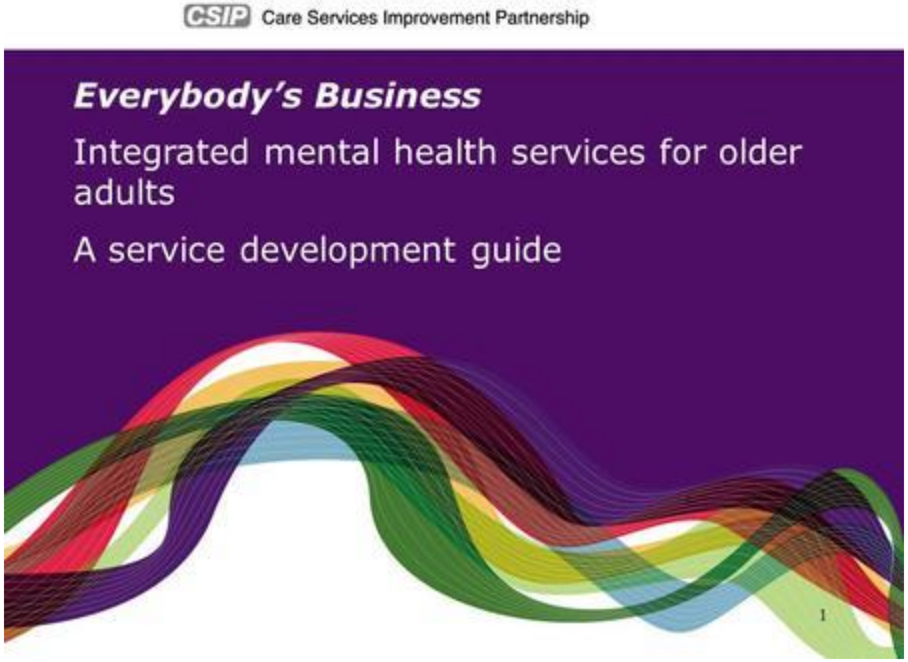


# Main Topics

- Overview of recent NICE guidance on management of behaviour in dementia
- Understanding the stressors that increase aggression in dementia
- Setting up the care environment to minimise those stressors
- Styles of communication and matching the level of communication to the need of the patient
- Setting up care delivery to minimise stressors
- Functional analysis of behaviour and making accurate observations
- Assessing the comparative risks of different styles of management – knowing when nothing is the right thing to do

# Everybody’s Business

Pack Page 60



CSIP Care Services Improvement Partnership

**Everybody’s Business**

Integrated mental health services for older adults

A service development guide

- “The ward environment should reflect the fact that although this is a clinical area, it is also the patient’s home for a variable period of time”
- **What makes a place homely?**
- **How do you recognise the function of different places?**

# Body Language

Your body language gives away your general attitude

- Breath out and drop your shoulders
- Smile and speak with kindness
- Don’t loom!  (or appear out of nowhere)

Pack Page 61

# Specialist nursing

- Immediate reduction of arousal using music therapy or singing, snoezlen, exercise, simulated presence and bird song but only during the activity
- Good evidence of effectiveness of massage and cognitive stimulation therapy
- Good evidence for effectiveness of alternative bathing techniques
- Strong evidence for effectiveness of behavioural management

Pack Page 62

# Promoting Calm

Incidence of aggression in different care homes varies widely. Low incidence associated with:

Seeing aggression as a natural response to being over-whelmed by demand
A mutually respectful relationship with clients
Encouraging the use of retained skills
Offering prompts and appropriate help
Looking for individual solutions rather than standard procedures
Regular clinical supervision
Permission and encouragement to innovate
Permission and encouragement to take as long as is needed
A sense of unity and common purpose in the staff team
Being confident in the knowledge base relating to dementia and aggression and to ethical boundaries
Seeing the process of engaging the client as the focus
of care rather than the specific task

# Functional Analysis

| Antecedants | Behaviour | Consequences |
|---|---|---|
| | | |
| | | |
| | | |

- Frequency charts
- ABC charts
- Time Sampling

Pack Page 64

- Remember that mood, facial expression, general level of activity may all give useful information as well as specific behaviours

- Also, speech is a behaviour – listen to what people say

- Functional Analysis seeks to uncover what the person can't tell us – what they are trying to achieve, what they are thinking and feeling, what associations they are making – you need a psychologist to help with formal functional analysis

# Approaching People: experiment 1

- In threes
- Get one person to be a patient sitting in a chair
- Try going up to them from in front, to one side, behind
- Try standing by them or crouching down
- What feels most comfortable for the patient?
- Now swap round and see if you all like the same things
- Now try it blindfold or with one eye covered

Pack Page 65

# Eating Experiment 1

- Eat with your non dominant hand and your eyes closed
- Be fed by someone who feeds you in silence
- Be fed by someone who is talking to someone else
- Be fed with something without knowing what it is
- Experiment with how fast you like to be fed and how much you like on the spoon

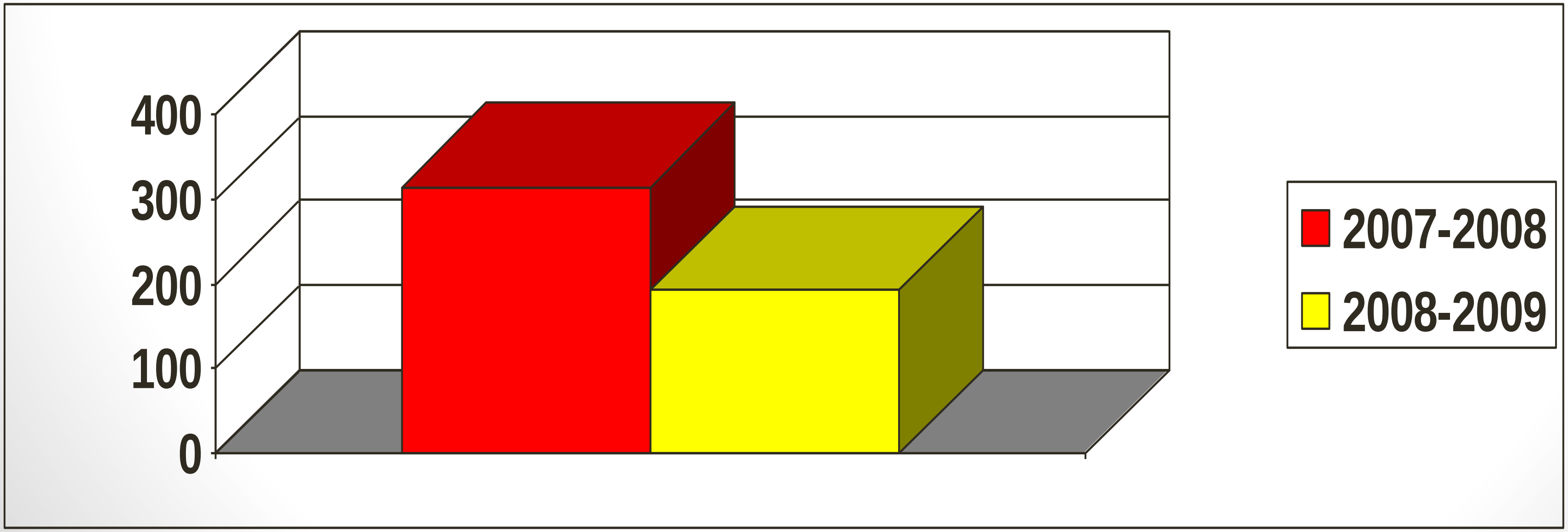
Pack Page 66

# Outcomes?

- **Huge increase in staff confidence**
- **Sustained reduction in staff sick leave**
- **Commended by the Health and Safety Executive when they visited**
- **Precisely matches the best practice recommendations of NICE**
- **The only dementia-specific training that HCSWs receive**

# Number of reported physical assaults (patient to staff & patient to patient) for 12 month period April 2008 to March 2009 & comparable figures for 12 month period April 2007 to March 2008

- 315 reported incidents for period April 2007 to March 2008
- 192 reported incidents for period April 2008 to March 2009
- 123 fewer incidents in 2008-2009 compared to corresponding period 2007-2008 which represents a significant reduction of 39%
- Number of incidents has continued to reduce
- 60% reduction in injury arising from assault



# Embedding Training

- **Part of an integrated approach to reducing risk involving security officer and formal audit to ensure efficacy**
- **Supported by train the trainer events**
- **Supported by complex case discussion from psychology**
- **Supported by hot-spot training from training department for individual patients**

The Eiffel Tower - from April 1888 to May 1889

The British
Psychological Society
Promoting excellence in psychology

Division of
Clinical Psychology

# Psychological Best Practice in Older People's Inpatient Services

November 2016 Dr Kate Ross

# Local Beginnings: The Stafford Project

Pack Page 71

- Grounded Theory
- Action Research
- Solution Focused Therapy

# Objectives

1. To develop the psychological mindedness of the local staff group

2. To adapt the structures and mechanisms of the ward to improve the patient journey/ care pathway

3. To improve multi-disciplinary working

4. To reduce length of stay

# The Journey: research or management?

- **Grounded Theory Method** (GT) is a systematic methodology in social sciences involving the construction of theory through the analysis of data

Pack Page 73

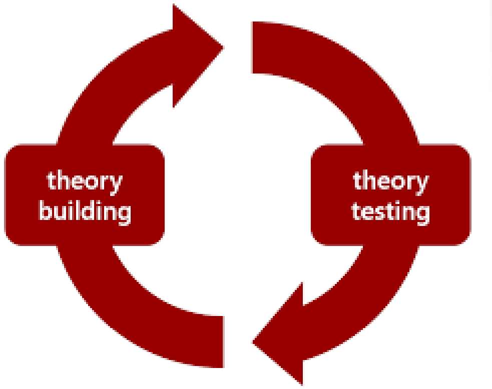
- The aim of grounded theory is: *'to generate or discover a theory'* (Glaser and Strauss, 1967)

Pack Page 74

# Action Research

- A problem solving approach to research based on a series of iterative trials to pilot and refine change
- **Denscombe (2010) : action research's purpose is to solve a particular problem and to produce guidelines for best practice**

# How do you start?



**When moving towards a change it is necessary to develop a vision** that will be the pillar to success in focusing the right strategies towards the change. It must be easy to communicate to others, attainable, understandable and something that is a shared vision with the stakeholders. It needs to **determine the values** that are central to change and **clarify how the future will be different from the past.**

**Visions are necessary for people to make a goal** and to make decisions in the right direction efficiently. **A vision should capture the heart and mind of the individuals involved** especially those in the leadership role. This will set the stage for the change and give people an understanding of a potentially complex system. It provides a focus that inspires and guides action.

# Brief Solution Focused Therapy

On a scale of 1-10, how good are things now?

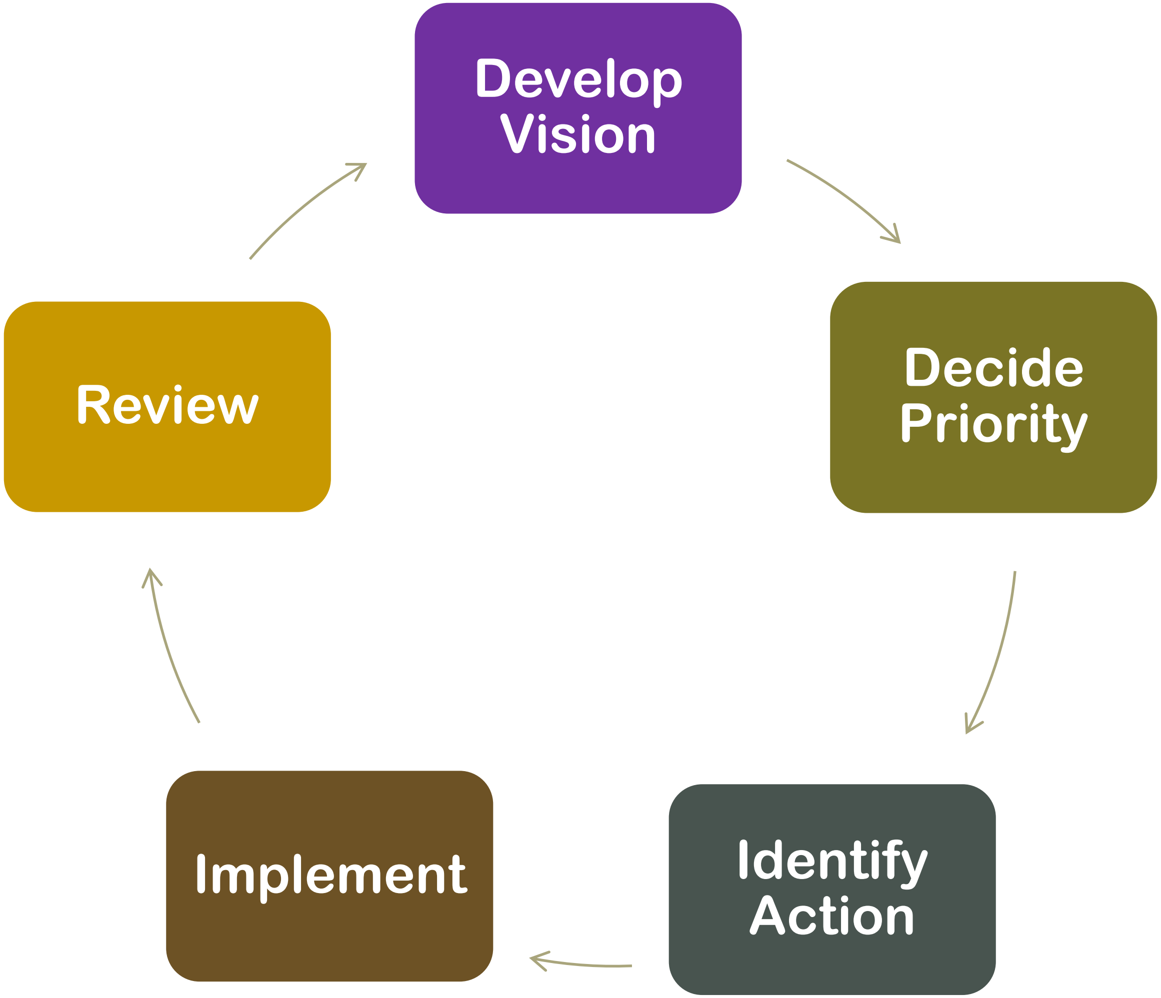
Pack Page 76

What would your ideal solution be?

- Atheoretical
- Allows the recipient to define their own vision of better or improved
- Allows the recipient to set the priorities for change
- Designed for individual therapy but I’ve used it with staff groups before
- Depends on repeatedly measuring the groups progress towards a pre-agreed goal

What would need to change to move one point along the scale?

# Key processes


Develop Vision

Decide Priority

Identify Action

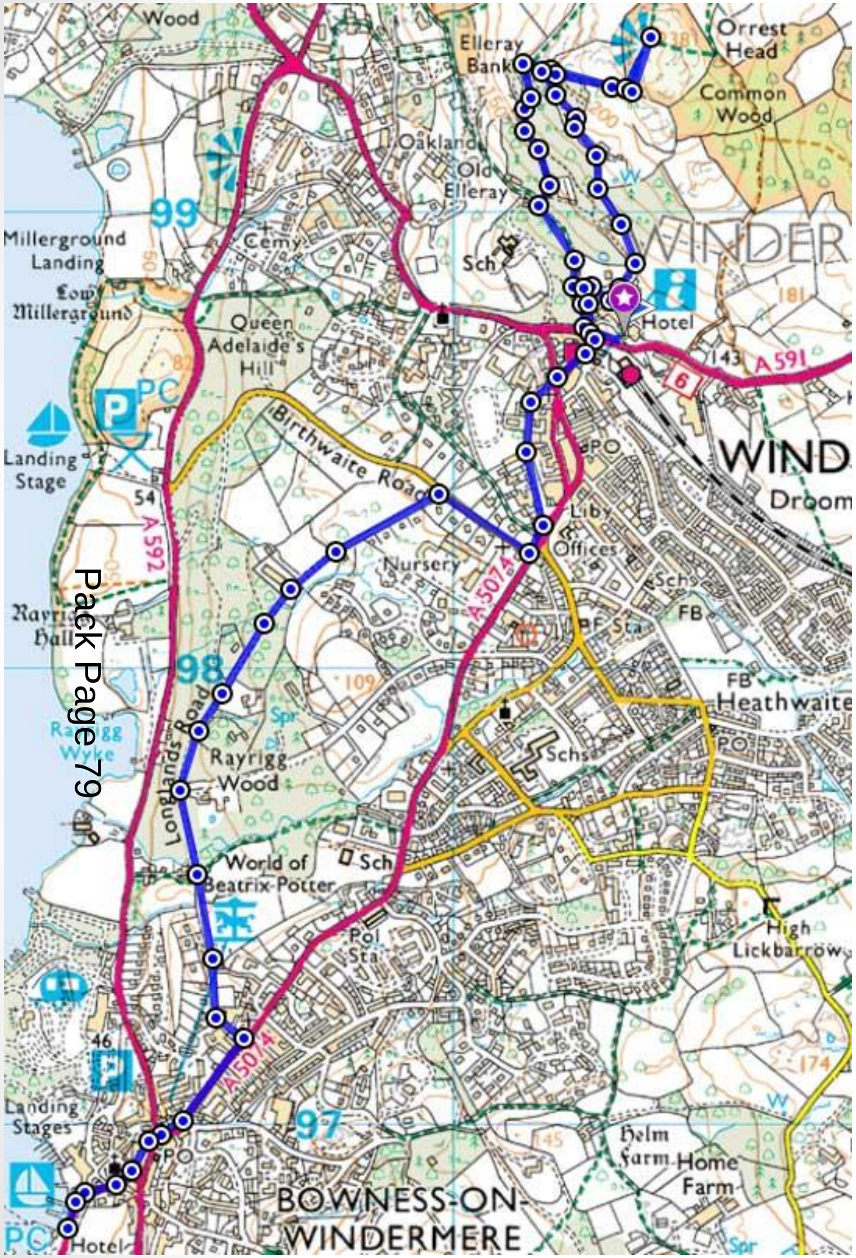
Implement

Review

Pack Page 77

# Initial Vision

- A menu of ideas for activity for patients to chose from
- Spaces for people to read and paint
- Better visual access to all areas so no-one at the end of the corridor
- Therapeutic environment, wet rooms, games rooms
- All tasks become therapy
- More structure for staff and patients
- Joint nursing and psychology groups
- Time to involve patients, more 1:1 time
- Care planning
- Patients involved with running the ward and doing tasks
- Use therapy skills
- Patients involved with every step of their journey
- A week in advance visible on a board
- Good physical health care
- People to be able to do more – a kitchen
- An activity for morning and evening every day
- Availability of computers and leisure equipment
- Model of assessment, intervene, review, discharge … that relates to stages not dates … so we can discuss where people think they are and follow their progress through
- Motivational care plans to encourage people to use the skills they've got
- Help from psychology to get things organised and structured
- We keep people longer than we should because of housing, social needs and family dynamics
- Reflective practice groups
- Formulation sessions
- A structured day



# SMART?

- Absolutely not – and it doesn't need to be
- Detailed and inclusive
- On a scale of 1-10, ward judged themselves a 6
- They set a realistic target of 8.9
- And their confidence of achieving it was 7.9

Guiding principles

**All care is therapy**

**All people are of value**

# Outcomes

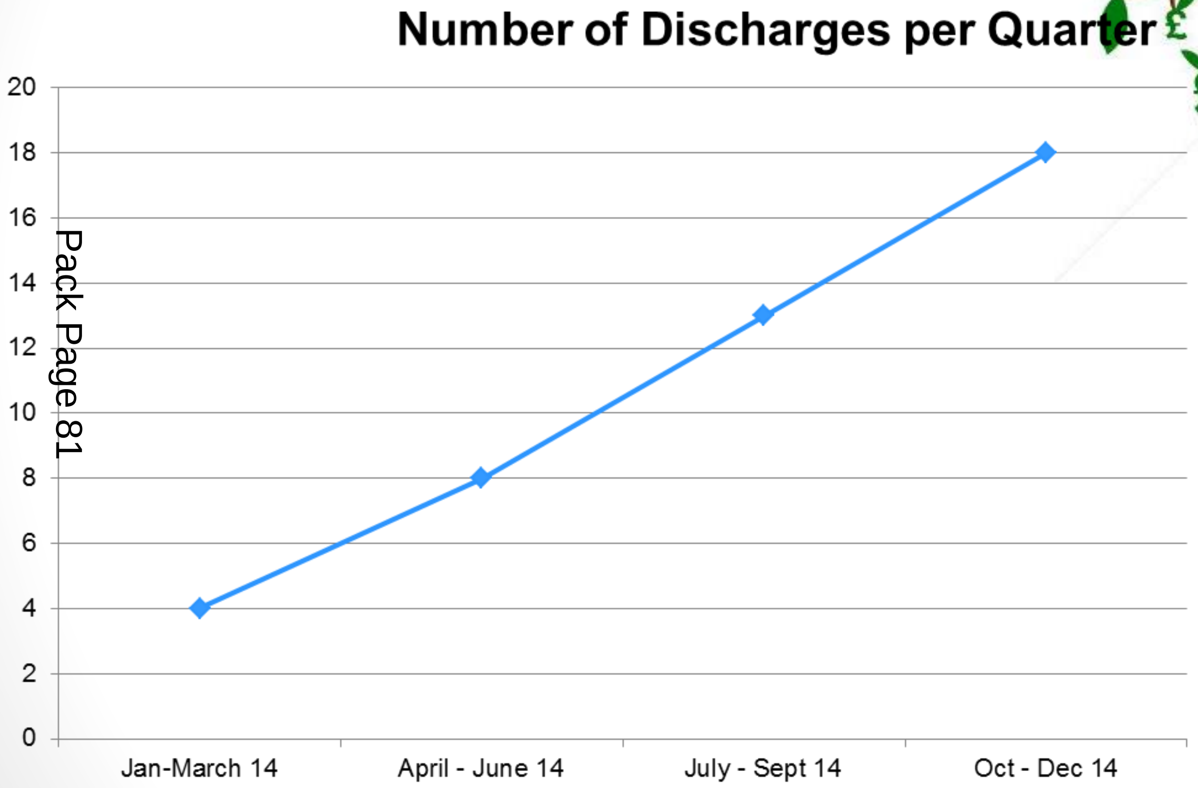
To Start With:

- On a scale of 1-10, ward judged themselves a **6.0** for quality of care.
- They set a realistic target of **8.9**

12 Months Later

| | |
|---|---|
| Overall quality of care | **8.8** |
| Staff relationships with patients | 8.4 |
| Multidisciplinary working | 8.2 |
| Monitoring of people's progress | 8.2 |
| Staff relationships with carers | 7.9 |
| Confidence of staff team | 7.6 |
| Care for people with dementia | 7.4 |
| Care for people who are highly anxious | 7.2 |
| Patient-led goal setting | 6.9 |
| Interventions reflect patients own priorities | 6.7 |

# And Greater Efficiency!



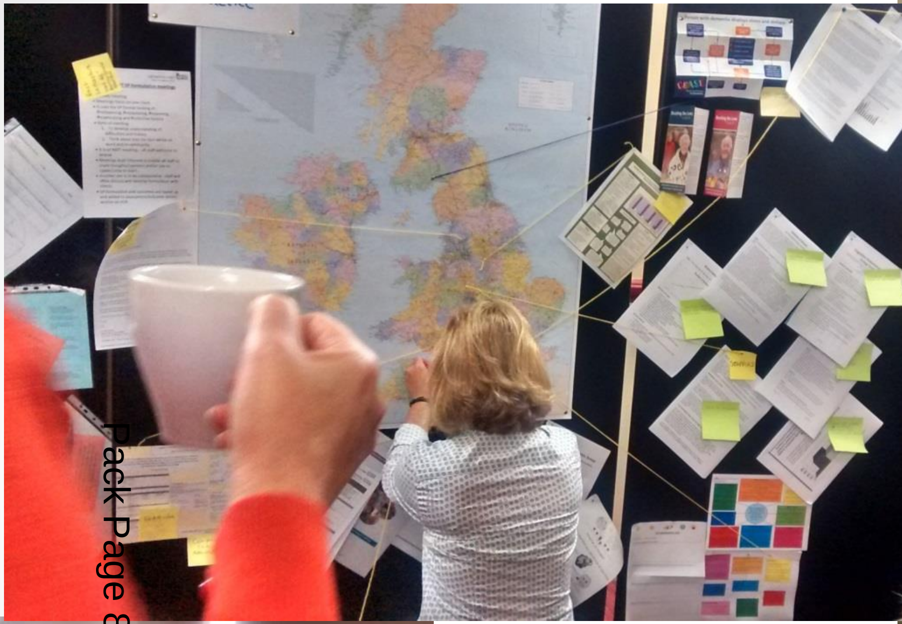
Pack Page 81

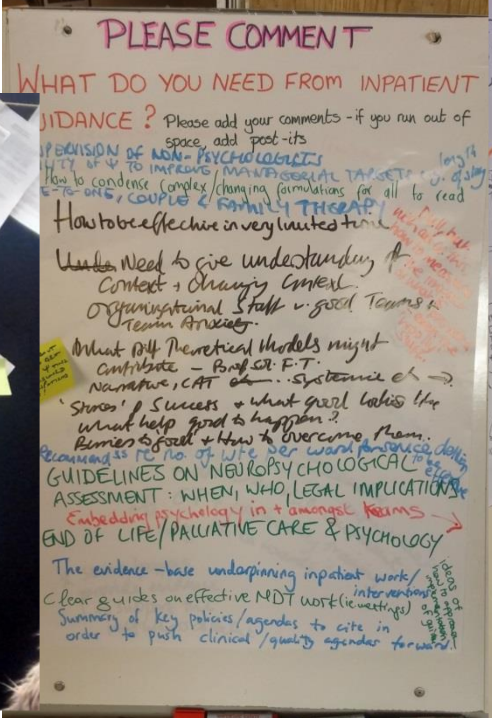
# Theory derived

Pack Page 82

The process of creating a vision that is used in brief solution-focused therapy can be used in organisational change to help groups of staff define and agree their own ambitions for a service. In this way, change is created from the bottom-up, the people doing the job generate the solutions, and resistance is very low.

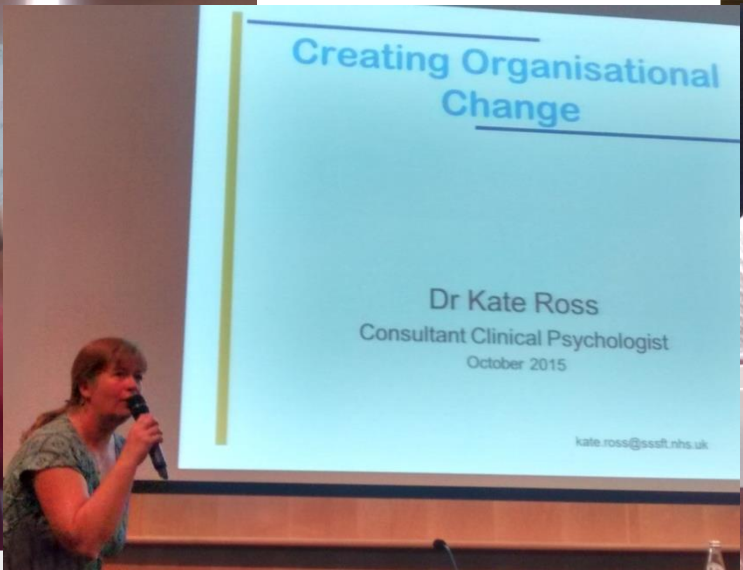
# Spreading the Message





PLEASE COMMENT

WHAT DO YOU NEED FROM INPATIENT
IDANCE ? Please add your comments - if you run out of space, add post-its
PERVISION OF NON-PSYCHOLOGISTS
ITY OF Ψ TO IMPROVE MANAGERIAL TARGETS e.g. length of stay
How to condense complex/changing formulations for all to read
E-TO-ONE, COUPLE & FAMILY THERAPY
How to be effective in very limited time
~~Unde~~ Need to give understanding of Context + changing context.
Organisational Staff v. good Teams + Team Anxiety.
What diff Theoretical Models might contribute – Brief Sol. F.T. Narrative, CAT ~~etc~~ .. Systemic etc →?
'Stories' of Success + what good looks like what help good to happen?
Barriers to good + How to overcome them.
Recommendations re no. of wte per ward/service delivery to be effective
GUIDELINES ON NEUROPSYCHOLOGICAL ASSESSMENT: WHEN, WHO, LEGAL IMPLICATIONS
Embedding psychology in + amongst teams →
END OF LIFE/PALLIATIVE CARE & PSYCHOLOGY
The evidence-base underpinning inpatient work/interventions
Clear guides on effective MDT work (ie. meetings)
Summary of key policies/agendas to cite in order to push clinical/quality agendas forward.
Ideas of how to approach implementation of guidance



Creating Organisational Change

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October 2015

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# Business Case to DCP

Pack Page 84

**Create evidence**

- Survey
- Workshop
- Examples of good practice
- Filmed interviews
- Web resources
- Artwork

**Deliver CPD**

- Conference
- Training materials
- CPD events
- Student and trainee placements
- Evidence-based guidance

**Increase Profile of Psychology**

- Links with AIMS and other stakeholders
- Availability of formal guidance demonstrating benefit of psychology and psychological approaches

# On the National Stage

- Poster Presentation in Westminster … May 16
- Presentation to AIMS July 2016
- Establishment of Facebook page and twitter account and e-mail network
- Establishment of dropbox of images and evidence
- Creation of videos of good practice
- Funding to produce of Good Practice Guidance

# Current Project

**Developing Psychological Best Practice in Inpatient Services for Older People**

**OBJECTIVE: Increase the clinically relevant evidence base relating to older adult inpatient services and produce good practice guidance for clinicians.**

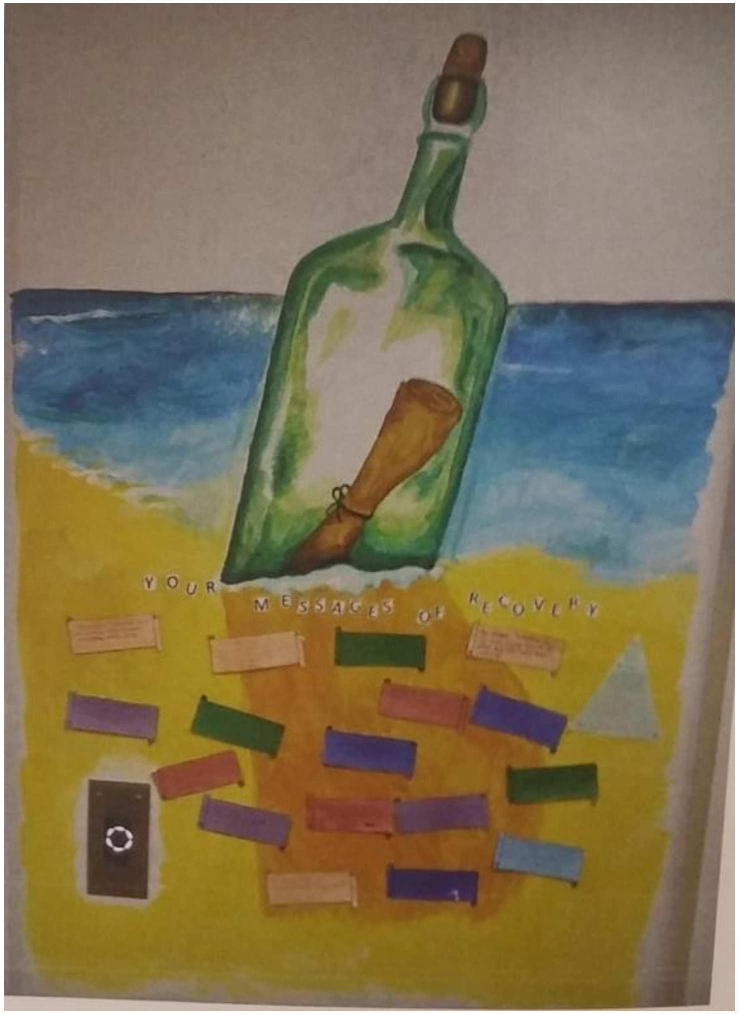
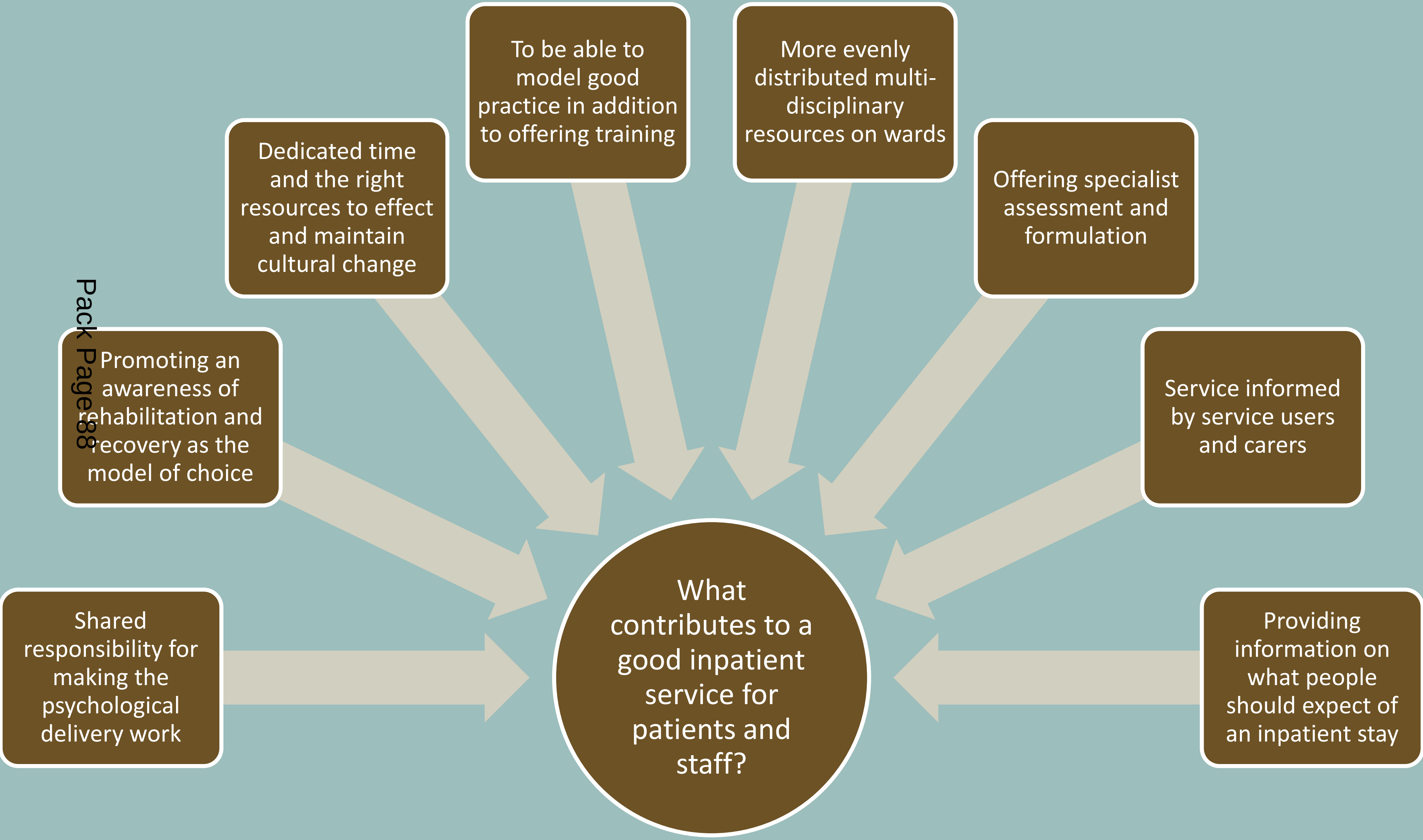


Image from a hospital in Cheltenham where patients leave each other messages of hope – a message in a bottle

# Other National Developments

- **FPOP is working with AIMS to make a definite recommendation around psychology resourcing for inpatient wards. A work in progress but we are recommending a minimum of 2½ days a week so that the psychologist can be a proper member of the ward team.**



What contributes to a good inpatient service for patients and staff?

Shared responsibility for making the psychological delivery work

Promoting an awareness of rehabilitation and recovery as the model of choice

Dedicated time and the right resources to effect and maintain cultural change

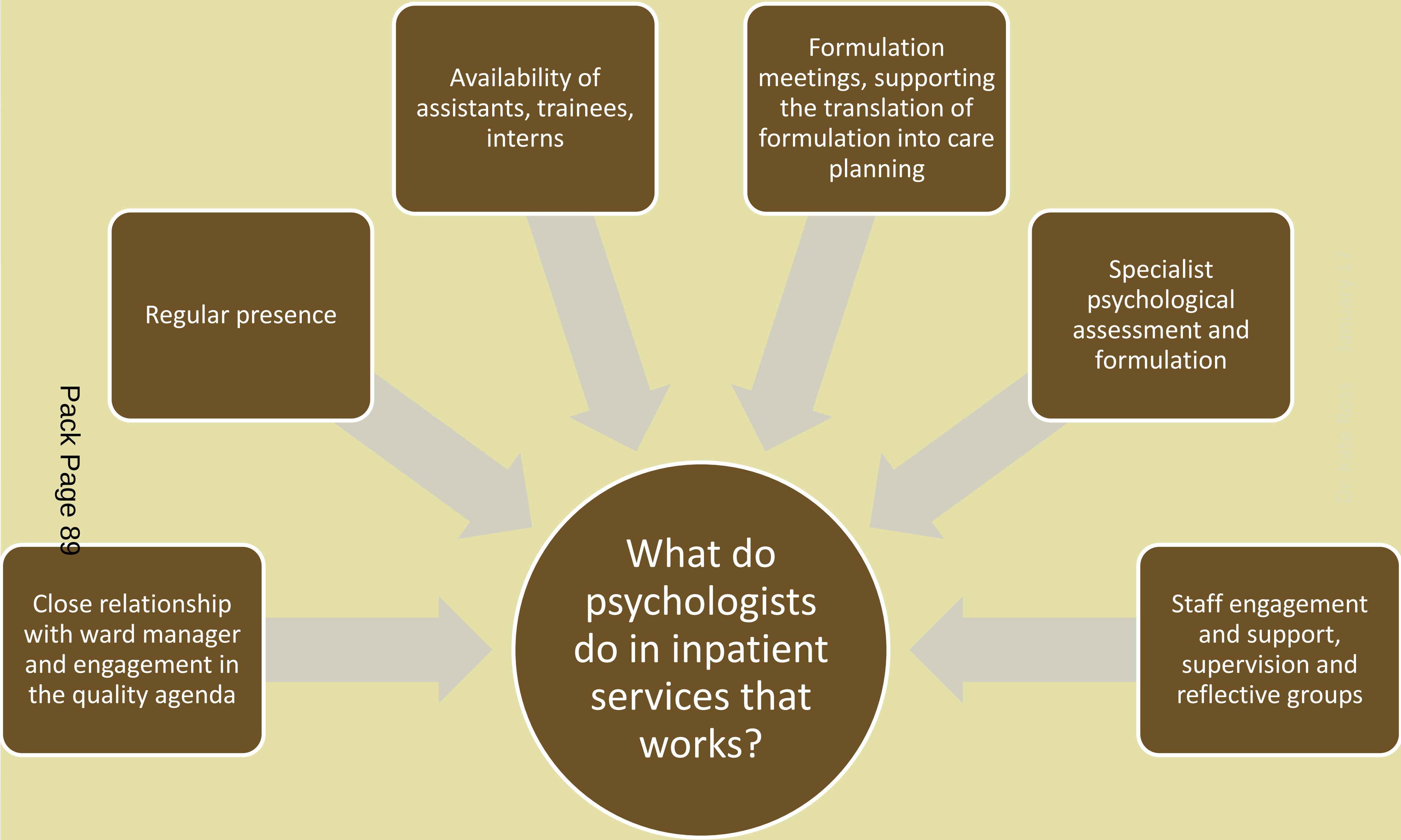
To be able to model good practice in addition to offering training

More evenly distributed multi-disciplinary resources on wards

Offering specialist assessment and formulation

Service informed by service users and carers

Providing information on what people should expect of an inpatient stay



What do psychologists do in inpatient services that works?

Regular presence

Availability of assistants, trainees, interns

Formulation meetings, supporting the translation of formulation into care planning

Specialist psychological assessment and formulation

Close relationship with ward manager and engagement in the quality agenda

Staff engagement and support, supervision and reflective groups

# Reflective Practice groups & team based formulation sessions

**CONTENT**

- Longitudinal formulation (understanding of the importance of life story)
- Shaping of care plans
- Developing new narratives
- Understanding from a systemic perspective

**PROCESS**

**East Lancashire**

- Weekly MDT meetings focusing on 1 SU
- Uses 5Ps model for formulation (predisposing, precipitating, presenting, perpetuating, protective)

**Staffordshire and Shropshire**

- Weekly MDT meeting focusing on 1 SU
- Uses Laidlaw’s age-adapted CBT model. Discussed with SU post-meeting and integrated into proforma for admission planning

**Pennine Care**

- Proforma with prompts to help access each component - core beliefs & Padesky’s hot-cross bun to delineate aspects within presentation
- Discussed & developed with SU post-meeting & integrated into written communications

**Leicestershire**

- Uses model of Schwartz rounds (in addition to formulation groups)

**Somerset**

- Newcastle model

**Birmingham & Solihull**

- Newcastle model, 5Ps & CBT model

**Cardiff & Vale**

- Run by 2 Clinical Psychologists, formulation fed back into ward round

**Greater Manchester**

- Assistant Psychologist develops formulation for each person admitted (meeting with carers, behavioural obs charts, notes review)
- Behavioural management plan follows person on discharge

# Reflective Practice groups & team based formulation sessions

**OUTCOMES**

Staff report changes in their own practice:

- Greater psychological understanding
- Improved recovery focused care
- Compassionate therapeutic alliance
- Increased staff confidence
- Improved ability to provide a consistent approach
- Positive management of complex problems.

Measured reductions in:

- Average length of stay
- Readmission rates
- Harm and falls during admission

# Currently in the Process of Writing Guidance

- **Aiming for publication June 2017**
- **Chapter Structure:**
  - **Introduction**

1. **Key Aims – what is your core purpose**
2. **Therapeutic Engagement**
3. **Formulation**
4. **Communication**
5. **Cultural Change**
6. **Patient Journey**
7. **Avoiding Psychological Harm**
8. **Tips from the Coal Face**

# Found Poetry

It may seem like a change in any policy is rare
But subtle little changes increase the quality of care
Because there's more than just pay in which we find rewards
You've got to consider elements of psychologically minded wards
And although patients being angry and confused is awful
We're here to help the team be more compassionate and thoughtful

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# North Wales Public Health Team

# Dementia: Prevention and Early Intervention

**Author:** Dafydd Gwynne, Principal Practitioner

**Date:** 22nd February, 2012

**Version:** 1

**Publication/ Distribution:**

Public - Internet

**Review Date:** N/A

**Purpose and Summary of Document:**

Dementia presents a significant public health concern. Any interventions that could reduce the burden of the condition by preventing or delaying its onset could not only provide health and well-being benefits to the person with dementia, but to society in terms of reduced carer responsibility and improved productivity, and also the public purse in terms of reduced health and social care costs. This is especially pertinent with regards to an increasing population of older people projected for North Wales.

This report outlines the current evidence relating to prevention of and early intervention in dementia amongst older people, and an overview of the resulting economic impact.

**Work Plan reference:** North Wales Dementia Planning Group

# Table of Contents

# 1 Executive Summary, Conclusions and Recommendations

This report outlines the current evidence available relating to prevention, early intervention, and costs of late onset dementia. It is limited to these areas, and therefore doesn't consider other aspects or themes of dementia care in detail, for example integrating health and social care, promoting independence, carer support, impact on social and personal relationships, managing challenging behaviour, and managing advanced dementia.

Dementia presents a significant public health concern; overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years, are attributable to it. Dementia prevalence roughly doubles every 5 years from the age of 65 onwards(1). It has been recently estimated that dementia costs the UK £23bn a year, presenting a greater cost than cancer (£12 billion per year) and heart disease (£8 billion per year) combined(2). Most of this cost, £12.4 billion per year, is met by unpaid carers, with the rest made up of Social Care costs (£9 billion), health care (£1.2 billion) and productivity losses (£29 million). Population projections estimate an increase of 68% in the number of people with dementia in Wales between 2011-2030 (specifically 88% for males, and 57% for females)(3). Delaying the onset of dementia by five years would halve the number of UK deaths due to the disease to 30,000 a year(4).

The strength of evidence around dementia prevention is currently not strong. Much more research work is required, but it is apparent that it is a theme currently receiving significant academic attention. However, the evidence that is available suggests that the most promising approach to reducing the prevalence of all forms of dementia is a more general promotion of healthy lifestyles, particularly for those in mid-life. It has been estimated that by promoting and adopting healthy lifestyles in middle age, an individual's risk of developing dementia could be reduced by approximately 20%(5).

The evidence also highlights the value of early intervention and diagnosis, as up to two thirds of people and their families are living with dementia unaware of its existence(6). Early intervention, both pharmacological and non-pharmacological, can help to slow the progress of dementia and its symptoms. It can also help to better prepare individuals and their families for the future of living with the condition. However, early diagnosis does carry ethical implications, and consideration needs to be given to ability to consent and the potential benefit and harm for each individual case.

In addition, the literature also promotes the key role played by carers of those with dementia; prevention and early intervention is also important here. Service commissioners need to consider carer needs in all service planning, in order to support them to maintain their caring role whilst maximising health and well-being outcomes for themselves and those for which they provide care. This will also help to avoid or delay admission of those with dementia to care settings, thereby reducing the pressure on health and social care services.

As more evidence comes to light, Public Health professionals, in collaboration with academic bodies, the voluntary sector, and health and social care services in particular, should seek to strengthen the evidence base for implementation of effective interventions. Due to the health gain and economic impact on the population across the life course, addressing the impact of dementia should remain high on the Public Health and partnership agenda.

**Recommendations:**

1 In supporting the planning and commissioning of dementia services, Public Health Wales should advocate for a strong emphasis on implementing evidence-based preventative and early interventions.
2 Public Health Wales should highlight the links between dementia prevention and other Local Public Health Strategic Framework priority areas, such as tobacco control, obesity, alcohol, and mental well-being.
3 Lifestyle intervention and risk reduction should be prioritised for adults aged 40-64; this will have added health gain benefits over and above those of reducing the risk of dementia, and will therefore likely be more cost-effective.
4 Promote access to social activities for older people, in community and residential settings e.g. AgeWell Centres, Over 50s Clubs or Walking Groups.
5 Identify the specific needs of people with a Learning Disability, especially individuals who have Down's syndrome. This may involve additional training across health and social services to raise awareness of early onset dementia amongst this population; promote access to the annual health checks for people with a learning Disability; and, to highlight the specialist support that is available to reduce the impact of a diagnosis of dementia on the individual and family members/carers.
6 Highlight role of frontline health and social care staff in identifying dementia symptoms and timely referral to specialist diagnostics, such as memory clinics, to facilitate formal diagnosis. Ethical issues regarding early diagnosis and consent should be carefully considered on an individual basis. Service commissioners may need to consider training needs of GPs and primary care teams, specifically in relation to dementia, and generally for older people's mental health.

7 The risk for individuals with Mild Cognitive Impairment in particular should be highlighted, whilst standardising the process of providing regular assessment via the memory clinics across BCUHB, supported by the Dementia Advisors when in post.

8 Those undertaking health checks for other high-risk groups, for example those who have had a stroke and those with neurological conditions such as Parkinson’s disease, should also be aware of the possibility of dementia.

9 Promote the role of family members in identifying potential symptoms of dementia in older people, and their early involvement in planning future care needs of relatives who have an official diagnosis.

10 Service commissioners need to consider the specific needs of informal carers of people with dementia. Improving access to services such as educational support programmes, stress management, and cognitive behavioural therapy have been shown to have positive outcomes for the carer and to delay the institutionalisation of the person with dementia. It is important to continue to recognise the ongoing role of third sector agencies in supporting carers, in addition to those with dementia.

11 Early intervention in dementia does help secure more positive outcomes. For people with mild-moderate dementia, there is evidence of effectiveness for pharmacological (such as acetylcholinesterase inhibitors) and non-pharmacological (such as group cognitive stimulation programmes) interventions – further detail is provided in this report. Securing improved access to these should be considered by health and social care service commissioners, promoted via the specialist Memory Clinics, and supported by primary care.

12 Research work on the implementation of preventative or early intervention dementia interventions needs to consider the economic impact, in addition to any other primary outcomes measures. Public Health Wales and Besti Cadwaladr University Health Board should aim to maximise regional opportunities to engage in academic fora, in order to ascertain what recent evidence may be applicable in Wales.

# 2 Introduction

## 2.1 Purpose of this report

This report should be considered as part of the Public Health Wales evidence provided to support the work of the North Wales Dementia Planning Group. It builds on the comprehensive report by the National Public Health Service for Wales in 2008(7) which provided a model and mapping of future dementia prevalence and service implications in Wales.

This report outlines the current evidence available relating to prevention and early intervention of late onset dementia i.e. dementia that is diagnosed in individuals at or over the age of 65 years. Early onset of dementia can also occur, but is much less common under 65 years of age, accounting for 2.2% of all people with dementia in the UK; interestingly the figure for BME groups is 6.1%(4).

This report also outlines the most recent costs associated with dementia care and, although currently limited, the cost-effectiveness evidence regarding preventative interventions.

## 2.2 Methodology

Due to time constraints, literature searches were conducted within PubMed, OVID, and Google Scholar for systematic reviews using the search terms "dementia, prevention, early intervention". The search also included identifying the most recent evidence from the Cochrane Database, NICE Guidelines, and leading Dementia and Alzheimer's Charities.

Leading academics in cognitive science from Bangor University's School of Psychology were also consulted, in order to ascertain the most relevant current papers that should be considered in the review.

## 2.3 Impact of Dementia

Dementia presents a significant public health concern. It is a debilitating condition which describes a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities(4). It is therefore not a natural part of ageing, and is caused by a variety of diseases which affect people in different ways. In terms of the dementia sub-types, a 30 year study in Sweden on 524 individuals with clinically diagnosed dementia identified Alzheimer's disease in 42.0% of the cases, vascular dementia in 23.7%, dementia of combined Alzheimer and vascular pathology in 21.6%, and frontotemporal dementia in 4.0% of the patients. The remaining 8.8% of the patients had other dementia disorders, including combinations other than combined Alzheimer and vascular pathology(8).

In comparison, the current NICE Guidelines(9) suggest that Alzheimer's disease accounts for around 60% of all dementia cases, and other common causes in older people include cerebrovascular disease (vascular dementia) and dementia with Lewy bodies (DLB) (accounting for 15–20% of cases each). Numerous other causes exist, including other degenerative diseases (for example, Huntington's disease), prion diseases (Creutzfeldt-Jakob Disease), HIV dementia and several toxic and metabolic disorders (such as alcohol-related dementia). Dementia also develops in between 30–70% of people with Parkinson's disease, depending on duration and age; the distinction between Parkinson's disease dementia (PDD) and DLB lies in the relationship between motor and cognitive impairment. If dementia precedes, or occurs within 12 months of, motor disorder, DLB is diagnosed; otherwise the convention is to use the term PDD(9).

The distribution of subtypes is different in men and women. Alzheimer's disease is more common in women (67% in women compared with 55% in men), while vascular dementia and mixed dementias account for 31% of all cases in men and just 25% in women. Among those with late onset dementia, 55.4% have mild dementia, 32.1% have moderate dementia and 12.5% have severe dementia(4).

People with Down's syndrome are at risk of developing Alzheimer's Disease about 30–40 years earlier than the rest of the population, although lifetime risk may not be different(10). The prevalence of dementia in people with learning disabilities without Down's syndrome is generally two or three times that expected in people over 65(11).

Dementia is more prevalent in people aged over 65, and prevalence roughly doubles every 5 years from this age onwards(1). This is highlighted in Table 1 below. Population projections estimate an increase of 68% in the number of people with dementia in Wales between 2011-2030 (specifically 88% for males, and 57% for females)(3). These projections are summarised in Appendix 1.

**Table 1.** Rates for men and women with dementia in the 65 and over population(3)

| Age range | Males | Females |
|---|---|---|
| | % | % |
| 65-69 | 1.5 | 1.0 |
| 70-74 | 3.1 | 2.4 |
| 75-79 | 5.1 | 6.5 |
| 80-84 | 10.2 | 13.3 |
| 85+ | 19.5 | 25.0 |

The proportion of deaths attributable to dementia increases steadily from 2% at age 65 to a peak of 18% at age 85–89 in men, and from 1% at age 65 to a peak of 23% at age 85–89 in women. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years, are attributable to dementia. Delaying the onset of dementia by five years would halve the number of UK deaths due to the disease to 30,000 a year(4).

## 2.4 Economic Impact

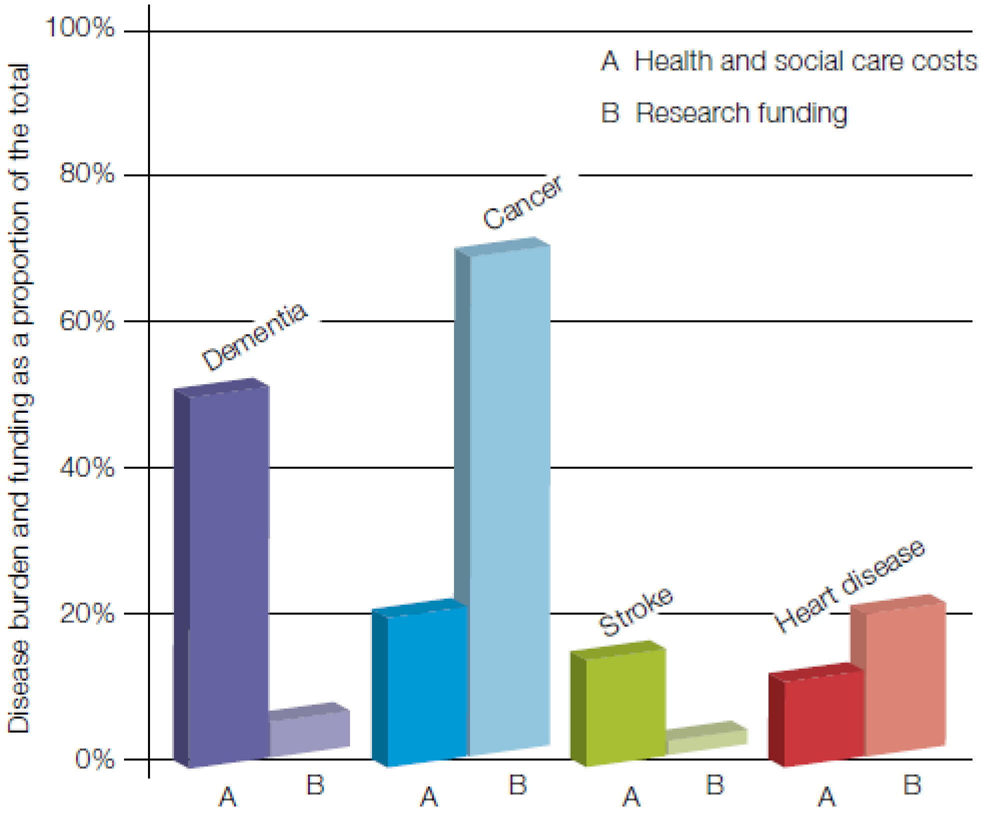
It has been recently estimated that dementia costs the UK £23bn a year, presenting a greater cost than cancer (£12 billion per year) and heart disease (£8 billion per year) combined(2). Most of this cost, £12.4 billion per year, is met by unpaid carers, with the rest made up of Social Care costs (£9 billion), health care (£1.2 billion) and productivity losses (£29 million). Considering the projected increase of 74% in dementia prevalence in Wales by 2030, if the same increase were to be applied to the total UK costs, this would mean an annual UK cost for dementia of over £40bn by 2030.

The authors of the same report estimate that each dementia patient costs the economy £27,647 per year, which is more than the UK median salary (£24,700). In contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year. This finding is supported by a recent European study that found, using slightly different costing parameters, that each person with dementia cost society €22,194 per annum(12). Appendix 2 highlights economic projections for total health and residential care expenditure Australia, from 2002-2062(13), which suggests how dementia is projected to move from the 8th highest in the rankings of %

health and residential aged care expenditure in 2002/3, to the 3rd by 2032/3, and the highest ranking by 2062/3, in relation to other conditions.

Also highlighted in the UK study(2) is the difference in government and charity funding to support research into dementia, in comparison to other health conditions, suggesting that for each person with dementia £61 is spent on research, compared to £295 for those with cancer; this is highlighted in Figure 1 below.

**Figure 1:** Health and social care costs and research funding by disease(2)



An American study found a significant difference in medical costs associated with different types of dementia suggesting that, compared with control patients without dementia, annual medical costs for Vascular Dementia patients were substantially higher (US$10,545) than costs for patients with Alzheimer's disease (US$3748)(14). Although Vascular Dementia patients accounted for only 6% of all dementia patients identified in the health plan, they had substantially higher prevalence rates for 10 cardiovascular conditions compared with Alzheimer's disease patients and controls. They concluded that the higher costs for dementia patients relative to controls were largely attributable to higher inpatient costs.

# 3 Prevention and Early Intervention

## 3.1 Risk Factors

Section 3 will focus on identifying risk factors, preventative & early interventions for the most prominent forms of dementia, namely Alzheimer's disease, Vascular Dementia, and a mixture of both. The current NICE guidelines suggest that earlier identification of dementia may allow secondary prevention interventions, as well as early mobilisation of support and resources(9).

A useful method of categorizing risk factors for dementia has been proposed as identifying factors that are, and are not, modifiable(9). Non-modifiable risk factors for dementia in general and Alzheimer's in particular include:

- advancing age
- genotype
- female gender
- having a learning disability, particularly Down's Syndrome.

Established risk factors that are (or are potentially) modifiable / preventable include:

- hypertension,
- excessive alcohol consumption,
- diabetes,
- depression
- head injury.

Although the evidence is not so strong, other modifiable (or potentially modifiable) risk factors that may impact on the risk of dementia include:

- obesity,
- raised homocysteine levels
- raised cholesterol levels.

In addition, a recent systematic review of evidence on potential risk factors and interventions for Alzheimer's disease and Cognitive Decline(1) presents a similar list of risk factors (summarised in Appendix 3). The NICE guidance(9) also notes that risk factors for vascular dementia overlap with Alzheimer's disease and include age, vascular risk factors (stroke, hypertension, diabetes and smoking) and apoE4 genotype. This assessment is also reflected in a recent study on controlling vascular risk factors, which suggests that it is increasingly recognized that many vascular risk factors seem to also be risk factors for Alzheimer's disease(15). Thus the customary clear distinction between vascular and degenerative dementia may be no longer be tenable. The authors add that a new concept is emerging that Alzheimer's disease and Vascular dementia are not necessarily two entirely separate entities; rather they could be viewed as part of a spectrum of dementias ranging from predominantly vascular to predominantly plaques and tangles (classic degenerative or Alzheimer's dementia) with many if not most cases a mix of both.

## 3.2 Dementia Prevention

The strength of evidence around dementia prevention is currently limited. Risk factors for developing dementia are well known, but studies targeting a reduction in these risk factors haven't yet shown a corresponding decrease in those people developing dementia. To date, prospective randomised controlled trials have not clearly demonstrated that modification of risk factors leads to a reduction in dementia rates(9).

However, the evidence that is available suggests that the best current advice to prevent dementia includes advocating healthy lifestyles (1;9;16-20), specifically:

- Stopping smoking
- Reduced alcohol intake (although low-moderate intake seems to have mild protective factor)
- Healthy diet (evidence not so strong) – nutrient rich, Mediterranean-style, high vegetable intake
- Physical Activity – regular physical activity, especially intensive activity, even into older age; impact on mental well-being and stress reduction; reducing midlife obesity
- Social activity – people more likely to engage in cognitive and physically stimulating activities; impact on mental and physical wellbeing; benefit of 'cognitive reserve' (combination of the benefits of education, occupation, and mental activities); reducing risk of depression; developing supportive social networks for those at risk of dementia and their families. Promoting 'Social Capital' i.e. the quantity and quality of social interaction, amongst older people will become increasingly significant, considering the projected increase in the number of older people who may be socially isolated in North Wales (Appendix 3 provides predictions on the number of people aged 65+ living alone in North Wales; the average increase from 2011-2030 being 43%).

The evidence seems to suggest that maintaining or adopting these lifestyle changes is especially important in mid-life(5) i.e. from 40-64 years of age, as risk factors for not only dementia, but numerous other cardiovascular, metabolic, and respiratory diseases and cancers can be significantly reduced during these years before moving into older age. In addition, the current NICE guidelines(9) suggest that for middle-aged and older people, primary health care services should review and treat vascular and other risk factors for dementia, such as smoking, excessive alcohol use, obesity, diabetes, hypertension and raised cholesterol levels. A recent BMJ Clinical Evidence report(5) suggested that by tackling the lifestyle risk factors in middle age, an individual's risk of developing dementia could be reduced by approximately 20%.

In terms of non-lifestyle preventative interventions, the evidence suggests that cognitive training can be beneficial in reducing the risk factors for developing cognitive impairment.

The evidence for pharmacological and non-pharmacological secondary preventative interventions i.e. when dementia has been diagnosed, is summarised in section 3.4.

## 3.3 Early diagnosis and intervention

The World Alzheimer Report 2011(21) highlights a surprising lack of research conducted into the effect of the timing of dementia diagnosis upon subsequent disease course and outcomes for the person with dementia and their carers. The report reflects on the recommendations of the Dementia Study Group of the Italian Neurological Society, which support early diagnosis on the grounds that it allows timely intervention against the causes of reversible dementias, the start of therapies that can slow disease progression, attention to medical co-morbidity, and support to people with dementia and their families. Other benefits of early diagnosis and intervention include(21):

1. Relief gained from better understanding – validation of concerns, and a framework for understanding the origin and nature of symptoms

2. Maximising decision-making autonomy – the chance to make important decisions about the future while still retaining mental capacity

3. Access to services – timely access to medical and preventative care, advice and support, all of which require a diagnosis

4. Risk reduction – safety at home, driving assessments, anticipating and avoiding adverse effects of medication

5. Planning for the future – early retirement, financial planning, safety and security issues

6. Avoiding or reducing future costs – chiefly through delaying or avoiding transition into a care home
7. Diagnosis as a human right – both to have access to an accurate diagnosis, and to be informed of it, or not, according to preference

The issue of preference of receiving a diagnosis, especially an early diagnosis, carries significant ethical implications. Although there are clear advantages to early identification of memory problems as highlighted above, careful consideration will be required with each individual case as to the potential benefit and harm of disclosing a diagnosis, as the evidence currently available does not clearly advocate a preferred approach.

In terms of dementia screening, the current evidence does not support general population screening(9). Rather, the most effective method of early intervention, after considering the ethical issues raised above, is to ensure that the person concerned with potential MCI, memory problems, or dementia symptoms is seen by their GP as soon as possible. The current NICE Guidelines(9) provide detailed recommendations as to the assessment process GPs should take to diagnose dementia or memory related problems in older people. However, in North Wales the investment in and development of specialist memory clinics (detailed on the next page) has resulted in these being the preferred location for such assessments. Therefore, in North Wales the role for primary care, and GPs in particular, should be to screen potential MCI or dementia cases, and to refer to the closest memory clinic for further specialist assessment. GPs also have an important role in identifying other possible causes of MCI or dementia and co-morbidities, such as:

- Depression: this can affect 20–30% of people who have dementia, and about 20% have anxiety(22). Psychosis (often delusions of persecution) and agitation/aggression also often accompany dementia. Each of these needs to be assessed and treated independent of the underlying dementia(23).
- Hypertension and other vascular risk factors
- Lifestyle check
- Medication review in order to identify and minimise use of drugs, including over the counter medication, that may adversely affect cognitive functioning

In this context, there is a clear important role for family members and carers. We know that the services they provide are invaluable, for both those that they care for, and the public purse. As the impact of dementia grows over the coming years, family members will have an increasingly important role to play in dementia prevention and early intervention.

As highlighted in the recent Department of Health Dementia Awareness Campaign(6), family members can help to spot the early signs of dementia in their older relatives. Stating that up to two thirds of dementia cases goes undiagnosed, the campaign suggests that people should speak to their GP if they, or someone they know, begin to exhibit certain signs of dementia, including:

- Difficulty remembering recent events, but not events that occurred long ago.
- Difficulty following conversations or TV programmes.
- Keep forgetting the names of friends or common objects.
- They keep repeating things they've already said, or have difficulty remembering what they were saying.
- They have difficulty with thinking and reasoning.
- They have mood changes, such as feeling anxious, depressed or angry about their memory loss.
- They feel confused in familiar environments.
- They hear that other people have started to notice and comment on their memory loss.

Memory clinics have a key role to play in the early identification and diagnosis of dementia(21). In the UK, the introduction of a new community-based memory service saw an estimated 63% increase in diagnoses by specialist services over a two year period, with 77% of referrals to the new memory service comprising those in the early stages of dementia, or with subjective impairment only(24).

Across North Wales, there are Memory Clinics in each area, taking referrals from primary care and working on standards set out in the 1000 Lives plus document 'Improving Dementia Care'(25). The clinics complete an assessment, share the results of the assessment with the patient and the family (if agreed by the patient), and should also provide information and advice and signpost to other services. The BCUHB plans for the forthcoming appointments of Dementia Advisors in each area should support this process, in addition to promoting early intervention and initiating dementia medication, where appropriate.

Mild cognitive impairment (MCI) has been defined as a syndrome of cognitive decline, greater than expected for an individuals' age and education level, which does not interfere notably with activities of daily living(9). Brain pathologies that lead to dementia all start well in advance of the onset of clinical signs and symptoms(21). MCI is not a diagnosis of dementia of any type, although it may lead to dementia in some cases as approximately 50% of people with MCI later develop dementia; therefore, primary healthcare staff should consider referring people who show signs of mild MCI for assessment by memory assessment services to aid early identification of dementia. Current notable practice in North Wales includes offering people with MCI regular (usually annual) appointments to monitor any further change, thereby facilitating early intervention in those deemed at being at higher risk.

Once dementia has been diagnosed, health and social care staff should aim to promote and maintain independence, including mobility(9). This should be reflected in care plans that should aim to maximise independent activity, address activities of daily living, adapt and develop skills, thereby minimising the need for support.

## 3.4 Pharmacological and Non-Pharmacological Interventions for People Diagnosed with Dementia

The evidence on effectiveness of pharmacological interventions for dementia is mixed. Evidence from the most recent NICE Guidelines(9) on pharmacological interventions for cognitive symptoms in people with Alzheimer's, non-Alzheimer's dementia and MCI are summarised below:

### a.) Pharmacological interventions for the cognitive symptoms of Alzheimer's disease

The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine are recommended as options for managing mild to moderate Alzheimer's disease. Memantine is recommended as an option for managing Alzheimer's disease for people with moderate Alzheimer's disease who are intolerant of, or have a contraindication to, AChE inhibitors or who have severe Alzheimer's disease.

All above drugs should be administered according to the following summarised treatment conditions – please refer to the NICE guidelines for the full list of conditions:

- Only specialists in the care of patients with dementia should initiate treatment. Carers' views on the patient's condition at baseline and follow-up should be sought.
- Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms.
- Patients who continue on treatment should be reviewed regularly using appropriate tools and by an appropriate specialist team
- If prescribing an AChE inhibitor (donepezil, galantamine or rivastigmine), treatment should normally be started with the drug with the lowest acquisition cost. However, an alternative AChE inhibitor could be prescribed if it is considered appropriate
- When using assessment scales to determine the severity of Alzheimer's disease, healthcare professionals should take into

account any physical, sensory or learning disabilities, or communication difficulties that could affect the results and make any adjustments they consider appropriate

- When assessing the severity of Alzheimer’s disease and the need for treatment, healthcare professionals should not rely solely on cognition scores in circumstances in which it would be inappropriate to do so, such as because of the patient’s learning difficulties or other disabilities, linguistic, language or other communication difficulties, or level of education
- For people with learning disabilities, tools used to assess the severity of dementia should be sensitive to their level of competence.

### b.) Pharmacological interventions for the cognitive symptoms of non-Alzheimer dementias and MCI

For people with vascular dementia, acetylcholinesterase inhibitors and memantine should not be prescribed for the treatment of cognitive decline, except as part of properly constructed clinical studies. For people with MCI, acetylcholinesterase inhibitors should not be prescribed, except as part of properly constructed clinical studies.

A recent thorough systematic review of evidence on potential risk factors and interventions for Alzheimer’s disease and Cognitive Decline(1) presents similar conclusions, namely that there is a lack of strong evidence and high quality trials to confidently assess their association with the conditions. The authors conclude that further research is required prior to be able to make recommendations on interventions. The findings are summarised in Appendix 4.

The most recent evidence from the Cochrane reviews(17) are summarised in Appendix 5. Again, the evidence for effectiveness in preventing or improving symptoms in Alzheimer’s disease, dementia in general or cognitive impairment is not strong for most interventions; the authors again suggest the need for more robust research.

### c.) Non Pharmacological Interventions

**Early stage dementia**: Some evidence for support groups for people with mild-moderate dementia of all types such as structured group cognitive stimulation programmes (for quality of life and depression), behavioural treatment (for depression) and cognitive rehabilitation (for goal performance, satisfaction and subjective memory impairment) may be helpful(9;21).

**For behaviour that challenges in people with dementia**: Should be offered an assessment at an early opportunity to establish likely factors that may generate, aggravate or improve the challenging behaviour. The assessment should consider: the person's physical health, depression, undetected pain or discomfort, side effects of medication, religious or cultural needs, psychosocial factors, physical environment, behavioural and functional analysis. Care staff and carers can then develop and review an individually tailored care plan that will help to address the behaviour that challenges.

## 3.5 Supporting Carers

A key function to consider in the dementia prevention and early intervention agenda is providing support for carers. If carer breakdown occurs, or family members are not prepared for a caring role and all the life changes that are implicit with it, outcomes for individuals with dementia are inevitably worsened and usually involve admission to a care setting. The Alzheimer's Society highlights research which suggests that carers of people with dementia experience greater strain and distress than carers of other older people(26). There are also clear implications for this in terms of the financial impact on health and social care services, considering the projected increase in dementia prevalence over the next 20-30 years.

There is strong evidence that caregiver education, training and support interventions promotes carer mood and helps to delay the institutionalisation of the person with dementia(21). The most recent NICE-SCIE Dementia Guidelines suggest that interventions involving training or stress management, or involving the person with dementia alongside the carer, appeared to have the largest effect on the carer's psychological health and well-being. The guidelines also suggest recommends that carers have access to a range of psychological therapies, such as cognitive behavioural therapy.

Locally, the Welsh Alzheimer's Society in North Wales has been delivering a 5-week dementia carer's education programme package. The packages are commissioned on a Local Authority basis, but are not core or continually funded. In addition, some Local Authorities don't provide the specialist dementia carer training, as the carers are offered more generic carer education packages. The evaluation of a programme held in south Denbighshire in 2009, costing approximately £3600, suggested that the 12 carers who attended rated the sessions as either good or excellent in terms of content, delivery, quality of information, and applicability for their own circumstances. They also commented on the value of the social contact with other carers in similar situations and the fact that transport and respite costs were reimbursed. In terms of improving future education programmes, they suggested that input from specialist dementia medical professionals around dementia progression and stages would be valuable.

Currently, most carer referrals to the Alzheimer's Society are from health and social care professionals, and tend to be for carers who are in crisis. The Society suggests that:

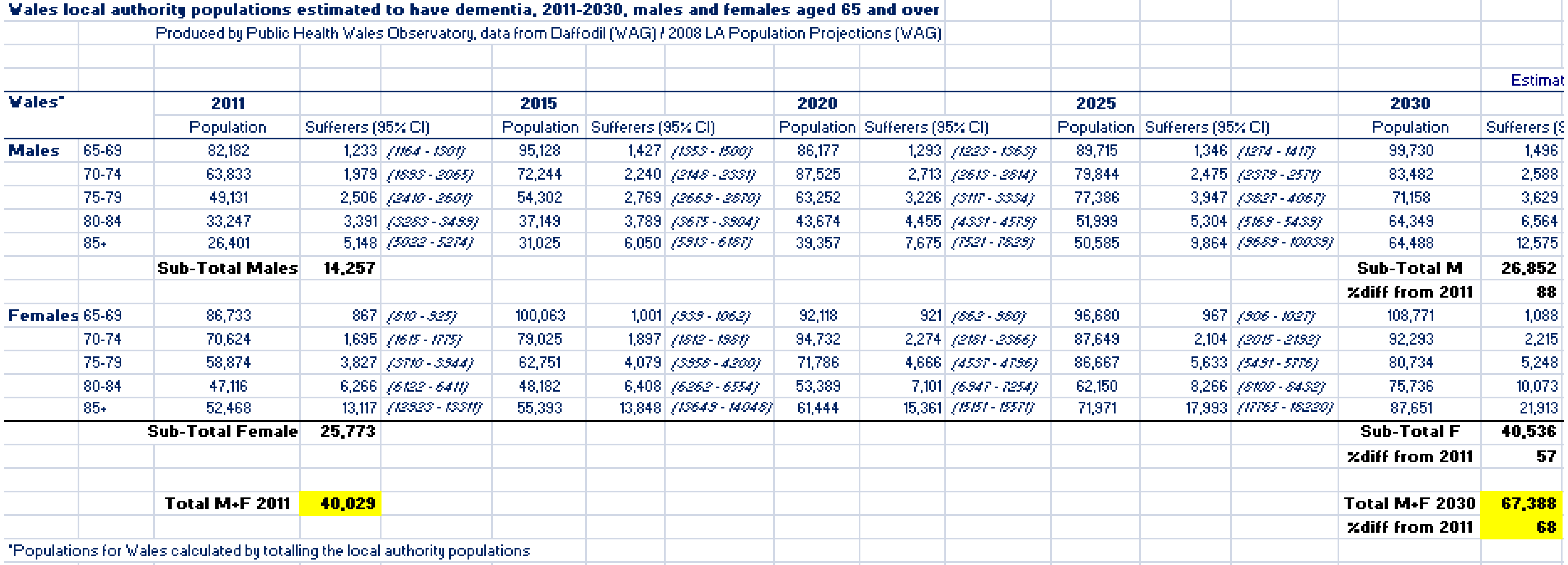
- there is an unmet need for training, with more focus required to support newly identified carers i.e. to avoid crisis
- inform local and regional health and social care commissioning processes to secure ongoing educational packages
- closer links with the packages and support from memory clinics e.g. support provided prior to discharge from memory clinics
- need to consider enhanced training for GPs and other frontline primary care staff in relation to dementia and older people's mental health in general
- strengthen links with the regional dementia advisors when in post

## 3.6 Cost effectiveness of dementia prevention interventions

In a recent presentation to an All-Wales Dementia Prevention Workshop hosted by Bangor University's Psychology department(27), it was emphasised that there was little evidence on specific cost effectiveness of interventions for dementia. The author concluded that:

- EuroCoDE study(12) recognised challenges in generating robust evidence on effect of dementia prevention
- Future studies needed to consider issues around uptake and context when attempting to draw conclusions around cost-effectiveness
- Many potential population level actions have an economic case based on complementary physical and mental health benefit; therefore, looking at the economic benefits of preventing dementia could strengthen case for some public health interventions
- The least known about the economic case relates to cognitive training & stimulation

# Appendix 1 – All Wales and North Wales Local Authority Population Estimates to have Dementia 2011-2030



**Wales local authority populations estimated to have dementia, 2011-2030, males and females aged 65 and over**

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

| | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | | | | Estimat |
| **Wales*** | | **2011** | | | **2015** | | | **2020** | | | **2025** | | | **2030** | |
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (9 |
| **Males** | 65-69 | 82,182 | 1,233 | *(1164 - 1301)* | 95,128 | 1,427 | *(1353 - 1500)* | 86,177 | 1,293 | *(1223 - 1363)* | 89,715 | 1,346 | *(1274 - 1417)* | 99,730 | 1,496 |
| | 70-74 | 63,833 | 1,979 | *(1893 - 2065)* | 72,244 | 2,240 | *(2148 - 2331)* | 87,525 | 2,713 | *(2613 - 2814)* | 79,844 | 2,475 | *(2379 - 2571)* | 83,482 | 2,588 |
| | 75-79 | 49,131 | 2,506 | *(2410 - 2601)* | 54,302 | 2,769 | *(2669 - 2870)* | 63,252 | 3,226 | *(3117 - 3334)* | 77,386 | 3,947 | *(3827 - 4067)* | 71,158 | 3,629 |
| | 80-84 | 33,247 | 3,391 | *(3283 - 3499)* | 37,149 | 3,789 | *(3675 - 3904)* | 43,674 | 4,455 | *(4331 - 4579)* | 51,999 | 5,304 | *(5169 - 5439)* | 64,349 | 6,564 |
| | 85+ | 26,401 | 5,148 | *(5022 - 5274)* | 31,025 | 6,050 | *(5913 - 6187)* | 39,357 | 7,675 | *(7521 - 7829)* | 50,585 | 9,864 | *(9689 - 10039)* | 64,488 | 12,575 |
| | | **Sub-Total Males** | **14,257** | | | | | | | | | | | **Sub-Total M** | **26,852** |
| | | | | | | | | | | | | | | **%diff from 2011** | **88** |
| **Females** | 65-69 | 86,733 | 867 | *(810 - 925)* | 100,063 | 1,001 | *(939 - 1062)* | 92,118 | 921 | *(862 - 980)* | 96,680 | 967 | *(906 - 1027)* | 108,771 | 1,088 |
| | 70-74 | 70,624 | 1,695 | *(1615 - 1775)* | 79,025 | 1,897 | *(1812 - 1981)* | 94,732 | 2,274 | *(2181 - 2366)* | 87,649 | 2,104 | *(2015 - 2192)* | 92,293 | 2,215 |
| | 75-79 | 58,874 | 3,827 | *(3710 - 3944)* | 62,751 | 4,079 | *(3958 - 4200)* | 71,786 | 4,666 | *(4537 - 4796)* | 86,667 | 5,633 | *(5491 - 5776)* | 80,734 | 5,248 |
| | 80-84 | 47,116 | 6,266 | *(6122 - 6411)* | 48,182 | 6,408 | *(6262 - 6554)* | 53,389 | 7,101 | *(6947 - 7254)* | 62,150 | 8,266 | *(8100 - 8432)* | 75,736 | 10,073 |
| | 85+ | 52,468 | 13,117 | *(12923 - 13311)* | 55,393 | 13,848 | *(13649 - 14046)* | 61,444 | 15,361 | *(15151 - 15571)* | 71,971 | 17,993 | *(17765 - 18220)* | 87,651 | 21,913 |
| | | **Sub-Total Female** | **25,773** | | | | | | | | | | | **Sub-Total F** | **40,536** |
| | | | | | | | | | | | | | | **%diff from 2011** | **57** |
| | | | | | | | | | | | | | | | |
| | | **Total M+F 2011** | **40,029** | | | | | | | | | | | **Total M+F 2030** | **67,388** |
| | | | | | | | | | | | | | | **%diff from 2011** | **68** |

*Populations for Wales calculated by totalling the local authority populations

Estimated counts

| **Isle of Anglesey** | | **2011** | | | **2015** | | | **2020** | | | **2025** | | | **2030** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | |
| **Males** | 65-69 | 2,500 | 38 | *(26 - 49)* | 2,590 | 39 | *(27 - 51)* | 2,351 | 35 | *(24 - 47)* | 2,336 | 35 | *(24 - 47)* | 2,418 | 36 | *(25 - 48)* |
| | 70-74 | 1,824 | 57 | *(42 - 71)* | 2,218 | 69 | *(53 - 85)* | 2,405 | 75 | *(58 - 91)* | 2,201 | 68 | *(52 - 84)* | 2,198 | 68 | *(52 - 84)* |
| | 75-79 | 1,302 | 66 | *(51 - 82)* | 1,571 | 80 | *(63 - 97)* | 1,948 | 99 | *(80 - 118)* | 2,133 | 109 | *(89 - 129)* | 1,967 | 100 | *(81 - 119)* |
| | 80-84 | 867 | 88 | *(71 - 106)* | 941 | 96 | *(78 - 114)* | 1,258 | 128 | *(107 - 149)* | 1,600 | 163 | *(140 - 187)* | 1,772 | 181 | *(156 - 206)* |
| | 85+ | 665 | 130 | *(110 - 150)* | 828 | 161 | *(139 - 184)* | 1,041 | 203 | *(178 - 228)* | 1,439 | 281 | *(251 - 310)* | 1,962 | 383 | *(348 - 417)* |
| **Females** | 65-69 | 2,466 | 25 | *(15 - 34)* | 2,890 | 29 | *(18 - 39)* | 2,430 | 24 | *(15 - 34)* | 2,495 | 25 | *(15 - 35)* | 2,661 | 27 | *(17 - 37)* |
| | 70-74 | 1,949 | 47 | *(34 - 60)* | 2,231 | 54 | *(39 - 68)* | 2,739 | 66 | *(50 - 81)* | 2,315 | 56 | *(41 - 70)* | 2,383 | 57 | *(43 - 72)* |
| | 75-79 | 1,500 | 97 | *(79 - 116)* | 1,701 | 111 | *(91 - 131)* | 2,019 | 131 | *(110 - 153)* | 2,497 | 162 | *(138 - 186)* | 2,124 | 138 | *(116 - 160)* |
| | 80-84 | 1,231 | 164 | *(140 - 187)* | 1,206 | 160 | *(137 - 183)* | 1,452 | 193 | *(168 - 218)* | 1,753 | 233 | *(205 - 261)* | 2,188 | 291 | *(260 - 322)* |
| | 85+ | 1,327 | 332 | *(301 - 363)* | 1,458 | 365 | *(332 - 397)* | 1,596 | 399 | *(365 - 433)* | 1,943 | 486 | *(448 - 523)* | 2,453 | 613 | *(571 - 655)* |

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

Estimated counts

| **Gwynedd** | | **2011** | | | **2015** | | | **2020** | | | **2025** | | | **2030** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | |
| **Males** | 65-69 | 3,662 | 55 | *(41 - 69)* | 4,134 | 62 | *(47 - 77)* | 3,537 | 53 | *(39 - 67)* | 3,516 | 53 | *(39 - 67)* | 3,940 | 59 | *(44 - 74)* |
| | 70-74 | 2,663 | 83 | *(65 - 100)* | 3,069 | 95 | *(76 - 114)* | 3,754 | 116 | *(96 - 137)* | 3,233 | 100 | *(81 - 120)* | 3,228 | 100 | *(81 - 119)* |
| | 75-79 | 2,107 | 107 | *(88 - 127)* | 2,278 | 116 | *(96 - 137)* | 2,667 | 136 | *(114 - 158)* | 3,295 | 168 | *(143 - 193)* | 2,863 | 146 | *(123 - 169)* |
| | 80-84 | 1,505 | 153 | *(130 - 176)* | 1,626 | 166 | *(142 - 190)* | 1,850 | 189 | *(163 - 214)* | 2,213 | 226 | *(198 - 254)* | 2,762 | 282 | *(251 - 313)* |
| | 85+ | 1,080 | 211 | *(185 - 236)* | 1,298 | 253 | *(225 - 281)* | 1,626 | 317 | *(286 - 348)* | 2,041 | 398 | *(363 - 433)* | 2,587 | 504 | *(465 - 544)* |
| **Females** | 65-69 | 3,643 | 36 | *(25 - 48)* | 4,106 | 41 | *(29 - 54)* | 3,543 | 35 | *(24 - 47)* | 3,730 | 37 | *(25 - 49)* | 3,925 | 39 | *(27 - 51)* |
| | 70-74 | 3,022 | 73 | *(56 - 89)* | 3,328 | 80 | *(63 - 97)* | 3,836 | 92 | *(73 - 111)* | 3,319 | 80 | *(62 - 97)* | 3,507 | 84 | *(66 - 102)* |
| | 75-79 | 2,551 | 166 | *(141 - 190)* | 2,669 | 173 | *(149 - 198)* | 3,014 | 196 | *(169 - 222)* | 3,502 | 228 | *(199 - 256)* | 3,045 | 198 | *(171 - 225)* |
| | 80-84 | 2,195 | 292 | *(261 - 323)* | 2,122 | 282 | *(252 - 313)* | 2,267 | 301 | *(270 - 333)* | 2,604 | 346 | *(312 - 380)* | 3,058 | 407 | *(370 - 444)* |
| | 85+ | 2,242 | 561 | *(520 - 601)* | 2,393 | 598 | *(557 - 640)* | 2,566 | 641 | *(598 - 684)* | 2,898 | 724 | *(679 - 770)* | 3,465 | 866 | *(816 - 916)* |

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

Estimated counts

| **Conwy** | | **2011** | | | **2015** | | | **2020** | | | **2025** | | | **2030** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | |
| **Males** | 65-69 | 3,703 | 56 | *(41 - 70)* | 4,220 | 63 | *(48 - 79)* | 3,799 | 57 | *(42 - 72)* | 4,044 | 61 | *(46 - 76)* | 4,349 | 65 | *(50 - 81)* |
| | 70-74 | 2,935 | 91 | *(73 - 109)* | 3,345 | 104 | *(84 - 123)* | 3,986 | 124 | *(102 - 145)* | 3,616 | 112 | *(92 - 133)* | 3,862 | 120 | *(99 - 141)* |
| | 75-79 | 2,490 | 127 | *(105 - 148)* | 2,574 | 131 | *(109 - 153)* | 2,996 | 153 | *(129 - 176)* | 3,596 | 183 | *(158 - 209)* | 3,289 | 168 | *(143 - 192)* |
| | 80-84 | 1,738 | 177 | *(153 - 202)* | 1,933 | 197 | *(171 - 223)* | 2,130 | 217 | *(190 - 245)* | 2,528 | 258 | *(228 - 288)* | 3,063 | 312 | *(280 - 345)* |
| | 85+ | 1,432 | 279 | *(250 - 309)* | 1,686 | 329 | *(297 - 361)* | 2,121 | 414 | *(378 - 449)* | 2,607 | 508 | *(469 - 548)* | 3,257 | 635 | *(591 - 679)* |
| **Females** | 65-69 | 3,956 | 40 | *(27 - 52)* | 4,414 | 44 | *(31 - 57)* | 4,077 | 41 | *(28 - 53)* | 4,352 | 44 | *(31 - 56)* | 4,865 | 49 | *(35 - 62)* |
| | 70-74 | 3,512 | 84 | *(67 - 102)* | 3,727 | 89 | *(71 - 108)* | 4,255 | 102 | *(83 - 122)* | 3,950 | 95 | *(76 - 114)* | 4,226 | 101 | *(82 - 121)* |
| | 75-79 | 2,934 | 191 | *(165 - 217)* | 3,179 | 207 | *(179 - 234)* | 3,412 | 222 | *(194 - 250)* | 3,920 | 255 | *(225 - 285)* | 3,664 | 238 | *(209 - 267)* |
| | 80-84 | 2,402 | 319 | *(287 - 352)* | 2,428 | 323 | *(290 - 356)* | 2,741 | 365 | *(330 - 399)* | 2,988 | 397 | *(361 - 434)* | 3,465 | 461 | *(422 - 500)* |
| | 85+ | 2,670 | 667 | *(624 - 711)* | 2,789 | 697 | *(652 - 742)* | 3,046 | 761 | *(715 - 808)* | 3,585 | 896 | *(845 - 947)* | 4,220 | 1,055 | *(1000 - 1110)* |

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

Estimated counts

| Denbighshire | | 2011 | | | 2015 | | | 2020 | | | 2025 | | | 2030 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | |
| **Males** | 65-69 | 3,001 | 45 | *(32 - 58)* | 3,715 | 56 | *(41 - 70)* | 3,286 | 49 | *(36 - 63)* | 3,347 | 50 | *(36 - 64)* | 3,938 | 59 | *(44 - 74)* |
| | 70-74 | 2,493 | 77 | *(60 - 94)* | 2,801 | 87 | *(69 - 105)* | 3,531 | 109 | *(89 - 130)* | 3,148 | 98 | *(79 - 117)* | 3,216 | 100 | *(80 - 119)* |
| | 75-79 | 1,811 | 92 | *(74 - 111)* | 2,111 | 108 | *(88 - 127)* | 2,497 | 127 | *(106 - 149)* | 3,172 | 162 | *(137 - 186)* | 2,851 | 145 | *(122 - 168)* |
| | 80-84 | 1,212 | 124 | *(103 - 144)* | 1,394 | 142 | *(120 - 164)* | 1,704 | 174 | *(149 - 198)* | 2,055 | 210 | *(183 - 237)* | 2,641 | 269 | *(239 - 300)* |
| | 85+ | 1,020 | 199 | *(174 - 224)* | 1,178 | 230 | *(203 - 256)* | 1,531 | 299 | *(268 - 329)* | 2,035 | 397 | *(362 - 432)* | 2,643 | 515 | *(475 - 555)* |
| **Females** | 65-69 | 3,186 | 32 | *(21 - 43)* | 3,806 | 38 | *(26 - 50)* | 3,645 | 36 | *(25 - 48)* | 3,602 | 36 | *(24 - 48)* | 4,292 | 43 | *(30 - 56)* |
| | 70-74 | 2,710 | 65 | *(49 - 81)* | 2,950 | 71 | *(55 - 87)* | 3,660 | 88 | *(70 - 106)* | 3,523 | 85 | *(67 - 102)* | 3,491 | 84 | *(66 - 102)* |
| | 75-79 | 2,096 | 136 | *(114 - 158)* | 2,444 | 159 | *(135 - 183)* | 2,715 | 176 | *(151 - 202)* | 3,387 | 220 | *(192 - 248)* | 3,280 | 213 | *(186 - 241)* |
| | 80-84 | 1,794 | 239 | *(210 - 267)* | 1,716 | 228 | *(201 - 256)* | 2,129 | 283 | *(252 - 314)* | 2,398 | 319 | *(286 - 352)* | 3,017 | 401 | *(365 - 438)* |
| | 85+ | 2,261 | 565 | *(525 - 606)* | 2,339 | 585 | *(544 - 626)* | 2,438 | 609 | *(568 - 651)* | 2,943 | 736 | *(690 - 782)* | 3,573 | 893 | *(842 - 944)* |

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

Estimated counts

| **Flintshire** | | **2011** | | | **2015** | | | **2020** | | | **2025** | | | **2030** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | |
| **Males** | 65-69 | 4,168 | 63 | *(47 - 78)* | 4,916 | 74 | *(57 - 90)* | 4,160 | 62 | *(47 - 78)* | 4,378 | 66 | *(50 - 81)* | 5,101 | 77 | *(60 - 94)* |
| | 70-74 | 3,327 | 103 | *(84 - 123)* | 3,705 | 115 | *(94 - 136)* | 4,514 | 140 | *(117 - 163)* | 3,846 | 119 | *(98 - 140)* | 4,069 | 126 | *(104 - 148)* |
| | 75-79 | 2,276 | 116 | *(95 - 137)* | 2,768 | 141 | *(118 - 164)* | 3,236 | 165 | *(141 - 190)* | 3,985 | 203 | *(176 - 230)* | 3,419 | 174 | *(149 - 200)* |
| | 80-84 | 1,497 | 153 | *(130 - 176)* | 1,676 | 171 | *(147 - 195)* | 2,211 | 225 | *(198 - 253)* | 2,643 | 270 | *(239 - 300)* | 3,298 | 336 | *(302 - 370)* |
| | 85+ | 1,123 | 219 | *(193 - 245)* | 1,389 | 271 | *(242 - 300)* | 1,806 | 352 | *(319 - 385)* | 2,516 | 491 | *(452 - 530)* | 3,315 | 646 | *(602 - 691)* |
| **Females** | 65-69 | 4,413 | 44 | *(31 - 57)* | 5,147 | 51 | *(37 - 65)* | 4,546 | 45 | *(32 - 59)* | 4,641 | 46 | *(33 - 60)* | 5,561 | 56 | *(41 - 70)* |
| | 70-74 | 3,545 | 85 | *(67 - 103)* | 3,944 | 95 | *(76 - 113)* | 4,833 | 116 | *(95 - 137)* | 4,290 | 103 | *(83 - 123)* | 4,395 | 105 | *(86 - 125)* |
| | 75-79 | 2,644 | 172 | *(147 - 197)* | 3,072 | 200 | *(173 - 226)* | 3,547 | 231 | *(202 - 259)* | 4,379 | 285 | *(253 - 317)* | 3,914 | 254 | *(224 - 285)* |
| | 80-84 | 2,013 | 268 | *(238 - 298)* | 2,135 | 284 | *(253 - 315)* | 2,584 | 344 | *(310 - 377)* | 3,038 | 404 | *(367 - 441)* | 3,791 | 504 | *(463 - 545)* |
| | 85+ | 2,140 | 535 | *(496 - 574)* | 2,296 | 574 | *(533 - 615)* | 2,650 | 662 | *(619 - 706)* | 3,323 | 831 | *(782 - 880)* | 4,187 | 1,047 | *(992 - 1102)* |

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

Estimated counts

| **Wrexham** | | **2011** | | | **2015** | | | **2020** | | | **2025** | | | **2030** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | | Population | Sufferers (95% CI) | |
| **Males** | 65-69 | 3,741 | 56 | *(42 - 71)* | 4,276 | 64 | *(49 - 80)* | 3,709 | 56 | *(41 - 70)* | 3,753 | 56 | *(42 - 71)* | 4,410 | 66 | *(50 - 82)* |
| | 70-74 | 2,661 | 82 | *(65 - 100)* | 3,233 | 100 | *(81 - 120)* | 3,928 | 122 | *(100 - 143)* | 3,426 | 106 | *(86 - 126)* | 3,481 | 108 | *(88 - 128)* |
| | 75-79 | 1,967 | 100 | *(81 - 119)* | 2,245 | 114 | *(94 - 135)* | 2,853 | 145 | *(122 - 169)* | 3,496 | 178 | *(153 - 204)* | 3,074 | 157 | *(133 - 181)* |
| | 80-84 | 1,342 | 137 | *(115 - 159)* | 1,468 | 150 | *(127 - 173)* | 1,790 | 183 | *(157 - 208)* | 2,325 | 237 | *(209 - 266)* | 2,880 | 294 | *(262 - 326)* |
| | 85+ | 1,016 | 198 | *(173 - 223)* | 1,270 | 248 | *(220 - 275)* | 1,634 | 319 | *(287 - 350)* | 2,149 | 419 | *(383 - 455)* | 2,902 | 566 | *(524 - 608)* |
| **Females** | 65-69 | 3,633 | 36 | *(25 - 48)* | 4,359 | 44 | *(31 - 56)* | 4,168 | 42 | *(29 - 54)* | 4,295 | 43 | *(30 - 56)* | 4,673 | 47 | *(33 - 60)* |
| | 70-74 | 2,939 | 71 | *(54 - 87)* | 3,346 | 80 | *(63 - 98)* | 4,148 | 100 | *(80 - 119)* | 3,986 | 96 | *(77 - 115)* | 4,121 | 99 | *(80 - 118)* |
| | 75-79 | 2,412 | 157 | *(133 - 180)* | 2,590 | 168 | *(144 - 193)* | 3,047 | 198 | *(171 - 225)* | 3,804 | 247 | *(217 - 277)* | 3,681 | 239 | *(210 - 269)* |
| | 80-84 | 1,912 | 254 | *(225 - 283)* | 1,990 | 265 | *(235 - 294)* | 2,217 | 295 | *(263 - 326)* | 2,649 | 352 | *(318 - 387)* | 3,340 | 444 | *(406 - 483)* |
| | 85+ | 2,255 | 564 | *(523 - 604)* | 2,352 | 588 | *(547 - 629)* | 2,634 | 658 | *(615 - 702)* | 3,104 | 776 | *(729 - 823)* | 3,831 | 958 | *(905 - 1010)* |

Produced by Public Health Wales Observatory, data from Daffodil (WAG) / 2008 LA Population Projections (WAG)

## **Appendix 2:** Dementia as a % of total health and residential care expenditure in Australia(13)

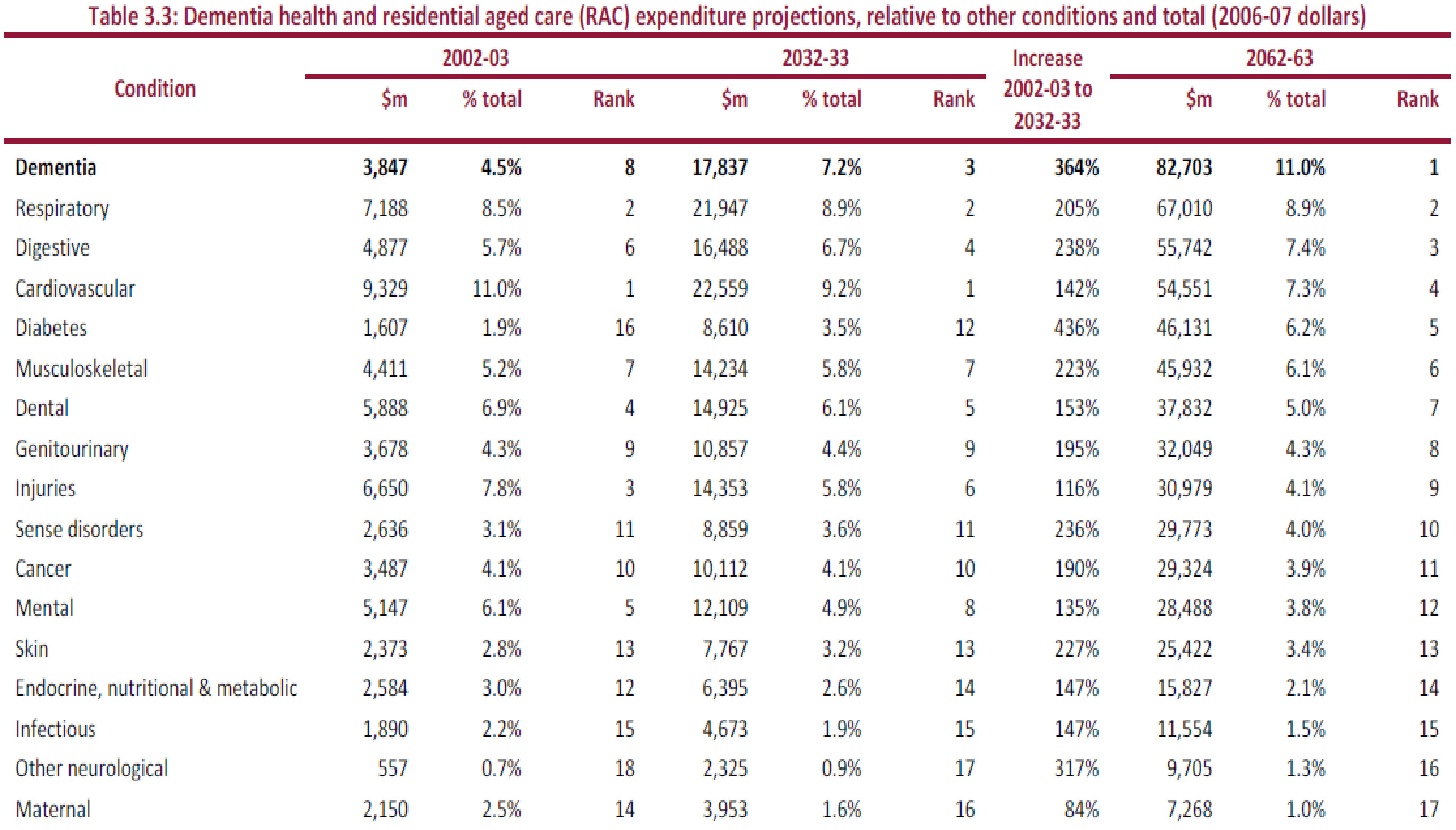


Table 3.3: Dementia health and residential aged care (RAC) expenditure projections, relative to other conditions and total (2006-07 dollars)

| Condition | 2002-03 | | | 2032-33 | | | Increase 2002-03 to 2032-33 | 2062-63 | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | $m | % total | Rank | $m | % total | Rank | | $m | % total | Rank |
| **Dementia** | **3,847** | **4.5%** | **8** | **17,837** | **7.2%** | **3** | **364%** | **82,703** | **11.0%** | **1** |
| Respiratory | 7,188 | 8.5% | 2 | 21,947 | 8.9% | 2 | 205% | 67,010 | 8.9% | 2 |
| Digestive | 4,877 | 5.7% | 6 | 16,488 | 6.7% | 4 | 238% | 55,742 | 7.4% | 3 |
| Cardiovascular | 9,329 | 11.0% | 1 | 22,559 | 9.2% | 1 | 142% | 54,551 | 7.3% | 4 |
| Diabetes | 1,607 | 1.9% | 16 | 8,610 | 3.5% | 12 | 436% | 46,131 | 6.2% | 5 |
| Musculoskeletal | 4,411 | 5.2% | 7 | 14,234 | 5.8% | 7 | 223% | 45,932 | 6.1% | 6 |
| Dental | 5,888 | 6.9% | 4 | 14,925 | 6.1% | 5 | 153% | 37,832 | 5.0% | 7 |
| Genitourinary | 3,678 | 4.3% | 9 | 10,857 | 4.4% | 9 | 195% | 32,049 | 4.3% | 8 |
| Injuries | 6,650 | 7.8% | 3 | 14,353 | 5.8% | 6 | 116% | 30,979 | 4.1% | 9 |
| Sense disorders | 2,636 | 3.1% | 11 | 8,859 | 3.6% | 11 | 236% | 29,773 | 4.0% | 10 |
| Cancer | 3,487 | 4.1% | 10 | 10,112 | 4.1% | 10 | 190% | 29,324 | 3.9% | 11 |
| Mental | 5,147 | 6.1% | 5 | 12,109 | 4.9% | 8 | 135% | 28,488 | 3.8% | 12 |
| Skin | 2,373 | 2.8% | 13 | 7,767 | 3.2% | 13 | 227% | 25,422 | 3.4% | 13 |
| Endocrine, nutritional & metabolic | 2,584 | 3.0% | 12 | 6,395 | 2.6% | 14 | 147% | 15,827 | 2.1% | 14 |
| Infectious | 1,890 | 2.2% | 15 | 4,673 | 1.9% | 15 | 147% | 11,554 | 1.5% | 15 |
| Other neurological | 557 | 0.7% | 18 | 2,325 | 0.9% | 17 | 317% | 9,705 | 1.3% | 16 |
| Maternal | 2,150 | 2.5% | 14 | 3,953 | 1.6% | 16 | 84% | 7,268 | 1.0% | 17 |

# Appendix 3

## Number of people aged 65 and over predicted to be living alone, North Wales, 2011-2030

| | *2011* | *2015* | *2020* | *2025* | *2030* | *% Change 2011-2030* |
|---|---|---|---|---|---|---|
| North Wales | 63,828 | 71,154 | 77,409 | 83,697 | 91,463 | 43.3 |
| Isle of Anglesey | 7,064 | 7,955 | 8,656 | 9,316 | 9,962 | 41.0 |
| Gwynedd | 11,204 | 12,206 | 12,890 | 13,636 | 14,524 | 29.6 |
| Conwy | 12,633 | 13,713 | 14,692 | 15,846 | 17,230 | 36.4 |
| Denbighshire | 9,822 | 11,051 | 12,239 | 13,342 | 14,846 | 51.2 |
| Flintshire | 12,274 | 13,984 | 15,341 | 16,658 | 18,471 | 50.5 |
| Wrexham | 10,831 | 12,246 | 13,591 | 14,899 | 16,430 | 51.7 |

Source: Welsh Government Statistical Directorate (Daffodil)

Figures are taken from the Living in Wales survey 2008.

## Appendix 4.

### **1.** Summary of findings on potential risk factors and interventions for Alzheimer's Disease(1)

| **Direction of association** | **Factors** | **Level of evidence‡** |
|---|---|---|
| Increased risk | APOE e4 genotype<br>Conjugated equine estrogen with methyl progesterone* | Moderate |
| | Some non-steroidal anti-inflammatory drugs*<br>Depressive disorder<br>Diabetes mellitus<br>Hyperlipidemia in mid-life<br>Traumatic brain injury in males<br>Pesticide exposure<br>Never married, less social support<br>Current tobacco use | Low |
| Decreased risk | Mediterranean diet<br>Folic acid<br>HMG-CoA reductase inhibitors (statins)<br>Higher levels of education<br>Light to moderate alcohol intake<br>Cognitively engaging activities<br>Physical activity, particularly high levels | Low |
| No association | Ginkgo biloba* | High |
| | Vitamin E*<br>Cholinesterase inhibitors* | Moderate |
| | Anti-hypertensive medication*<br>Conjugated equine estrogen<br>Omega-3 fatty acids*<br>Vitamins B12, C, beta-carotene<br>Homocysteine<br>Hypertension<br>Obesity<br>Metabolic syndrome<br>Early childhood factors<br>Occupational level<br>Lead | Low |
| Inadequate evidence to assess association | Saturated fat intake<br>Fruit and vegetable intake<br>Trace metals<br>High caloric intake<br>Memantine<br>Sleep apnea<br>Anxiety disorders | (Not applicable) |

| | | |
|---|---|---|
| | Resiliency<br>Non-cognitive, non-physical leisure activities<br>Agent Orange, Gulf War Syndrome<br>Solvents, aluminum<br>Genetic factors other than APOE | |

* Data from observational studies and RCTs.
Abbreviations: APOE = apolipoprotein E gene; APOE e4 = epsilon 4 allele of the apolipoprotein E gene; HMG-CoA = 3-hydroxy-3-methylglutaryl-coenzyme A; RCTs = randomized controlled trials
‡GRADE criteria (see Methods section)

## **2.** Summary of findings on potential risk factors and interventions for cognitive decline(1)

| **Direction of association** | **Factors** | **Level of evidence‡** |
|---|---|---|
| Increased risk | APOE e4 genotype<br>Low plasma selenium<br>Depressive disorder<br>Diabetes mellitus<br>Metabolic syndrome<br>Current tobacco use | Low |
| Decreased risk | Cognitive training* | High |
| | Vegetable intake<br>Mediterranean diet<br>Omega-3 fatty acids*<br>Physical activity*<br>Non-cognitive, non-physical leisure activities | Low |
| No association | Vitamin C, Vitamin E, beta-carotene supplements*<br>Conjugated equine estrogen*<br>HMG-CoA reductase inhibitors (statins)* | High |
| | Aspirin*<br>Dehydroepiandosterone*<br>Cholinesterase inhibitors*<br>Multivitamin supplement*<br>Vitamins B6, B12 and folic acid supplements* | Moderate |
| | Alcohol intake<br>Non-steroidal anti-inflammatory drugs*†<br>Anti-hypertensive medication*<br>Homocysteine<br>Hyperlipidemia<br>Anxiety disorders<br>Hypertension | Low |

| | | |
|---|---|---|
| | Obesity<br>Early childhood factors<br>Higher levels of education<br>Social network, social supports | |
| Inadequate evidence to assess association | Trace metals<br>Fat intake<br>High caloric intake<br>Gingko biloba*<br>Memantine<br>Sleep apnea<br>Resiliency<br>Occupational level<br>Traumatic brain injury<br>Toxic environmental exposures<br>Agent Orange, Gulf War Syndrome<br>Genetic factors other than APOE | (Not applicable) |

*Data from observational studies and RCTs.

† Not associated with decreased risk but may be associated with increased risk.

Abbreviations: APOE = apolipoprotein E gene; APOE e4 = epsilon 4 allele of the apolipoprotein E gene; HMG-CoA = 3-hydroxy-3-methylglutaryl-coenzyme A; RCTs = randomized controlled trials

‡GRADE criteria (see Methods section)

**Appendix 5**: Summary of current evidence from the Cochrane Dementia and Cognitive Impairment Group[17]

| **Intervention** | **No/limited/insufficient evidence of effectiveness** | **Some evidence of effectiveness** | **Clear evidence of effectiveness** | **Additional Information** |
|---|---|---|---|---|
| Memory Training*,** | | √ | | The results suggest that cognitive interventions do lead to performance improvements and that the size of the effects differs for different kinds of memory skills in healthy older adults and people with mild cognitive impairment. In particular, immediate and delayed verbal recall improved significantly through training compared to a no-treatment control condition but the improvements observed did not exceed the improvement in the active control conditions. |
| Treatment or Control of Type II Diabetes*,** | √ | | | There is no convincing evidence relating type or intensity of diabetic treatment to the prevention or management of cognitive impairment in Type II diabetes. |

| | | | | |
|---|---|---|---|---|
| Blood Pressure Lowering** | √ | | | There is no convincing evidence from the trials identified that blood pressure lowering in late-life prevents the development of dementia or cognitive impairment in hypertensive patients with no apparent prior cerebrovascular disease. However, for several reasons, including the differing methodologies of the trials, the number of drop-outs from the trials, and active treatment of subjects in the control groups, we were unable to assess definitively the effectiveness of antihypertensive treatments for preventing cognitive impairment and dementia in people with no evidence of previous cerebrovascular disease. |
| Omega 3** | √ | | | Available clinical studies comparing the occurrence of Alzheimer's disease between elderly persons with different levels of dietary omega 3 PUFA intake, suggest that risk of Alzheimer's disease is significantly reduced among those with higher levels of fish and omega 3 PUFA consumption. However, because these studies are not randomized trials, they provide insufficient evidence to recommend dietary and supplemental omega 3 PUFA for the explicit purpose of dementia prevention |

| | | | | |
|---|---|---|---|---|
| Statins** | √ | | | There is good evidence from RCTs that statins given in late life to individuals at risk of vascular disease have no effect in preventing AD or dementia. |
| Donepezil* | √ | | | There is little evidence that donepezil improved cognitive function, and no evidence that donepezil delays progression to AD, but it was associated with significant side effects. There is no evidence to support the use of donepezil for patients with MCI |
| Galantamine for Alzheimer’s* | | | √ | Galantamine improves global and cognitive symptoms at doses of 16 mg/day or greater, in people with mild to moderate Alzheimer's disease, for at least 6 months. Longer term use of galantamine has not been assessed in a controlled fashion.<br>Galantamine use in MCI is not recommended |
| Galantamine for Vascular Dementia* | √ | | | No consistent evidence of efficacy of galantamine in vascular cognitive impairment. |
| Ginko Biloba* | √ | | | The evidence that Ginkgo biloba has predictable and clinically significant benefit for people with dementia or cognitive impairment is inconsistent and unreliable |

| | | | | |
|---|---|---|---|---|
| Lecithin* | √ | | | Evidence from randomized trials does not support the use of lecithin in the treatment of patients with dementia |
| Melatonin* | | √ | | The analyses did not support the use of melatonin for treatment of cognitive impairment associated with dementia. Meta-analysis of psychopathologic behavior scale scores suggested that melatonin may be effective in treating these dementia-related disturbances |
| Nicergoline* | | √ | | Nicergoline may improve cognition and behavioural function of people with mild to moderate dementia; however, This drug has not been evaluated using current diagnostic categories such as MCI or in association with therapeutic agents of different nature such as cholinesterase or antioxidant drugs |
| Piracetam** | √ | | | Evidence for the efficacy of piracetam for dementia or cognitive impairment is inadequate for clinical use but sufficient to justify further research |

| | | | | |
|---|---|---|---|---|
| Procaine* | √ | | | There is some evidence from older studies that procaine preparations might improve memory in persons without cognitive impairment. However, the clear evidence of side effects suggests that the risks might outweigh the benefits. In the light of this, the strong marketing claims for procaine preparations should be withdrawn until trials of adequate size, duration and quality have been conducted |
| Vinpocetine* | √ | | | Insufficient evidence of benefits of vinpocetine for people with dementia |
| Folic Acid & Vitamin B12*,** | √ | | | The small number of studies which have been done provide no consistent evidence either way that folic acid, with or without vitamin B12, has a beneficial effect on cognitive function of unselected healthy or cognitively impaired older people |
| Vitamin B12* | √ | | | Evidence of any efficacy of vitamin B12 in improving the cognitive function of people with dementia and low serum B12 levels is insufficient |
| Vitamin B6*,** | √ | | | No evidence of benefit from vitamin B6 supplementation on mood or cognition of older people with normal vitamin B6 status or with vitamin B6 deficiency |

| | | | | |
|---|---|---|---|---|
| Vitamin E for Alzheimer’s* | √ | | | No evidence of the efficacy of vitamin E for people suffering from Alzheimer's disease (AD) and mild cognitive impairment (MCI) |
| Dehydroepiandrosteone (DHEA)** | √ | | | No current evidence for an improvement in memory or other aspects of cognitive function of non-demented older people following DHEA supplement |
| HRT** | √ | | | There is good evidence that estrogen or combined estrogen and progestagen therapy does not protect against a decline in overall cognitive functioning of older postmenopausal women with normal intellectual ability |

***Evidence for people who are cognitively impaired**

****Evidence for people who aren’t cognitively impaired**

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**Ysgrifennydd y Cabinet dros Iechyd, Llesiant a Chwaraeon**
**Cabinet Secretary for Health, Well-being and Sport**

Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref : MA - P/VG/8115/16

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13 January 2017

Dear John,

Thank you for your letter of 5 December. I note your comments on the Public Services Ombudsman for Wales (PSOW) Annual Report for 2015-16 which I received in July 2016.

You highlighted the increase in complaints about NHS organisations received by the Ombudsman's office and that the Ombudsman had explained a notable increase against Betsi Cadwaladr and Abertawe Bro Morgannwg University Health Boards.

Whilst I acknowledge the small increase in complaints to the PSOW over the past year, to put this in context, every year the Welsh NHS deals with around 18 million contacts in primary care, three million outpatient attendances and one million A&E attendances and 750,000 admissions to hospital.

Although the number of referrals to the PSOW has increased on an all Wales basis, the percentage of those upheld in full or in part is down by 2.8%. It is also important to note that the PSOW closed 813 health complaints last year but decided to investigate less than half he received and of those investigated around 86 were not upheld.

With regards to Betsi Cadwaladr and Abertawe Bro Morgannwg University Health boards it is worth highlighting that they both had fewer cases upheld by the PSOW leading to percentage decreases of 6.3% and 1.6% respectively.

The Putting Things Right process was introduced in April 2011, making it easier for people raise their concerns and therefore a rise in the number of complaints is to be expected. In 2014 an independent review into the Putting Things Right arrangements 'Using the Gift of Complaints' was undertaken by Keith Evans. The review concluded that Putting Things Right was a good overall approach to managing complaints and concerns but made over 100 recommendations.

NHS organisations have been implementing these recommendations, which include the need to support and empower staff to deal with concerns quickly and at source before they escalate into complaints. In 2015/16 there were 226 fewer formal concerns in NHS Wales than in 2014/15, a decrease of 3.3%. Organisations have made changes by introducing Patient Advice and Liaison Services (PALS) and ward sisters doing rounds at visiting times so families and carers have the opportunity to raise any concerns. The NHS in Wales has also made considerable progress in using a range of ways to proactively seek feedback and use this to drive improvements in services.

In direct response to the Ombudsman's findings and conclusions of his thematic report on Out of Hours care, my predecessor Professor Mark Drakeford, asked Dr Grant Robinson, as National Clinical Lead for Unscheduled Care, to review the report and advise him on a way forward. Dr Robinson suggested that a peer review approach would be a preferable way forward. The PSOW confirmed he was content with this suggestion and has been kept up to date with developments. This approach is consistent with the intention to further develop peer review in NHS Wales as a key method in driving continuous quality improvement which was supported by the Organisation for Economic Co-operation and Development (OECD) in their recent quality review. I referred to this peer review process when answering an urgent question on 13 December 2016.

Over the past few months a small group, including members of the RRAILS (Rapid Response to Acute Illness) Group and 1000 Lives Improvement have considered the PSOW report alongside other sources of evidence, including NHS Wales' ongoing commitment to tackling sepsis. As a result they recommended that it would be appropriate to focus the peer review on the response to the acutely sick or deteriorating patient. It is anticipated that this work will commence in the New Year. My officials have advised the Ombudsman about the proposed piece of work and he is content with the approach.

Thank you for raising these issues on behalf of the committee. I am copying this letter to Dr Dai Lloyd, the Chair of the Health, Social Care and Sport Committee.

Yours sincerely

Vaughan Gething

**Vaughan Gething AC/AM**
Ysgrifennydd y Cabinet dros Iechyd, Llesiant a Chwaraeon
Cabinet Secretary for Health, Well-being and Sport

By virtue of paragraph(s) ix of Standing Order 17.42

# Agenda Item 9

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