

## DAAG Policy Paper

"Full-length articles" of around 4,000 words (and not more than 4,500 words), mainly empirical, analyzing the impact of health systems, reforms and policies - both in terms of intended and unintended effects. In addition, more theoretical, conceptual or methodological papers can be submitted.

Title Page (incl. Acknowledgements, e.g. to sponsors, and Conflict of Interest statement) • Abstract • Introduction • Materials and methods • Results • Discussion • Conclusions (especially for policy-makers and international audience) • Appendices (will be included as online supplementary material if the manuscript is accepted).

### Understanding Dementia within National Dementia Policy: A Thematic Analysis

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### Introduction (400 words)

~~The term 'dementia' is used to describe a number of progressive degenerative conditions which cause a decline in cognitive functioning as a result of structural and chemical changes in the brain. It is a life-changing condition with a potentially devastating impact upon the individual and their family. Since the publication of the first UK National Dementia Strategy (DoH, 2009) subsequent policy initiatives paint a complex picture of care for People people with Dementia dementia (PwD). This article explores the dominant discourses underpinning these policies, in order to identify their implications for health and social care workforce training.~~

While not a natural part of aging, the risk of dementia increases with age. With the growing aging population across the world, the number of people with a form of dementia is estimated to rise significantly across all types of dementia and all age groups. ~~According to the World Health Organisation (Prince et al., 2014; WHO, 2017), it was estimated that almost 47 million people worldwide were living with a diagnosis of a dementia, and this is predicted to rise to 75 million by 2030 and 131.5 million by 2030 (Prince et al., 2015). It is clearly recognised that not everyone who grows old will develop a dementia and not everyone who develops a dementia is old. It is estimated that there are 42,325 people with YOD young onset dementia (onset < 65 years) in the UK (Dementia UK Update, Alzheimer's Society 2014). In the UK, In England, it is estimated that around 676850,000 people are have living with dementia (Department of Health 2015 Prince et al., 2014)~~

~~Dementia is a life-changing condition, with a potentially devastating impact upon the individual and their family. The term 'dementia' is used to describe a number of progressive degenerative conditions which cause a decline in cognitive functioning as a result of structural and chemical changes in the brain. The collective symptoms of 'dementia' type conditions often include a reduction in memory, reasoning, motor skills, sequencing difficulties, vision and perceptual disturbances, and communication skills, personality changes, and behavioural abnormalities, all of~~

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which can severely impact on an individual's ability to carry out daily activities. (Alzheimer's Society, 2017)

Since the publication of the first UK National Dementia Strategy (DoH, 2009) subsequent policy initiatives paint a complex picture of care for people with dementia. This article explores the dominant discourses underpinning these policies, in order to identify their implications for health and social care workforce training.

incorporating Fairclough's (1995, 2009) notions of Critical Discourse Analysis (CDA), 13 UK dementia policy documents were scrutinised to identify the dominant discourses underpinning policy documents in order to identify their implications for the content of health/social care workforce training programmes. This review was undertaken as part of a multi-phase, two-year project completed undertaken by the Dementia Care Education Action Group (DCEAG) to help to develop the health and social care workforce in the UK.

### Background (600 words)

Responding to the call from Health Education England (HEE) to ensure there is an effective workforce to provide care for people with dementia, Health Education England Thames Valley (HEE TV)- commissioned and commissioned proactive work was undertaken across the Thames Valley region to meet the HEE mandate. In January 2014, Health Education England Thames Valley (HEE TV) established the Dementia Academic Action Group (DAAG) to deliver a two year, three-phase project to develop, design, and deliver dementia awareness (Tier 1) training in the region in January 2014 and to support activities to meet the HEE TV training targets, as set out by HEE. The DAAG membership included representation from the University of West London, Oxford Brookes University, the University of Bedford, and the University of Northampton. The aim of the overall project was to inform the development of a coordinated approach to the design, development, and delivery of Tier 1 dementia awareness training for the health social care workforce in Thames Valley.

Phase 1 of the project consisted of a policy review national and local documents to identify what dominant discourses were underpinning the evolution of dementia policies; and a scoping review to identify what forms of Tier 1 dementia training was currently being delivered in the region. During phase 2, two training packages were designed, developed, and delivered to 2889 health and care workforce by four facilitators from the four HEIs. The training and resource materials were evaluated by the facilitators and workshop attendees during the final phase of the study. The final evidence-based training packages and resource materials have been available from HEE TV since May 2016.

The overall project consisted of This policy review of national and local documents was completed during the first Phase of the project to identify what dominant discourses were underpinning the evolution of dementia policies; and what were the implications of those discourses for the ways health and social care professionals and broader society could be trained to deliver compassionate care and promote the improved quality of life for PwD and their carers.

The aim central aims of this policy review were to ascertain the dominant discourses emerging from successive policy documents from 2009-14. The key findings for the review were then used alongside the scoping review in the project to underpin the subsequent development and delivery of the DAAG Tier 1 Dementia Awareness Training. As the first National Dementia Strategy and Implementation Plan was created for England to change attitudes towards people with dementia and the way they are cared for in 2009 (DoH, 2009), and this project began in January 2014 the

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parameters of the review were defined by the launch of the first National strategy and the start of this project, from 2009 to 2014.

the first National Dementia Strategy and Implementation Plan was created for England to change attitudes towards people with dementia and the way they are as a catalyst for change in the way people with dementia are viewed and cared for (DoH, 2009). Thus, 2009-2014 were chosen as the search period. 'Dementia' and 'Alzheimer's Disease' were used as generic keywords of the search in order to be as inclusive as possible. Policies were identified by searching the UK governmental website [www.gov.uk](http://www.gov.uk) which encompasses 24 ministerial departments (including the Department of Health) and 331 agencies and public bodies (including Health Education England, Medical Research Council, NHS England and Public Health England). The search terms resulted in 337 hits. Documents and text relating to 'correspondence', 'independent reports' and 'guidance' were removed. Then each identified document was screened for an explicit focus on dementia policy. This meant that recognised policies concerning *Improving Quality of Life for People with Long-Term Conditions* (Department of Health, 2013e) and *Improving Care for People at the End of Life* (Department of Health, 2013f) were not included in the analysis as they did not have an explicit focus on dementia. This resulted in a sample of 13 policy documents included in the analysis. See Figure 1 below:-

Fig. 1

- Department of Health (2009) Living Well with Dementia: A National Dementia Strategy;
- Department of Health (2010) Quality Outcomes for People with Dementia: Building on the Work of the National Dementia Strategy;
- Department of Health (2011a) The Ministerial Advisory Group on Dementia Research – Headline Report;
- Department of Health (2011b) National Dementia Strategy – Equalities Action Plan;
- Department of Health (2011c) Common Core Principles for Supporting People with Dementia: A Guide to Training the Social Care and Health Workforce;
- Department of Health (2012a) Prime Minister's Challenge on Dementia – Delivering Major Improvements in Dementia Care and Research by 2015;
- Department of Health (2012b) General Medical Services – Contractual Changes 2013/14;
- Department of Health (2013a) Making a difference in Dementia: Nursing Vision and Strategy;
- Department of Health (2013b) Improving Care for People with Dementia;
- Department of Health (2013c) The Prime Minister's Challenge on Dementia – Delivering Major Improvements in Dementia Care and Research by 2015: Annual Report of Progress;
- Alzheimer's Society (2013) Building Dementia-Friendly Communities: A priority for Everyone;
- Department of Health (2013d) Dementia: A State of the Nation Report on Dementia Care and support in England;
- Department of Health and Prime Minister's Office (2013) G8 Dementia Summit Declaration

Initially, a thematic analysis (Braun & Clarke, 2006) was used to identify 5-five organising themes from within the documents; these were then subjected to critical discourse analysis (CDA) to identify the dominant discourses underpinning them. The 13 identified policy documents were read in their

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entirety for familiarisation and to locate dementia within healthcare, social, and personal contexts. On a second reading, coding was undertaken at the paragraph-by-paragraph level because this was considered the best compromise between line-by-line coding, where context is often lost, and section-by-section coding where more nuanced detail may be overlooked (Braun & Clarke, 2006). Initial notes were made in the margins to denote relevant ideas and observations and generate codes. These codes were then collated to form the 5-five organising themes in Figure 2 below:-

Fig. 2 Five organising themes

1. Locating Dementia;
2. Socially positioning People with Dementia;
3. Healthcare Professionals;
4. Dementia Training; and
5. Dementia Awareness.

Using Fairclough's notions of CDA (1995, 2009), the five themes were then each subjected to a CDA process. CDA This focuses on revealing the power and ideology within texts and how this is transmitted through discourse in terms of the cultural codes or systems of language, that legitimise some claims (or ways of thinking) by endorsing them as factual and authoritative while deriding or silencing other ideologies as untruthful or not relevant. By revealing the inequalities and interests 'created, perpetuated or legitimated by texts through the persuasive influence of power by dominant groups' (O'Hara, 2014, p137), CDA challenges the dominant group's moral, political and cultural values (and institutions) and offers different spaces in which to understand dementia and to improve the quality of life of pPeople living with dementia (PwD). By analysing these themes an understanding of the cultural perceptions and economic and political factors can be gleaned. In turn, these perceptions can be addressed and, if necessary, challenged in dementia education.

The CDA process ~~was done by considering~~ considered the different forms of textual, social and discursive practices. This part of the analysis was accomplished by denoting textual practices and their meaning. Once completed the codes relating to textual practices were grouped together in terms of the underpinning dominant discourses. The same process was then undertaken for discursive practices and then social practices. Discussion ensued between the researchers about the meaning of each margin note in order to establish negotiated consensus whereby textual practices (emboldened in extracts) were tagged with the underpinning discursive (italicised in extracts) and social practices (underlined in extracts) associated with them. Textual practices involved a close consideration of the uses of language to talk about dementia. Social practices identified the wider power structures and ideologies concerning how dementia is viewed within health and social care and wider society. Discursive ~~Practices-practices~~ were defined by the ways in which information in the text is justified or warranted (Jacobs, 2006). The textual practices refer to the use of language including word connotations (indicating particular frameworks of meaning), overlexicalisation (repetitions and over-persuasion), intertextuality, (heightening authoritativeness) and presupposition (identifying the taken-for-granted). Discursive practices relate to the ways in which information in the text is justified or warranted through the use of metaphor, hyperbole (exaggeration) and deontic modality (persuasion); and social practices relate to the power structures and ideologies (via authoritative, oppressive and stigmatising discourses) which posit particular ideological understandings of dementia and how it

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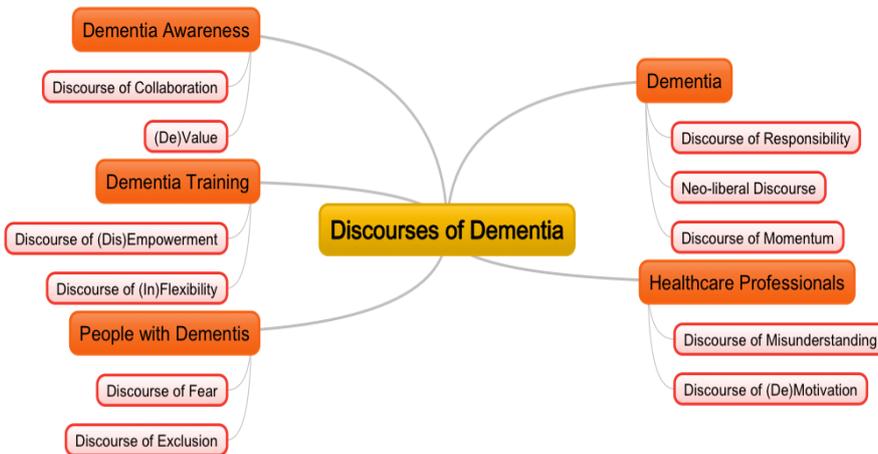
to the research. What the research has revealed about the discourses of dementia are not to be seen as closely connected and not distinct entities. Figure 3 is a graphical illustration of the dominant discourses arising through the thematic and subsequent discourse analysis:-

**Findings**

Themes first

Then discourses

Fig. 3: Dominant Discourses within 5 Organising Themes



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Socially positioning people with dementia (see below)  
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No discourse surrounding healthcare professionals are included in the findings below

**Findings**

**Discourses of Theme 1: Locating Dementia**

Within the policy documents, dementia was represented as a growing societal issue underpinned by discourses of responsibility, *economy-neo-liberalism* and momentum. Responsibility was placed with 'the whole of society as well as government' (DoH, 2012a) with specific disciplines within health and social care cited as pivotal to achieving a cultural change across UK society. Responsibility for earlier diagnosis rested with GP's, whereas nursing staff were held responsible for providing high quality care. Financial rewards were offered for pro-actively recognising and diagnosing dementia:

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*reward practices for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia". (Department of Health, 2013c:4)*

Local Authorities and Clinical Commissioning Groups were held responsible for ensuring that sufficient investment was made locally in order for GP's to meet dementia targets:

*“There is evidence that such services (early diagnosis and intervention) are cost effective, but will require extra initial **local** investment to be established”. (Department of Health, 2009:33)*

*“We call for support from **CCGs** and **local authorities**, working with their partners and local communities, to fulfil the ambition that two thirds of people with dementia have a diagnosis and access to appropriate post-diagnosis support”. (Department of Health, 2010:21)*

~~It is suggested that~~Perhaps related to this discourse of responsibility is a discourse of neo-liberalism. Neo-liberalism is a concept which promoted free trade through reductions in government spending and increased privatisation—~~it~~ which forms a regulated market economy. In some narratives within dementia care, there is a sense that the provision of care is ~~target~~-driven by economic and hence political targets rather than being quality driven:

*“The NAO (National Audit Office) advocated a ‘**spend to save**’ approach, with upfront **investment in services** for early diagnosis and intervention, and improved specialist services, community services and care in general hospitals resulting in **long-term savings**...” (Department of Health, 2009:94-95)*

Whilst ~~the~~ discourses around dementia care ~~were~~ issued by central government, this discourse of neo-liberalism ~~saw that~~ locates commissioning powers ~~set~~ firmly with local government which inevitably cast ~~led to people with dementia~~ PwD as dependent on their local authorities competing commissioning priorities. Moreover, the dementia agenda is positioned as

*“The worldwide **cost of dementia care** is around \$600 billion. If dementia care were a country, it would be the world’s 18<sup>th</sup> largest economy, ranking between Turkey and Indonesia. If it were a company, it would be the biggest in the world by **annual revenue**, exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion)”. (Department of Health, 2013d:5)*

*“... the imperative to focus on local accountability and local delivery has been underscored by reports published by the National Audit Office (NAO – January 2010) and the Public Accounts Committee (PAC – March 2010)”. (Department of Health, 2010:9)*

*“One thing is clear: the Prime Minister’s Challenge on dementia has created a **new momentum** in health and social care, research and across society as a whole **to do more** to help and support people with dementia, their carers and families”. (Department of Health, 2013c:4)*

This discourse of momentum locates improving dementia care as symbolic of the UK’s societal values.

## Discourses of Theme 2: Socially Positioning People with Dementia

Two dominant discourses [concerning the social positioning of people with dementia-PwD](#) were identified, that of *exclusion* and *fear*. [Both discourses drew on the notions of](#)

*“The stigma of dementia creates a background where both the public and non-specialist professionals find it **hard to talk** about dementia, and seek to **avoid** addressing...”*  
(Department of Health, 2009:25)

Whilst policy appeared to position [people with dementia-PwD](#) as partners in health and social care decision making, [the policy discourses message was clear, also placed](#) commissioning decisions [were the remit of](#) care professionals and practitioners:

*“GPs and other clinicians who come into regular contact with people with dementia and their carers will have primary responsibility for the commissioning for health care...”* (Department of Health, 2012:8)

~~There was evidence within~~ While this policy ~~scoping analysis which suggested~~ [identified a messages](#) of inclusion [of the voice of PwD, indeed a by-valuing of that the voice of those with a diagnosis, the](#) [relegation of voice as ‘advisory’ rather than imbued with ‘decision-making’ power was evident. but](#) ~~these were tokenistic and~~ Through such discourses, a nod to voice was overshadowed by power held at local authority and institutional levels. [The voice of PwD held little power to effect change in itself.-](#)

[Alongside an apparent marginalisation of PwD within policy discourses, fear](#) appeared as an emotional experience. [At once, fear of PwD could be inculcated here but particularly highlighted was the fear felt by PwD within the political review:](#)

*“Imagine feeling **confused and afraid** because close friends and relatives seem like **strangers**; being unable to leave the house **alone** because you might not be able to find your way back; or seeing **the fear** in your loved one’s face, as they **struggle to make sense** of familiar surroundings”.* (Department of Health, 2013c:3)

[The highlighting of fear as a dominant discourse to describe PwD is recognised as being may](#) [constitute](#) a barrier to seeking a diagnosis (Van Vliet, et. al., 2011). [Indeed, the](#) discourse of fear, [coupled with stigma](#), is linked to “inactivity in seeking and offering help” (Department of Health, 2009:26):

*“...dementia is not **very well understood**. People often don’t ask for help because there’s still a **stigma attached to it**”.* (Department of Health, 2013b:1)

~~This~~ Such fear mitigates the political rhetoric around earlier diagnosis and would suggest that greater proactive strategies are needed to influence societal attitude from ~~that of one of~~ fear to [wards](#) that of acceptance.

### **Theme 3: Discourses of Dementia Awareness and Training**

Discourses of (de)evaluation, (in)flexibility and (dis)empowerment were identified as dominant within policy pertaining to dementia awareness and training.

There was evidence of a positionality which places [people with dementia](#)PwD as able to contribute to relationships, families and communities but were often prevented from doing so:

“Despite wanting to do more, people feel **restricted by their condition** or health and hold **low expectations** about being able to contribute”. (Alzheimer’s Society, 2013:25)

Stigma contributes to a devaluation of people with dementia in society:

“People with dementia talk about **stigma** and **social isolation**. They report **losing friends** following their diagnosis, seeing people cross the street to avoid them, **feeling lonely**, and struggling to use local services”. (Department of Health, 2013c:12)

An increase in dementia awareness across society was seen as a solution to combat the feelings of low social and personal value defined by people with dementia.

Recognition that dementia affects people of different genders, ages and ethnicities is highlighted in discourse of (in)flexibility as evidenced in the following quotes:

“The commissioning pack makes it clear that specific attention should be given to **disadvantaged groups** to ensure **equality** of access and that services are **sensitive and appropriate to particular needs**”. (Department of Health, 2011b:13)

“Ask the *National Dementia Strategy Workforce Advisory Group* to **consider issues relating to equality** in education and training and opportunities for work in this area”. (Department of Health, 2011b:16)

Whilst the need for diversity and equality are called for, there is little in terms of acknowledging the diverse forms of dementia. Symptomologies and disease progression were ill defined and dementia was often presented as a homogenous disease, which over simplified and failed to capture the nuances of the different dementia types. This may reinforce professional misunderstandings.

Empowerment refers to the ability of people with dementia to resist discourses which position them as subordinate:

“You (Health and Social Care Workforce<sup>1</sup>) should... **do things together** with the person rather than for them, supporting their **own choices even if you regard this as risky**. Risk-taking is a part of everyday life – a person with dementia is no different”. (Department of Health, 2011c:10)

However, the disempowerment articulated in the policy review locates GPs and nurses as [the](#) gatekeepers [of](#) ~~to~~ choice and control. This results in [potentially](#) oppressive healthcare practices which [can develop to serve](#) ~~in~~ the interest of service providers rather than [people with dementia](#)PwD themselves.

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<sup>1</sup> Our addition in brackets.

Dementia is recognised as an important societal issue which requires broad cultural change; ~~however, but~~ little power is held by people with dementia to enact that change. Issues around the economics of care mean that GPs, local authorities and CCGs maintain the status quo. Little consideration is given to the different types of dementia which results in a simplistic view of a complex condition.

## Discussion

In this article, the necessity of critically engaging with dementia policy is highlighted. Taking policy at face value indicates strong policy directives working positively to improve the lives of people with dementia. Initially, these policies were framed in an idealistic ~~and an almost utopian~~ vision of a future in which ~~people with dementia PwD~~ are well integrated in society to live the best life that they can. ~~While this is an important vision to strive for, However, this face value perspective it can~~ obscures the inherent and sometimes negative and hidden messages that also underpin our current thinking and action for people with dementia. These discourses position ~~people with dementia PwD~~ as misunderstood, burdensome, marginalised and powerless (Alzheimer's Society, 2015) despite rhetoric about listening to their voices and addressing unequal power dynamics in healthcare service, as well as community contexts (Gove, et al, 2017).

The National Dementia Strategy (Department of Health, 2009) was highly critical of the current state of readiness to ~~appropriately~~ respond ~~appropriately~~ to dementia, and outlined a statement of intent for future progress. Improved awareness of dementia was a fundamental mechanism to meet the vision of dementia care (Department of Health, 2013). Nevertheless, the policies were defined through a medicalised lens, which posits early diagnosis as the fundamental way to improve quality of life for people with dementia. Over time, policies became more practical, specific and directive in which roles and responsibilities for driving change were allocated. Such allocations are firmly based, but not exclusively in the health and social care domains. More recently, broader community leaders have been called upon to support the agenda via the championing and development of dementia friendly communities (Heward, et al, 2017). The key issues outlined in the policies are underpinned by a series of discourses that frame the ways in which understandings of dementia and people with dementia are set.

Without doubt, this analysis indicates that positive change to integrate ~~people with dementia PwD~~ within society is sought and is happening, if slowly. The analysis signals a need for caution in the implementation of dementia policy such that negative perceptions, values and attitudes can be challenged. For instance, the notion that people can live well with dementia (appropriately supported) in community settings is a social aim. This requires active listening and empowering actions to predominate without the constraints of healthcare 'gatekeeping' practices. ~~However~~ well intentioned, ~~which if policy continues to undermine this with dominant discourses suggesting the continuing existence of a greater power imbalance, the impact of policy can begin to can often~~ stifle the ~~empowerment~~ process and maintain the current status quo, ~~either and~~ perpetuating community exclusion ~~or slowing the integration process~~. The recognition that living well with dementia requires the promotion of social understandings of the realities of dementia is evident, if not totally explicit in policy. Effecting such socio-cultural change to enable this to happen is a more difficult task.

Successive UK policy initiatives have highlighted the need to improve the knowledge and skills of the professional workforce (Department of Health, 2009; Department of Health 2015; Surr et al, 2017), as well as raising community awareness in order to deliver more effective support and care to people with a diagnosis and their families (Department of Health, 2015). This has led to a plethora of dementia education and training programmes of varying quality being developed and delivered. Recent government requirements to increase and account for the numbers of NHS staff trained in Tier 1 Dementia Awareness (Department of Health, 2013, 2014) may also have resulted in programmes being developed which lack efficacy or quality (Surr et al. 2017). Greater evidence is needed to ascertain the necessary components for effective dementia education and training for the dementia care workforce. A recent systematic review of 'effective dementia education and training for the health and social care workforce' (Surr et al 2017) has highlighted the need for efficacious educational programs ~~are to be~~ under-pinned by practice based learning and theory; delivered by experienced facilitators; involve active face-to-face participation; and have a total duration of at least 8 hours with individual sessions of 90 minutes or more. The training should also be applicable to the roles and function of those being trained.

### Conclusion

In terms of the content and focus of dementia education and training, this policy review, completed as part of the HEETV DAAG project, has ~~also~~ indicated the need for education and training courses and campaigns to move away from the more disease oriented and towards a more person focused presentation of people with dementia, and challenge the community to look at themselves in order to reduce stigmatising situations and processes. Key implications for the content and delivery of future programmes should include increasing awareness of dementia policy and explaining the main drivers for change in practice with people with dementia across health and social care arenas making dementia more central to their everyday roles. Consideration should be given to how empowerment needs to be understood as a complex concept that goes beyond gatekeeping and advocacy and into active listening and action (Haley, et al, 2017). There needs to be a realisation that living a good quality of life for people with dementia and their families/carers is not dependent on health and social care services. Instead, the integration of such services into everyday dementia friendly community context is paramount.

~~Future training should recognise the heterogeneity of dementia in terms of different forms of dementia and populations affected; including training on delivery of culturally sensitive care (APPG, 2013). The misconceptions of health and social care professionals should also be challenged where appropriate, particularly where the views are held that nothing can be done for people with dementia; dementia is a normal part of the ageing process; people with dementia lack the capability to make informed choices and decisions about their care; and that people with dementia require medication to contain behavioural disturbances. Future students and trainees should also be encouraged to understand the notion of stigma and how it complies to and constrains people with dementia and their families/carers; and be aware of the power dynamics that influence care giving and care receiving. Above all, contemporary dementia education and training should be built on the beliefs that people come first and dementia is secondary to personhood (National Dementia Declaration 2010/2017). People with dementia should be seen as valued and contributing to society.~~

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As a society, the implications of being 'Dementia Un-Aware' within social and organisational contexts can be quite devastating for people with dementia and their carers/families. The effects of stigma can prevent people seeking an early diagnosis or receiving little or inadequate post diagnostic support. "Stigma prevents people with dementia from living well with their condition" (Alzheimer's Society, 2009b); "From preventing early intervention to discrimination in the workplace or lack of access to services, stigma prevents people with dementia from living well with their condition it is therefore essential that we increase society's understanding of dementia via evidence based training and education so that the quality of life of those affected can be improved. This will place them in a more informed position to seek a diagnosis, plan for the future, and make more appropriate use of health and social services throughout the course of their condition" (Alzheimer's Society, 2009b).

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Need following refs:

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