

Disclosure of the diagnosis of dementia: Benefits and risks

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Abstract

According to the estimates in the World Alzheimer Report 2015, there are 46.8 million people living with dementia worldwide in 2015. The number of older people living in higher income countries is projected to increase by just 56%, 138% in upper middle income countries, and 185% in lower middle income countries and by 239% in low income countries, during 2015-2050. Ensuring early diagnosis becomes a priority strategy which benefits the person with dementia and their caregiver. Despite the improvements, currently in England approximately two thirds of the people with dementia do not have a formal diagnosis. In contrast there are no clear strategies and priorities in developing and low income countries where the burden is quite high. Everybody has a "right to know" about the diagnosis, condition, information, and advice available to the people with dementia. There are associated risks and benefits of disclosing a diagnosis of dementia, both to the person with dementia and their carer. This paper aims to critically examine risks and benefits of disclosing the diagnosis of dementia. A relevant literature search was conducted to critically discuss the benefits and risks of disclosure of diagnosis. The present paper has categorised and critically discussed the benefits and risks of disclosure. The author concludes that the benefits of disclosure outweigh the risks of disclosure. Disclosure of diagnosis can improve the quality of life of people with dementia.

Keywords: Risks, Benefits, Dementia, Disclosure.

Introduction

According to estimates in the World Alzheimer Report 2015, by Alzheimer's disease International's, there are 46.8 million people living with dementia worldwide in 2015. This number is estimated to double in every 20 years and reach 74.7 million in 2030 and 131.5 million in 2050. These estimates are 12-13% higher than those reported in World Alzheimer Report 2009.

According to World Alzheimer Report 2015, the number of older people living in higher income countries is projected to increase by just 56%, 138% in upper middle income countries, and 185% in lower middle income countries and by 239% (a more than three-fold increase) in low income countries, during 2015-2050. With this increasing number of older population and age being one of the important risk determinant of dementia, ensuring early diagnosis becomes a priority strategy which benefits the person with dementia and their caregiver (Department of health (DOH), 2009, World Alzheimer Report 2015).

With the increasing efforts in UK such as - Prime Ministers Challenge on dementia, Scotland's dementia strategy 2013-2016, Dementia Incentive Scheme Enhanced Service, National dementia strategy 2009 in England which prioritised diagnosis of dementia, have all contributed to satisfactory increase in diagnosis rates. However despite these improvements, currently in England approximately two thirds of the people with dementia do not have a formal diagnosis (Banerjee et al., 2007). In contrast there are no clear strategies and priorities on early diagnosis in developing and low income countries where the burden is quite high.

People with dementia and their caregivers would prefer to have the diagnosis of dementia disclosed rather than withholding it (Hellstrom and Torres, 2013). In contrast few people want the diagnosis of dementia not to be disclosed and expect that their wishes to be respected (Mitchell, McCollum and Monaghan, 2013). Every person with dementia has a "right to know" about the diagnosis, condition, information, and advice available to himself. The people with dementia also have the right to be supported (Alzheimer's Society, 2014).

The skills of the professionals are also important determinants of poor experiences of disclosing the diagnosis, both for the person with dementia as well as the caregiver/ family (Manthorpe et al., 2013), and hence good communication, good listening skills, sensitivity and compassion are some of the skills important for the professional who delivers the diagnosis (Mastwyk et al., 2014). Despite this there has long been a debate on whether it is useful in disclosing the diagnosis of dementia or not. Along with this, there are increasing challenges in diagnosing dementia as the diagnostic process is complex and there are lot of conditions that can be a reason for dementia and it is very difficult to arrive at a definitive diagnosis. The disclosure of diagnosis is also debated around the ethical and the practical uses of disclosure. There is a very limited body of research on the benefits and risks of disclosure of diagnosis of dementia. This present piece of paper discusses the risks and benefits of disclosure of diagnosis of dementia.

Benefits and risks of disclosure of diagnosis of dementia

Right to know: “The benefits of disclosure of diagnosis include right to know. The person with dementia has the right to know about the diagnosis of his condition, information and advice available to him to manage his condition. The people with dementia also have the right to be supported. The right to know about the diagnosis also helps in confirmation of suspicions and better understanding of his condition, opportunities for future planning. Disclosure of diagnosis also helps in facilitating the focus on the abilities rather than the disabilities of the persons with dementia. Knowing the diagnosis will aid in positive adaptations within the family and also increases spouse relationships. It also facilitates access to early treatment (Robinson et al., 2011 and Bamford et al., 2004). However the reasons for not disclosing the diagnosis included “emotional upset, earlier distressing experience, rejection, stigma and embarrassment, no effective medical care available, may cause suicide tendencies in patients.

Wish of the person with dementia

The people with dementia wish that the diagnosis of dementia to be disclosed to them. The disclosure may cause initial distress but may not have any long term effects. It is also found that the people with dementia and the caregivers/ family will accept that the diagnosis of dementia and its disclosure to be an ongoing process (Robinson et al., 2011). In contrast it is also be found that the disclosure of dementia to the person with dementia and caregivers to be a direct approach (Mastwyk et al., 2014)

Hence it is essential that the wishes of the person with dementia to be considered while the diagnosis are disclosed. Good communication skills, listening skills, are essential for the professional delivering the diagnosis and also that a written information should be accompanied with verbal diagnosis so that the information can be recollected (Manthorpe et al. 2013 and Mastwyk et al., 2014).

Distress: Negative emotional distress is likely to be seen amongst the people who are not been disclosed of the diagnosis (Carpenter et al. 2008).

The disclosure of diagnosis of dementia is compared with the historical way of disclosing the diagnosis of cancer. In the earlier days in 1960 almost all the health care professionals used to withhold the diagnosis of cancer due to the fact that the cancer diagnosis disclosure was harmful and that it was not curable but now in recent years there is a huge shift in the disclosure of diagnosis of cancer this shift in the disclosure of diagnosis in not very much attributed to the better treatment availability and outcomes but the stigma associated with cancer is different as compared to that in 1960's. It is also interpreted that once the initial reactions to the diagnosis of dementia comes

down, the people use a range of coping strategies and adapt to the information. The main reason for the professionals in withholding the diagnosis was that the disclosure would cause distress, depression and risk of suicide (Lee, Roen and Thornton 2014).

In contrast is reported that non-disclosure can cause further confusion and distress. People with dementia will not understand what is happening to them. People who had the diagnosis withheld reported reduction in stress after disclosure (Pratt and Wilkinson (2003).

Planning, managing and decision making

Timing of diagnosis is an important determinant for planning the support and interventions for the people with dementia. It is found that early diagnosis help in better transitions for the person with dementia and the carers. Early diagnosis improves the opportunities for self directed support and interventions. These in turn provide the person with dementia and the carers with skills and resources to improve the quality of life and independent decision making capacity.

Early diagnosis and disclosure also helps in making key decisions related to legal and financial provisions for the future such as making a will, placing a power of attorney. It is also found that the person with dementia can make advanced decisions or living wills, to refuse treatment, the person also can access the information about symptoms and services and can plan for support needs. It is found that the emotional distress is although evident with disclosure but for majority of the people with dementia it is short term (Milne 2010).

Even though disclosure of diagnosis will help in planning and making arrangements for the future, making arrangements for the future for the person with dementia is difficult (Keady and Gillard, 2002) and they may also feel pressurised into making decisions and experience a loss of control early on themselves (Ilfie and Manthorpe, 2004). But knowing the diagnosis is empowering and helps people be proactive in managing the condition for some of them (Carpenter et al., 2008).

Evidence also suggests that early diagnosis and treatment (both pharmacological and non drug treatments) are likely to have maximum effect in the early phase of dementia. Early diagnosis improves quality of life of people with dementia and carers. It delays in transition of person with dementia into care homes (Mittelman et al., 2007). In home care and support on early diagnosis reduces the rate of institutionalization by 22% (Gaugler et al, 2005). The quality of life of people with dementia improves and behavioural symptoms are reduced by early disclosure of diagnosis and support services (Banerjee et al, 2007).

The non-pharmacological interventions such as education, support groups, counselling, and cognitive behavioural therapy have the ability to maintain

cognitive function, independence, reduce depression, and improve caregiver mood (Price, Bryce and Ferri, 2011) and early access to such non pharmacological interventions help in improving the quality of life of people with dementia and delay institutionalization. (Brodsky et al 2003; Gaugler et al, 2005; Banerjee et al, 2007). Hence a timely disclosure by the practitioners will help in accessing such supports. Lack of utilization of such services will lead to social isolation, institutionalization, and behavioural issues. This may lead to worsening of the symptoms and lead to care giver demoralization.

Pharmacological interventions can also be accessed if the diagnosis of dementia is disclosed timely. These pharmacological interventions delay advancement of dementia and improve the quality of life of people with dementia (National Institute of Clinical Excellence NICE, 2006). However, it is found that pharmacological interventions during the early stages of dementia have the greatest effect (Iliffe and Drennon, 2001). It is reported that medication gave people hope (Hutchings et al 2010), however others reported that medication had limited benefits (Harman and Clare, 2006).

Hence, disclosure of a diagnosis may be beneficial, as people will have gateway to use potentially effective pharmacological treatments. However, evidence of the effectiveness of pharmacological treatments is uncertain and treatment may not be beneficial for everyone

The prevalence of depression is high among the people diagnosed with early stage of dementia which can be attributed to the fact that the people with early dementia are aware of cognitive changes and losses they experience (Robinson, Clare and Evans, 2005). Hence it becomes evident that early and timely diagnosis of dementia will help in the management of conditions that coexist with dementia like depression (Price, Bryce and Ferri, 2011). It is also found that not disclosing the diagnosis of dementia will help in protecting the person with dementia from unnecessary distress (Waldorff, Rishoj and Waldemar, 2005).

Psychological / emotional reactions

Psychological/ emotional reactions to disclosure of diagnosis of dementia does not occur routinely (Carpenter et al, 2008). Both negative and positive psychological reactions can occur among the persons with dementia and their family. Reactions to the diagnosis of dementia will be turned out by the way the diagnosis was informed, the mental wellbeing and coping mechanisms and the previous experiences of dementia (Bunn et al., 2012). It is important that those disclosing the diagnosis should follow evidence based recommendations in order to make the diagnosis (Price, Bryce and Ferri, 2011).

It is evident that the disclosure can have negative psychological impact (Maki and Yamaguchi, 2013). It

is also found that diagnosis resulted in a negative emotional impact such as hopelessness, fear, sorrow, despair, lack of insight and denial including defensiveness and anger (Aminzadeh et al 2006). It is found that disclosure of a dementia diagnosis will have an impact on a person's self-esteem, confidence and personhood (Bamford et al (2004). The disclosure may lead to maladaptive coping strategies including self-blame and externalization.

In contrast positive reactions associated with disclosure are also found such as sense of validation, time to adjust and come to terms with the diagnosis. It is reported that disclosure will relieve the distress once a reason for cognitive impairment is provided and a plan of treatment is devised (Carpenter et al, 2008). Validation of cognitive experiences, opportunities for personal growth, positive coping responses such as optimism and hope, time to address feelings of loss and more quality time spent with families are some of the positive emotional reactions associated with disclosure of diagnosis (Pratt and Wilkonson, 2001; Aminzadah et al, 2006; Milne and Peet, 2008).

Admitting that grief may be present as an initial reaction to the disclosure of a diagnosis, it is found that this can subside over time and people positively adjust to their diagnosis (Lee et al, 2013). It is also found that the risks of suicide after a diagnosis of dementia are also to be found associated to the disclosure of diagnosis of dementia but the risk suicidal behaviour in persons with dementia is very less and seen especially in the first three months after the diagnosis (Draper et al 2010)

Stigma and loss of personality

Labelling is one of the common risks of disclosure of diagnosis of dementia on the person with dementia and their carer. The disclosure of diagnosis of dementia may affect a person's self-identity, personality and personhood (MacRae, 2010). Disclosure of diagnosis of dementia will immediately change the attitude of the family towards the person and the family becomes 'carer' even though the person with dementia is still able to manage and may not need help, this will have negative consequences for the family and for the person with dementia himself (Garland et al, 2005). The social interactions and relationships of the people with dementia change after diagnosis. The people with dementia experience a reduced sense of status within the society upon disclosure of diagnosis (Katsuno, 2005). Their activities become restricted as they are less able or 'not allowed to perform' (Beard and Fox, 2006). The person with dementia feels it challenging to hold their roles and responsibilities (Vernooij-Dassen et al, 2006).

Stigma is an important risk of disclosure of diagnosis of dementia. Person with dementia and their carer experience self-stigma and also stigma within society (Manthorpe et al, 2013). The stigma can also be

experienced from the health care providers (DOH, 2009). Stigma leads to embarrassment, anxiety and it also prevents person with dementia and the carers from sharing the diagnosis and seeking help and support (Werner, P, Goldstein, D and Heinek, 2011, Robinson, Clare and Evans, 2005). However with the recent advancements in managing dementia it is seen that the attitude towards dementia is changed but the stigma is still persisting. Hence raising awareness, public education and creating dementia-friendly communities are important in combating stigma.

Memory loss in old age is considered normal dementia and is labelled with mental illness and madness. Isolation from the family, friends and society due to the stigma associated with diagnosis of dementia was reported among the ethnic communities across the world (Alzheimer's disease and Related Disorders Association of Victoria (2008). This leads to create negative themes and perceptions related to dementia and discourage seeking diagnosis and treatment.

Misdiagnosis

The diagnosis of dementia is very complicated because of the fact that conditions such as depression, brain tumour, urinary tract infections, confusion, also present with symptoms similar to dementia and it is difficult to arrive at an accurate and definitive diagnosis. This might ultimately lead to misdiagnosis (Iliffe et al, 2005). The criticism is also in relation to high false positives due to the fact that clinical diagnosis is completely dependent on screening by the GP and also due the fact that there is an acute lack of specific measurable biomarkers for dementia diagnosis. Hence "false positives" and "misdiagnosis" are the important risks for disclosing the diagnosis of dementia. (Iliffe and Manthorpe, 2004).

Anxiety for the person with dementia and his family, access to harmful treatments, unnecessary investigations, and mistrust in the GP are some of the potential risks of misdiagnosis or over diagnosis (Brunet 2014). The risk of incorrect diagnosis might lead under treatment of treatable depression and also misdirection of patients to inappropriate services (Iliffe and Manthorpe 2004). The knowledge of early dementia, symptomology, readiness to conduct a screening interview and alertness to cognitive and behavioural changes in elderly patients are some of the prerequisite qualities and skills amongst the GP's. However Brodaty et al. (2006) suggests that the false positive rate of commonly used diagnostic instruments is less than 1%.

Despite the fact that majority of the people would like the diagnosis of dementia to be disclosed, significant minority would prefer limited information or no information (Keating et al. 2005). Among a group of primary care patients with positive screening tests it was found that half of them refused assessment further with a fear of losing driving licence, a job, or health

insurance (Talbot et al. 2005, Boustani et al. 2008) these findings stresses the need to disclose or not to disclose on the individual bases and not a routine disclosure.

The diagnosis of dementia has practical implications like health insurance, mortgages, employment etc. Social labelling of dementia is associated with lack of dignity, isolation from family, society and dependence (Bunn et al (2012) and professionals must respect the wishes of the people not to be disclosed about the diagnosis.

Conclusion

The disclosure of diagnosis of dementia to the person with dementia and the carers should be weighed against the benefits and risks. With the discussions above the author concludes that the benefits of disclosure outweigh the risks of disclosure. According to the charter of rights a professional has an obligation to inform the diagnosis and relevant information. But at the same time the professionals should be sensitive enough to respect the wishes of the person. The professional should also be culturally sensitive and competent and should disclose the diagnosis the way the culture permits him.

By holding or not disclosing the diagnosis we are disempowering the people with dementia at the same time suppressing them with the so called inability in decision making, dependency. The major risk for people with dementia is the social reaction to dementia in terms of labelling it and stigmatizing the condition. The author concludes that there should be increased efforts in this area to remove stigma.

With the combined efforts of the government and communities risks of disclosing diagnosis of dementia can be reduced and can improve the quality of life of people with dementia.

There is a growing evidence to disclose the diagnosis of dementia but is supported with a limited body of qualitative study and hence there is need for larger studies to substantiate the benefits of disclosure of diagnosis of dementia.

References

1. Alzheimer's Disease International (2015). World Alzheimer Report 2015. The Global Impact of Dementia, An Analysis Of Prevalence, Incidence, Cost And Trends: Alzheimer's Disease International.(2015) <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
2. Alzheimer's Disease and Related Disorders Association of Victoria (2008), Perceptions of Dementia in Ethnic Communities, Alzheimer's Australia Vic.
3. <https://fightdementia.org.au/sites/default/files/20101201-Nat-CALD-Perceptions-ofdementia-in-ethnic-communities-Oct08.pdf>
4. Alzheimer's Society (2014b). Right to Know campaign - diagnosis and support. Available from: <http://www.alzheimers.org.uk/earlydiagnosis>

5. Aminzadeh, F., Byszewski, A., Molnar, F.J. and Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health* [online], 11(3), pp. 281–90.
6. Banerjee, S., Willis, R., Matthews, D., et al. (2007). Improving the quality of dementia care – an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry* [online]. 22, pp.782–8.
7. Bamford, C., Lamont, S., Eccles, M., Robinson, L., May C. and Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry* [online]. 19, pp.151–69.
8. Brodaty, H., Green, H. and Koschera, A. (2003). Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *American Geriatrics Society* [online]. 51, pp. 657– 64.
9. Boustani, M., et al., 2008. Measuring primary care patients' attitudes about dementia screening. *International journal of geriatric psychiatry*, 23, 812–20.
10. Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L. et al (2012). Psychosocial Factors That Shape Patient and Carer Experiences of Dementia Diagnosis and Treatment: A Systematic Review of Qualitative Studies. *PLoS Med* [online]. 9(10), pp1-12.
11. Brunet, M (2014) Targets for dementia diagnoses will lead to overdiagnosis, *BMJ* 348.
12. Carpenter, B and Dave, J. (2004). Disclosing a Dementia Diagnosis: A Review of Opinion and Practice, and a Proposed Research Agenda. *The Gerontologist* [online]. 44(2), pp.149-58.
13. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168221/dh_09_4052.pdf
14. Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy* [online] London: Department of Health. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168221/dh_09_4052.pdf
15. Draper, B. Peisah, C. Snowdown, J. and Brodaty, H. (2010). Early dementia diagnosis and the risk of suicide and euthanasia. *Alzheimer's and Dementia* [online]. 6(1), pp.75-82.
16. Garland, L., Dew, M.A., Eazor, L.R., Dekosky, S.T. and Reynolds, C.F. (2005). Caregiving burden and psychiatric morbidity in spouses of a person with mild cognitive impairment. *International Journal of Geriatric Psychiatry* [online] 20(6), pp.512-522.
17. Gaugler, J.E., Kane, R.L., Kane, R.A. and Newcomer, R. (2005). Unmet care needs and key outcomes in dementia. *Journal of American Geriatric Society* [online]. 53(12), pp. 2098– 105.
18. Hellstrom, I. and Torres, S. (2013). A wish to know but not always tell – couples living with dementia talk about disclosure preferences. *Aging & Mental Health* [online]. 17(2), pp.157–67
19. Hutchings, D., Vanoli, A., McKeith, I., Brotherton, S., McNamee, P., Bond, J. (2010) Good days and bad days: the lived experience and perceived impact of treatment with cholinesterase inhibitors for Alzheimer's disease in the United Kingdom. *Dementia* [online]. 9 pp. 409–425. <http://www.tandfonline.com/doi/abs/10.1080/13607863.2012.742491#.VhpGD46ON88>
20. Iliffe, S., De Lepeleire, J., Van Hout, H., Kenny, G., Lewis, A., Vernooij-Dassen, M., et al. (2005). Understanding Obstacles to the Recognition of and Response to Dementia in different European Countries. *Aging and Mental Health* [online]. 9(1), pp.1–6.
21. Iliffe, S. and Manthorpe, J. (2004). The hazards of early recognition of dementia: a risk assessment. *Aging & Mental Health* [online]. 8(2), pp. 99–105.
22. Katsuno, T. (2005). Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Ageing and Society* [online]. 25(2), pp. 197–214.
23. Keady, J., and Gilliard, J. (2002). Testing times: The experience of neuropsychological assessment for people with suspected Alzheimer's Disease. In P. Harris (Ed.), *The Person with Alzheimer's Disease: Pathways to Understanding the Experience* (pp. 3–28). Baltimore: Johns Hopkins University Press.
24. Keating, D., et al., 2005. Advance directives for truth disclosure. *Chest*, 128, 1037–9.
25. Lee, S.M., Roen, K. and Thornton, A. (2013). The psychological impact of a diagnosis of Alzheimer's disease. *Dementia* [online]. 13(3), pp.289-305.
26. Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J. et al (2013) From Forgetfulness to Dementia: clinical and commissioning implications of diagnostic experiences. *British Journal of General Practice*.
27. Mastwyk, M., Ames, D., Ellis, K., Chiu, E., Dow, B (2014) Disclosing a dementia diagnosis: what do patients and family consider important? *International Psychogeriatrics* 26: 8 1263-72.
28. MacRae H (2010) Managing identity while living with Alzheimer's disease. *Qualitative Health Research* [online]. 20(3), pp, 293-05.
29. Maki, Y. and Yamaguchi, H. (2014). Early detection of dementia in the community under a community-based integrated care system. *Geriatrics Gerontology International* [online]. 14 (2), pp.2–10
30. Milne, A. (2010) Dementia screening and early diagnosis: the case for and against *Health, Risk and Society* 12: 1 65-76
31. Mitchell, G., McCollum, P. and Monaghan, C (2013). The personal impact of disclosure of a dementia diagnosis: a thematic review of the literature. *British Journal of Neuroscience Nursing* 9(5), pp. 223-8.
32. Mukadam, N., Cooper, C., Basit, B., Livingston, G. (2011), "Why do ethnic elders present later to UK dementia services? A qualitative study", *International Psychogeriatrics*, vol. 23, no. 7, pp. 1070-7.
33. NICE. (2006) *Dementia: Supporting People with Dementia and Their careers in Health and Social Care*. [online]. Available from: <http://guidance.nice.org.uk/CG42/NICEGuidance/pdf/english>
34. Pratt, R. and Wilkinson H. (2001). *Tell Me the Truth: the Effect of Being Told the Diagnosis from the Perspective of the Person with Dementia*. Stirling: The Mental Health Foundation.
35. Pratt, R. and Wilkinson, H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia* [online] 2(2), pp.181-199. [Accessed 10 September 2014]. Prorok, J.C., Horgran, S., Seitz, D.P. (2013), "Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies", *CMAJ*, vol. 185, no. 14, pp. 669-80.
36. Prince M, Bryce R, Ferri C. 2011. *Alzheimer's Disease International—world Alzheimer report 2011: the benefits of early diagnosis and intervention*. [online] Available online at <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>.

37. Robinson, L., Tang, E., Taylor, J.P. (2015) Dementia: timely diagnosis and early intervention *BMJ* 350:h3029 <http://dx.doi.org.ezproxy.stir.ac.uk/10.1136/bmj.h3029>
38. Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K. & Manthorpe, J. (2011), "The transition to dementia: individual and family experiences of receiving a diagnosis: a review", *International Psychogeriatrics*, vol. 23, no. 7, pp. 1026–43.
39. Talbot, A., et al., 2005. Driving cessation in patients attending a memory clinic. *Age and ageing*, 34, 363–8.
40. Vernooij-Dassen, M., Derksen, E., Scheltens, P. and Moniz-Cook, E. (2006) 'Receiving a diagnosis of dementia: the experience over time'. *Dementia*, 5(3), pp. 397-410.
41. Waldorff, F.B., Rishøj, S. and Waldemar, G. (2005). Identification and diagnostic evaluation of possible dementia in general practice: A prospective study. *Scandinavian Journal of Primary Health Care*. [online]. 23(4), pp. 221-6.
42. Werner, P, Goldstein, D. and Heinik, J. (2011). Development and validity of the Family Stigma in Alzheimer's Disease Scale (FS-ADS). *Alzheimer Disease and Associated Disorders* [online]. 25(1), pp. 42-8.
43. Young Dementia UK. (2014) About Young Onset Dementia. Oxfordshire: Young Dementia UK. Available from: <http://www.youngdementiauk.org/dementia.htm>