



HEALTH SCRUTINY PANEL

DEMENTIA IN MIDDLESBROUGH

EXECUTIVE SUMMARY

INTRODUCTION

“Its an inevitable part of ageing”

“There’s nothing you can do about it”

1. The two statements above are often heard in everyday life when people talk about Dementia. Both are widely believed to be true and both are wrong.
2. In considering the topic of Dementia, the Panel has spoken to a wide range of people, representing different agencies and at times representing different viewpoints on what is needed to address the coming pressures that Dementia will bring.
3. Before this paper documents the evidence it has gathered, or possible approaches to dealing with the questions posed by Dementia and its rising prevalence, it sets out the data it has considered regarding the huge challenges that Dementia will pose in the coming years. Secondly, there is the financial and social cost that Dementia will pose for future generations.
4. The topic of Dementia has never had a higher national profile than the one it currently enjoys and this is the case for a number of reasons. The Government has undoubtedly given the topic a much greater political profile. By publishing the first ever National Dementia Strategy¹, the government has increased the level of discussion around a topic that was not spoken about enough and was not considered to be as big a problem as it is.
5. Quite apart from the moral act of raising the profile of Dementia and how society tackles it, there is also a financial necessity to do so. The

¹ Please see

http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH_083362

preamble of the National Dementia Strategy and *Paying the Price*², a recent report by the *Kings Fund*, highlights the staggering financial cost of Dementia to the UK economy. The total cost of Dementia care in 2007 for England was estimated at £14.8 billion, with a projected rise to £34.8 billion by 2026, which represents a rise of 125%. In 2007 it was estimated that 582,827 people in England had Dementia. By 2026, it is projected that this will rise to 937,636, which equates to a 61% increase.

6. It is also undoubtedly a bigger issue in the public consciousness, partly due to a number of high profile public figures who have publicised their personal experiences. This has undoubtedly done Dementia a great service, in raising the profile of a condition, which is going to require a bigger and bigger proportion of health and social care budgets.

CONCLUSIONS

7. The Panel has received a substantial amount of evidence to indicate that once a diagnosis is achieved, the range of services available to the people of Middlesbrough is good, with the Woodside clinic being mentioned to the Panel on a number of occasions as an excellent service. It is clear to the Panel, therefore, that there are a number of excellent facilities and services available in Middlesbrough, the development of which has been led by the Council's Department of Social Care and NHS Middlesbrough. Nonetheless, it has been brought into sharp focus for the Panel that for whatever reason, a substantial number of people with Dementia have difficulty in accessing such specialist services.
8. On the basis of the evidence considered, the Panel is confident that all local agencies accept that there is a lot of work to be done in Dementia services and are keen to play, and are playing, their part. The Panel has also heard the unanimous view that if services for Dementia continue to be delivered 'as they always have been', services will not be able to meet the future demands placed upon them. Such unanimous recognition of the pressing need for change encourages the Panel and such a consensus is the first step to implementing the necessary wide-ranging improvements.
9. The Panel is still, even after a number of discussions on the topic and consideration of a great deal of written material, far from convinced that established patient pathways exist for people with Dementia. The Panel would like to see strategies established which outline what a patient and their carer(s) can expect from the first time they visit General Practice with concerns and the sorts of steps they will be taken through and the sorts of support they will be offered. Whilst anecdotal in part, a lot of what the Panel has heard would indicate that

² http://www.kingsfund.org.uk/research/publications/paying_the_price.html Paul McCrone, Sujith Dhanasiri, Anita Patel, Martin Knapp, Simon Lawton-Smith ISBN: 978 1 85717 571 4

it is a genuine struggle for patients and carers to navigate the system and access the support they require. This should not be the case. Related to this, the Panel is particularly concerned about those people of less assertive dispositions who will not want to push the system and thereby 'give up' at the first hurdle. The Panel is concerned that all too often such people are disappearing from the system and fending for themselves, until the Dementia is extremely advanced.

10. On the basis of the evidence that the Panel has received, older people's acute psychiatry liaison services at James Cook University Hospital do not have anything like the capacity required to deal with the workload they are expected to meet. The Panel is particularly concerned to hear that clinicians at JCUH sometimes do not refer people to the acute liaison psychiatry service due to a feeling that they will not be seen, despite concerns for their mental health. The Panel feels that this highlights the lack of capacity perfectly. The Panel has not been able to entirely establish whether this is symptomatic of a lack of resources or a case of resources not being used in the most effective manner, although the Panel suspects that there is an element of both involved. Nonetheless, the Panel is absolutely clear that the current level of service, with its current level of capacity, is not acceptable. Of great concern to the Panel is that a significant number of patients with Dementia, will be entering and exiting JCUH, and missing the opportunity to have their needs highlighted.
11. The Panel has heard that two thirds of people with Dementia will never receive a formal diagnosis. The Panel sees this as very worrying and in need of urgent attention. Without a formal diagnosis from an appropriately qualified professional, people with Dementia are not able to access the specialist assistance they are entitled to and require. When a situation exists where two thirds of sufferers of a condition do not receive a formal diagnosis, the Panel does not feel able to conclude that the condition is appropriately addressed in the local population.
12. Related to the topic of increasing the numbers of accurate referrals and diagnoses would be the importance of making early diagnoses as there is a substantial body of evidence to indicate that there are a number of things that can be done to delay the advancement of Dementia.
13. On the basis of the evidence received, the Panel is left with the view that there is a lack of capacity within General Practice, in relation to how the symptoms of Dementia are potentially identified and appropriate referrals are made. The Panel has heard the view expressed on a number of occasions that some parts of General Practice are seen as a barrier to those seeking help for suspected Dementia. The Panel acknowledges the many pressures placed on General Practice and accepts that not all General Practitioners can be experts in all aspects of physical and mental health. Nonetheless, the Panel has heard the view expressed more than once that General

Practice is perceived by some to be a barrier in seeking a referral to appropriate mental health services. With that in mind, the Panel can see nothing to stop the Practice Based Commissioning model, other than a lack of will, being employed to develop a further level of Dementia expertise in General Practice that all of Middlesbrough's General Practice could engage with when felt necessary. This would ultimately be concerned with ensuring that there are more appropriate referrals to specialist services for those suffering from Dementia.

14. The Panel has spent a great deal of time considering what happens to those people who receive a diagnosis, immediately after the diagnosis. The Panel has heard that there is a lack of support for patients and carers of those diagnosed with Dementia, especially with low level Dementia. The Panel has heard that a lot of information is made available, although there is very little support for people to be guided by someone and there is a sense that people are required to interpret the information for themselves. The Panel contrasts this with when one considers the experience of those newly diagnosed with cancer, who can access advice and guidance from specialist services before they even leave the medical facility premises where they receive the diagnosis. On the basis of the evidence that the Panel has received, the same can not be said of those receiving a diagnosis of Dementia, especially at a low level. It appears that there are more services for those with advanced Dementia.
15. The Panel has learnt that the local health and social care economy looks towards the *Alzheimer's Society*, quite rightly, to provide a lot of the support services that could be available to patients and carers, due to the Society's expertise and experience. The Panel feels this is correct, although would like to highlight the fact that there appears to be a lack of capacity in the local *Alzheimer's Society* to deliver such services across Middlesbrough to the desired standard. The local health and social care economy is therefore left in the curious position of accepting that the statutory sector shouldn't and perhaps isn't able to offer 'softer' support services to patients and carers, but with a local voluntary sector that does not currently have the capacity to meet anticipated demand. In addition, the Panel does not feel that the support structures currently in place are sufficiently assertive, or have a sufficiently high profile to assist most people in need for such support.
16. The Panel would also like to highlight the role of carers for those with Dementia. As is the case in many other areas of poor mental health, carers are shouldering a great deal of the strain for those people with Dementia. Whilst the Panel is aware of a number of services available to Carers, the Panel would encourage the local health and social care economy to seek and develop services for carers, and crucially, the profile of such services. Particularly, the Panel feels that thought should be given to how out of hours services Dementia support could be developed and what campaigns could be organised to reduce Dementia's stigma and thereby normalise the condition to some extent.

17. The Panel would also like to raise the topic of Dementia Cafés and the possibility of their use in Middlesbrough. The Panel has heard about the concept of a Dementia Café and has completed some research about where and how they are used. The Panel feels that this is something that could be explored in Middlesbrough, at very little financial cost and is something that could greatly assist those with Dementia and those caring for those with Dementia. Overview & Scrutiny at Middlesbrough Council would be happy to assist in the development and introduction of such a service in any way it can.

Recommendations

18. The Older Peoples' Inreach Acute Liaison Psychiatry Service at JCUH, operated by TEWV, should be developed to the extent where it has the capacity to deal with the likely calls on its time, which is far from the case at the moment. The Panel sees this as a shared responsibility amongst the local health and social care economy and feels this should be treated as urgent.
19. That the Middlesbrough Practice Based Commissioning Cluster scopes and invests in a specialised Dementia services for use across General Practice in Middlesbrough. Such a resource would ensure that there is the necessary expertise and capacity in General Practice to increase the amount of accurate and appropriate referrals for those with suspected Dementia. The Panel recognises that neither the PBC Cluster or NHS Middlesbrough can implement such a service in isolation. NHS Middlesbrough has a responsibility to support the PBC framework as much as it can in delivering such a vision. General Practice has a responsibility to actively engage in the debate, as the current picture of a one third diagnosis rate for Dementia must be challenged.
20. That NHS Middlesbrough and Middlesbrough Council further develops Dementia Advice services. Such services should be located, or at least heavily advertised, in places where people will typically receive diagnosis of Dementia.
21. That NHS Middlesbrough and Middlesbrough Council invests, as a priority, in an appropriate number of Dementia Advisor Posts as envisaged in the National Dementia Strategy. To fill the position of this sort that is currently vacant would be an excellent start. These posts should be proactive, contact people who are newly diagnosed and guide the patient and their carers through all stages of the journey, paying specific attention to the 'softer' services that people rely upon so much.
22. The Panel recommends that NHS Middlesbrough and Middlesbrough Council develop and open a Dementia Café for the use of patients and carers. Such a facility could be operated in established premises, to

keep down capital costs. It would provide patients and carers with an opportunity to meet with people going through similar experiences and would allow patients and carers the opportunity to speak with professionals in a relaxed, informal and 'normal' environment.

23. NHS Middlesbrough and Middlesbrough Council should consider in detail whether the local *Alzheimer's Society* and associated third sector organisations, currently have the capacity and appropriate funds, to deliver the sorts of 'softer services' that are envisaged as being developed and that are the speciality of the sector. The Panel would like to hear the outcome of that exercise.
24. The Panel recommends that the local health and social care economy investigate methods to increase awareness of the condition and thereby challenge the perception that it is a 'normal' part of ageing. In so doing, it is hoped that the stigma could also be challenged. Whilst anecdotal, the Panel feels that the stigma associated with Dementia probably prevents some people accessing the services they need.
25. The Panel is aware of the advancements made recently in services for Carers, particularly out of the Life Store. The Panel would urge the local health and social care economy to keep the needs of Dementia Carers at the forefront of its thinking when developing Dementia services.
26. The Panel recommends that staff on wards at JCUH which deal with a high proportion of older people should continue to receive training on how to recognise poor mental health symptoms amongst older patients. Such training, however, is intrinsically linked to the urgent work required in ensuring that the older people's acute liaison psychiatry service has the capacity to deal with referrals when they are received.