



The
British
Psychological
Society

**Response to the Department of Health consultation:
Transforming the Quality of Dementia Care: Consultation on a national
dementia strategy**

The British Psychological Society thanks the Department of Health for the opportunity to respond to this consultation.

The British Psychological Society ("the Society") is the learned and professional body, incorporated by Royal Charter, for psychologists in the United Kingdom. The Society is a registered charity with a total membership of almost 50,000.

Under its Royal Charter, the key objective of the Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge".

The Society maintains the Register of Chartered Psychologists and has a code of conduct and investigatory and disciplinary systems in place to consider complaints of professional misconduct relating to its members. The Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

We are content for our response, as well as our name and address, to be made public. We are also content for the Department of Health to contact us in the future in relation to this consultation response. Please direct all queries to:-

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This response was prepared on behalf of the Society by Dr Sinclair Lough, CPsychol, member of the Division of Clinical Psychology and Chair of the Division's special interest group for psychologists working with the elderly (PSIGE), with contributions from a number of other members of the Society (please see Appendix A for full details). We hope you find our comments useful.

Martin Crawshaw

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Chapter 1 – Improved Awareness

1. Are the outcomes, recommendations and suggested means of achieving them the right ones?

The Society considers the outcomes and recommendations set out in the draft strategy to be both relevant and appropriate and that the invitation to comment is a timely one.

A common attitude to dementia is one of resignation while older people, in particular, continue to associate mental illness with senility, stigma and persecution. Further education is needed on the facts of dementia, including the fact that it is not necessarily an inevitable consequence of living longer and can be managed like any other illness. We agree with the external reference group's recommendations regarding education re: ageing and memory impairment.

We have some concerns that services will be overwhelmed by people without memory problems unless those within the system, especially potential gate keepers (e.g. General Practitioners [GPs]), are well trained and confident in screening for whether people should be further referred for specialist assessment. There is therefore a need for good co-ordination of the publicity campaigns with the service provision increases and adaptations. Furthermore, the lack of services for people requesting diagnosis early on means that there is a danger that people will be referred following a publicity campaign and inappropriately reassured that they do not have a dementia - because, currently, a severe level of difficulty on the Mini Mental State Examination (MMSE) is used to make a diagnosis of dementia. However, it is possible that people with concerns about their memory could attend memory cafés (as run by the Alzheimer's Society) as a first port of call. The Society recommends that the availability of memory cafés should be highlighted in the strategy.

The draft strategy tends to portray dementia in somewhat 'black and white' terms, with little mention of either Mild Cognitive Impairment (MCI) or the fact that not all persons with a diagnosis of MCI convert to a dementia. The drive by the Croydon Memory Service (Banerjee, Willis, Matthews, Contell, Chan & Murray, 2007) resulted in an estimated 63% increase in referrals. Of these, 68% scored 25 and above on the MMSE. Therefore, on strict interpretation of the MMSE, these persons would have been classed as either unimpaired or suffering from MCI. If this result were to be repeated in a national drive then much work would need to be directed at counselling for diagnostic uncertainty and at ongoing monitoring and reassessment.

On a related note, we recommend that the strategy should advocate the use of the *Addenbrooke's Cognitive Examination – Revised (ACE-R)*, which incorporates the MMSE, rather than the MMSE alone. The ACE-R is a much more sensitive and specific instrument for the detection of dementia and only takes a few minutes longer to administer than the MMSE (Mioshi et al, in press).

Awareness of dementia in people with learning disabilities, particularly in adults with Down's Syndrome, has increased significantly and is now well recognised in most parts of the country, with screening services either being available or in development.

2. *Is there anything that has been missed to help us improve public and professional awareness of dementia?*

The draft strategy makes several important points to help improve public and professional awareness of dementia, covering the need for training and support for healthcare professionals as well as focusing on healthy lifestyle as a preventative strategy. The emphasis on prevention is of particular interest since it both engages and focuses the public mind on positive action rather than merely seeking to overcome the problems.

The recommendation is comprehensive; however, there is a question as to what is meant by a “timely diagnosis”. For whom might the diagnosis be considered timely, bearing in mind that some families may need time to process and adjust to this diagnosis and its implications? Furthermore, it is worth acknowledging that families from minority ethnic groups may have different beliefs about dementia and the stigma associated with this illness and may therefore not seek an early diagnosis. Also, how will the timeliness of diagnoses be assessed? Is it feasible to have the same time scale used across the country, given large regional and borough differences?

The draft strategy highlights the considerable stigma and misunderstanding of dementia that arises at a population level as well as with many staff who work with people with dementia. In addition to those matters highlighted, this also arises because of a lack of knowledge as to how to understand different behaviours and interact with someone with a complex, deteriorating, neurological condition. This issue is exacerbated with dementia, compared with other long term neurological conditions because, once one positive approach has been learnt/experienced, the degenerative nature of the condition means that the skill or approach often needs to be adapted and altered frequently. Fear often arises from a lack of understanding of the communication, movement and neuropsychological disorders that people are confronted with. As many staff working with people with dementia do not have formal training, myths are often perpetuated even in those services which one might expect to have developed highly skilled, and specialist, approaches.

Modelling is an extremely effective way of overcoming prejudices and fears and of developing skills, particularly in relation to the effective and appropriate development of people’s existing interaction skills. Modelling is likely to be more effective if public information campaigns include examples of why someone may be acting in a certain way and of appropriate interactions with people with dementia. Examples could address a wide variety of presenting difficulties throughout the stages of dementia. The Society considers this approach would be likely to dispel myths about the early stages of dementia and to support people in learning about ideas that may help people with more severe dementia. It is therefore important that any publicity is not limited to lists of symptoms and medical/psychiatric treatment options.

Modelling to the mass population could be achieved by means of short television clips (i.e. of just a few minutes). Since many staff working with people with dementia do not have developed skills in this area it would be important for appropriate, highly trained professionals with good skills in working in this area be used to advise on making any such publicity. Such professionals would include nursing dementia specialists, clinical psychologists, speech and language therapists, occupational therapists and physiotherapists.

As stated in the draft strategy, dementia touches a large and increasing population. It is therefore very important that, in order to develop an effective workforce for the future and to enable social support to be maintained at its highest possible level, children who may be interacting with grandparents or elderly neighbours are supported in being exposed to positive modelling. This, in itself, is likely to increase positive interactions, maintain

relationships for longer and reduce the breakdown in social support.

Awareness needs to increase in staff groups as well as the general population. Common difficulties in developing staff confidence in this knowledge often include the time to follow-through training. Although, in the long-term, follow-through will save time, secondary services currently are often crisis driven, making it difficult for time to be found to change practice: the strong support of management is therefore needed.

The Society considers it important that training be made a core component of audit for all people working with dementia (especially those working in care homes), and that statutory standards and mechanisms for auditing reflective elements and cultural change be introduced.

3. What can you or your organisation do to help implement the recommendations?

Clinical psychologists are trained and able to provide education and training to staff, relatives and clients in understanding the behaviours, emotions, cognition and relationship issues and in supporting awareness of positive interactions and approaches.

There is currently a funding battle between private care homes and secondary community mental health services as to provision of preventative education and dealing with the behaviour problems that often arise with a poorly skilled and poorly supported workforce. Clinical psychologists in Community Older Adult Mental Health Services could be effectively commissioned, alongside other appropriate professionals, to do preventative outreach work with private nursing homes rather than only being available when behavioural problems or other crises arise.

Training for care staff from statutory, private and voluntary homes for people with learning disabilities has commenced in many areas of the country; either through training provided by clinical psychologists from local services, or by the purchase of training from specialist psychologists in the field of learning disabilities and dementia. This training aims to help care staff and families to understand dementia, how it presents in people with learning disabilities, and the philosophy of care needed to ensure that behaviours are less likely to occur. A DVD that has just been produced by the Down's Syndrome Association featuring a clinical psychologist advising about *The Philosophy of Care* has enhanced this.

Clinical psychologists could advise on what should be included in modelling clips, provide training in schools and/or provide advice and support to other organisations regarding material to include in training.

The Society recommends that educational and occupational psychologists should be asked to advise on how best such campaigns should be formed and targeted in order to be effective for both staff groups and the general population.

Clinical psychologists with doctoral research skills may be able to offer core support in setting up audit processes to measure outcomes regarding change in approach, as well as knowledge, in clinical settings.

Psychologists are instrumental in undertaking vital research on mental health issues. A highly visible research focus on dementia and related issues would help raise awareness.

Universities also have a role to play in spreading knowledge and raising awareness through psycho-educational courses, specialist training courses and counselling programmes to suit both academic and professional interests.

Chapter 2 – Early diagnosis and intervention

1. *Are the outcomes, recommendations and suggested means of achieving them the right ones?*

The Society supports the general trend of the consultation suggestions. In our view, there should be a focus on developing the infrastructure to support people with an untreatable condition. Evidence from the learning disability literature on dementia has not been included and would add support to the arguments for early diagnosis and intervention.

Early diagnosis is not clearly defined. Many people develop biological prodromal features and mild cognitive impairment. A proportion of these will go on to develop dementia. Many people will have symptoms that are similar to those of dementia (e.g. undiagnosed thyroid difficulties in adults with Down's Syndrome) but early assessment can result in appropriate treatments being put in place.

Although it is clinically possible, very few people currently are given a diagnosis of mild cognitive impairment, support to adapt to this, and then both monitoring to establish whether there is development of dementia and support in adjusting to the diagnosis. The process involves significant psychometric assessment, by clinical psychologists, and is not widely available.

Most people currently receive a diagnosis once their difficulties are becoming severe and measurable on the MMSE. This is a broad-brush tool, which highlights gross cognitive deficit and does not enable early diagnosis. The MMSE therefore gives a diagnosis at a stage when it is already pretty clear to the client/ family. The Society considers it necessary for a standard screening tool to be adopted in primary care. At the secondary level, we recommend the replacement of the MMSE by the ACE-R (for the reasons outlined in our answer to Question 1, above).

Therefore there are six issues that the Society believes need to be addressed:-

1. At what point do the population want diagnosis? Although there are opinions either way on this, the point at which most people would want this knowledge has not been established. Furthermore, stigma is likely to affect any mass population assessment or survey. Clinical psychologists and social psychologists may be well placed to implement such an evaluation, if undertaken.
2. The aim of having a rapid assessment is a good one; however, it needs to be acknowledged that some families may need time in order to process and come to terms with assessment and the diagnostic process. Therefore, a rapid diagnosis may not be helpful in all situations and it is necessary for this process to be sensitively managed and person- or family-centred. The Society supports the general trend of the consultation suggestions. In our view, there should be a focus on developing the infrastructure to support people with an untreatable condition.

3. Given the incidence rates of dementia, we recommend a significant increase in screening services.
4. It should also be acknowledged that there will be resource implications for services as it is likely that, with increased public awareness and knowledge, referrals will increase. This increase will need to be managed and funded by the NHS and social care services.
5. If early diagnosis is wanted, there are significant implications as to how the neuropsychological assessments that are usually required for this might be provided. Normally, clinical psychologists are required to provide this level of assessment and to follow up at early intervention. This would require a significant shift in the staffing of teams.
6. Early diagnosis will mean that more people may require psychological help to come to terms with the diagnosis and its implications for all aspects of the person's life – this will be a major resource issue for services.

All service users are keen to emphasise the importance of training for professionals involved in diagnosis, treatment and support. Clearly, an early diagnosis may help alleviate anxiety if it enables a plan of intervention towards improving quality of life. Carers emphasise the need to recognise the impact of diagnosis on family life and relationships. Good communications skills, including active listening and sensitive awareness of the various needs of the people involved, may contribute toward a more hopeful outcome.

It is important to emphasise the point that assessment is not just about diagnosis – rather, it is a formulation of the needs of the person with dementia and of the care and support system. From a clinical psychology perspective, the chapter heading is limiting and possibly also blinkering. To initiate an effective intervention, it is necessary to have a diagnosis and formulation which identifies not only the biological, but also the psychological and social, changes associated with dementia.

The Society has reservations about a “core set of assessment tools” as being too prescriptive. It would be valuable for the National Institute for Health and Clinical Excellence (NICE) to regularly review evidence on the power and effectiveness to assess cognitive domains. This is even more of an issue for people with learning disabilities where there are major issues in assessment because of the pre-existing levels of cognitive impairment.

2. *Is there anything that has been missed to help enable early diagnosis and intervention?*

Neuropsychological assessment provided by clinical psychologists is one of the key components in supporting early diagnosis and differentiation of functional from organic disorders. This skill base is currently not available in large quantities in many Trusts: there is no funding for this, as it is accepted without question that the MMSE is a sufficient measure of deterioration for diagnosis to be recognised.

If assessment were to move earlier it would require clinical psychological assessment. The current number of clinical psychologists would not be sufficient to meet future demand.

The diagram on p.24 includes reference to breaking the diagnosis well. In our experience, consultant psychiatrists often see this as their area of expertise and are unwilling to relinquish this role. Unfortunately, it is not uncommon for the person with dementia to be

unable to retain the information or to be distressed by the way they have received it. We would find it useful to have more explicit criteria about what is meant by 'breaking the diagnosis well' in order to improve practice and highlight training needs. These criteria should identify: the need to allow time to process the information; the sensitivity and complexity of communication skills required; and the need for the information to be tailored to the individual and their network.

Some carers have commented on the need for training those who want to care informally for their relatives at home but both lack the necessary knowledge and skills and feel unqualified to make decisions about treatment options, interventions and future care-provision on their relatives' behalf. We propose an inclusive approach be adopted to supporting information needs, in order to build confidence in all those who need it.

It is important to note that there will be a proportion of patients who will report concerns about their memory and continue to worry about their abilities even when these are not borne out on formal testing/assessment but . It is likely that these patients' concerns about their 'memory problems' are, rather, an expression of some other form of psychological distress. This may relate to issues of ageing, poor physical health and increased dependency needs. These patients will require access to other services, such as psychology, for an assessment to determine whether talking therapy would be a helpful way of further exploring and making sense of these underlying concerns.

3. Do you agree that the diagnosis of dementia should be made by a specialist?

It should be noted that earlier diagnosis of dementia is likely to be more complex and tentative than later diagnosis, when the clinical presentation generally would be clearer. It should also be acknowledged that such an important diagnosis should be confirmed and communicated by an experienced expert.

The Society considers it to be very important that specialist teams provide diagnosis. The multidisciplinary components of diagnosis, resulting from the variety of complex neurological aspects encompassed by the condition, means that it is important that a team is available to assess and diagnose. This team should include a specialist community psychiatric nurse, psychiatrist, clinical psychologist, occupational therapist, and speech and language therapist. This approach has resource implications which will need to be considered and addressed

It is important that the diagnosis of dementia should be made by a specialist who is fully informed about the facts of the illness and is able to support the patient's information needs. This means avoiding the tendency to overwhelm the person with copious information and instead provide the necessary information at the appropriate time.

4. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to a GP first?

The experiences of service users suggest that their needs are best served by specialist centres providing memory services and that these centres operate as a first port of call to encourage self-referral and help-seeking behaviour.

However, a contributor to this response who is working in a Memory Clinic service which had a trial of open referrals found there was a large increase in referrals and that many of these were inappropriate. The resources implications of this may mean that a clear and robust screening process in primary care is required in order to make sure that referrals are appropriately managed and signposted. Furthermore, there are specific health screens that need to be conducted prior to making a differential diagnosis.

The Society therefore suggests that referrals should continue to be through a GP with the proviso that GPs will need to have training to encourage them always to think about the possibility of dementia in all age groups: for some GPs, dementia is almost synonymous with old age and is often a hypothesis not considered in the under 65s. We recommend that screening at the primary care level should use a validated protocol such as the 6CIT (Brooke & Bullock, 1999). Further screening at the secondary level could use the ACE-R with interpretation from a clinical psychologist, who would then conduct any necessary neuropsychological assessment.

However, it is possible that people with concerns about their memory could attend memory cafés, as run by the Alzheimer's Society, as a first port of call. These provide a psycho-educational service and could empower people if they have to deal with an unsupportive GP. As stated above, the Society would welcome the availability of memory cafes being highlighted in the strategy.

Arguments about increasing access and reducing stigma, so that people access diagnostic services, should be addressed through educational campaigns.

Within Learning Disabilities services, many of the service users are already known to the specialist Community Learning Disabilities teams (CTPLDs) and referrals may come from a wide variety of sources depending on local arrangements.

5. How would the dementia advisers be able to ensure continuity of care?

The draft strategy proposes a care pathway supported by a model of collaborative care. On past experience, however, dementia collaboratives are undermined through lack of communication between agencies or arms of service and/or the need to compete for limited resources. The result is too many unsustainable initiatives. Overcoming these difficulties will require workable communication systems and adequate resources. Dementia advisors could play a pivotal role in ensuring that the various services work together for the benefit of service users.

This role has much in common with a care-coordinator's role yet is likely to be held by relatively junior or unqualified staff. Will these dementia care advisers have the authority to implement services effectively or will they end up becoming frustrated? They can only successfully carry out this role if all services mentioned in the strategy are genuinely in place. The Society would welcome further clarification of the role of the adviser and the type of organisation which should be responsible for them. We would also welcome clarification of who would act in this role, the career pathway and the supervision arrangements.

We consider there to be a need for various models of the role of dementia advisor to be evaluated within the context of the existing statutory and non-statutory providers.

In our view, resourcing current fundamental services to a core acceptable level is the first long term priority.

6. What can you or your organisation do to help implement the recommendations?

Clinical psychologists can provide each of the following:-

- support to multi-disciplinary teams with early differential diagnosis through neuropsychological assessment skills;
- training to staff in how to give a diagnosis, how to provide post diagnostic support (e.g. including cognitive strategies/carer support regarding psychological and behavioural concerns) and pathways within organisations that meet clients' psychological needs in emotional adjustment to, and coping with, diagnosis;
- Training others in:
 - psychological approaches in care;
 - recognising and supporting management of co-morbid mental health conditions.

There are many packages of information already available for people with dementia. Clinical psychologists can advise on the following areas in information packages: cognitive, behavioural and emotional disorders, concerns and management of these, and how to lay out booklets in order to be readily accessible.

Interested parties (such as psychologists working in higher education institutions), supported by adequate funding and the British Psychological Society, could be instrumental in the development and piloting of material in local areas as well as in monitoring and evaluating performance.

Chapter 3 – High-quality care and support

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

The Society strongly supports the recommendations in this chapter regarding the provision of improved care and the reduction of abuse and neglect. We also support the maintenance of specialist Older People's Mental Health (OPMH) teams and the development of liaison teams as providing both direct specialist input to the individual and a consultative role to other generic services. The means of achieving outcomes involve the provision of high quality training to enable high quality care tailored to individual needs.

The Society does have some concerns, however, which relate to the following:-

- provision of, and accessibility to, day and respite services - these should be funded through councils;
- funding models for acute physical care needs, which do not account for the needs of a person who has dementia (who will need more staff input and often longer and more specialist approaches to any physical rehabilitation and to returning home);

- ensuring that specialist dementia beds meeting the mental health needs of clients with severe behavioural and emotional difficulties arising from dementia are maintained in the face of changes to acute hospitals;
- the addressing of palliative care needs.

2. *Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?*

The consistent message is that high standards of care are compromised by lack of knowledge, expertise and confidence in dealing with dementia and related issues. The Society's view here is that the status of care-workers must be raised by instituting mandatory skills training to the order of a skills-based scale linked to appropriate monetary reward.

We recommend that training in dementia care should include basic training from occupational therapists, psychologists, speech and language therapists and physiotherapists as to the neurological difficulties that people have. This training should also address how these difficulties relate to emotional, relationship, memory, communication, and personality changes as well as to movement disorders and to environmental issues. Finally, the training should also cover the different strategies in communication, psychological support and occupational support that are appropriate and why this is the case.

We further recommend that the education should not be one-off and that it should have a clear audit trail which measures outcome. Care staff should be able, and enabled by management, to have the time to implement what has been learned effectively and in an ongoing way. Currently, it is all too easy for a one-off training to be funded but the practice not given a chance to develop in homes. Development of staff workbooks for each individual with Down's Syndrome and dementia have been an effective tool to support high quality and person centred care (Dodd, Kerr & Fern, 2006).

In our view, there needs to be greater recognition that changes in living situation will have an adverse effect on people with dementia, as it takes the person away from their familiar environment to one where they are disorientated and confused. The Society recommends a much greater focus on increasing the support, where feasible, to maintain the person in their familiar environment. This support may need to include increases in home care and, if the person is already living with residential services, in levels of staffing.

A key issue in services for people with learning disabilities is the provision of 'waking night staff' in registered care homes in order to maintain people within familiar settings as the dementia progresses. Increases in staffing require increases in funding and the current system within social services is often slow, leaving both the person and staff at risk. The Society urges an overhaul of the system to foster the provision of safe and speedy responses.

The draft strategy focuses on general medical care but does not look at the extensive need for services at the severe end of the spectrum in dementia care run by mental health services (often referred to as organic wards) and intensive home treatment teams. It is important that these are also examined, standards set and level of needs identified. In addition, the draft strategy does not focus on the extensive social and social care needs and how these can be met.

Recommendation 11, *Improved dementia care in care homes*, highlights psychiatric intervention. One of the problems with psychiatric intervention, unless well resourced and well set up, is that the psychological approaches are not integrated or not sufficiently well understood and implemented to be effective. Throughout the strategy 'psychiatric intervention' should be denoted as Mental Health Services or Specialist Dementia Services. Furthermore, it needs to be specified that this should include attention to specialist psychological and other therapeutic approaches providing input to services.

These service teams should be additionally commissioned and resourced to provide ongoing support, teaching and supervision for those who provide care for people with dementia; specifically, for day care and residential/nursing homes funded by social services. Staff in these environments face the difficult, ongoing, daily challenge of providing care for people with dementia and their families and may need help to understand and process the feelings that can be stirred up by this work.

Currently, commissioning boundaries and low levels of clinical psychologists and other therapists employed prevent people from being aware of what is available from psychologists and other therapists. Psychological interventions do not all need, and are not all provided by, clinical psychologists. However, in order for there to be culture change in dementia management, particularly in relation to reducing high levels of inappropriate psychotropic medication, an increase in clinical psychologists advocating for increase in psychological approaches and supporting skills development in colleagues is extremely important.

Councils should be required to assist the third sector in providing support groups for people with dementia, to increase both support for community working and support for the client. In addition, we suggest more elaboration of the range of services that can provide daytime activity, moving away from the 'one size fits all' notion of day services.

As noted in the draft strategy, patients with dementia are often very distressed and disoriented in hospitals. Patients without dementia find this very upsetting. The Society therefore recommends 24-hour specialist dementia care in hospitals, with people trained in supporting other clinicians in providing appropriately for the needs of people with dementia while they are in hospital.

Liaison psychiatry is often not provided over the full 24 hours. It also rarely includes psychological approaches and assessments. The Society suggests that a specialist *Older People's Liaison Team* be linked to each general hospital. We also recommend the provision of specialist dementia care beds and services in hospitals.

The proposal to commission OPMH liaison teams is therefore welcomed. There is likely to be considerable demand for neuropsychological assessment within these teams if the liaison teams have to call on psychology services within existing Community Mental Health Teams (CMHTs) or the memory services. This is likely to lead to delayed discharges (due to the relative shortage of psychology in many OPMH services. Although details are provided (p.42) of how such liaison teams might typically be made up, these state a "psychologist/therapist" which appears to miss the point: a therapist is not going to be able to complete the neuropsychological aspects and is more likely to be of benefit in the CMHT than in the liaison service. An example of a good-quality liaison team and how it operates would be useful. Such teams presently appear few and far between.

Any recommendations on high quality care and support will only be effective if the reason why people with dementia have a "worse outcome" in hospital is due to lack of awareness and training. If the "worse outcomes" are due to lack of time for professionals to devote to people who are likely to need more time, then these recommendations will fail.

There also needs to be closer attention to meeting the physical health needs of clients in specialist dementia settings. We agree that there should be a focus on access to intermediate care to reduce crisis inpatient admissions to physical and mental health acute beds.

Closer linkage with the national End of Life Strategy is required to ensure that people with dementia can access all the types of care and support available to other people with terminal conditions.

The full implementation of the Mental Capacity Act (MCA) and Advanced Decisions (as part of the End of Life Strategy) would greatly facilitate the achievement of the goals but only if positively monitored and with sufficient available resources. The separation of funding between health (free) and social care (increasingly rationed) does not facilitate this.

3. *What more could be done in acute care, home care and care homes?*

The Society recommends that:-

1. The profile of the care worker be raised in relation to training, qualifications and reward systems and agencies be made more accountable by monitoring the standards of domiciliary care.
2. Confidence in care homes be built by the imposition of rigorous monitoring and on-the-spot inspection procedures.
3. Quality of life for residents be improved by improving staff ratios and quality of care through high quality training.
4. The physical environment of care homes be improved to ensure that they are dementia-friendly and do not exacerbate the problems of dementia.

It is the Society's view that, in order for training and care not to be wasted or lost, it is vital to give staff who deliver care greater material rewards, the opportunity for professional pride, and a career path. We acknowledge that this has financial implications but unless the issue is grasped it is unlikely that lasting changes will be achieved.

There is mention, in the draft strategy, of the challenges of providing quality care to older people with dementia in care homes. In the Society's view, training and care should be consonant with an ethos of "Person-centred Dementia Care" as developed by Tom Kitwood (Kitwood, 1997) and refined by the work of Dawn Brooker (Brooker, 2007). Tools developed to monitor person centred care (i.e. Dementia Care Mapping) should be utilised to monitor care quality.

We recommend that all care homes should have activities as an essential audited and accountable part of their day programme. Organisers should be trained in supporting people with dementia and in understanding how activities can be adapted to encourage occupation of these with the most severe needs as well as those functioning well. Nursing homes need support in adapting nursing routines when they have a caseload with considerable physical difficulties so that clients' needs no longer have to fit around nursing handover times. Too many clients are left in bed with nurses providing what little emotional and practical support they have time for. We no longer accept this with young people with learning disability. We should not accept this with people with dementia.

There needs to be greater recognition of the physical aspects of ageing and dementia, particularly in relation to appropriate pain recognition and managements – evidence suggests that many of the ‘challenging behaviours’ may be a result of the person with dementia being in pain. Health Action Plans could be introduced for all people with dementia, not just those with learning disabilities, and should include details of pain signals, recognition and management.

The Society would also find it helpful if staff in these settings could be involved in the development of individualised “life books” for people with dementia. This would help staff to get to know and understand the person they are caring for in order to provide better quality care. Ideally, “life book” work is something that could also be raised when a person is first diagnosed and something that they could actively be involved in compiling.

Discussion is provided (pp.46 and 49) of the lack of engagement of people in residential settings and the commissioning of specialist mental health in-reach services into care homes. Often, the lack of engagement is due to failures in systems. It could be argued there is a potential role for clinical psychology here in terms of identifying system issues and of providing training, leadership and motivation. Adequate psychology within such a specialist mental health in-reach service could also help with the identification of mental health and behavioural difficulties, the addressing of staff stress, and the creation of a more therapeutic environment (all as outlined on pages 47-48). The Society urges a move away from the highlighting of psychologists’ potential roles in terms of providing a service in response to crises to ones relating to the provision of a more preventative approach to improving the psychological aspects of the environment of older people in residential care.

We recommend the inclusion of the need for meaningful occupation as part of the process of care while the person with dementia continues to live at home.

The needs of younger people with dementia should be explicitly noted as requiring especial consideration. This may require commissioning on a larger scale to meet their individual needs, for instance in residential care.

All dementia care environments, including acute hospitals, should have compulsory environmental assessment and adaptation including appropriately supported assistive technology (A.T.) to support adaptation for people with dementia. There are tools available to do this. This move would be likely to improve orientation, independence, mood and wellbeing and to reduce disorientation, wandering, and behavioural problems as well as unnecessary deterioration.

Regarding assistive technologies such as telecare - the success of this recommendation will depend on the extent to which family and carers are frail and/or cognitively impaired. A full and contemporary range of assistive technology should be available and there will need to be an appropriately trained professional who is assigned the role of matching need to services.

There have been major advancements in assistive technology at a European level. The European Commission has been funding research and development of A.T. for specific populations of potentially vulnerable people, such as older people and people experiencing dementia, and identifying appropriate (and inappropriate) A.T. to meet the needs of people (in, perhaps, a smart housing environment). It is essential that issues of assistive technology be explored at a European level in order to maximise existing knowledge of availability and appropriateness.

A priority should be to amend the existing model of care housing - which tends to exclude people experiencing any level of dementia - whilst at the same time identifying and developing a suitable model for assisted living.

4. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?

Personalising the care agenda means offering choice. Many relatives and friends want to be actively involved in caring but lack the necessary psychological support. In our view, a care agenda should provide an option for attending to the health, training, informational and counselling needs of informal carers. Personalisation of care should also offer a choice of location for respite care, including one based at home.

5. What can you or your organisation do to help implement the recommendations?

Psychologists have made important contributions both to the definition and management of person centred care and to interventions for challenging behaviours. At the implementation stage the British Psychological Society needs to raise the profile of psychological contributions, and lobby for relevant material to be included in the Commissioning guidance.

The Faculty of Learning Disabilities from the British Psychological Society is working jointly with the Faculty of Learning Disabilities from the Royal College of Psychiatrists to produce joint guidance on the assessment, treatment and support of people with learning disabilities who develop dementia. This should be published later this year and will be launched at their joint conference in April 2009.

It is essential that representatives from the Society's divisions of clinical, counselling, and health psychology are included in any Department of Health discussion group.

Clinical psychologists could be involved more in liaison teams to nursing/care homes and wards to give advice and support on behavioural, cognitive and personality matters and working with systems.

If invited, clinical psychologists and other specialists from learning disabilities and neuro-rehabilitation would be pleased to comment on the nature and implementation of useful changes (learning disabilities psychologists engaged in similar work in the 1970s). Importantly, this involvement might highlight the current significant level of under-investment in older people's services in comparison to clients with similar needs.

Clinical psychologists are skilled in working with staff teams to support increased psychological practice in everyday care. Currently, commissioning boundaries and low levels of clinical psychologists employed in this area result in people being aware of what is available from psychologists but also prevent psychologists being able to provide their services. Where there are clinical psychologists, they can provide consultation and training to homes and hospitals on adaptations and approaches that may support psychological wellbeing, person centred care and the management of distress and challenging behaviour.

We urge consideration of how the transition from reactionary services to preventative services with increased psychological approaches is to be managed.

Chapter 4 – Delivering the National Dementia Strategy

1. *Are these outcomes, recommendations and suggested means of achieving them the right ones?*

Setting benchmarks appears appropriate. However, there are no guarantees, in the current climate, that there will be any incentives for the benchmarks to be met. There is no detail of additional sustained funding for the significant increase in service provision that would be needed to provide anything near the ideals set out in the draft strategy.

The Society urges strong pressure be applied to ensure funding is made available for the implementation of these recommendations. Otherwise, there is a danger that specialist mental health service for people without dementia will become the poor relation to dementia, with both services remaining under-provisioned and failing to meet clients' needs. This is because funding may be easily focused on dementia away from functional mental health conditions.

The recommendations outlined in the draft strategy need to be established at the same time as an ongoing provision of funding to raise service to a fundamental acceptable level of provision and a commitment that this will increase appropriately as volume increases. Without this the guidelines will, like all previous documents of this type in this area, make little difference.

Where benchmarks are being set, it will be important that psychological and social factors are also used to set benchmarks. The Bradford dementia care group (Brooker, 2007) have measures that are appropriate to consider. Clinical Psychologists with doctoral level research skills and knowledge of psychological and psychosocial research and audit should be involved in supporting services in setting appropriate benchmarking outcomes.

Research should include qualitative, social and psychological research. In addition to diagnosis-focused research, there is a need for research into psychological needs and interventions throughout the span of the disease. Given the large social impact of dementia in the future, we propose that this should include a social constructionist view of disease and society and of how the community can, and does, interact with dementia. It should also address how both positive and negative cycles develop. Clinical psychologists are ideally placed to conduct research into these complex areas.

The Society considers there to be a particular need for increased training and provision of psychological approaches across the board from diagnosis, supporting post-diagnosis counselling, and increased meaningful activity, to support for co-morbid mental health conditions. There should be an improved awareness of psychological approaches to the behavioural, emotional and cognitive needs of people with dementia and those of the community who care for them.

To meet this need, there will be a requirement for a significant increase in expertise and of the workforce, including an increase in the attention paid to clinical and counselling psychology training in dementia. Due to current staffing limitations in older peoples' services, there are shortages in clinical psychology placements for older adult services. It is expected that this is also the case in other specialities (e.g. occupational therapy) and may need addressing across professions.

2. *Is there anything that has been missed that would help to ensure high quality care and support for people with dementia and their families?*

The Society recommends that benchmarking and research should include person centred and psychological approaches. These make a significant difference to quality of life and use of medication. If there are no benchmarks there will be little incentive for these matters to be followed up.

3. *What are your priorities for implementation? What can and should be done first?*

1. It is clear that these changes cannot be made without additional funding. There needs to be pump priming and clear, long-term investment for any service to be able to implement change which will be effective and remain so.

2. There are evident areas which could make a fundamental change in the provision and expectation of quality of life of people with dementia. The Society considers that the following should be priorities:-

- dementia friendly environments should be made compulsory in all dementia care environments;
- training and supporting all staff in any environment in which people with dementia are cared for and supporting a change in management of all care and nursing homes and hospitals.

Both of the above would create a fundamental change in the demands on secondary services and would require an increase in the numbers of professionals able to support staff working in dementia care settings.

4. *What should the timetable for implementation be?*

The Society has no suggestion to add in response to this question.

5. *What can you or your organisation do to help implement the recommendations?*

Please see details in other sections.

6. *Does this draft strategy fully address issues of equality and diversity, and the needs of particular groups?*

Yes, but the Society considers that the particular needs of younger people with dementia and those with learning disabilities require further highlighting.

General comments

Do you have any other comments you would like to make in relation to this consultation?

Generally:

The approach and general ideas in the draft strategy are welcomed if effectively implemented. The Society has strong concerns that there will be no additional and long term funding to enable the clear and effective strategies that can make the change required to have a service which provides for the basic long-term psychosocial needs of people with dementia.

As the external reference group highlighted:

“It will not be acceptable to drive up awareness without developing proper responses. It will not be fair to create extra provision if the workforce has no extra skills or knowledge to offer. And whilst there is a huge scope for redirecting current effort that is frequently ineffective or sometimes directly harmful, you will need to find extra investment provided from the centre and from localities for service development”... ..

“Without providing some new resource there is a serious risk that this strategy and implementation plan will not result in the transformational change that we are all aiming for.”

The appendices of the draft strategy highlight that ‘up front’ investment will be needed to enable early intervention, which may have long-term saving. They also highlight the many caveats to savings potential including the need for all elements to be commissioned together for the system changes to work. These acknowledgments of the significant funding required to change current fundamental processes is not explicit enough in the main document.

Given the lack of knowledge, stigma, and discrimination in services, which carries through into funding decisions, this direction is poor. For the final document to have any useful or lasting effect it will need to state significant levels of initial investment and subsequent long term funding. This statement needs to be accompanied by standards, measures of these and a statutory obligation for the standards to be met.

Without significant incentive for PCTs/Trusts to meet the strategy, dementia will continue to be a low priority. Specific guidance to PCTs on how to commission suitable services for younger people with dementia would also be helpful.

The Society considers there to be a clear need for the strategy to emphasise resource implications and to clarify funding.

While the benefits accruing from early assessments and diagnoses are clear, there are also practical and ethical concerns for employment, childcare, driving and insurance arising from early assessments. These issues are frequently overlooked by services and services users. We urge that the strategy considers ethical issues and how they may be addressed in pre- and post-diagnostic counselling.

The research agenda is a crucial element. We urge that the strategy ensures appropriate levels of research funding for small-scale, action research and service development, especially for interventions to mediate the effects of dementia and improve functioning and quality of life.

The Society agrees that families and patients need a care pathway which is easy to access and facilitates both diagnosis and high quality ongoing care. However, we are concerned that, with the advent of the new medications, we have moved away from a holistic approach to caring for the person with dementia and supporting their families. A range of interventions that address the range of biological, psychological and social factors that can be affected must be available and used when appropriate across all stages of the patient "journey".

Specifically:

1. The draft strategy is clear (p.22) that non-dementia work completed by mental health teams should not be affected as a result of the dementia strategy. This point may need particular emphasis for psychologists. For example, psychologists will be essential within dementia services in order to meet NICE guidance on neuropsychological assessment. With the increased focus on dementia, those psychology services that currently have long waiting lists, are under-resourced or have recruitment difficulties, may find that their limited existing psychology provision is expected to provide an increased proportion of their time to dementia work, to the detriment of non-dementia work.
2. With the increased numbers of people receiving an early diagnosis of dementia, there are likely to be repercussions on the demand for non-dementia services within existing primary and secondary mental health services, including those provided by psychologists: e.g. increased referrals for people with early dementia or mild cognitive impairment (MCI) who are depressed. In many secondary mental health teams, psychology is still the most stretched service. The additional money required to top-up existing Community Mental Health Teams for older people (as mentioned on p. 77), will need to include a significant investment in psychological services if the relative shortage of psychological approaches is not to worsen. A serious attempt to include older people in the Improving Access to Psychotherapies programme will also be needed to help address this.
3. It is stated (p. 48) that "commissioners should consider whether this could all be achieved by extending the existing capacity, rather than setting up a separate service". There is a danger here that commissioners may simply commission more of the same types of services they already have. Many Trusts still have a medically biased workforce within older people's services. Clear guidelines are needed for commissioners to ensure that they invest appropriately to develop the predominantly psychosocial aspects of the service that will be required to successfully implement the dementia strategy. The reference (p. 47) to "the effectiveness of old-age psychiatric intervention" implies a very medical model. To succeed with the improvements suggested on pages 47-48 (many of which are psychosocial rather than medical/biological), there needs to be a truly multi-disciplinary, in-reach, mental health service, not managed by psychiatry but working in line with New Ways of Working. If homes are encouraged to refer only to psychiatry, then access to psychosocial services may be limited depending on the attitude of the particular psychiatrist concerned.
4. In relation to the question posed on p.53 of the draft, a priority is that the specialist mental health and liaison services need to be put in place (without disrupting existing mental health services for older people).
5. There is something of an assumption (in question 2, p. 54 "Is there anything that has been missed to help us deliver the National Dementia Strategy?") that services will develop in the multi-disciplinary way outlined in the draft without any accompanying acknowledgement that the medical model currently dominates many dementia

services. Although this is only specific to certain Trusts, without clear guidance in the strategy on this issue, such Trusts are likely to continue with psychology remaining a very small (or missing) part of their teams.

6. The commissioning of memory services for early diagnosis and intervention (outlined in Appendix 4 p. 77) – appears to be based on an average of about 25 hours clinical time for each referral to the service. If it is assumed about 10 hours are taken up to do the initial multi-disciplinary assessment and feedback, this leaves only 15 hours for a year to support/intervene. Once travel, admin, continuing professional development, supervision and liaison time is taken from these 15 hours, it does not leave a great deal to provide support for the individual and their carer. Group interventions may help to overcome this but will not be appropriate for all, and the financial figures seem a little low in order to provide a high quality service. Also, it is not clear whether these figures include the investment required for the liaison and in-reach teams.

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Appendix A: Society Members who Contributed to the Response

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End.