

BENEFITS OF TIMELY DEMENTIA DIAGNOSIS

A REPORT FOR
CONSIDERATION
IN PRIMARY CARE



for

DAA Dementia
Action Alliance
Action Group on Diagnosis and Post-Diagnostic Support



Commissioned in Association with the Department of Health

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PART ONE

I INTRODUCTION

“Action by GPs to boost rates of early dementia diagnosis for patients is of little or at least unproven value, and can have too many negative consequences.” “No, it’s hugely and undeniably valuable.” The tendency has been towards two camps and entrenched positions. Very recently, however, we have seen increasing consensus that: an early/timely diagnosis should be made when requested by patients and carers or when there are clear potential benefits for them... and that working constructively with GPs and supplying more and effective post-diagnostic support for patients and carers is essential. A 5 June 2013 stakeholder’s meeting at the Kings Fund, convened by NHS England and the BMA, showed how strong the potential for professional consensus and effective action has become. Focus points included better post-diagnostic support for patients and carers, information prescriptions, and prospects for prevention. The report of that meeting, “Dementia Consensus” leads our Dossier of literature below and is highly recommended.

THIS PRESENT REPORT SERVES A DUAL PURPOSE. For all stakeholders it provides a snapshot of current views regarding early/timely diagnosis, and literature references of potential value for both appreciating each other’s views and progressing together from common ground. The work in this regard will be **ongoing**, with the Dementia Action Alliance Action Group seeking to facilitate cooperation in making such progress.

FOR GPs AND PRIMARY CARE SPECIFICALLY, our purpose from the outset was to identify and make practical some actions and solutions available now for the benefit of patients and carers. Our challenges were:

- to distil these into a single page for GPs, on the basis that they are time poor - and appreciative of effective prospects stated simply.
- to work directly with GPs on reducing the workload for surgeries, and associated costs, while providing much more effective 24/7 support and empowerment for patients and carers.

Part One of our report derives from our ongoing work and literature reviews - seeking to provide immediate and practical options for GPs and CCGs. In Part One we effectively bypass much of the richness of opinion in the rest of our report, in favour of such practical and immediate wins. In **Part Two** we then go on to present and consider a wide range of stakeholder views (and we highly recommend taking the time to read the “Detailed Contributions to the Debate”). In reporting these views, and in supplying a Dossier of literature and references for both parts One and Two, our purpose is to facilitate further understanding and cooperation within and between stakeholder groups.

2 WIN – WINS FOR GPs AND PATIENTS

A. TAKE A STEP BACK from diagnosis to causes: Dementias are linked to Non-Communicable Diseases including diabetes, coronary heart disease and stroke through common factors and treatment pathways. They share many of the same lifestyle and risk factors including smoking, harmful alcohol levels, high blood pressure, high cholesterol, inactivity and obesity. We can think in terms of prevention or at least mitigation in many cases. Even in most cases of Alzheimer's, vascular lesions are a significant contributing factor. Patient compliance can be highly motivated by the prospect of preventing/mitigating such feared conditions as dementias and strokes.

B. PREVENTION and EARLY DIAGNOSIS/INTERVENTION: The current DES encourages us to case find patients who are exhibiting signs of cognitive impairment (important for stroke/'silent stroke' as well as dementias). This is not the same as a memory tests, as we are assessing frontal lobe (or executive) function. Such cognitive change gives us an early warning system for both stroke and dementias, and is conveniently measurable.

Basic health checks could also become highly productive. Dementias, stroke and other brain diseases have common mechanisms. These, and non-communicable diseases like diabetes and CVD, involve neurological and vascular conditions that most often coexist. We know that stroke and type 2 diabetes can be viewed as being largely preventable if the risk factors that cause them are managed, and we now know that we can at least delay the onset of dementia in these patients just by doing the same thing. Thus behaviour change regarding lifestyle as above, and the managing of major medical risk factors like hypertension and lipid and glycaemia management, can have a real impact upon peoples' lives in terms of prevention or at least the speed at which they develop dementias, including Alzheimer's. Early interventions are also vital in terms of crisis prevention for people with dementias and co-morbidities.

C. DIAGNOSE THEM EARLY AND WISH THEM GOOD LUCK? Treatment options can be limited (particularly for Alzheimer's), and diagnosis too often leads to patients and carers left to pretty much fend for themselves. Where an early diagnosis is patient / carer requested, or can result in potentially helpful medical intervention - including early interventions and management for co-morbidities - the benefit can be clear. In any case the potential psychosocial benefits of early diagnosis can be huge, given a good range of support being made available to patients and carers. To that end the DAA Action Group on Early Diagnosis and Guideposts Trust are supplying GPs with all DAA member highly localised Information Prescriptions, created with and for GPs and community pharmacies. These will provide high-level patient and carer support while reducing GP workloads and costs.

3 EFFECTIVE POST – DIAGNOSTIC SUPPORT FOR GPs AND CCGs

A number of DAA member post-diagnostic support programmes are working to fill the great need for effective support for patients and carers. The DAA Action Group, working with the Guideposts Trust, is combining forces with the membership and with NHS England to help coordinate these efforts - *with a view to synergy rather than conflict and the re-invention of wheels.*

Currently the Action Group are piloting a programme in and with GP surgeries, providing highly localised information prescriptions created with and for GPs and backed by a 24/7 telephone helpline. Phone support is by knowledgeable people who are trained to listen, and not work from a script. A GP issued Information Prescription (GP IP) acts as a portal to provide the appropriate and timely local help of the over 700 Dementia Action Alliance organisations and further support and help resources, including local third sector and statutory. Patients and carers are dependably guided from prescription onwards - with the vital further benefit of ameliorating stress and health damage to carers as well. An empowering essential for GPs and CCGs is that this provision of much-needed support reduces workload and costs, rather than increasing them. Potentials from crisis prevention in terms of both money and people's suffering can be substantial in primary care and for the NHS, including crisis admissions avoidance.

GP IPs enable GPs to be sure that patients and carers have immediate access to and help with comprehensive, local and timely information and support - dealing with one of the biggest problems with early diagnosis. The GP IP and phone line are a proven reality, with the help of the DAA and DH, based on many years of Guideposts Trust effective service delivery and developing cooperation with other highly regarded DAA members. They are also extremely cost effective. Cost levels are not speculative, but based on existing and successful pilot/prototype delivery. External evaluation for further staged rollout will be robust.

This programme scales up to a locally based, coordinated national service. It is inclusive of all DAA members services, allowing people with dementia and carers to be directly involved in providing as well as benefiting from the guidance and solutions.

The DAA Action Group is committed to a 2013-14 initiative to make comprehensive **all-member** information prescribing and post diagnostic support work through and for GPs, CCGs and community pharmacies. The potential savings from crisis prevention from such approaches, in terms of both money and people's suffering, can be enormous per practice, let alone per CCG. Further benefits to the NHS, to patients, and to carers health from crisis prevention and admissions avoidance, are predictable and quantifiable.

PART TWO

4 EARLY DIAGNOSIS: VIEWS OF KEY STAKEHOLDERS

We transition here from GP-specific work to our snapshot of current views regarding early diagnosis. We trust this will have value for primary care and all stakeholders in considering the range of views and progressing together from common ground.

Our starting point for this piece of work was a perception that the debate over the benefits of dementia diagnosis has too often been bogged down in entrenched positions.

'Sceptical' healthcare professionals and others - who often care passionately about improving outcomes for people with dementia - are certainly prepared to agree that there are benefits to be had from accurate and timely diagnosis, but wish to see these thought through and deliverable before they will support the substantial increase in diagnosis rates demanded by the Prime Minister and others. They often see the 'pro' camp as insisting that the case for increasing diagnosis rates as an end in itself is proven, without specifying exactly what that case consists of or how potential benefits of diagnosis can be actualised and delivered to patients, carers, and the nation's health and social care.

On the other hand, many 'believers' accuse their opponents of wilfully ignoring a wealth of evidence for the benefits of early diagnosis, instead focusing solely on the relative paucity of effective interventions. In the absence of a cure, healthcare practitioners often retreat into therapeutic nihilism, say their critics.

The Dementia Action Alliance, together with the Department of Health, decided to try to move the debate along by conducting a detailed examination of the case for early diagnosis, and any potential harm which might follow from a diagnosis.

We proceeded by conducting quantitative surveys of four groups of stakeholders – the member organisations of the Dementia Action Alliance, general practitioners, members of the Royal College of Nursing and members of the British Psychological Society. In total we received 183 responses (78 from the DAA, 47 from the RCN, 33 from the BPS and 25 from the RCGP), containing 864 individual benefits. Many of these were duplicates, in that the same sentiments were expressed in slightly different ways. Following de-duplication, we were left with 25 distinct benefits for people with dementia, four for their families and carers, and four for health and social care professionals, for the health and social care system and for the public at large.

The 25 benefits for people with dementia further fell into six broad categories, ranging from the patient's initial reaction to receiving a diagnosis to their ability to plan issues up to and including the end of their lives.

In addition, we asked the professional groups – RCGP, RCN and BPS – for their views on the possible harm which might result from a diagnosis of dementia. Their answers fell into 10 groups, including an 'other' category.

We believe that this survey has provided a fairly comprehensive examination of the constituent parts of the cases for and against a radical increase in dementia diagnosis rates. It should now be possible to build on our work in considering which elements of the arguments are supported by sound evidence, which are partially substantiated by research and which appear to have little or no foundation at all.

It is striking, for example, that one of the most frequently cited benefits of diagnosis was mental well-being (in the form of adjustment to the fact of having dementia, elimination of other possibilities, better understanding of what you are experiencing and generally reduced anxiety), while the most commonly cited harm that may flow from diagnosis was the exact opposite – increased anxiety, alarm and depression. This area has been relatively well researched, as the qualitative contributions we received demonstrate.

However, some of the other psycho-social benefits of diagnosis, such as the ability to plan and access services, appear to be less well researched and may require further work – especially given their relative importance in terms of the case for diagnosis.

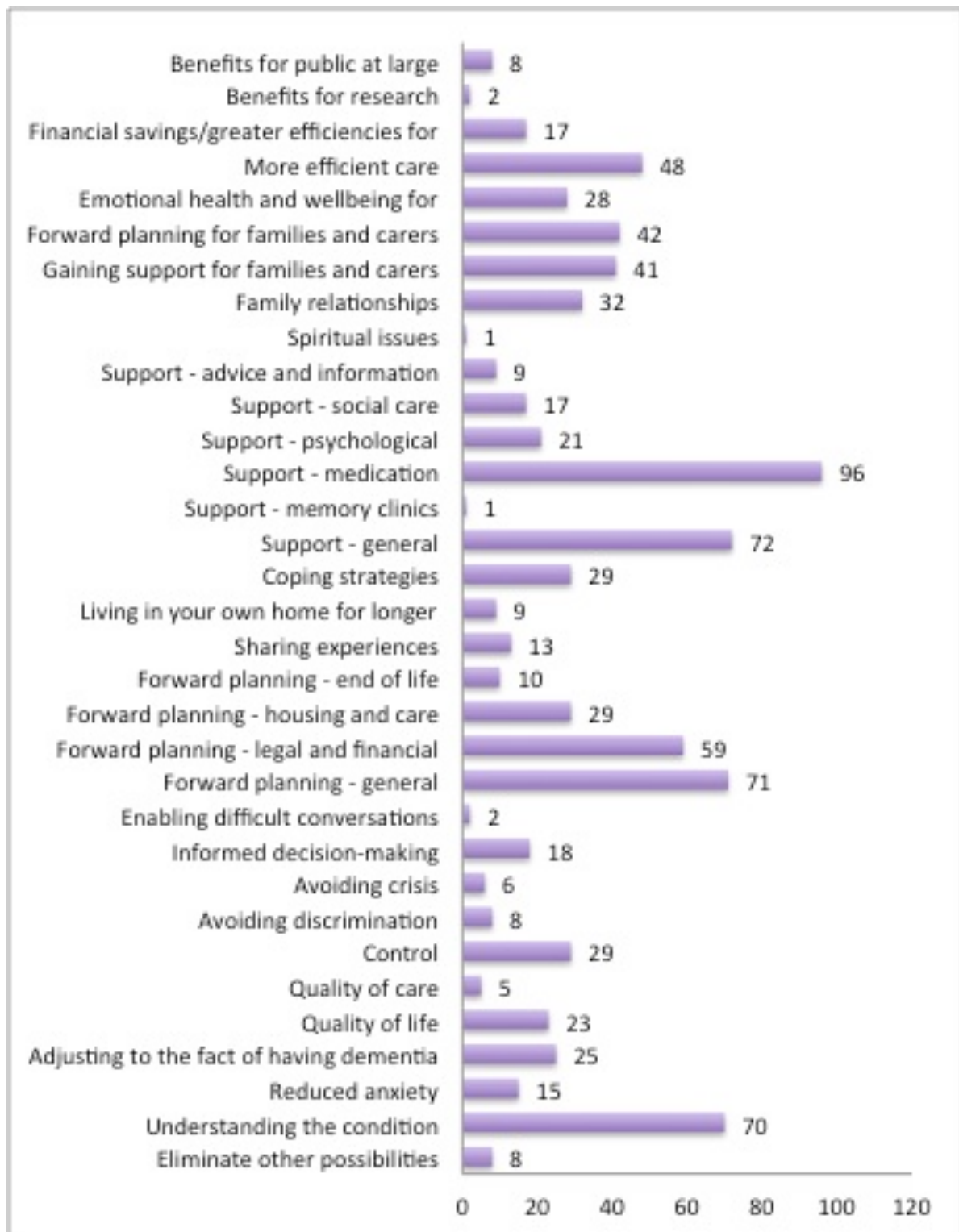
Indeed, while access to medication stands out as the single most important individual benefit claimed in the survey, it appears less important than the ability to plan, to access services and to adjust emotionally and psychologically to the fact of having dementia when the responses are placed in the natural groups. Although the medical profession holds the keys to dementia diagnosis, our survey suggests that the benefits that might be unlocked as a result are not in the main medical at all.

Detailed survey results

A total of 183 responses were received to our consultation in September, October and November 2012. Of these, 78 were from representatives of DAA member organisations and/or individual DAA activists, 47 were from members of the Royal College of Nursing, 33 were from members of the British Psychological Society and 25 were from members of the Royal College of General Practitioners.

Respondents were asked to list all the benefits they knew of which were claimed to follow from a diagnosis of dementia (at any stage – not restricted to early diagnosis). In total the 183 responses included 864 individual claimed benefits. Many of these were duplicated benefits.

The full list of claimed benefits extracted by the DAA Action Group on Diagnosis is as follows:



It's immediately apparent from this list that access to medication and treatment is the biggest single benefit claimed by respondents. However, the benefits break down into a number of simple categories as follows:

Initial response to diagnosis	117
Taking charge	91
Planning for the future	159
Living well with dementia	61
Accessing services	151
Medication	96
Family benefits	143
Benefits for healthcare professionals/system	77

The main area of benefit claimed for dementia diagnosis by our respondents was therefore around planning for the future, closely followed by gaining access to services including social care and specialist psychological support, and the benefits felt by family and friends. The benefits of eliminating other possible causes, understanding the condition and moving out of a state of uncertainty were also pronounced.

This would seem to directly counter what the Royal College of Nursing calls the 'paternalistic' argument against diagnosis. It also challenges the 'therapeutic nihilism' case, which says that since little can be done in terms of effective medical treatment, there's little point in diagnosing dementia.

There were some marked differences in the way various professional groups approached these questions, as the following tables illustrate:

	DAA	BPS	RCN	RCGP	Total
Eliminate other possibilities	1	0	7	0	8
Understanding the condition	36	15	16	3	70
Reduced anxiety	6	5	3	1	15
Adjusting to the fact of having dementia	7	9	4	5	25
Quality of life	12	3	7	1	23
Quality of care	4	0	0	1	5
Control	16	3	8	2	29
Avoiding discrimination	3	3	2	0	8
Avoiding crisis	1	2	1	2	6
Informed decision-making	12	2	4	0	18
Enabling difficult conversations	1	1	0	0	2
Forward planning - general	23	19	20	9	71
Forward planning - legal and financial	12	11	19	7	59
Forward planning - housing and care	14	5	10	0	29
Forward planning - end of life	2	2	2	4	10
Sharing experiences	6	4	3	0	13
Living in your own home for longer	6	0	3	0	9
Coping strategies	16	9	0	4	29
Support - general	28	16	24	4	72
Support - memory clinics	1	0	0	0	1
Support - medication	31	17	35	13	96
Support - psychological	14	4	3	0	21
Support - social care	6	4	3	4	17
Support - advice and information	6	2	1	0	9
Spiritual issues	1	0	0	0	1
Family relationships	15	10	4	3	32
Gaining support for families and carers	18	5	12	6	41
Forward planning for families and carers	18	7	11	6	42
Emotional health and wellbeing for families and carers	13	3	10	2	28
More efficient care	22	11	9	6	48
Financial savings/greater efficiencies for system	13	2	2	0	17
Benefits for research	2	0	0	0	2
Benefits for public at large	4	2	1	1	8
Initial response to diagnosis	49	29	30	9	117
Taking charge	49	14	22	6	91
Planning for the future	51	37	51	20	159
Living well with dementia	38	13	6	4	61
Accessing services	86	26	31	8	151
Medication	31	17	35	13	96
Family benefits	64	25	37	17	143
Benefits for healthcare professionals/system	41	15	12	9	77

The single biggest individual benefit cited by DAA members was the peace of mind that came from understanding the condition. BPS members rated forward planning most highly. RCN members cited access to services - and RCGP members said that medical treatment was the most important benefit of diagnosis.

Once responses had been aggregated, access to services was the most significant area of benefit claimed by DAA members. However, all three groups of healthcare professionals surveyed reported that the ability to plan future care, accommodation, financial and legal affairs and end of life was the most important benefit to be gained – even more so than medical treatment.

We also asked the three groups of healthcare professionals a separate question about the **potential harm** that might flow from diagnosis.

	BPS	RCN	RCGP	Total
Alarm, distress, fear, depression	11	27	18	56
Discrimination, stigma, exclusion, loss of rights	8	19	9	36
Impact on family and friends	2	7	5	14
Loss of control	3	5	3	11
Abuse	1	3	0	4
Mistaken diagnosis	2	3	4	9
No harm	3	2	1	6
Impact on health and social care services	3	2	1	6
Lack of adequate post-diagnostic care	4	1	7	12
Other	1	5	7	13

All three agreed that the negative psychological impact of diagnosis was the greatest potential negative consequence of diagnosis. The social and legal impact of being labelled as someone with dementia also featured strongly in their responses.

5 DETAILED CONTRIBUTIONS TO THE DEBATE

The **RCN** commented that:

There are a number of benefits related to this area that are commonly cited by both organisations and those affected by dementia and, reflected in the published literature.

Firstly there is the potential benefit that early diagnosis can lead to early intervention which may prevent crises and delay the time to admission for residential or institutional care. Secondly, there is a perception that early diagnosis empowers the person affected to articulate their wishes for the future and, whilst retaining capacity, to have discussions about LPOA, end of life care and other associated matters.

Thirdly, there can be earlier access to pharmacological treatments that may offer symptomatic relief and, in some cases, potentially modify the illness and slow down progression. Additionally there can be early access to non-pharmacological interventions aimed at resolution and 'living well' with dementia. Fourthly, there is an emphasis placed upon respecting the autonomy of the person affected and upholding the right to know and the topic could start to translate into a Human Rights discourse.

There are other benefits associated with the person themselves that include having an understanding to explain what is happening and being able to attach a name or label to it. Indeed being given an early diagnosis in a supportive way can reduce levels of stress and anxiety for people with dementia. Similarly being able to understand symptoms, especially changes in mood and behaviour, from a perspective of illness is often cited as helpful within the family. With the right support and information, including access to psychosocial interventions; families/ carers can develop coping strategies and maintain caring roles; which can delay institutionalisation.

One other benefit appears to be that some people who are afforded an early diagnosis are sharing their experiences and contributing positively to raising awareness of the illness. Anecdotally these people report feeling they have a useful role and are able to contribute to society. Other contributions may include taking part in research to support further understanding of the illness and future treatments.

Finally, and from a purely organisational perspective, there is the benefit of being seen to do the right or expected thing. As comparison data and league tables are made available through the Alzheimer's Society it is important that organisations are seen to be performing well or at least no worse than the national average.

In summary the benefits may include:

- receiving information and support at an early stage
- accessing available drug and psychological treatments
- being able to plan better for the future
- supporting the wider family to understand more about the diagnosis and how they can support the person living with dementia
- contributing to raising awareness and having a 'role'
- taking part in/ contributing to research

In response to the question “Are there benefits to not having a diagnosis? Is there potential harm that may follow from diagnosis?” the RCN commented:

A paternalistic view of dementia care will advocate for protecting the person with dementia from harm or unnecessary distress. An alternative view is that paternalism is fuelled by the needs of others who do not know how to respond emotionally or practically after the diagnosis is disclosed. Often the paternalistic discourse will cite that disclosure can lead to depression, emotional catastrophic reactions and even suicide. There is, however, limited evidence to support such claims. Published studies suggest that there are no clinically significant changes in mood following disclosure – see as an example, Carpenter et al, 2008 ‘Reaction to a dementia diagnosis in individuals with Alzheimer’s disease and MCI’ *Journal of American Geriatrics Society* 56(3) 405-412, which concludes that the diagnosis does not prompt a catastrophic emotional reaction in most people and may provide relief once symptoms are explained and understood.

Some evidence exists to suggest that short term mood changes can occur but that, even without intervention, there is a natural resolution – as an example see work cited in ‘The Person with Alzheimer’s Disease’ edited by Phyllis Braudy Harris.

In considering the area of risk one is minded to ask if we can assess or diagnose too early and indeed if it is ethical to do so. In considering this stance it would be important to think about the impact of labelling the person as having a dementia. Such a label is subject to stigma and to malignant social psychology. The diagnosis may itself be seen as equating to mental incapacity thereby minimising the autonomy of the individual. Equally any changes in mood or behaviour may be dismissed as a part of dementia rather than being explored further. Significant emphasis may be placed upon forgetfulness, its itemisation, measurement and monitoring, to the exclusion of the person.

For the person himself there may be a threat to selfhood, a loss of status and role, possibly a significant economic threat and fears of becoming a burden to others. For the nearest person there is the imposition of the role of carer, which may be as stigmatising as labelling their spouse or parent or partner with dementia, and which may serve to define them in the eyes of others.

Carers can adopt the role of ‘carer’ and its associated responsibilities even early on in the illness when the person may need less help. (Garand et al., 2005) This can result in caregiver burden and psychiatric morbidity associated with the role.

For some people who get a diagnosis later in the illness when their capacity to retain and understand the information associated with the condition is affected; there may be need to consider how this is relayed. However this does not rule out the need for a diagnosis and whilst difficulties may arise in relation to sharing diagnosis; benefits in terms of accessing support, information and treatments remain as relevant.

However these potential dis-benefits are more a result of negative or inadequate responses by others to the condition and efforts should be placed on challenging stigma, adapting responses and providing therapeutic support rather than withholding diagnosis due to paternalistic concerns.

In response to the question: ‘For each identified benefit are you aware of evidence that supports this as a benefit of diagnosis? Is there evidence to the contrary?’ the RCN commented:

There is some evidence to support the benefits that have been identified but this is patchy.

In respect of early intervention, there are some good systematic reviews of carer support, the most recent by Elvish et al (2012) which builds on the previous reviews and does produce good evidence that psychological interventions, especially CBT, can be effective in promoting coping in carers.

For people with dementia the evidence of benefit from early intervention is less clear. In respect of pharmacological interventions there is good and solid evidence of benefit but less so for non-pharmacological approaches, the main exception is probably the work from Spector et al (2003) around cognitive stimulation therapy.

There is a body of qualitative work associated with people with dementia using support groups, well-being groups etc but these tend to be isolated small scale evaluations which suggest short term gains, mostly very short term, with no evidence of longer term benefit.

In response to the question ‘If there is no hard evidence is there a moral or business case that should be presented?’ the RCN commented:

Clearly there is a moral case to be made that relates to the right to know and principles of autonomy that will begin the discourse around human rights.

In response to the question: ‘Are there benefits that lack evidence but which merit further research?’ the RCN commented:

Almost all the identified benefits require further research. However, there are some that perhaps have a greater importance.

Firstly the efficacy of early intervention for people with dementia is an area that appears to lack credible and reliable research evidence, especially in relation to long term benefits. As part of this it would be useful to examine which interventions are of most benefit at the point of diagnosis and how these might be best delivered.

Secondly, the impact on specific groups which would include, for example, people with a learning disability who are subsequently diagnosed with a dementia.

Thirdly, it may be of interest to identify whether or not people in the early stages of dementia do actually use the opportunity to plan for the future or not and how this might best be enabled and supported.

The *NHS Confederation* listed the following benefits of dementia diagnosis:

1 Improved outcomes;

2 Care planned more appropriately around individual needs

Evidenced by: The NHS Confederation's 2010 report *Acute awareness: improving hospital care for people with dementia* highlighted research that suggests 50 per cent of people with dementia in general hospitals are not recognised as having dementia. Early identification can play an integral role in ensuring patients' physical and mental wellbeing does not decline during their stay in hospital, provided the appropriate systems are in place to capture important information. A potential tool for this latter purpose, identified in the report, is the Alzheimer's Society's *This is Me* leaflet (which we also referenced in our *Delivering Dignity* report earlier this year).

3 Length of stay in acute care can be reduced and discharge planning improved in hospitals that provide liaison psychiatry services for people diagnosed with dementia.

Evidenced by: The Confederation's Mental Health Network published a briefing in 2012 called *Liaison Psychiatry – the way ahead*, which examined the benefits of liaison psychiatry services in tackling the mental health needs (such as depression, dementia or delirium) of people who are being treated primarily for physical health problems or symptoms. The report says that liaison psychiatry can deliver better health outcomes for patients at a lower cost to the NHS. For example it is possible for a liaison psychiatry service to reduce lengths of stay for older inpatients in particular and generate savings of as much as £5 million a year for a typical 500-bed general hospital.

The report also recommends that:

"every general and acute hospital should have a dedicated inhouse liaison psychiatry service" (with the "scale and nature of which should vary according to local needs").

"long-term development of liaison psychiatry is likely to lie primarily in the expanded provision of community-facing services".

4 Enhancing patient experience and empowerment.

The *World Alzheimer Report 2011*, published by Alzheimer's Disease International, specifically focused on the benefits to be gained from early diagnosis and intervention. It notes that "Early therapeutic interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying institutionalisation."

The previous Government's *National Dementia Strategy* of 2009 pointed to the empowering effect of early diagnosis for people with dementia, plus their families and carers. They can gain increased understanding of the condition, while also being able to make appropriate choices about their care and support needs as early as possible.

5 Releasing savings that could be invested elsewhere to ensure more effective care, e.g. follow-up services, support for an increasing number of carers.

A funding model developed by the London School of Economics for the National Audit

Office in 2007 found that in relation to fractured hip cases alone, "effective identification of patients with dementia as they enter hospital, and more proactive, coordinated management of their care and discharge (provided a suitable discharge destination is available) could produce savings of between £64 million and £102 million a year nationally."

Additional comments:

We think it is also worth highlighting the following areas that are particularly important when examining early dementia diagnosis.

Training for all relevant health and social care staff

The Commission on improving dignity in care, convened by the NHS Confederation, Age UK and the Local Government Association, advocated that all staff who may be involved in the care of people with dementia have the requisite skill set. In their report *Delivering Dignity*, the Commission recommended that "All health and social care staff involved in the care of people who may have dementia need to have the necessary skills to provide them with dignified care, developed through basic training and continuous professional and vocational development in dementia. All care staff must have basic skills in communicating with a person with dementia, including how to demonstrate warmth and kindness".

Impact of potential increased demand on services

Action may need to be taken to ensure capacity within follow-up services is sufficient to effectively manage any increased demand. Care plans will require information, support and resources to be available across the piece if they are to prove of most benefit to patients. This issue was flagged by many respondents to the All-Party Parliamentary Group on Dementia's recent work on *Unlocking Diagnosis*. It will be important to understand the impact of the recently introduced Commissioning for Quality and Innovation (CQUIN) payment for dementia diagnosis.

The National Council for Palliative Care made the following comments:

The National Council for Palliative Care (NCPC) fully supports the drive towards improved dementia diagnosis rates. Articulating the benefits of diagnosis is critical in helping the public and professionals to understand that it is possible to live well with dementia. There are many benefits of diagnosing early, our response focuses on two:

Receiving a diagnosis is a benefit, an end and a right in itself

A lack of awareness, support and services for people with dementia and their families contributes to a “nothing can be done” mentality. That is, an attitude of ‘What use is there in telling the person they have dementia when they’re unlikely to get the full support they need’. Often the intention is kindness: there is a desire not to unnecessarily upset the person and make life more difficult (because of the negative side effects of receiving a diagnosis such as losing one’s driving license, ability to get travel insurance etc). However this attitude fails to recognise the benefit of diagnosis as an end and a right in itself.

People have a right to understand what is causing the changes in mood, behaviour and/or ability to perform tasks commonly experienced in the early stages of dementia. Not having an explanation for such changes is terrifying both for the person experiencing it and for family and friends. There are many stories of couples on the edge of divorce because one partner was acting secretly or suspiciously, leading the other to suspect an affair, and people losing their jobs because they find themselves unable to perform their daily duties. This is a reality thousands of people are living with today, with some people living for months or years before receiving an explanation.

The failure to diagnose 60% of people living with the condition should therefore be viewed as a human rights failure. This would not be tolerated in the case of cancer (as it once was); it should not be tolerated in the case of dementia.

Early diagnosis provides an opportunity to plan for the future

A failure to diagnose deprives people of the window of opportunity to make plans for their future whilst they still have the capacity to do so. Whilst it is not impossible to make plans in the later stages of dementia or deliver what the person ‘probably would have wanted’, it is harder. The progressive nature of dementia and its impact on cognition can be made more tolerable by early planning. This process is formally known as Advance Care Planning (ACP), and involves giving people with dementia an opportunity to think, talk about and record their wishes so that decisions can be made on the basis of their best interests at a future time when they are unable to make or communicate their preferences. This might include making advance decisions to refuse treatment such as cardiopulmonary resuscitation (CPR) in circumstances where this would be ultimately futile and unnecessarily distressing. It might also include applying for Lasting Power of Attorney (LPA) so that a trusted family or friend can make decisions on one’s behalf. People can also express preferences about the day-to-day care and support they might like to receive, for example whether they prefer baths or showers, or to be entertained by having the TV on or music on. Early diagnosis, couple with the right information and support, allows people with dementia the time to think about these important decisions and communicate their wishes with their family and friends in

a relaxed way, rather than decisions being left to the last minute, rushed and based on guesswork. The impact of not knowing someone's wishes affects family and friends too: people often blame themselves long into bereavement for not making the right choices for their loved ones.

NCPC and the Dying Matters coalition have produced a volume of work which helps people to have conversations about the future including the end of life. *Difficult Conversations for dementia* for example, articulates some of the benefits of talking about this early on:

"The thing is, once you've spoken about these things (as hard as it might be), you can put them away and focus on enjoying things"

"I'm happy that Mum's wishes will be carried out and that it's all so comfortable, and that she's comfortable with it too"

"We were prepared for the situation that hit us"

- People with dementia, carers and former carers from *Difficult Conversations for dementia* (NCPC, 2011)

This work showed that more needs to be done to ensure that at the time of diagnosis, GPs and other professionals give people with dementia and their carers information and advice regarding planning for palliative and end of life care. While these discussions may be difficult for a professional to initiate, they are vital to ensure that planning can occur while a person with dementia still has the capacity to express their wishes. NCPC and Dying Matters are running a series of training sessions to help build confidence in GPs to have these difficult conversations. A leaflet called *Time To Talk?* has been developed to support this.

A late diagnosis or delayed information can mean that people with dementia miss out on the opportunity to have some control over their future and death. The impact of this can be profound and far-reaching.

More information can be found in:

- *Difficult Conversations: Making it easier to talk to people with dementia about the end of life* (2011) NCPC
<http://shop.ncpc.org.uk/public/shop/default.aspx?Search=Difficult+Conversations+for+Dementia>
- *Time To Talk? Starting end of life care conversations with people affected by dementia* (2012) Dying Matters coalition
www.dyingmatters.org/sites/default/files/user/Leaflet%2011_WEB.pdf
- *Good Decision-Making – the Mental Capacity Act and End of Life Care: Summary Guidance* (2012) NCPC
<http://shop.ncpc.org.uk/public/shop/default.aspx?Search=Good+Decision-Making>
- *The Power of Partnership: Palliative care in dementia* (2009) NCPC
<http://shop.ncpc.org.uk/public/shop/default.aspx?Search=The+Power+of+Partnership>
- *Out of the Shadows: End of life care for people with dementia* (2009) NCPC
<http://shop.ncpc.org.uk/public/shop/default.aspx?Search=Out+of+the+Shadows>

Alzheimer's Research UK commented that:

Diagnosing dementia is vitally important. It gives patients the opportunity to access treatments, care and support, which can improve thinking skills and quality of life. Several drug and non-drug treatments are effective in mild dementia, and some are more effective when started earlier in the disease (see 1 below for evidence).

Diagnosing dementia also allows people to plan ahead and make choices about their future care, while they have capacity to make such important decisions. It enables them to access treatments and therapies and decide to take part in research if they wish (see 2).

Diagnosing dementia early is also important for research into new treatments. Current treatments cannot slow or halt the progress of Alzheimer's or other dementias. However, several treatments in the pipeline aim to do this¹. Dementia is a progressive disease, getting worse over time. Therefore, it is likely that these future treatments will be most effective early in the disease, when there is least damage to the brain². Early diagnosis is important to identify patients who could take part in clinical trials and benefit from such treatments. It is possible that the point where treatments are most likely to work is as soon as pathology appears, even before dementia symptoms emerge and a diagnosis can be made. More research is needed to address these issues as it is not currently possible to predict which people with pathology will go on to develop dementia³.

Interventions effective in early dementia

Acetylcholinesterase inhibitors are drug treatments licensed to treat mild to moderate dementia. These drugs can improve cognitive skills and functioning⁴.

Cognitive stimulation can also help people with mild to moderate dementia, improving cognitive function⁵.

Support and education for caregivers (including elements of training, support, enhanced coping and respite) can improve caregiver mood and quality of life and delay institutionalisation of the person being cared for⁶.

¹ <http://www.nature.com/nrd/journal/v10/n9/full/nrd3505.html>

² <http://www.ncbi.nlm.nih.gov/pubmed/22133718> and <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2819840/>

³ <http://www.ncbi.nlm.nih.gov/pubmed/22748938>

⁴ Birks J. Cholinesterase inhibitors for Alzheimer's disease. *Cochrane Database Syst Rev* 2009;(1):CD005593.

McShane R, Areosa Sastre A, Minakaran N. Memantine for dementia. *Cochrane Database Syst Rev* 2009;(2):CD003154.

⁵ Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *Br J Psychiatry* 2003; 183:248-254.

Onder G, Zanetti O, Giacobini E, Frisoni GB, Bartorelli L, Carbone G et al. Reality orientation therapy combined with cholinesterase inhibitors in Alzheimer's disease: randomised controlled trial. *Br J Psychiatry* 2005; 187:450-455.

Niu YX, Tan JP, Guan JQ, Zhang ZQ, Wang LN. Cognitive stimulation therapy in the treatment of neuropsychiatric symptoms in Alzheimer's disease: a randomized controlled trial. *Clin Rehabil* 2010; 24(12):1102-1111.

⁶ Olazaran J, Reisberg B, Clare L, Cruz I, Pena-Casanova J, Del ST et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord* 2010; 30(2):161-178.

There is also some evidence that behaviour therapies and support groups can help treat depression in early dementia⁷. It's possible that physical activity⁸ can also help people in the early stages of dementia.

Interventions that more are effective in early dementia include acetylcholinesterase inhibitors. Evidence suggests that taking these drugs earlier, and for longer, may be associated with less cognitive decline and longer survival⁹.

There is also evidence to suggest that early intervention and support for carers may be particularly beneficial in delaying or preventing institutionalisation.¹⁰

More research is needed into the effectiveness of social, psychological and disease modifying treatments for people in early stage dementia.

Planning ahead and making decisions.

Recent research has suggested that while a diagnosis of dementia can be a severe shock, it can also be positive; confirming suspicions, explaining symptoms and allowing people plan for the future¹¹. Other research suggests that both people with mild dementia, as well as their family members and carers, would want to be told the diagnosis¹². It is important to note that the impact of a dementia diagnosis can depend on how it is made¹³.

⁷ Batsch NL, Miller RV. An Assessment of Needs for Serving Individuals Diagnosed With Alzheimer's Disease and Related Dementias in the Early Stages. *Alzheimer's Care Today* 2009; 10(3):140-155.

⁸ Blankevoort CG, van Heuvelen MJ, Boersma F, Luning H, de JJ, Scherder EJ. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. *Dement Geriatr Cogn Disord* 2010; 30(5):392-402.

⁹ Molinuevo JL, Berthier ML, Rami L. Donepezil provides greater benefits in mild compared to moderate Alzheimer's disease: implications for early diagnosis and treatment. *Arch Gerontol Geriatr* 2011; 52(1):18-22.

Rountree SD, Chan W, Pavlik VN, Darby EJ, Siddiqui S, Doody RS. Persistent treatment with cholinesterase inhibitors and/or memantine slows clinical progression of Alzheimer disease. *Alzheimers Res Ther* 2009; 1(2):7.

Rountree S, Pavlik V, Chan W, Doody R. P4-102: Persistent antidementia drug treatment and survival in an Alzheimer's disease (AD) cohort. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 4[4], T698-T699. 1-7-2008.

¹⁰ Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA* 1996; 276(21):1725-1731.

Gaugler JE, Kane RL, Kane RA, Newcomer R. Early community-based service utilization and its effects on institutionalization in dementia caregiving. *Gerontologist* 2005; 45(2):177-185.

¹¹ Connell CM, Boise L, Stuckey JC, Holmes SB, Hudson ML. Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist* 2004; 44(4):500-507.

Derksen E, Vernooij-Dassen M, Gillissen F, Olde RM, Scheltens P. Impact of diagnostic disclosure in dementia on patients and carers: qualitative case series analysis. *Aging Ment Health* 2006; 10(5):525-531.

¹² Pinner G, Bouman WP. Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *Int Psychogeriatr* 2003; 15(3):279-288.

Fahy M, Wald C, Walker Z, Livingston G. Secrets and lies: the dilemma of disclosing the diagnosis to an adult with dementia. *Age Ageing* 2003; 32(4):439-441.

¹³ Lecouturier J, Bamford C, Hughes JC, Francis JJ, Foy R, Johnston M et al. Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Serv Res* 2008; 8:95.

There is little research into the impact of the timing of a diagnosis on disease course and outcomes for the person with dementia and their carers. However, many experts and patient groups suggest that an early diagnosis can bring the following benefits (taken from <http://www.alz.co.uk/research/WorldAlzheimerReport2011ExecutiveSummary.pdf>):

- Optimising current medical management – attention to treatable causes, exacerbating factors, and medication review
- Relief gained from better understanding – validation of concerns, and a framework for understanding the origin and nature of symptoms
- Maximising decision-making autonomy – the chance to make important decisions about the future while still retaining mental capacity
- Access to services – timely access to medical care, advice and support, all of which require a diagnosis
- Risk reduction – safety at home, driving assessments, anticipating and avoiding adverse effects of medication
- Planning for the future – early retirement, financial planning, safety and security issues
- Improving clinical outcomes – slowing or stabilising cognitive and functional decline
- Avoiding or reducing future costs – chiefly through delaying or avoiding transition into a care home
- Diagnosis as a human right – both to have access to an accurate diagnosis, and to be informed of it, or not, according to preference

More research is needed into the effects of early diagnosis on disease course and patient outcomes.

The *Alzheimer's Society* commented that:

Diagnosis rates are currently poor and the government commitment to increase them is welcomed since they do need to be improved. It is estimated that across the UK only 41% of people with dementia receive a diagnosis.¹⁴ Remaining undiagnosed prevents people from gaining access to support and services which are available to them and which will enable them to stay independent for longer. Early intervention is important as both pharmacological and non-pharmacological approaches are more effective when offered early. NICE recommends that both approaches should be offered from the early stages of the illness.

The process of receiving a diagnosis is a means to an end, not an end in itself. It is a first step to getting a comprehensive package of support in place. It is this package, tailored to the individual's needs and circumstances, which will help people to maintain their quality of life and cope with the symptoms of dementia.

If the person with dementia is not signposted to adequate support and information following on from diagnosis then they will not be able to access the full range of benefits outlined above. Those people who do not receive adequate information or support following diagnosis can be left feeling isolated.¹⁵ Given the benefits that can follow from adequate support post-diagnosis, it is important that we continue to work towards not only better diagnosis levels but also better quality diagnosis and support for people with dementia. In addition to appropriate communication of diagnosis and signposting to sources of further information, there is also a need for a shorter diagnosis process including quicker referrals from GPs to memory clinics.

The main advantages from an individual's perspective are:

- Access to medication (where appropriate)
A common misperception is that there is little that can be done to help people with dementia, but actually there are treatments that can help individuals to maintain a good quality of life. An accurate diagnosis can open up access to drug treatments that will slow down the progress of Alzheimer's or that will control the vascular risks for Vascular Dementia.
- Ability to rule out any other (potentially treatable) conditions. Particular conditions that are often confused with dementia are delirium and depression.
- Maintaining people's physical health can help to avoid a decline that could precipitate the need for hospital treatment or residential care.¹⁶
- Access to services and support
There are a number of specific types of services that have the potential to improve the quality of life of people with dementia. Services that enable people to carry on with their interests and hobbies can help people to maintain their abilities.

Individuals with dementia may be able to access services such as:

- Support groups
- Dementia Support Workers/Dementia Advisers
- Social activities
- Access to a social worker.

¹⁴ Alzheimer's Society, *Mapping the Dementia Gap*

¹⁵ APPG, *Unlocking diagnosis*

¹⁶ APPG, *The £20 billion question*

These interventions are more effective the earlier they become available and so Alzheimer's Society would always advocate the earliest diagnosis possible.

Access to benefits such as Attendance Allowance or reduction in council tax payments.

Improved ability to plan for the future.

- Financial matters such as setting up direct debits for payment of bills or establishing appropriate support.
- Legal matters such as putting in place a power of attorney.
- Making decisions about future care provision while they still have the capacity to do so.
- The recognition that they may be less able to adapt to changes in the future can prompt individuals to make the changes to their home now that will enable them to stay independent for longer.
- Allow people to prioritise their life, e.g. do they want to spend more time with their family or go on that holiday of a lifetime while they can.

If the person with dementia is being cared for by a family carer, then interventions which support the person with dementia can also lead to benefits for carers. Caring can be complex and put strain on an individual, but diagnosis can also open up specific benefits for the carer:

- Access to carers assessments
- Information and education specifically for carers
- Day and night respite care.

An All-Party Parliamentary Group inquiry found that diagnosis is a key element in providing cost-effective dementia services. Although dementia costs the UK £23 billion a year, the evidence is that much of this money is spent inefficiently on poor-quality care.¹⁷ Early diagnosis would enable early intervention and investing in services for people with lower levels of need can prevent crises and the need for costly, intensive services, such as beds in acute hospitals.¹⁸ An economic metric published by the Department of Health in 2009 demonstrated the financial benefits of early diagnosis in delaying admission to hospital and to care homes. The cost savings potentially associated with early diagnosis are therefore of benefit to healthcare providers, governments and taxpayers as well as to individuals and their carers.

Accurate diagnosis also has specific benefits for healthcare providers, enabling them to plan their services and train their staff more effectively.

In addition to the benefits outlined above, it is important to remember that people have the right to know what is happening to them. A diagnosis can answer many questions and bring the reassurance of understanding what is happening and where to seek support.

Furthermore, it is important that the capacity and decisions of people with dementia are protected. A diagnosis of dementia can support decision planning. The right to make

¹⁷ APPG, The £20 billion question

¹⁸ APPG, The £20 billion question

choices is enshrined in the Mental Capacity Act and so it is important to get a diagnosis so that the support provided is appropriate. A diagnosis may also offer some protection from discrimination under the Equality Act.

The APPG report found that although there is a growing evidence base on cost-effective interventions in dementia care, this evidence has not been used as effectively as it could be to improve the quality and cost-effectiveness of services.¹⁹ Too much resource is still being put into costly hospital care when community services are of more benefit and are more cost effective. Alzheimer's Society believes that the evidence in favour of early and accurate diagnosis is clear, but that there is still some way to go towards implementing the changes which are required.

¹⁹ APPG, *The £20 billion question*

Reinhard Guss of the *British Psychological Society* commented that:

As some of the below may sound sceptical regarding the current drive towards early diagnosis, it may be helpful to emphasize general support for this direction first, perhaps by quoting Barbara Pointon, who speaks movingly about the “lost years” while Malcolm experienced increasing symptoms, was still relatively able, but mis-diagnosed as ‘stressed’ or ‘depressed’ and when asked about what early diagnosis would have meant to them says “we would have had such a great time, we would have had a ball!”.

Statistical research evidence on the timing of diagnosis in dementia suggests that with early diagnosis costs are reduced as the person, their family and environment adjust to the diagnosis, plan ahead and utilise support in a way that prevents crisis and avoids premature admission into care. While this is true in a statistics based approach, individual differences mean that early diagnosis is not necessarily the right approach for everyone.

Psychologists prefer to talk about timely diagnosis, emphasizing that the timing of the diagnosis has to be right for an individual person. It is during the process of pre-diagnosis counselling that we establish whether receiving a diagnosis is what the person wants at the time and whether for their personality, life circumstances and coping style the diagnosis is going to be helpful to them. [our emphasis]

Clinical Psychologists in Memory Services are often involved in psychological therapies around the edges of Dementia Assessment Services, for example in engaging people who are doubtful about or resistant towards a diagnosis. For example, while earliest possible diagnosis is a clear advantage to people with an information seeking and active coping style, whereas people with more avoidant ways of coping can be caused considerable harm through ill timed diagnosis.

A thorough approach to giving pre-diagnostic information, seeking informed consent and assessing the coping style and abilities of the person safeguard against the risk of adverse reaction to the diagnostic process and diagnosis itself, and help to identify those who will need additional support.

The way a diagnosis is communicated also has a major impact on whether or not it proves to be of benefit or to the detriment of the person with a dementia. In addition to the difficulties with diagnosis that is obfuscated by euphemisms to the point of being incomprehensible to the person with cognitive impairment or delivered in a brutally simplistic manner, the setting and its implications also have an impact: for example when the family is told separately from the person with dementia or the clinician addresses only the relative while the person is in the room.

Early diagnosis in itself therefore is not necessarily helpful – the benefits of early diagnosis, particularly for the large proportion of people with a less actively information seeking coping style, depend on the quality of the aftercare provided. While a large proportion of the population may well be able to benefit with relatively low key and low levels of post-diagnostic input (by dementia advisors, voluntary sector offers such as peer support groups and dementia cafes, etc) there is a significant minority who will require additional and more specialist support in order to adjust to a dementia diagnosis in a way that is helpful in the longer term and prevents additional mental health

problems (typically forms of anxiety and depression, but also OCD or PTSD) developing. In particular people who have had poor parenting or early traumatic experiences and coped by becoming independent and self sufficient, are at risk of adverse reactions to diagnosis, and indeed to the experience of cognitive impairment.

Further benefits of early diagnosis have been demonstrated not only since medication has become available, but a range of psychosocial interventions (for example the work of Aimee Spectre, Bob Woods, Esme Moniz-Cook, Ian A. James, Linda Claire, Georgina Charlesworth) are increasingly well evidenced as at least equally as effective as medication. One of the dangers of the current drive to higher rates of early diagnosis in the context of a resource limited NHS is the shifting of staff and resources to the diagnostic process and away from the provision of aftercare. Many services are already stretched to the point where these evidence base interventions are not available at all, or only to a small percentage of patients.

Many of the post-diagnostic interventions in dementia are based on Neuropsychological thinking and findings, and in the current discussion awareness of the role and function of Neuropsychological assessment and interventions seems to be somewhat overlooked. The earlier a diagnosis is sought in the development of a dementia, the more it will necessarily rely on Neuropsychology. Despite the identification of early genetic markers, of tests for proteins in the cerebrospinal fluid, of increasingly accurate and affordable scans, the corroboration of biomedical and radiological evidence and subjective experience remains the gold standard Neuropsychological assessment.

The way that Neuropsychology is integrated in the diagnostic pathway will enhance or detract from the helpfulness of an early diagnosis. DAA Member and Kent's Dementia Service User Envoy Keith Oliver describes the gradual process of his Neuropsychological assessment, including the feedback sessions and discussions of his performance as essential in his coming to terms with his diagnosis. The assessment of retained skills (besides the assessment of deficits that aid diagnosis) and how best to utilise these for cognitive coping strategies is in itself an intervention that emphasises coping and living well and actively despite cognitive impairments.

In the current climate of changes in the commissioning process, Neuropsychology is often seen as an expensive specialist service, which is only referred to in exceptional circumstances (and apart from the bulk of diagnostic activity), thus losing the benefits described above. There is a danger that early diagnosis becomes confused with the drive to increase the rate of diagnosis. In a situation where many people in moderate to later stages of dementia remain undiagnosed, the diagnosis rate can quite easily be increased by GPs, hospital doctors or specialist nurses providing diagnosis, using simple screening tools which confirm diagnosis in the later stages, while truly early diagnosis will need to rely on Neuropsychology.

Finally, a brief note on Mild Cognitive Impairment (MCI): the earlier a population is seeking diagnosis, the more frequent will there be insufficient severity or evidence for a diagnosis of dementia to be made, and the more often even full Neuropsychological assessment will only serve as a baseline for re-assessment in the future. In these cases the practice of many services is to discharge immediately, with varying arrangements for re-testing and follow-up. In addition, where the boundary is drawn between MCI and actual dementia varies in the practice of individual doctors.

A large proportion of people with MCI will develop more clearly recognizable signs of dementia within two to three years, while living with a high degree of uncertainty, and indeed cognitive impairment. Without specialist support and aftercare for people with MCI we are in danger of wasting opportunities for early interventions and assistance to adjust, and unless we can ensure that an MCI diagnosis is not given as a “kinder” or cheaper alternative to dementia we are in danger of repeating Malcolm and Barbara Poynton’s experience of losing the three years during which they could have “had a ball”.

David Truswell of the Central and NW London NHS Trust commented:

I think that the main benefits are having time to consider the implications of the diagnosis and discuss them in an informed way with relatives, partners and carers. It also offers the opportunity for the person diagnosed to make any plans, complete unfulfilled wishes, and identify any advanced directives they may want to make. It also provides them with time to set up support arrangements that are more attuned to their individual preferences.

As I am particularly concerned with the impact of dementia in Black and Minority Ethnic (BME) communities, I think the challenge of managing the stigma of dementia in these communities make it important that people have as much time as possible to accommodate themselves to the diagnosis and help relatives to understand. For BME communities there may be not only specific cultural practices/ beliefs that need to be accommodated within the care and support needs of the person but families may be scattered across the world with people wanting to make plans to travel to see key relatives while they still have capacity.

Please consider early versus late diagnosis

I think late diagnosis increases carer burden, and the risk of service users accessing emergency services as a result of crisis, usually linked to other health issues whose management is compromised by the undiagnosed dementia, e.g. falls, routine infections, other chronic health co-morbidities not managed effectively due to impact of dementia. Late diagnoses increase the risk that the patient presents in crisis to urgent or emergency care, with existing support systems on the point of breakdown and the a largely unknown medical history at the point of first presentation. With BME patients all this is compounded by cultural alienation.

Please consider the question from doctor, patient and family/carer perspectives.

Doctors are likely to be even more reluctant to diagnose dementia in BME patients because of professional beliefs that BME communities themselves informally socially support such patients and also routine diagnostic instruments may be poorly suited to people who do not have English as a first language.

Patients will minimise the impact of symptoms on their daily lives and be more likely to place themselves at risk (e.g continuing to drive)

Carers and families may not know how to give accurate help and suffer health risks themselves due to stress and lack of support or even may become abusive towards the sufferer.

Please consider if there are any benefits form NOT having an early diagnosis

In the absence of any available information and support on an on-going basis post-diagnosis, then there is case for not diagnosing, assuming this decision is reached on a case by case basis (some people just want to know anyway). As good practice diagnosis should be accompanied by a clear information and support plan that can be reviewed and gradually upgraded as support needs increase over time.

Please consider if there is any potential harm that might follow from a diagnosis

Harm would follow if:

1. The diagnosis was delivered insensitively
2. The professionals failed to ascertain who else apart from the patient needs to know either at the same time as the patient or very soon afterwards
3. No signposting to further advice or support was given

The *Department of Health* commented:

The Government's position on the need for a timely diagnosis of dementia is set out in the Prime Minister's challenge on dementia which states that:

"Surveys show us that people with dementia would like early diagnosis. And we know that with early intervention, and access to the right services and support, people with dementia can continue to live well with dementia for many years."

We believe that people with dementia who do not receive a timely diagnosis are more likely to end up in a crisis situation; are unable to benefit from the type of care and medication that they need; and are more likely to enter residential care earlier in the course of the illness, rather than remaining at home for as long as possible which most people with dementia and their families clearly desire. A timely diagnosis also greatly helps carers in providing them with information and understanding about the condition, how it is likely to progress, and allows them to access the support they need.

While there may always be value in further research in this area, we do not believe that there are any major gaps in evidence that are holding the Department back from a policy perspective. The information available and the research work already undertaken indicates that people with dementia and their carers recognise the value of receiving a timely diagnosis; that they both benefit from the diagnosis in terms of being more able to plan for the future; and that they are able to live better with the condition.

The evidence on the benefits of receiving a timely diagnosis is in our view compelling and is the basis for the action taken by the Department of Health to increase diagnosis rates. This includes a range of measures including:

- the public awareness campaigns that have taken place in recent years, designed to encourage people to seek a diagnosis where they are experiencing memory problems;
- the introduction in April 2013 of the Dementia Commissioning for Quality and Innovation (CQUIN) goal, to include measures of the quality of dementia care in hospital. This has led to over 4,000 people a month being referred for further investigation, for example to a memory service, which will contribute to improving dementia diagnosis rates.
- working with the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP) to assure and improve the quality of memory services for people with memory problems and dementia;
- dementia diagnosis has been prioritised by both the Department of Health through the NHS Mandate and by NHS England, who have set the first ever national ambition to improve dementia diagnosis rates. Our aim is that, by 2015, over two-thirds of people with dementia should have a diagnosis, with appropriate post-diagnosis support; and
- as part of the GP contract for 2013/14, a new Direct Enhanced Service (DES) has been introduced for take up by GPs to reward practices for having a proactive, case finding approach to the assessment of patients who may be showing the early signs of dementia.

The *National Care Forum* commented:

Benefits include:

- 'peace of mind' not intended as a pun...but in the sense that the person now knows what they are dealing with.
- Ability to plan in an informed way with the family
- Make decisions
- Consider what it means financially and if still working
- Consider and determine what support to utilise if available
 - Opportunity to mobilise support
 - Increase understanding
 - Have informed conversations albeit they may be difficult.
 - Assist with decision making

Possible benefits from not having a diagnosis might include:

- Persons choice
- Mental wellbeing could be adversely affected by being informed of the diagnosis

Potential harm that might follow from a diagnosis might include

- Stigma
- Discrimination especially re access to treatment and if of working age
- Emotional wellbeing may be destabilised
- Fragmentation of family if other members are unable to cope

THE WORK BEGUN WITH THIS REPORT IS ONGOING. The DAA Action Group on Diagnosis and Post-Diagnostic Support will continue to focus on areas of potential consensus between stakeholders for effective cooperation and progress. Our intention is to act as enablers for primary care to be aided and supported - in both considering the issues and having immediate and advantageous courses of action for the benefit of all.

7 DOSSIER

Literature To Consider

The following literature references may be of use in considering the logic and evidence base for the range of views in this report - and for progressing together from common ground. Many are additional to the references in the report itself.

NHS England - BMA “Diagnosis Consensus” 5 June 2013 report of stakeholders meeting

http://www.dementiaaction.org.uk/assets/0000/3808/NHS_England_BMA_Diagnosis_Consensus.pdf

ALCOVE European Union Joint Action on Alzheimer’s programme of work on Early Diagnosis and Interventions:

- Final synthesis report http://www.alcove-project.eu/images/pdf/ALCOVE_SYNTHESIS_REPORT_VF.pdf
- Full list of recommendations <http://www.alcove-project.eu/images/alcove-recommendations.pdf>

EVIDEM www.evidem.org.uk

NB. “Dementia diagnosis in primary care: thinking outside the educational box” - Iliffe et al, and vital further relevant content - projects/reports/links

Barnes and Yaffe “Dementia Numbers Prevented 2011”

http://www.dementiaaction.org.uk/assets/0000/3809/Barnes_and_Yaffe.pdf

G8 Camp David 2012

http://www.dementiaaction.org.uk/assets/0000/3810/G8_Camp_David_2012.pdf

Ritchie et al - ‘Preventing Dementia’

http://www.dementiaaction.org.uk/assets/0000/3811/Ritchie_et_al.pdf

PLOS Medicine

Essential work from Martin Prince, Carol Brayne and others

<http://www.plosmedicine.org/search/simple?from=globalSimpleSearch&filter/journals=PLoSMedicine&query=system+change+dementia&x=12&y=12>

Glasgow University Dementia Assessment Report Feb 2013

http://www.dementiaaction.org.uk/assets/0000/3822/Glasgow_University.pdf

Insight Solutions - Understanding Prevalence

http://www.dementiaaction.org.uk/assets/0000/3826/Insight_Solutions.pdf

UKHF Obesity Related Dementia

<http://www.dementiaaction.org.uk/assets/0000/3823/UKHF.pdf>

Cognitive Assessment in Dementia - précis BPS

http://www.dementiaaction.org.uk/assets/0000/3989/Cognitive_assessment_in_dementia_BPS.pdf

BMJ 'Head to Head' Mar 2013

<http://www.dementiaaction.org.uk/assets/0000/3815/BMJ.pdf>

Rasmussen response BMJ Dec 12

http://www.dementiaaction.org.uk/assets/0000/3824/Rasmusen_response_BMJ.pdf

International Innovation - 'A Stroke of Genius' V. Hachinsky

http://www.dementiaaction.org.uk/assets/0000/3817/International_Innovation.pdf

Lancet - 'Preventable Senility' V. Hachinsky

<http://www.dementiaaction.org.uk/assets/0000/3818/Lancet.pdf>

Nuffield Report - 'Reclaiming a Population Health Perspective'

http://www.dementiaaction.org.uk/assets/0000/3819/Nuffield_Report.pdf

Post Diagnostic Support - Faculty of Psychologists

http://www.dementiaaction.org.uk/assets/0000/3825/Faculty_of_Psychologists.pdf

World Alzheimer's Report 2011

http://www.dementiaaction.org.uk/assets/0000/3821/World_Alzheimer_s_Report.pdf

James Lind Alliance - Dementia Priority Setting

www.alzheimers.org.uk/dementiapsp

www.lindalliance.org/DementiaPSP.asp