

Alzheimer's Society response to the Department of Health Personal Care at Home consultation on regulations and guidance

Alzheimer's Society is the leading care and research charity for people with all forms of dementia. We operate through England, Wales and Northern Ireland. There are 570,000 people living with dementia in England and thousands of carers supporting them. Proposals to reform the care and support system are very important to people affected by dementia. As the Government has identified, people with dementia and their families are amongst the hardest hit by the costs of care. Ensuring a more effective care and support system will also help to deliver the National Dementia Strategy for England.

Summary of Alzheimer's Society response

- As the guidance and regulations are currently drawn, few people with dementia will benefit from free personal care at home. We would like the Department of Health to clarify how many people with dementia it expects will benefit.
- Assessment for free personal care should be carer blind. People should not lose out on access to free care or resources because they have the benefit of support from a family carer.
- We would like clarification on whether meeting one of the critical criteria will mean someone is classified as meeting the critical criteria.
- People with dementia may not meet the ADL requirements unless these are changed. We suggest for example splitting the ADL on behaviour management and personal safety.
- People with dementia often need prompting and supervision to meet personal care needs. The need for prompting and supervision should be included in the guidance and regulations as meaning that someone has a need in relation to personal care.
- Assessment needs to reflect fluctuating capacity and ability.
- Food preparation should be included within the ADLs.
- Help with mobility should be included within the ADLs.
- The definition of personal care in Scotland should be adopted, including the amendment on food preparation which appears to have sorted out confusion in Scotland.
- We would welcome clarification as to what is meant by 'significant help'.
- We do not support the right of local authorities to refuse free personal care to people who have refused a reablement package.
- Any guidance on reablement should reference the benefit that can be found for people with dementia, to be consistent with the National Dementia Strategy.
- Assessors will need to understand dementia.
- There should be portability in assessment consistent with proposals for a National Care Service.
- There needs to be clarity on the freedom that can be exercised in making use of a budget for free personal care as part of a personal budget.
- There needs to be an appeals process.
- People in critical and substantial bands should all be reassessed prior to launch of free personal care.

Question 1: Do you agree with the substance of the proposal as set out in the document? If not, why not?

The proposals in the consultation are:

- To introduce free personal care at home for people with the highest needs in England from October 2010. It is intended that this Bill will be the first step to setting up a National Care Service.
- To introduce 'reablement' or intensive support for people who need home care for the first time to help them regain their independence
- £670 million will be made available to fund these two measures.

Overall comments

Alzheimer's Society believes the proposal to introduce free personal care at home with the highest needs is a contribution to the debate on social care. This policy is targeted at a small number of people with dementia and we will need to consider it in light of the proposals contained in the forthcoming White Paper on the future funding and delivery of social care as a whole to understand whether the proposals deliver on the need for quality care at a fair price for people with dementia.

People with dementia are hardest hit by the current system of charging for care because the majority of their needs are classed as 'social care' and because they are the largest users of long term care in care homes. As dementia is a progressive condition, many people will need help with personal care needs, such as help with washing and eating. It is vital that any policy on charging for social care eases the financial burden for people with dementia.

In Phil Hope's Ministerial statement announcing the Bill he said: 'The Bill guarantees free personal care for the 280,000 people-including those with serious dementia or Parkinson's disease-with the highest needs.' We are concerned that the proposed criteria for eligibility for free personal care are a high hurdle for people with dementia in their own homes and that few people with dementia with high level needs will qualify. We are calling on the Department of Health to provide evidence and case studies to show how people with dementia will benefit from the measure and suggest in this response ways to tweak or refine the criteria to make sure that people with dementia can benefit.

We have consulted with people working in Alzheimer's Society services in order to understand whether people with dementia might actually benefit from the proposal. Our response is informed by these experiences.

1) We are concerned that few people with dementia will meet the 'critical' criteria for free personal care because they have a carer.

The consultation proposes that in order to qualify for free personal care at home individuals will have to be assessed as 'critical' within the Fair Access to Care (FACS) assessment bands.

FACs critical band is predominantly concerned with reducing risk to independence or other consequences if needs are not addressed. The

presence of a carer will minimise the range of risks that a person with dementia may face; therefore, many people with dementia living in their own homes with high needs are unlikely to meet the critical FACs criteria.

We believe assessment of critical need must be made on the basis of the individual presenting need, followed by an assessment of which of those needs carers would be willing to meet. It is vital that people with dementia are not excluded from free personal care because they have the support of a carer.

Set out below are examples from the critical criteria and reasons why people with dementia may struggle to meet the criteria if they have a carer:

- It is unlikely that a person's 'life is, or will be threatened' if they live with a carer.
- Critical criteria includes 'when there is, or will be, an inability to carry out vital personal care or domestic routines.' As dementia progresses, many people with dementia are unable to carry out vital personal care and often this is performed by carers. If a carer is carrying out vital personal care, it is likely the person will be assessed as not eligible for free personal care or not deemed at risk.

We are also calling on the Department of Health to clarify whether meeting one of the criteria of critical needs (presuming the requirement for 'significant help' with four or more activities of daily living are met) will be enough for a person to qualify for free personal care at home.

One of the concerns raised by some MPs at the Second Reading of the Bill is that family carers may withdraw from caring if free personal care is introduced. There is no evidence of this happening in Scotland, which has had a policy of free personal care since 2002. Research from the JRF found that the introduction of free personal care has not reduced the level of informal caring. Free personal care at home supports informal carers and helps them provide other forms of care¹.

2. Most people with dementia with critical needs live in care homes and would therefore not be eligible for free personal care

Very few people with dementia without a carer will meet the criteria for free personal care because they will have moved into a care home. Furthermore, people with dementia living in the community with a carer will struggle to meet the criteria for the reasons outlined above unless the assessment is carer blind. The majority of people with dementia in receipt of NHS Continuing Care are living in care homes and, in our experience, people often struggle to get NHS Continuing Care at home often because PCTs say they are unable to provide the service. We are therefore sceptical that people with dementia with the highest needs will benefit from the measure.

¹ David Bell and Alison Bowes (2006) Lessons from the funding of long-term care in Scotland, JRF (<http://www.jrf.org.uk/publications/lessons-funding-long-term-care-scotland>)

3. We are concerned that many people with dementia will not meet the 4 ADLs or meet the critical criteria 'an inability to carry out vital personal care or domestic routines' as described despite having a substantial level of need. We suggest separating behaviour management from ensuring personal safety.

Some of the most challenging and specific problems for people with dementia relate to the ADL on behaviour management and ensuring personal safety. These are factors that often get so problematic that it becomes impossible for the person to remain in their own home. One option would be to separate 'behaviour management' from 'ensuring personal safety'. This would help to make the ADLs more dementia appropriate.

4. Clear reference is needed to the fact that a need exists when someone with dementia cannot complete personal care tasks without prompting and supervision.

Dementia is a complex condition and everyone experiences it differently. Many people with dementia find they can carry out some personal care routines, with varying degrees of difficulty, but only when prompted by care staff or carers. Providing personal care to someone with dementia is often very different to providing care to a frail older person because the person with dementia can easily become confused and distressed and resist essential care. Careful prompting and supervision plays a critical role in the care of many people with dementia. For example, a person may be able to

- swallow medication if reminded
- chew food or drink if it is placed in front of them, even if they are unable to obtain or prepare food themselves
- wash themselves if encouraged and supervised
- maintain continence if they are reminded to use the toilet

Alzheimer's Society believes prompting and supervising needs to be included in the definition of the ADLs and guidance. This is because a person with dementia with higher needs may be able to carry out activities of daily living, such as getting washed or dressed themselves, but only if supervised and prompted.

5. Assessment of the needs of people with dementia must reflect fluctuating capacity and ability.

Because the abilities and mental capacity of a person with dementia will often fluctuate, for example, the ability to get dressed or eat will change from day to day, a degree of flexibility needs to be included in the guidance to ensure accurate and comprehensive assessment of a person's needs over time. It is also vital that carers are involved in the assessment process for free personal care, and the guidance needs to make this clear. Assessors must have the skills required to understand dementia.

Question 2. Is the level of detail proposed for the regulations appropriate? If not, why not?

a.) Comments on definition of free personal care.

The consultation sets out a proposed definition of free personal care in the home. We favour the definition of personal care used in the Community and Health Care Scotland Act 2002 as amended in 2009 in relation to food preparation for use in the regulations (set out in Appendix 1).

In Scotland personal care was defined when free personal care was introduced in 2002, and amended in 2009 to include food preparation. This definition has proved acceptable when defining the limits of what should be provided free of charge. Therefore, it may prove to be a useful definition to establish what care should be provided to those in the critical FACs band in their own homes.

b.) Mismatch between definition of free personal care at home and criteria. The definition of personal care could lead to some confusion because it does not match the six basic categories of ADLs. Furthermore, we would welcome clarification in the regulations on what exactly is meant by 'significant help' with everyday activities. 'Significant' could be interpreted in several ways, for example 'considerable amount' or 'considerable effect.' It could lead to disputes and/or refusal for funding unless better defined.

c.) Food preparation. The description of the ADLs suggests that unless a person needs physical assistance with eating they will not meet that particular ADL. This will exclude many people with dementia because they are more likely to need help with obtaining and preparing food. For example, a person with dementia may be able to eat and drink food if it is placed in front of them and/or with the supervision and prompting from a carer.

d.) Mobility. The definition of personal care in the consultation does not refer to help with mobility, for example helping a person get out of bed or a chair, although it features as one of the activities of daily living. Alzheimer's Society recommends that help with mobility is included as part of the definition of personal care.

e.) Medication. Help with managing and monitoring of medication is included as one of the ADLs, yet it is not included in the proposed definition of personal care. Clarity is required here. Alzheimer's Society is calling for help with managing and monitoring of medication to be included in the definition of personal care, and suggests that the costs of including this will be negligible.

f.) Conditions attached to provision of reablement support.

We are concerned about the proposal for the regulations that councils could refuse free personal care if a person has declined the offer of a reablement package. There may be important reasons why a person may refuse an offer of an intensive support package that need to be considered and it would also prevent individual choice, for example:

- If the individual decided that the package being offered did not meet their needs or was inadequate.
- Concern that the person with dementia may have around perceived strangers coming into their homes for a short period of time.
- A person with dementia might suggest that family members are available to provide intensive support when this may not be the case
- Fluctuating behavioural symptoms may mean that a person with dementia is assessed by the local authority as 'not co-operative' on the particular day of a 'reablement' assessment. This may unfairly act as a barrier to an individual benefiting from free personal care in the future. Dementia is an unpredictable and complex condition.
- The proposal appears against the spirit of the Mental Capacity, e.g. the right to refuse treatment and exercise individual choice over care and support services.

There are a variety of circumstances where people with dementia might benefit from a reablement package. For example, if a person with dementia was living in their own homes satisfactorily but was admitted to hospital following a fall, for example. After leaving hospital a reablement package could be put into place to help the person to adjust to living in their own home again and re-establish old routines. However, people with dementia have in the past been excluded from packages of care because of the misguided view that they would not benefit. The new guidance issued by the Department on intermediate care last year explicitly states that people with dementia must not now be excluded from intermediate care. Evidence suggests that reablement of this kind provides a higher quality of care to people with dementia and has strong potential to deliver efficient use of public funds. We would like to see any of the guidance and communication that develops on reablement specifically talking about the relevance of reablement to people with dementia.²

Alzheimer's Society is calling for:

- DH to establish a clear definition of 're -ablement', which should be included in the regulations.
- Clear guidance that identifies people with dementia as a key group that may benefit from the measure and case studies. We are concerned that people with dementia may be wrongly excluded from reablement because of the erroneous view that they might not benefit.
- The guidance to set out preferred time-frames for councils to put a 'reablement' package in place. We are concerned that there might be lengthy waiting lists for this kind of support.
- Clarity about how people might be able to access it, eg through self referral, GPs or acute hospitals, and re-assurances that they will be enough assessors with the right skills to consider applications.
- Reassurances that people with dementia and their carers will be involved in the assessment process for 'reablement', and this is clearly set out in the guidance. People must be able to exercise individual choice.

² Department of Health. Halfway Home: updated guidance for the NHS and Local Authorities. London 2009; Alzheimer's Society. Counting the Cost. London. 2009

The consultation states that guidance will cover what a reablement package could include, and suggests physiotherapy, occupational therapy and the installation of telecare or adaptations to the home. We would support these suggestions, but also believe that the package could include a support worker. Their role might be to work with the person with dementia to support them to re-establish daily routines and/or put them in touch with voluntary or statutory sector care and support services. We recommend that helping the person prepared food for themselves is included as part of a programme of reablement.

Question 3. Is the balance right between regulations and guidance? If not, why not? Please see comments made in question 2

Question 4. Is there anything that you feel should be in the guidance rather than regulations, or vice versa?

a.) Skills of assessors. Guidance should include the need for assessors to have training and skills to recognise the needs of people with dementia, as a key group that the government has identified should benefit from this measure.

b.) Standardised assessment tool. In general, we endorse the proposals to develop a standardised assessment tool to ensure personal care needs are assessed consistently, and this will be included in the guidance. Alzheimer's Society believes this assessment should also allow for portability. This will mean that people will know that should they move to a different area of the country, the local authority in the new area will recognise the level of need they are assessed as having and will be required to meet those needs, should they choose to move closer to family for example, consistent with the approach being developed for a National Care Service.

c.) Personal budgets. The consultation proposes that the eligible person may receive personal care as part of a personal budget either as services provided by the council or in the form of direct payments. The guidance should seek to clarify that there would be no restriction as to how the personal budget or direct payment could be used as long as personal care needs are met. This would help carers who may be willing to carry out intimate personal care yet would like flexibility to provide other forms of support or address their own needs.

d.) Councils' responsibility for meeting care costs. Alzheimer's Society agrees with the following statement in the consultation for inclusion in the guidance: 'Councils will need to retain the flexibility to meet care costs in excess of any indicative amount or range in cases where the person's assessed personal care needs cannot be met within it. There is a statutory duty to meet the assessed care needs of individuals, though in certain cases, a care home may be the only option for meeting these.'

However, we would argue that this should be in regulations rather than guidance to ensure that it happens. 'Must retain' would be more appropriate than 'will need to retain'.

Question 5. Has anything been omitted from this document that should be included in either the regulations or the guidance?

a.) The guidance must set out the appeals process for those people refused funding. We understand that this will be via the local complaints process. Furthermore, the Local Government Ombudsman must have the capacity to deal with possible disputes.

b.) Definition of free personal care. The proposed definition of free personal care excludes food preparation, medication management and mobility (such as through using a hoist to help a person out of bed or a chair). This needs to be clear in the guidance and to potential beneficiaries of the policy who may expect free personal care to include these elements.

Question 6: Which of the three options do you feel would be most appropriate for allocating the amount needed for personal care needs to eligible individuals?

Three ways of allocating budgets to local authorities to deliver free personal care at home are suggested in the consultation document:

1. Indicative budgets could be set by the Department of Health based on average costs of providing a service at a set amount
2. Indicative budgets could be set by the Department of Health but within a range to reflect varying costs around the country
3. Councils could assess the costs of each individual.

Alzheimer's Society favours option 3, but would support the view that there needs to be recognition in the funding formula that there are very different costs in different areas of the country.

Question 7: Do you have any further comments on the allocation of the amount needed for personal care needs to eligible individuals?

No further comments.

Question 8: Do you have any comments on the aspects of implementation outlined in the document?

No further comments.

Question 9: In particular, do you have comments around any level of retrospection?

Key points in the consultation:

- Before implementation date of 1 October, councils may want to:
- Identify those persons in the critical band of FACS who are already receiving free personal care, those who may benefit from intensive support and those who might qualify for free personal care.

Alzheimer's Society is calling for:

- Local authorities to reassess all those people in both the 'substantial' and 'critical' bands to establish whether they will qualify for free personal care. This should commence significantly in advance of the implementation date.

Question 10: Do you have any comments on the collection of new data and its relation to existing information.

In light of the fact the government has identified people with dementia as key beneficiaries of the Bill, it is important data is collected on the numbers of people with different conditions including people with dementia from the implementation date.

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Appendix 1:

The definition of personal care used in the Community and Health Care Scotland Act 2002

1 As regards the personal hygiene of the person cared for—

- (a) shaving;
- (b) cleaning teeth (whether or not they are artificial) by means of a brush or dental floss and (in the case of artificial teeth) by means of soaking;
- (c) providing assistance in rinsing the mouth;
- (d) keeping finger nails and toe nails trimmed;
- (e) assisting the person with going to the toilet or with using a bedpan or other receptacle;
- (f) where the person is fitted with a catheter or stoma, providing such assistance as is requisite to ensure cleanliness and that the skin is kept in a favourable hygienic condition;
- (g) where the person is incontinent—
 - (i) the consequential making of the person's bed and consequential changing and laundering of the person's bedding and clothing; and
 - (ii) caring for the person's skin to ensure that it is not adversely affected.

2 As regards eating requirements, the preparation of, or the provision of any assistance with the preparation of, the person's food including (without prejudice to that generality)—

- (a) defrosting, washing, peeling, cutting, chopping, pureeing, mixing or combining, cooking, heating or re-heating, or otherwise preparing food or ingredients;
- (b) cooking, heating or re-heating pre-prepared fresh or frozen food;
- (c) portioning or serving food;
- (d) cutting up, pureeing or otherwise processing food to assist with eating it;
- (e) advising on food preparation; and
- (f) assisting in the fulfilment of special dietary needs,
 - but not the supply of food (whether in the form of a pre-prepared meal or ingredients for a meal) to, or the obtaining of food for, the person, or the preparation of food prior to the point of supply to the person.”.

3 If the person is immobile or substantially immobile, dealing with the problems of that immobility.

4 If the person requires medical treatment, assisting with medication, as for example by—

- (a) applying creams or lotions;
- (b) administering eye drops;
- (c) applying dressings in cases where this can be done without the physical involvement of a registered nurse or of a medical practitioner;
- (d) assisting with the administration of oxygen as part of a course of therapy.

5 With regard to the person's general well-being—

- (a) assisting with getting dressed;
- (b) assisting with surgical appliances, prosthesis and mechanical and manual equipment;
- (c) assisting with getting up and with going to bed;
- (d) the provision of devices to help memory and of safety devices;
- (e) behaviour management and psychological support.