

From:- Tony Alexander, Alzheimer's Society,

To:- The Petitions Committee, Welsh Assembly, Cardiff

Petition :- P-04-456 Dementia – This Could Happen To You

1 The Alzheimer's Society provides various advisory services in England and Wales for patients living with dementia (not only Alzheimer's disease) and their families. One of these services is assisting families whose relatives have been refused NHS Continuing Healthcare. The writer is one of seven voluntary advisers providing this free assistance.

2 The assessment process is complicated. This is a simplified explanation. The writer is happy to provide a more detailed explanation to the Committee if it considers this would assist.

3 To qualify for funding the patient must have what is termed a Primary Health Need which is established by considering the patient's needs level across twelve criteria (called domains). The NHS guidance provides that if there is a Priority need level in any one of those domains, or two Severe needs levels, then that would probably indicate eligibility. If the patient has

- (a) one Severe need level and needs levels in other domains, or
- (b) a number of domains with High and or Moderate needs levels

then this may also indicate eligibility.

4 Once the needs levels for the twelve domains have been assessed then further considerations are made in relation to the circumstances of the patient and the interaction of those needs to consider the nature, intensity complexity and unpredictability of the patient's condition before determining eligibility.

5 Please see the attached spreadsheet showing the assessments for 66 patients (62 English and 4 Welsh) over the period from March 2012 to February 2013. These would all have been refused NHS CHC in the first instance. These patients would typically be suffering from moderate to severe dementia, with little or no short or long term memory. As dementia progresses, patients cognition deteriorates and their needs for this domain increases. This is reflected in that 44 of these patients (i.e. two thirds) had Severe cognition needs levels. Eleven had High needs and these include the four patients from Wales where the maximum needs level for the cognition domain is High.

6 Applying the guidance referred to in Para 3 above to any patient it is apparent that if there is a needs level of Severe for any domain, then it increases the chance of that patient being found eligible for NHS CHC. As the maximum needs level for Cognition in Wales is High, it means that patients in Wales are less likely to qualify than their English counterparts where the maximum is Severe.

5 It might be thought that as the maximum needs levels in the Welsh assessment system contain more Severses than the English system that this would mean that Welsh dementia patients were in a better overall position as they had a better chance of being assessed with Severe needs levels on those other domains where there is a maximum of Severe in Wales and only High in England. However in practice this is not the case as can be seen from the spreadsheet. Cognition is the one domain where, because of the nature of the condition, it is certain that dementia patients will attain maximum needs levels as the disease progresses. The consequence of this anomaly between the Welsh and English assessment systems is that patients with dementia in Wales are discriminated against insofar as eligibility for NHS Continuing Healthcare funding.

6 There is another inhibiting factor affecting patients in both England and Wales, which is that assessors in the NHS believe that as the disease progresses the patient's psychological and emotional needs (one of the other domains considered in an assessment) actually decrease. As

far as the writer is aware there is no medical research as authority for this belief, but there is research to the contrary. As a result of this belief assessors frequently reduce the needs level for this domain where paradoxically the maximum level in Wales is Severe and is High in England.

7 It is a well known fact that in these times of austerity that the Health Service is under severe pressure to reduce costs. NHS CHC is a soft target and although budgetary constraints are not supposed to influence eligibility, there is anecdotal evidence to indicate that Boards apply a rationing policy. This is indirectly evidenced by the attached spreadsheet from which it can be seen that all these patients were refused CHC in the first instance even though all of them had either one severe needs level or in the eleven cases where there were no severe needs, then a number of domains with Highs and Moderates, which according to the guidelines summarised in Para 3 above would also indicate possible eligibility. In other words, unless a patient has one Priority or two Severes then the chances of obtaining funding at first instance is limited.

Domain Scores

	Behaviour	Cognition	Psychological & Emotional	Communication	Mobility	Nutrition	Continenence	Skin	Breathing	Drugs	ASC	Other
1	H	S	H	H	H	L	H	H	L	M	N	N
2	N	S	M	H	H	H	M	H	L	L	L	N
3	M	S	M	H	H	H	M	M	H	M	L	N
4	S	S	L	M	N	L	M	M	N	M	N	N
5	H	H	L	M	N	L	L	L	N	H	N	N
6	S	S	H	N	L	H	L	N	N	M	N	N
7	N	S	H	H	H	M	M	M	N	M	L	N
8	M	S	L	H	H	H	M	M	N	M	L	N
9	H	S	L	M	H	L	M	L	N	H	L	N
10	S	S	M	H	H	H	M	M	N	S	N	N
11	S	S	M	M	H	H	M	M	N	H	N	N
12	N	S	L	H	H	H	M	M	N	H	M	N
13	S	S	M	M	L	L	L	N	N	M	N	N
14	S	S	M	H	H	H	M	M	L	M	N	N
15	N	S	L	M	M	L	M	M	N	L	N	N
16	H	S	M	M	L	H	M	N	N	M	M	N
17	H	S	M	M	H	H	M	M	N	M	N	N
18	N	S	N	H	H	S	H	M	L	P	N	N
19	S	S	L	H	N	L	M	N	N	H	N	N
20	M	S	H	H	N	L	H	N	N	N	N	N
21	M	S	L	M	H	H	M	M	N	L	M	N
22	H	S	M	M	H	L	M	M	N	H	L	N
23	S	S	M	M	L	L	M	M	N	M	N	N
24	N	M	H	M	H	L	L	M	N	M	N	N
25	H	S	M	H	H	L	H	H	N	L	N	N
26	M	S	H	H	H	H	M	M	N	M	M	N
27	L	S	L	H	M	H	M	M	M	H	L	N
28	M	S	M	H	N	H	M	M	N	M	H	N
29	L	S	L	H	H	H	M	M	L	H	N	N
30	H	S	M	H	H	H	M	M	N	L	N	N
31	S	H	M	L	N	N	L	L	N	H	L	N
32	L	S	L	H	H	H	M	M	L	H	H	N
33	S	S	M	H	H	L	M	M	N	L	N	N
34	S	S	H	M	H	L	M	L	N	H	L	N
35	M	S	H	H	H	M	M	M	N	H	N	H
36	H	S	M	H	H	H	H	M	N	L	N	H
37	M	S	L	H	H	H	M	M	N	M	L	N
38	L	S	H	M	H	H	M	M	N	H	L	N
39	S	S	H	H	H	M	M	M	L	H	H	N
40	H	S	M	H	H	H	M	M	L	M	L	M
41	S	S	H	L	H	M	M	M	N	M	N	N
42	L	S	L	H	H	H	M	M	N	H	H	N
43	M	H	H	M	H	H	M	S	N	S	L	N
44	N	S	M	H	H	M	M	M	N	L	L	N
45	N	S	N	H	M	L	M	L	N	N	N	N
46	H	H	L	L	L	L	L	L	N	L	N	N
47	L	H	L	M	H	H	M	M	N	L	L	N
48	N	H	L	M	M	L	M	M	N	H	N	N
49	N	S	N	H	H	L	M	L	N	L	N	N
50	L	S	L	H	M	L	M	M	N	M	N	N
51	H	S	L	H	H	L	M	M	N	M	N	N
52	M	S	M	H	H	L	M	M	N	L	N	N
53	M	S	H	H	H	M	M	N	M	N	N	N
54	H	S	L	H	N	L	L	L	N	M	N	N
55	M	S	M	M	M	L	M	M	N	M	N	N
56	M	H	M	H	H	M	M	M	L	H	N	N
57	M	S	M	H	M	M	L	L	N	L	N	N
58	H	H	M	L	L	L	M	M	N	M	N	N
59	L	S	L	H	H	H	M	M	N	M	L	N
60	M	S	H	H	H	M	M	M	N	M	N	N
61	H	S	L	H	M	M	M	M	N	M	N	N
62	M	S	M	H	H	H	M	M	N	M	M	N
63	M	H	H	H	H	M	M	M	L	M	N	N
64	M	H	L	H	H	L	M	M	N	M	N	N
65	H	S	H	H	N	L	L	M	N	M	N	S
66	N	H	N	H	H	H	M	M	N	M	N	L