

The Debenham Project

(Dementia - Caring for the Carers)

Summary: This study estimates the prevalence and growth of Dementia in Debenham and its nearby villages. It concludes that, currently, there are likely to be just under 70 people with the illness with about 2/3 being cared for in the community and 1/3 in some form of residential care. The overall figure is expected to rise to 110 by 2025, and to 150 by 2035.

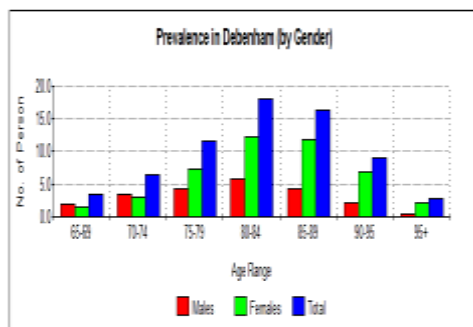
A major requirement for any project is to establish the potential market for its services. In this case this means trying to establish how many people in the Debenham area have Dementia and the variation in terms of age, gender, degrees of symptoms and the nature of their care. There are no accurate statistics for a variety of reasons:

1. Accurate and early diagnosis is difficult.
2. There is a common fear of seeking a diagnosis and a denial of symptoms until the illness is well established.
3. The mechanism for collecting statistics is patchy and often variable in quality.
4. Dementia is often misdiagnosed as depression and vice-versa or recorded as confusion in the presence of other ailments.
5. The proportion of carers of people with Dementia who register their situation with the GP practice and/or social services is believed to be very low.

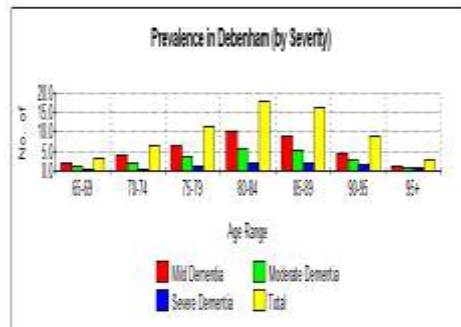
The net result is that official statistics generally heavily understate the scale of the problem. However, there have been a number of studies which have collected quantitative evidence from which estimates of the prevalence of dementia in the UK population have been made**. These have been carefully examined and their results combined to provide the best possible estimates for the UK as a whole, and for regional variations [1]. These have been widely accepted by Government [2], Local Authorities [3], and other agencies [4] for the purposes of developing strategies and resource plans .

Broadly, and on a national scale, about 1.1% of the population has Dementia, and although there is a significant number of people with early-onset Dementia the vast majority fall within the 65+ years category. The prevalence of the illness rises rapidly with age to the level of almost 1 in 3 in the 90+ age group. Approximately 2/3 of those with Dementia are cared for in private homes, usually by close relatives and friends. The number of people with Dementia in residential care rises significantly beyond the 85-90 year age group as does the proportion with severe symptoms. The prevalence of Dementia is expected to increase by as much as 40% by 2025 [1].

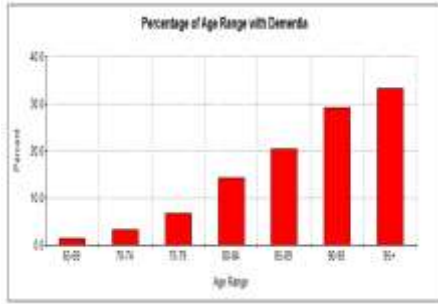
In order to plan the provision of individual services and activities and to determine the need for long term facilities such as Day, Residential and Nursing care we need to estimate the prevalence of Dementia, and its growth in local terms i.e. actual numbers. Using the above national estimates and projections, together with local census [5], age distribution [6] and population growth data [7], the following figures have been produced. They provide the expected number of persons with Dementia both as totals and as subsets. The figures are adjusted to 2010 unless otherwise stated.



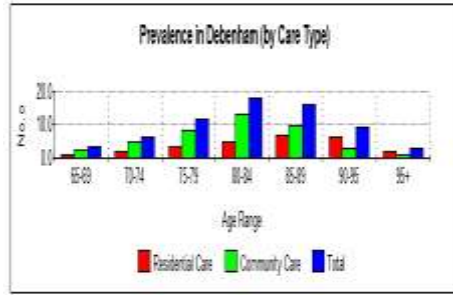
Total: 68; Males: 23; Females: 45
Figure 1. Prevalence by Gender



Total: 68; Mild: 37; Moderate: 22; Severe: 8
Figure 2. Prevalence by Severity



Proportion of 65+age group: 21%
Figure 3. Percentage within Age Group



Total: 68; Residential: 25; Community: 42
Figure 4. Prevalence by Care Type

For the purposes of this study the catchment has been assumed to be Debenham and its surrounding villages within a radius of 3 miles. This sets the current 'local' population at approximately 4500 of which about 2400 are resident in Debenham itself. An alternative approach is to use the catchment area of the High School which would increase the 'local' population to about 6500. NB: This would require all estimates of the 'local' prevalence of Dementia to be increased pro rata.

It is estimated that in Debenham and it's immediate environment there are about 68 people with Dementia of which about 2/3 are women. In terms of age group, the numbers peak around the mid eighties, but the proportion with Dementia in any age group continues to rise exponentially. The reason for the fall off of actual numbers lies in the rapid increase in mortality beyond the age of 85 [1]. As expected the severity of symptoms increases with age. About 42 out of the total number of persons with Dementia are cared for in independent private households within the community whilst the remainder (25) are cared for in residential or nursing care homes. Beyond the age of 90 the dominant type of care is residential/nursing. This is due to the difficulty of caring for someone as their symptoms become more severe combined with the increasing likelihood that their primary carer dies before them [1].

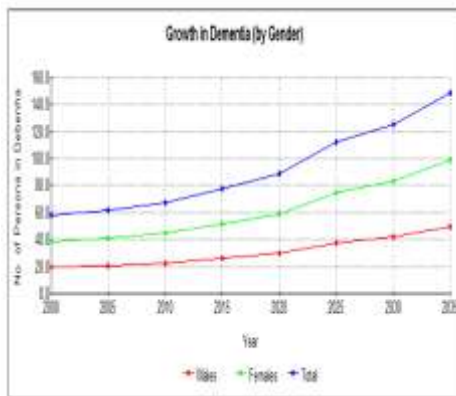


Figure 5. Growth by Gender

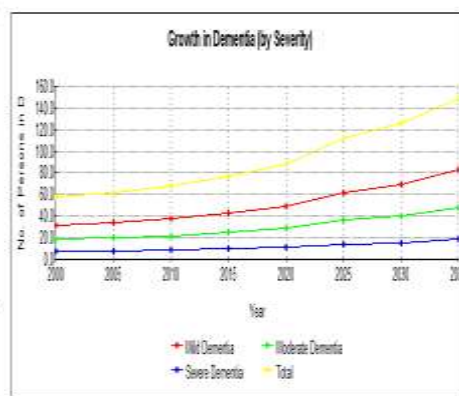


Figure 6. Growth by Severity

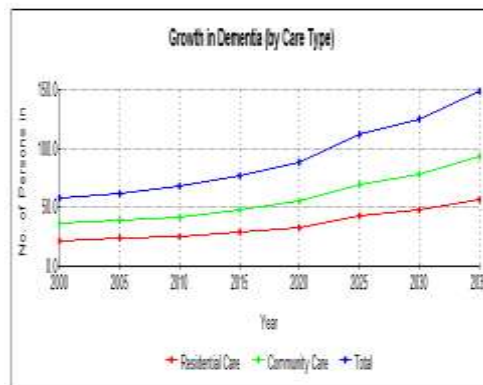


Figure 7. Growth by Care Type

The population has been predicted to grow by roughly 0.6% pa [8] but with improvements in mortality the percentage that are over the age of 65 is rising steadily through 20%. In Suffolk, the rate of increase is likely to be significantly greater - estimated to reach 25% by 2021 [9] (this has not been factored into these estimates). However, the key aspect is that we are going to be living to much older ages - living into our 90s is becoming commonplace! Because of the long and progressive nature of Dementia and the exponential incidence with age (Figure 3.) it is estimated that the total prevalence of Dementia in the over 65s will increase by 38% by 2022 and by 154% by 2042[1]. These would be extremely speculative figures were they based purely on statistical extrapolation. However, there are very sound physiological and demographic reasons to take such relatively large increases seriously. The only chance of reducing the dominating prevalence of Dementia lies in delaying its onset, reducing its rate of progression and finding a cure.

Without any major change in the prevention and treatment of the illness the Debenham catchment area will have to care for a total of about 90 people with Dementia by the year 2020, 110 by 2025 and 150 by 2035. This does not take into account any differential expansion of the elderly population [9] because of our rural nature. The analysis suggests that approximately 40% will require residential, secure or full nursing care.

Finally, levels of early onset Dementia need estimating. This is important by virtue of the extremely long period for which care will be needed. The National Study separates early and late onset Dementia and suggests that the prevalence of early onset is about 0.02% [1] Which would indicate that there may be 1 or 2 with the condition in the Debenham area. However the study also states that this is very likely to understate the situation by as much as 3 times. If this factor is applied and the prevalence with age group for both early and late onset are set side by side it appears that both may be part of the same distribution. Thus for the purposes of planning we should not draw any significant distinction between the two forms of the illness.

** NB: This analysis is based upon the best scientific and epidemiological peer reviewed studies available, collected and analysed by the foremost experts in the field. The studies have been compared and collated and then subjected to Delphic review in order to come to the best possible consensus about the current and future prevalence of Dementia [1]. However, it remains an estimate which is based on limited (compared, say, with Cancer) statistical data. Therefore, we should be careful not to assume an accuracy which the use of detailed numbers and graphical presentation often suggests. The general levels and the trends are almost certainly of the right order but there remain significant areas of uncertainty. The main area lies in diagnosis - 1. it seems likely that there is a systemic fear of acknowledging the illness, so diagnosis is unlikely to be sought until symptoms have become obvious and 2. it is routinely reported that when symptoms are mild or the person with Dementia presents well in the consultations, specialists fail to adequately take into account the evidence of the carers. The net result is that these estimates understate the prevalence of Dementia in its early stages. It may also be the case that, especially in rural areas, family carers are reluctant to seek help out of family loyalty and independence.

1. Dementia UK, Knapp M & Prince M, Alzheimer's Society 2007
2. The National Dementia Strategy, Bannerjee S & Owen J, Department of Health 2009
3. Living With Dementia, Suffolk County Council 2009
4. Respect for Dementia Strategy, Suffolk Mental Health Trust 2009
5. Office for National Statistics, www.statistics.gov.uk 2009
6. Resident Population Estimates for Suffolk, Suffolk County Council 2007
7. Resident Population Statistics for Mid-Suffolk, Office for National Statistics, www.statistics.gov.uk
8. Estimates of Total Population of Areas in Suffolk, Suffolk County Council 2005
9. Projected Changes in the Population, Anglia University, Suffolk County Council 2008