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Introduction.

One hundred and twenty-six cases were seen for the study and followed up, and a brief clinical vignette is given on each in the following section of the Appendix. When analysing the data for the results, the individual stories are lost, and this chapter attempts to regain a sense of the subjects having real lives. The effects of the illness on the subjects and families is also highlighted.

There is a format to try to orientate the reader through each case. No identifying features have been included, to keep the cases anonymous. The onset and presenting features are briefly described, together with any relevant past medical details or points of interest. The clinical case note diagnosis is then given. Interestingly in the case notes, this hardly ever included the term presenile. A brief resume of the individual at the first assessment is given next, including any relevant medication the subject was on. The result of any available scan is given, and the study DSM3R diagnosis stated. The decision as to the grouping given, is not discussed in detail. Sometimes this simplification can appear to ignore obvious risk factors. Any relevant risk factors, not already mentioned, are described. The course of the illness during the next year, and the findings at the second assessment are then given. No details of individual assessment scores are provided here.
First began to dement aged about 56 years old, and was referred aged about 63. The family noticed he was anxious and needed time off work. He appeared to be less caring, and his driving deteriorated. There was a rapid worsening of his memory and intellect, and he began to drink heavily.

The clinical diagnosis was of an atypical dementia.

At the time of the first assessment he was 65 years old and in a nursing home. He presented as a large man, who was unable to walk without support, and did so with a markedly stiffened gait. He would regularly burst into tears with no obvious precipitant.

He had been admitted to the nursing home about 2 years before (in 1992), as his wife suffered from severe rheumatoid arthritis and was unable to cope with the heavy work involved in caring for him. He had been doubly incontinent and wandering at that time.

A previous CT scan result, date unknown, showed atrophy, and was compatible with a vascular aetiology for dementia.

He fulfilled the DSM3R criteria for severe Alzheimer's dementia, McKhann possible.

Risk factors included: a family history of dementia in his mother. The heavy alcohol consumption early in the course of the illness was another notable feature, with his previous consumption estimated at about 10 units per day, for 6 days a week over 29 years.
Subsequently over the next 15 months between the two assessments, there were small changes suggestive of gradual ongoing deterioration, but nothing of a severe nature.

**ma2.**

First began to dement aged about 55 years old. She lived with her brother and sister in appalling circumstances. Her brother had a learning disability, and her sister suffered from a paranoid illness, with additional motor problems. She was said to have had a low premorbid IQ.

The diagnosis was of presenile-onset dementia, unspecified type.

At the time of the first assessment she was 60 years old and in long-term hospital care. She presented as a very small, frail lady, occasionally repeating a phrase such as "where are we?" and apparently unable to cooperate with any requests. She had a fixed, staring expression, with open mouth, tending to hold her sides as she walked, and pacing constantly on the ward.

The illness had initially been characterised by frontal signs, especially disinhibition, long- and short-term memory deficits, and parietal signs.

A CT scan done in October 1988, revealed atrophy.

She fulfilled the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors included the family history of unusual presentations in the siblings, as noted.

Subsequently in the year after her first assessment, she was felt to be depressed, and there was a general deterioration in her health, such that by the end of the year she was profoundly
demented and doubly incontinent. She died of bronchopneumonia in November 1994, and a PM was performed. The histological features were hard to interpret, but were felt to indicate a variant of Pick's, called progressive subcortical gliosis. See Hulette and Crain (1992) and Verity and Wechsler (1987).

aa3.

First began to dement at the age of about 51 years old. The family noticed that after an incident of possible head injury in 1984, she was more confused and there was subsequently a gradual increase in her difficulties in communicating. She had a congenital bilateral deafness. Her family felt she had suffered much stress premorbidly.

The clinical diagnosis, made when she was 58 years old, was of an atypical dementia.

At the time of the first assessment, she was 60 years old, and presented as a quiet, docile, gentle woman with a contented manner, severe hearing problems and severe aphasia. At that time she was living with her son, with intermittent respite care. He was under great stress, with disturbed sleep because of her wandering, and problems because of taps and cookers being left on.

In December 1991, a CT scan was reported as showing atrophy.

She met the criteria for DSM3R moderate Alzheimer's dementia, McKhann possible.

Risk factors included a possible head injury.

She was re-assessed 15 months later, in a nursing home. She appeared cheerful and active on her feet, but there was a
reported deterioration of her continence and ability to dress. She was also noted to have extreme hoarding behaviour.

Ib4.

First began to dement at the age of 53 years old, in about 1982, and was referred aged 60. The family had noticed little things, such as him becoming impatient and easily worried, and there was a gradual increase in his level of confusion. In 1987, when he was seen for a diagnosis, he had difficulties in writing, and was tending to lose the thread of conversations. Since 1990, he had progressively become more amnestic, apathetic and irritable. A trial of anti-depressants failed to relieve the symptoms.

The clinical diagnosis was of a possible Alzheimer's presenile dementia.

At the first assessment he was 64 years old and in long-term hospital care. He presented as a severely impaired man, unresponsive and with marked myoclonic jerks, who at times appeared to be very distressed.

His wife was heavily involved in his care, even in the hospital, and was finding it very emotionally hard to take time off from visiting.

A CT scan done in August 1989, had shown atrophy.

He met criteria for DSM3R severe Alzheimer's dementia, McKhann possible.

When seen at the second assessment, just over a year later, he was entirely bed-bound, moaning and grimacing, with bruxism and twitches.

First began to dement aged about 63 years old and was referred at the age of 65. The family noticed she was more dishevelled in appearance and erratic in her job attendance. She was living alone, leaving her door unlocked and the gas on. She was refusing home help or day care, and was not eating the meals-on-wheels provided.

At the time of the first assessment she was 66 years old, and in a nursing home. She presented as a small, friendly lady with a good social facade and caring manner, whose cognitive deficits became apparent on formal testing.

There was no CT scan result available.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann possible.

She was on medication for hypertension.

During the next year there was a gradual and subtle deterioration of her memory and cognitive functioning.

Was first referred at the age of 57 but the changes had been reported by his wife the previous year. She first noticed that in about 1987, he was different, becoming vague and inconsiderate. The bank he worked in had become concerned at the way he dealt with customers. Since his retirement in 1988, she had noticed a gradual deterioration in his memory and a tendency to
stare, and complain of headaches. The changes were predominantly those of personality, in particular tactlessness, with childlike and inappropriate behaviour, and a general reduction in performance, such as manual dexterity.

The clinical diagnosis was of Multi-infarct dementia, but the possibility of Alzheimer's was also raised.

At the first assessment he was 62 years old and living with his wife at home. He presented as a small, neat, and considerate man. There was no evidence of abnormality on cognitive testing but the wife's account was strongly suggestive of a change in personality as detailed above. She also described fluctuations in his presentation.

The scan result (date uncertain) had been consistent with lacunar infarcts.

He did not meet the DSM3R criteria for dementia, at the assessment.

Risk factors included: hypertension, for which he was currently treated; and a history of head injury. There was a family history of what may have been schizophrenia or some other mental illness in his mother and sister.

The changes in the following year were minimal, and cognitive testing remained good, but the wife's account continued to reveal problems and an impression of overall decline.

ja8.

First began to dement at the age of about 63 years and was referred at 64. The family noticed she was repeating questions, and her cooking skills were becoming chaotic.
The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment she was 66 years old and living at home with her husband. She presented as a neat, friendly but very anxious lady, with a good social facade.

She had been on the lazabamide study, until just prior to the first assessment. Other notable features were that her insight was making her very sensitive and her husband said she denied anything was wrong. She would firmly believe her mother was still alive and insist that steps be taken to contact her, and became violent when her wishes were not met.

Her husband was frustrated and especially distressed because of the rapidity of her decline, and uncertainty about the future course of the illness. He had found it hard when the GP had initially been taken in by her social facade.

A CT scan done in April 1992, was normal.

She met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

Risk factors were: a possible head injury as a child aged 10 years, when she was in a road traffic accident.

Subsequently during the next year between assessments, there had been a grossly rapid deterioration in her, necessitating admission to long-term care. In the few months prior to this she had failed to settle in day care and had become aggressive at home.

When seen at the second visit, she was suffering from marked extrapyramidal features and obvious tremor. She had lost weight, and appeared extremely anxious and agitated. She tended to breathe very fast and was very distracted, trying to get up
several times during the short examination. She occasionally banged her hands repeatedly on the chair. She still had some verbal ability and responded to social cues, but inappropriately wanted to kiss me.

She displayed one of the most dramatic declines in the follow-up phase, and was severely demented by the second assessment having been in the mild category at the first. The possibility of Lewy Body dementia could be raised, due to features including hallucinations and marked extrapyramidal signs.

**mb10.**

First began to dement aged about 59 years old. Her husband noticed she was unable to express herself, and was progressively more forgetful. She also had problems with spatial disorientation, and day-to-day functioning.

The clinical diagnosis was of presenile Alzheimer's dementia.

At the time of the first assessment she was 61 years old, and living at home with her husband and brother. She presented as a slightly obese, rather vacant, but pleasant and docile lady. Her ability to communicate was very limited. She was on antidepressants at the time.

A CT scan (date uncertain) had revealed mild atrophy.

She fulfilled the DSM3R criteria moderate Alzheimer's dementia, McKhann probable.

Subsequently during the next year, there was a rapid deterioration culminating in a collapse whilst she was on holiday and her death, four months later, of bronchopneumonia. No PM was performed.
First began to dement aged about 63 years old and was referred at the age of 64 years old. The family noticed that whilst he continued drinking, something was different - he appeared to be more unsteady on his feet, with poor vision and slurring of speech.

The clinical diagnosis was of alcohol-related cognitive impairment.

At the first assessment he was 64 years old and living at home with his wife. He presented as a well-built, friendly and slightly deaf man, who smoked heavily. He spent all day sitting at home.

No scan was available.

He fulfilled the DSM3R criteria for mild Alcohol-related dementia.

The most detail on his past alcohol consumption was of 6 units daily, 6 days a week, for 28 years.

When seen for the second assessment, there were improvements as he was drinking less. He was cleaner and more alert in appearance and manner.

The diagnosis was less certain on the second assessment, but he remained in the mild category.

First began to dement at the age of 53 years old. The family had noticed a sudden onset of confusion, short-term memory loss, confabulation, ataxia and there came to light a history of secret drinking.
The clinical diagnosis was alcohol-related cognitive impairment and Korsakoff's Psychosis.

The presenting features were of a fairly acute deterioration in 1991. There was loss of ability to communicate, and she was needing help with the activities of daily living. There were also signs of cerebellar ataxia, dyskinesia, dysarthria and marked cognitive defects. The situation had persisted as the same since.

At the time of the first assessment she was 55 years old, and living at home with her husband. She presented as an extremely akathisic, restless woman, of slight build. Her severe dysarthria made communication difficult, and she lacked facial expression. Another notable feature was her gait, which was with small mincing steps, and her right hand held stiffly out in front of her.

A CT scan (date uncertain), showed atrophy.

She met the DSM3R criteria for moderate Alcohol-related dementia.

The details of her alcohol consumption were unavailable.

Subsequently during the next year the changes were minimal, with no real progression in the deterioration.

**db18.**

First began to dement at the age of 64 years old. Her cognitive deficit was noticed when she was admitted for a hysterectomy in 1991, when she had appeared confused. It was thought possible that this was a fluctuating state. By 1992 she appeared well to her GP, however on assessment for the study, she was obviously impaired.

The clinical diagnosis was of possible Alzheimer's dementia.
At the first assessment she was 65 years old, and living on her own at home. She presented with a good social facade and smartly presented, denying her problems and slightly irritable. However, she had forgotten the appointment previously agreed on. There were some concern over her self care, and ability to cook adequately and safely for herself. The GP was notified.

The result of a CT scan done in January 1995, was normal.

She met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

No risk factors were identified.

Subsequently during the next year, there was a small amount of decline. After she fractured her hip in November 1994, she obtained extra services at home. However, she was refusing home help and often unwilling for visits by the health visitor to be made. When seen for her second assessment, there was a hint that her personal hygiene was worse.

19.

First began to dement at the age of 58 years old, and was referred at this time. The family noticed poor recent memory and a lack of self care. She had had a low to average premorbid IQ.

The clinical diagnosis was presenile dementia, no type specified, and was initially only included as a possible case for the study.

At the time of the first assessment she was 59 years old, and living at home with her daughter. She presented as a cheerful, slim woman with an apparent lack of understanding of events around her.
A CT scan done in November 1992, was normal.

She fulfilled the criteria for DSM3R moderate Alzheimer's dementia, McKhann possible.

Risk factors included: current treatment for hypothyroidism; a suggestion of a possible family history, but few details apart from that the mother and maternal aunt had been delusional; a history of head injury; and a past alcohol consumption of about 12 units per day over eleven years.

The changes over the next year were not substantial.

**eb20.**

First began to dement at the age of 59 years old, when she was referred for an assessment. She was investigated for "jerky spasms" and "transient absences" and poor short-term memory. The history was one of fluctuating confusion over a 2-4 year period, the patient claiming this to have been for longer (over 11 years).

The clinical diagnosis had been one of a possible dementia.

At the time of the first assessment she was a 61 year old, and living at home with her ex-husband. She presented as a small, perky, but rather anxious lady. She spent her time in a dark bedroom, surrounded by electronic games and videos, awaiting treatment from the district nurse for her psoriasis. She was rather slow at times on testing, but otherwise performed well on neuropsychological testing.

A CT scan done in February 1992, revealed atrophy.

She did not fulfil the criteria for DSM3R dementia. Therefore she was placed in the possible category.
Risk factors were: a history of vascular headaches; and having been on phenobarbitone for over 10 years.

When seen again, she was not greatly changed, but a little more dishevelled and admitting to loneliness, since her ex-husband had moved away. There was no evidence of decline.

**ba21.**

First began to dement aged about 61 years old. She had had eye problems in the early 1980's and was seen by the neurologists, who believed these were possibly due to small strokes. She had an obvious stroke in July 1988 and by August 1993 there was a marked deterioration in her mental and physical state.

The clinical diagnosis was of Multi-infarct Dementia.

At the time of her first assessment she was 66 years old and was living with her husband at home. She presented as an obese, immobile lady with a docile, pleasant manner but with limited ability to communicate because of severe dysphasia (especially expressive). On neurological examination there was evidence of an old stroke. She was on treatment with aspirin.

No scan result was available.

She fulfilled the DSM3R criteria for moderate Multi-infarct dementia.

Risk factors included: a previous stroke; and high blood pressure.

Subsequently during the next year the changes were of mild deterioration in speech, feeding and also a moderate further reduction in mobility, possibly the result of further small strokes.
sb23.

First began to dement at the age of 61 years old, and was referred at the age of 64. Her relatives found her forgetful and tending to burn her food and forget her keys.

The clinical diagnosis was of mild presenile Alzheimer's dementia, although this was only tentatively given.

At the first assessment she was 66 years old and was living at home, attending a day hospital. She was rather irritable and tired looking.

A CT scan result, dated March 1989, was normal.

She met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

During the next 14 months she was admitted to a nursing home where she settled in very well and ate more healthily than she had done previously. Her memory deficits remained.

fb25.

First began to dement at the age of about 59 years old. There is no real history of the presentation available. He had a history of chronic alcoholism and came requesting help for this, and was found to have a failing memory and cognitive deficits.

The clinical diagnosis was of a possible Alcohol-related dementia.

At the time of the first assessment he was 62 years old and he presented as a rather slow, slightly deaf man, with a degree of intact social facade. At that time he was living in an Old Veteran's Home, which provided a substantial degree of practical support, such as meals and a laundry service.
There was no scan available.

He met the DSM3R criteria for moderate Alcohol-related dementia.

The risk factors included: a possible history of head injury; hypertension; and an alcohol history of about 20 units daily, over an unspecified number of years.

Subsequently during the next year, there were no real changes, and the condition did not appear to be a progressive one. He continued to drink.

**mb26.**

Mild cognitive impairment had been noted when she was 39 years old, but the clinical diagnosis of hepatic encephalopathy/Alcohol-related dementia was made when she was 45 years old.

At the first assessment she was 45 years old, and in hospital for the treatment of physical complications of drinking. She presented as a small lady with a distended abdomen, a slightly truculent manner and obvious cognitive impairment on testing.

No scan was available.

She met the criteria for DSM3R moderate Alcohol-related dementia.

No details of her drinking history were available.

She was seen for the second assessment when awaiting a transfer to Part IV accommodation. The condition did not appear to be deteriorating, but short-term memory problems persisted.
jb27.

First began to dement at the age of about 65 years old. The family noticed him wandering aimlessly and becoming forgetful and 'slow'. There was a rapid deterioration. He also had Chronic Lymphatic Leukemia, Insulin Dependent Diabetes Mellitus, and a history of vascular disease.

The clinical diagnosis was of uncertain type, either a vascular or Alzheimer or mixed dementia.

At the time of the first assessment he was 66 years old, and had been in long-term care for 2 months, previously cared for by his wife, with respite admissions.

A scan (date uncertain), was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann possible.

Risk factors included: ischaemic heart disease; peripheral vascular disease; and hypertension.

Subsequently during the next month after the first assessment, there was a continued deterioration and further sudden deterioration and death on 17/5/94, of a presumed myocardial infarction. No post-mortem was done.

db30.

First began to dement at the age of 56 years old and was referred at the age of 57. The family noticed a deterioration of his memory, dysphasia, acalculia, reduced conversation, unsteadiness and loss of confidence. He would do strange things like putting raw eggs on top of haggis.
His clinical diagnosis was of presenile Alzheimer's dementia.

At the time of his first assessment he was 62 years old and in long-term hospital care. He presented as a restless man who made no coherent responses. He had Non-Insulin Dependent Diabetes Mellitus.

The scan result (uncertain date), was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors included: a head injury in 1984; and a possible past heavy alcohol consumption (with no details available); and a possible history of high blood pressure.

Subsequently during the next year, the changes were of a continued deterioration.

mb32.

First began to dement aged about 64 years old, when her family noticed she had progressive difficulty with her speech, and was unable to express herself meaningfully. She was muddled and began doing strange things, like putting food into odd places.

The clinical diagnosis was of focal cortical dementia, likely to be Alzheimer's dementia.

At the time of the first assessment she was 67 years old and living at home with her daughter. She presented as a slightly defensive lady, with a good social facade and a degree of insight. She had a pleasant manner, but severe aphasia.

A CT scan done in July 1992, showed diffuse atrophy.
She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

Risk factors included: a possible stroke, and current treatment with Aspirin; and a familial history of two relatives with possible dementia.

Subsequently during the next year, the changes were of a continued deterioration. She was moved into a nursing home in November 1994, approximately 7 months after her initial assessment. When seen for the second assessment, she seemed very content, chatting and singing continuously.

**kb34.**

Was first thought to have cognitive impairment aged 39 years old.

The clinical diagnosis was of possible alcohol-related cognitive impairment.

At the time of the first assessment he was 41 years old, and living in supported accommodation. Other notable features were a history of epilepsy, longstanding bilateral deafness and blindness due to an accident. He had also suffered injuries following a fall at home.

A CT scan in March 1992, revealed generalised atrophy.

He did not meet the DSM3R criteria for dementia.

There was a history of heavy but unspecified alcohol consumption.

After a year there was no evidence of cognitive decline, and he still did not meet the criteria for dementia.
First began to dement aged 56 years old, and was referred at the age of 62. The family noticed her speech becoming slurred and behavioural changes, with reduced communicativeness, and a general inability to cope.

The clinical diagnosis was of Multi-infarct dementia.

At the first assessment she was 66 years old and in long-term care, where she had been since August 1990. She presented as a lady with a strong hand grip, whimpering and with no ability to communicate or respond. At that time she was being treated with anti-depressants, Aspirin and anti-hypertensive medication.

No report of a scan was available.

She met the DSM3R criteria for severe Multi-infarct dementia.

Risk factors included: a stroke in 1987; and a history of hypertension.

Subsequently during the next year, the changes were the development of tonic clonic seizures which were treated with Phenytoin. She subsequently appeared chair-bound, open-mouthed with alert eyes, and a chesty cough. Her left hand was severely contracted and there were twitching movements of her right hand and mouth.

First began to dement aged about 59 years old, and was referred at the age of 61. The family noticed her turning up at the door unexpectedly, leaving the cooker on and food rotting in the fridge. She became paranoid at work and her memory
deteriorated, as did other abilities, eventually leading to her wandering and being aggressive. Before admission she was living alone as her son and daughter-in-law were living some distance away and the situation became too difficult to manage with her living independently.

At the time of the first assessment she was 70 years old and in long-term hospital care. She presented as a smiling, silent, chair-bound lady, with contracted limbs. There was minute twitching of her mouth, arms and left leg.

No scan result was available.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

There was no significant change at the second assessment.

gc40.

First began to dement aged about 56 years old and was referred at the age of 59. His wife noticed he was forgetful about the routes he used to know and exhibited bizarre behaviour (such as doing a U-turn on the motorway). By the age of 60 (in 1989) he was incontinent, perseverating, and had developed antisocial behaviour. He was admitted to long term care because of family problems.

The clinical diagnosis was of an atypical presenile dementia, possible thought to be Pick's or Alzheimer's type.

At the time of the first assessment he was 63 years old and in a nursing home. He presented as a large man, unable to communicate. However, he knew where his room was, how to use the lift, hold the door open, and do his shoe laces. He displayed
some repetitive behaviour and continually got up to go during the examination.

A CT scan result from 1988, was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Subsequently during the next year, there was a gradual deterioration and he presented as a startled, restless man unable to be properly examined because of extreme restlessness. He was mumbling "yes" continuously. Staff reported him urinating in the lift bucket, cramming food in his mouth and occasionally choking, and always needing to keep pieces of furniture in the exact same position. At the same time he managed to dress himself, but clean clothes had to be provided by the nursing staff.

**bc44.**

First began to dement at the age of 58 years old and was referred when he was 60. The family noticed he was tense and forgetful, leaving the front door open, and having difficulties with his new job, leaving work incomplete and having "funny turns" or panic-like episodes (differentially diagnosed as mini-strokes or dyspepsia). In 1989 the pathology was felt to be frontal in quality, and possibly compounded by alcohol. By June 1991 he was becoming violent and was talking to himself. He was admitted to hospital in March 1992 and then into a nursing home 2 months later.

The clinical diagnosis was of an atypical dementia.

At the time of the first assessment he was 67 years old, and in a nursing home. He presented as a tall man, with no ability to answer questions, who appeared unwilling to sit and kept moving
constantly, with small steps and a slight list to the right, keeping his hands in his pockets.

The result of a CT scan in October 1987, showed global atrophy.

He met the criteria for DSM3R severe Alzheimer's dementia, McKhann probable.

A risk factor was a family history of his father having dementia in his 80's.

Subsequently during the year, the changes were of a decline and his subsequent death in October 1994. No post-mortem as done.

ic46.

First began to dement at the age of about 55 years old. The family noticed that she was more nervous generally and couldn't always find the right words in conversation. She appeared to have drop attacks and complained of a constant headache. Her memory appeared impaired and she displayed less ability to perform tasks.

The clinical diagnosis was of Alzheimer's disease.

At the time of the first assessment she was 58 years old and was living at home with her husband. She presented as a pleasant woman with an anxious manner, and was very sensitive about her problem. Thus the testing had to be done very carefully to avoid upset. She was able to express her frustration at losing things, and getting lost outside.

Her husband felt enough help was on offer, and the illness was not currently at a stage where this would be really necessary or acceptable to his wife.
A CT scan result in July 1993, was reported as normal.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

There were no apparent risk factors.

Subsequently during the next year, the changes were of a continued gradual deterioration.

ic47.

First began to dement in her early 40's and was referred at the age of 61. Initially her family had noticed that she began to repeat things and get lost, and had appeared to have had a slight stroke. Her husband gave up work to care for her and there was a slow and gradual deterioration of her behaviour. By 1988 she was very aggressive.

The clinical diagnosis (established with some difficulty) was a presenile dementia of uncertain type, possibly thought to be Multi-infarct dementia.

At the time of her first assessment she was 67 years old and in long-term hospital care. She presented as a tiny, frail lady, holding a soft hedgehog. She was very active on her feet and mumbling incomprehensibly most of the time.

A CT scan done in August 1988, revealed a cerebral infarct.

She met the DSM3R criteria for severe Multi-infarct dementia.

An identified risk factor was a history of stroke.

Subsequently during the next year, the changes were of a continued gradual deterioration. When seen again she was
walking with tiny steps and repetitively saying "oh-oh-oh" and laughing.

**mc48.**

First began to dement at the age of 65 years old, when her family noticed that she was more forgetful and tended to purchase the wrong shopping and repeat herself.

The clinical diagnosis was of uncertain type of presenile dementia, possibly mixed Alzheimer's/Multi-infarct dementia.

At the time of the first assessment she was 67 years old and was living with her husband at home. She presented as a small, anxious-looking lady, breathing rapidly because of chronic obstructive airways disease. She was irritable and refused to try the cognitive assessment. She walked with a slight stoop, loss of arm swing and small-stepped gait.

Her husband was distressed, but unable to agree to her going into long-term care.

A CT scan (uncertain date), was normal.

She fulfilled the DSM3R criteria for moderate Alzheimer's dementia, McKhann possible.

The only identifiable risk factor was a history of hypertension.

Subsequently during the next year, the deterioration was of a gradual nature, and she became more docile in her manner. She had a startled but otherwise expressionless face and had developed a mild pill rolling tremor, especially of the left hand. Her speech was less clear. She became very agitated during the examination, which therefore had to be abandoned.
ic49.

First began to dement at the age of 48 years old, and was referred at the age of 53. The family had noticed that he had been forgetful since his early 40's, and from 1988 onwards, there were increasing problems with his memory, speech and repetitiveness. The deterioration meant that he had to give up his work with the gas board. He was investigated for his lethargy and poor concentration.

At the time of the first assessment he was 54 years old and had been in long-term care since September 1993. He presented as a small, active, aphasic man, with a stooped posture and slow gait.

A CT scan done in June 1993 was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors included: a family history, since his father had suffered from a similar illness in his early 50's; and he had had a mild head injury about 15 years previously.

Subsequently during the next year, the changes were of a decline and an onset of seizures in February 1995, after which he was chair-bound and died in June 1995 with bronchopneumonia. No post-mortem was done.

ic52.

First began to dement aged about 55 years old. After the death of his mother, he was found to be living in isolation, paranoid and deteriorated, with personality problems and periods of intermittent confusion and double incontinence. He presented with a history of hypertension, extrapyramidal symptoms and a shuffling gait.
The clinical diagnosis was of Multi-infarct dementia.

At the first assessment he was 60 years old and in long-term hospital care. He presented as a large-framed man, with a cheerful, loud manner and some extrapyramidal features.

A scan result in June 1989 showed multiple deep seated infarcts secondary to hypertensive arteriosclerosis. A repeat scan showed evidence of hydrocephalus and lacunar infarcts.

He met the criteria for DSM3R severe Multi-infarct / Alcohol-related dementia.

Risk factors included: a history of stroke; high blood pressure; and a past alcohol history of unknown quantity.

Subsequently during the next year, the changes were severe. After a series of strokes and chest infections, he was unable to move or feed himself. He suddenly deteriorated in May 1995, and died of a stroke. No post-mortem was done.

hc53.

First began to dement aged about 59 years old and was referred at the age of 65. The family noticed she was leaving lights on at work, buying double of things, burning the dinner, playing with childrens' toys and losing her memory.

The clinical diagnosis was of presenile dementia of uncertain type.

At the time of the first assessment she was 70 years old and in long-term hospital care. She presented as a quiet, docile lady, with a very firm hand grip.
A CT scan done in September 1988, showed atrophy.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

There was a family history, as a brother and an uncle had been reported to have had a similar dementing condition.

Subsequently during the course of the next year, the changes were of a slow continued deterioration.

cc56.

Was 52 years old when she was diagnosed with Korsakoff's Psychosis.

At the first assessment she was 60 and presented as a plethoric lady, with a gentle manner, who was rather hard of hearing.

She was living with her son at home, and fulfilled the DSM3R criteria for moderate Alcohol-related dementia.

Her alcohol history suggested a consumption of 39 units per day, 7 days a week over a period of 15 years.

After a year, her son felt that her mental state was slightly improved. There was no significant change apparent on testing.

ac57.

First began to dement at the age of about 63 years old.

The family noticed that following a flu-like illness, he was clumsy and inappropriate, wandering and leaving the fire on, occasionally wetting himself and unsteady on his feet.
The clinical diagnosis was of uncertain type, possibly mixed Alzheimer's / Alcohol-related dementia.

He initially improved (although with some residual symptoms) casting the diagnosis into doubt, but then deteriorated further again.

At the first assessment he was 66 years old, and living at home with his wife, but did not require much supervision. He presented as a quiet, elderly-looking man, with a bulbous nose, who lacked much facial expression, and had generally flattened responses.

A scan result in April 1990, showed widespread atrophy, including of the cerebellum.

At the time of his first assessment, he did not meet the DSM3R criteria for dementia, since there was not enough evidence for memory deficit. He was therefore placed in a possible category.

Risk factors included a history of alcohol abuse, 25 years of daily intake of half a bottle of spirits (15 units) daily. There was also a history of head injury in 1990.

Subsequently during the next year, his wife reported that he had begun to drink again, although she was attempting to intervene by restricting his access to money. She had noticed that his gait had become more shuffling, and generally that he was less able to do things. On cognitive testing, there was a mild, general but significant decline in his memory scores. There was also a mild worsening of aphasia, as evidenced by him not being as able to follow instructions, and a mild worsening of agnostic problems, evidenced by less ability to recognise coins and pictures.

He now fulfilled the DSM3R criteria for mild Alzheimer's / Alcohol-related dementia.
First began to dement at the age of 53 years old. The family noticed a fairly acute onset of poor memory, which worsened gradually, and an inability to take in information. He was drinking fairly heavily until about 1991.

The clinical diagnosis was of Korsakoff's Psychosis.

At the first assessment he was 56 years old, and was living at home with his wife. He presented as a small, roundish gentleman with a rather blunted affect. He had a history of Manic Depressive Illness, and was on Lithium treatment.

A scan done in March 1991, revealed temporal atrophy.

He did not meet the DSM3R criteria for dementia, as there was no evidence for general cognitive deficit. He was therefore placed in a possible group.

An identified risk factor was the past heavy alcohol consumption, until about 1991, of one bottle of vodka daily for about 11 years or more, previously.

Subsequently during the next year, the changes were noted to be of an overall slowing, with evidence of agnosia and apraxia. A gradual decline in function, and personality change, were confirmed by his wife. He now met the DSM3R criteria for mild Alcohol-related dementia.

First began to dement aged 38 years old, and was referred aged 41. She had been diagnosed with hereditary spastic paraparesis at the age of 18 years old, when the first physical
manifestations began as she had difficulty walking. See Rothner et al (1976); Went (1964); Bruyn (1964); Frey (1972).

She had been in residential care for many years before the dementia began, with a worsening of her memory and increased moodiness and irritability, and occasional aggression.

She was 43 years old when first seen for the study, presenting as a cheerful lady, in a wheelchair, with physical problems and cognitive disability.

A Magnetic Resonance Imaging (MRI) scan done in July 1993, showed marked cerebral atrophy.

She met the DSM3R criteria for severe dementia, 'Rare' (or 'Other') type in the study.

This is a hereditary condition which her deceased sister also suffered from.

She deteriorated both physically and mentally over the next year, and was occasionally rude to the staff and deluded at times. However she was friendly on my visit, although with severe cognitive impairment. She remembered that her parents had seen me, and the staff also reported patchy memory like this. She was spending more time in bed, because of pressure sores.

cd64.

First began to dement aged about 50 years old and was referred aged 54. She seemed different to her family, being more depressed, and would tend to sit and stare into space. She neglected the housework and cooking, and her memory appeared to deteriorate.
The clinical diagnosis was of possible dementia. At her assessment by the neurologist when she was 55 years old, the diagnosis was of a likely depressive pseudodementia.

When first seen for the study she was 56 years old, and was living at home with one of her daughters. She presented as a slow, slightly obese lady with a rather detached manner. The family felt the problem tended to fluctuate. Other notable features were a history of anxiety and a stressful (possibly abusive) relationship previously with her ex-husband.

A CT scan done in August 1992 showed an early minor degree of frontal atrophy.

She met the DSM3R criteria for mild Alzheimer's dementia, probable McKhann.

Subsequently during the next year she moved into her own flat with her son. According to the family, the changes were of mild continued deterioration. However this was not apparent on the testing. She appeared to perform slightly better on testing, although she still had mild impairments consistent with the first testing.

bd68.

First began to dement at the age of about 63 years old and was diagnosed at this age. The family noticed she was less motivated, and had difficulty dressing. She was disorientated, muddled and confused at times. Her worsening self care and wandering, meant it necessary for her to go to long-term care in a nursing home.

The clinical diagnosis was of Multi-infarct dementia.

At the time of the first presentation she was 69 years old, and in a nursing home. She presented as a docile, rather withdrawn
lady, who tended to leave large pauses before answering, and needed help to walk, and prompting for activities. She was on treatment for depression, cardiovascular disease, and Non-Insulin Diabetes Mellitus.

A CT scan done in August 1989, showed evidence of periventricular haemorrhages.

She met the DSM3R criteria for severe Multi-infarct dementia.

Risk factors included: a stroke; and hypertension.

Subsequently during the next year, there were no big changes, and the nursing staff reported day-to-day fluctuations. She was very slow and seemed drowsy, and she walked with a shuffling, small-stepped gait, with one person. She responded little, but occasionally gave a clear reply. The staff reported her to be generally subdued, occasionally smiling or weepy. Overall, they found her brighter than previously, and reported a dramatic but short-lived response to madopar.

First began to dement aged about 49 years old and was referred aged 61. The family noticed she was more forgetful and self-absorbed, and tended to pick fights. She had become markedly worse in the year since the age of 60. There had been difficulty in making the initial diagnosis and in 1991, it had been felt that there was insufficient evidence for it. However, by 1992 there had been a deterioration of her short-term memory and housework skills. Behavioural problems also arose, so that her son had moved in to help run the house and care for her.

The clinical diagnosis was of uncertain dementia type, possibly Alzheimer's.
At the time of the first assessment she was 63 years old and was living with her son at home, with regular respites. She presented as a sad looking, docile lady, who was able to respond to some demands, but was unable to do cognitive testing because of her severe aphasia. Other noteable features were a premorbid personality described as nervous, and past treatment for hypothyroidism. She was on anti-hypertensive medication.

A CT scan in February 1991, was reported as normal.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann possible.

Risk factors included: hypertension; and a history of ischaemia.

Subsequently during the next year, the changes were of a continued deterioration.

**md74.**

First began to dement in her early 50's and was referred at the age of 54 years old. The family noticed that after her husband's death in 1976, she stopped doing the housework and looking after her teenage daughters. By the age of 54 years old, she was leaving the gas on, and not able to cook. She was leaving the home in her nightclothes and neglecting herself. She became withdrawn and uncommunicative, and her balance was poor. She displayed emotional lability and became dysphasic.

At the time of the first assessment she was 59 years old, and in long-term hospital care. She presented as a severely demented chair-bound lady, with an anxious expression. She tried to eat anything that came near her mouth and constantly chewed her dentures. She would often ask "what?" but not apparently understand the answer. She had severe flexion contractures of her hands (especially the left). She was noted to have
Parkinsonian features, and it had been queried as to whether this was idiopathic or not.

A CT scan result, from March 1989 showed atrophy.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann possible.

Risk factors included: a possible stroke and previous Aspirin treatment; past history of hypertension; peripheral vascular disease (and treatment for this). There was also a family history, as her mother had suffered from a similar illness at an early age.

During the year, between assessments, there was a slow gradual deterioration, but this was not very noticeable since she was already at a low level of functioning when seen for the first assessment.

ded76.

First began to dement at the age of 59 years old and was referred in that year. Her family noticed her having difficulties at work as a shop manageress as she was not coping, and was moody and disorientated. Her writing changed, she walked like an old woman, and was unable to manage her money. She would get lost and lay the table wrong, and forget switches. She progressively had difficulties with dressing and the other activities of daily living.

The clinical diagnosis was of uncertain dementia type - either Alzheimer's or MID.

At the time of the first assessment she was 64 years old, and in long-term hospital care. She presented as a large, immobile lady with little response. She occasionally opened her eyes, and moved her left leg with distress, when a blood sample was taken.
Her husband was under great strain, visiting twice daily. He subsequently had a stroke.

A scan (uncertain date) had shown a possible lacunar infarct, and moderate global atrophy.

She met the DSM3R criteria for severe Multi-infarct/Alzheimer's dementia, McKhann possible.

Risk factors included a possible stroke.

During the year there was a continued deterioration, and she became much quieter and less agitated, and lost a substantial amount of weight. She had extreme contractures of both arms.

mf77.

First became aware of his difficulties at the age of 54 years old and was referred at the age of 56. He was concerned about his increased 'emotionality' and tendency to be irritable and tearful. He felt his memory had deteriorated, such as forgetting names and being less able to do sums. He had retired in 1982, from his job as an engineer, due to ill health. When assessed by the clinical psychologist in October 1992, there was found to be no difference between his current and premorbid intellectual functioning. There were significant deficits in verbal and visuospatial memory, visuomotor tracking and attention, but no frontal signs.

The clinical diagnosis was of uncertain type of dementia, possibly subcortical type.

At the time of the first assessment he was 58 years old. At that time he was living at home but not really requiring care. He was somewhat preoccupied by his health and the attitudes of doctors he had met. His wife's account was that of a predominant change
in personality, rather than in memory or other areas of deficit, and reported fluctuations in his state.

A CT scan result done in July 1992, revealed a degree of atrophy.

He met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

The subsequent changes over the next year, were not noticeable, there was even some slight improvement in memory function. The possibility that this is not a progressive impairment could be raised, and the diagnosis could be questionable.

mf78.

First began to dement at the age of about 48 years old and was referred aged 50. The clinical history was of hypertension diagnosed in 1983, a small stroke in 1986 subsequently treated with Aspirin, and Wernicke's/Korsakoff's diagnosed in 1987 secondary to alcohol abuse. Although the eye signs and ataxia improved, she was left with poor short-term memory and orientation problems.

The clinical diagnosis was of Korsakoff's Psychosis, aggravated by cerebro-vascular disease.

At the time of the first assessment she was 55 years old, living in a supervised home with constant supervision. She presented as a large-framed, socially pleasant woman, with a marked wide-based gait.

A scan done in July 1986, showed small infarcts.

She met the DSM3R criteria for severe Alcohol-related dementia.
Risk factors included: the history of heavy alcohol abuse, 15 units per day 7 days a week for an unknown number of years. Also the cerebrovascular disease risks of a history of hypertension and a past stroke.

Subsequently during the next year, the changes were variable, and her deficits patchy. She continued to manifest some attention-seeking behavioural problems. She was found to be drinking again. No major changes were apparent.

rf79.

First began to dement aged about 60 years old, and was referred aged 62. The family noticed she couldn't operate the cash till at work, and had a mild expressive and nominal dysphasia. She seemed weepy and low, and although a course of antidepressants helped slightly, her memory gradually got worse. It was clinically thought possible she was having small strokes.

The clinical diagnosis was of Alzheimer's disease.

At the time of the first assessment she was 67 years old, and was living at home with her husband. She presented as a pleasant, socially-skilled lady, with no striking disability. She had a rather acromegalic appearance.

A CT scan done in September 1989, revealed frontal atrophy.

She fulfilled the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

Subsequently during the next year, the changes were minimal, with a reported mild worsening of memory. This was not apparent on testing, neither were there the emergence of any behavioural difficulties. The progress of the dementia was therefore slow.
First began to dement aged 51 years old, and was referred at the age of 57. Her family noticed that following a D&C operation, she was less confident, and occasionally talked jibberish and 'froze up' in conversation. She left work three years later, and appeared vague and depressed, with a loss of her usual activities, such as knitting. Her speech worsened, and she seemed to forget how to use cutlery. Prior to her admission to long-term care in October 1989, she was agitated, and expressed thoughts of self harm, and was awake 24 hours a day.

At the time of the first assessment she was 62 years old, and in long-term hospital care. She presented as a chair-bound lady, in a twisted position, moving her legs in a writhing manner. There was no real response from her.

A scan result in August 1987, revealed a little global atrophy. She had also had a SPECT scan in 1988.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

There were no identifiable risk factors in this case.

Subsequently during the next year, she appeared to become generally more drowsy, with a constant sucking in of her lower lip and minute writhing/jerky movements of the muscles of both hands.

First began to dement at the age of about 29 years old. The family and those who knew him, noticed a fairly sudden, severe patchy memory loss, blunted mood and then progressively worse
self-care. He appeared dishevelled and confused, uncommunicative and was prone to violent outbursts.

The diagnosis was uncertain, and the possibility of a psychotic illness was raised.

At the time of the first assessment he was 31 years old, and in an assessment ward awaiting long-term placement. He presented as a large man with a very erratic ability to answer questions. He was stubborn and refused to cooperate at times.

Noteable features of his past were a history of drug abuse, and a past history of a possibly severe head injury, sustained during an attack whilst in prison.

A CT scan result was normal, but a SPECT in June 1991, revealed significant abnormalities, of asymmetrical uptake into the temporal lobe and reductions in the medial temporal cortex on the left and the basal ganglia. A Magnetic Resonance Image scan (MRI) in October 1992, showed a linear streak extending laterally from the right lateral ventricle, of uncertain origin.

He met the DSM3R criteria for severe dementia, 'Rare' (or 'Other') type (undefined) in the study.

Risk factors included: a history of past heavy drug abuse; and a possible severe head injury.

At the second assessment, the history was one of a gradual worsening of his function. It became impossible to complete testing as he refused to hand back the ophthalmoscope, and when given a pen just drew a circle repeatedly. His ability to answer questions was poor. Some of his answers appeared surprising in view of his impairments, for example when asked to name a watch he said "Rolex" He had a rather jovial manner until asked to give back the ophthalmoscope, and often said "yeah".
First began to dement at the age of 58 years old, and was referred at the age of 59. The family noticed she was not able to do the housework as well as usual, and had become irritable and weepy.

The clinical diagnosis was of Multi-infarct dementia.

At the time of her first assessment she was 61 years old and was living at home with her husband, and attending day hospital. She presented as a slightly overweight lady, with a cheerful manner. She was on Aspirin treatment.

There was no scan result available.

She met the DSM3R criteria for moderate Multi-infarct dementia.

Risk factors included: hypertension; and history of head injury.

Subsequently during the next year, the changes were of an obvious worsening of her mental state. There were no real changes in the services being used, or wanted by the couple.

First began to dement at the age of 60 years old. His family noticed that whilst he was on holiday, he became more aggressive and would forget who people were. He often muddled his words, and appeared uncoordinated. He began wandering, and appeared confused and hallucinated. Another notable feature was a diagnosis of Parkinson's disease in 1988.

The clinical diagnosis was of uncertain dementia type, possibly Lewy Body dementia, because of presentation features of a
cognitive decline as outlined, in combination with Parkinsonian features.

At the time of the first assessment, he was 61 years old, and lived with his wife at home, with respite admissions. He was on Aspirin treatment.

She was coping by denying the nature of his illness.

A CT scan done in October 1993, was normal.

The DSM3R diagnosis was of severe Alzheimer's dementia, McKhann probable.

There were also several vascular risk factors: peripheral vascular disease; a history suggestive of TIA's; and a possible stroke.

Subsequently during the next year, the history was of a rapid deterioration, necessitating his admission to long-term care, and death of bronchopneumonia a year after the first assessment. No post-mortem was done.

First began to dement aged about 43 years old. His wife and their three teenage children, noticed him becoming increasingly forgetful and disorientated, despite abstinence from alcohol. He had a history of bronchitis, hypertension and angina.

The clinical diagnosis was of a dementia of uncertain type; Alcohol-related/ vascular/ Alzheimer's.

At the time of the first presentation he was 49 years old, and living at home with his wife. He presented as a rotund, cheerful man with obvious areas of cognitive impairment. He had been on
antidepressant medication, since November 1993. Other medication included Aspirin and anti-hypertensives.

A CT scan done in June 1989, showed a little atrophy and there was no change by November 1990. The CT scan done in June 1995, was reported as normal.

He met the DSM3R criteria for moderate dementia, Alzheimer/Multi-infarct/Alcohol-related.

Risk factors included: a possible history of Transient Ischaemic Attacks (TIA's) in 1990 and a possible stroke; hypertension; a history of possible head injury; and he had been a heavy drinker, at most 3 bottles of whisky daily (60 units), for about 25 years.

At the second assessment, he was being assessed in hospital, after a fairly sudden decline in his mood and cognitive functioning. He had become disorientated at the day centre. He described depressive symptoms. He felt unable to do things, had insight into his memory loss, was contemplating suicide and felt unable to enjoy anything. He described visual hallucinations of animals and auditory hallucinations.

The clinical psychology assessment revealed poor immediate recall and numeracy, but not the typical picture expected with alcohol-related impairment. The cognitive picture seemed patchy and he appeared very alert in some areas, not consistent with a global picture. Only serial assessments would reveal the true nature of the condition.

mg94.

First began to dement at the age of 62 years old. Her family noticed the change in her after an admission to hospital, because of physical complications of her alcohol problem. She also had developed late-onset Diabetes Mellitus, controlled by diet.
The clinical diagnosis was of Korsakoff’s Psychosis.

She was 70 years old at the first assessment and in long-term hospital care. She presented as a belligerent lady, who refused to cooperate either with an interview or full examination.

The result of a CT scan, done in September 1987, had been normal.

She met the DSM3R criteria for severe Alcohol-related dementia.

Risk factors included: a history of heavy alcohol consumption (but no details were available).

Subsequently during the next year, the changes were minimal, she appeared to remain stable and not to deteriorate. However she co-operated with an interview on this occasion.

**ah99.**

First began to dement at the age of about 57 years old. Little is known of his past as he was admitted to hospital, of no fixed abode.

As an inpatient he was found to be behaviourally disturbed and to have a severe amnestic syndrome.

The clinical diagnosis was Korsakoff’s Psychosis/Alcohol-related dementia/amnestic syndrome after a subdural haematoma in 1991.

At the time of the first assessment he was 60 years old, and in long-term hospital care. He presented as a small man, very active on his feet, who rarely sat still, but tended to race up and down the ward with a small-stepped gait. He was reported to be
aggressive, and had a degree of dysphasia. It was not possible to take a blood sample from him.

A scan result in May 1991, showed a chronic subdural haematoma.

He met the DSM3R criteria for severe Alcohol-related dementia.

Risk factors for the dementia were primarily a long history of alcohol abuse, but of uncertain quantities. There was a history of head injury in May 1991, and subdural as noted above. No family history was available.

Subsequently during the next year, the changes were of a continued deterioration. He was wearing a crash helmet, because of falling. However, he was less active on his feet. Oro-facial dyskinesia was apparent, but the neuroleptic medication had been stopped. He was unwilling to co-operate with a full cognitive examination, but remained in reasonable humour throughout.

First began to dement aged about 54 years old, and was referred at the age of 64. The family noticed that since some work abroad had finished, he was unable to find other work. He became obsessive about money, and irresponsible about borrowing. The GP tried a course of antidepressants. He continued to appear rational, and only later was there evidence of his memory failing. It became apparent that he was having strokes. His personality changed, and he became more irritable and eventually began wandering and appeared disorientated. He became dysphasic, (both expressive and receptive) after a large stroke in 1993, and there was a step-wise deterioration in his cognitive abilities and judgement.

The clinical diagnosis was of Multi-infarct dementia.
At the time of the first assessment he was 65 years old, and in long-term hospital care. He presented as a large, but very thin man, who appeared distressed, and was constantly grimacing. He was able to establish eye contact. He was unable to support himself standing and would make angry roaring noises. Mild Parkinson's was noted.

A CT scan, done in 1990, showed a temporo-parietal haematoma.

He met the DSM3R criteria for severe Multi-infarct dementia.

Risk factors included: heavy past alcohol use - about 4 units daily for an unspecified time; and strokes as noted.

Subsequently, during the next year, the changes were of a continued deterioration in health and functioning, with generalised wasting and chest infections and his death on 5/1/95.


The neuropathology examination revealed the presence of a insular cystic infarct, and extensive Alzheimer-type changes. The amyloid angiopathy appeared responsible for the majority of the ischaemic changes in the white matter.

**nh104.**

First began to dement at the age of 59 years old, and was referred at the age of 62. The family noticed she had a gradual memory impairment, and that initially she was accusing her husband of withdrawing money from their account. Subsequently she became dysphasic, with right/left disorientation and dyspraxia.
The clinical diagnosis was of Multi-infarct dementia.

At the time of the first assessment, she was 64 years old and was living at home with her husband, attending the day centre. She presented as a pleasant, rather overweight lady, with some preservation of social facade, but severe disability, particularly of visual recognition, drawing and receptive aphasia. She was unable to read fluently, and was generally very slow in her movements.

Her husband denied any real difficulties in coping with his wife's illness, despite her severe problems.

A CT scan done in August 1992, showed marked multiple infarcts. She met the DSM3R criteria for moderate Multi-infarct dementia.

An identified risk factor was hypertension. She was not taking her anti-hypertensive medication reliably.

Subsequently during the next year, the changes were gradual. The changes were in her activities of daily living, and being unable to cooperate with instructions in the CAMCOG. She had stopped attending the day centre. She was very slow in her movements and thinking.

First began to dement aged about 60 years old, and was referred aged 64. He became aware of this, and began reading up about memory. Gradually he became incontinent, disinhibited and fatuous, with inappropriate laughter. He was apathetic and his personal hygiene deteriorated. There was evidence of nominal aphasia, apraxia, poor concentration, and he was irritable and frustrated. He had been physically very heavy to manage at
home, being incontinent and constantly up at night. The situation came to a head when his wife had needed to go into hospital for an operation.

The clinical diagnosis was of Multi-infarct dementia.

At the time of the first assessment he was 68 years old and in long-term care. He presented as a large, ruddy-faced man, walking with a zimmer. He was restless and irritable, tending to repeat himself and perseverate in conversation. He was mildly disinhibited and labile, frequently bursting into tears.

A CT scan done in March 1991 had shown atrophy, but nil obviously vascular.

He met the DSM3R criteria for severe Multi-infarct dementia.

Risk factors included: hypertension, and treatment for this; a possible stroke; a family history of his mother having had a stroke, and then being confused.

Subsequently during the next year, the changes were of a slight gradual deterioration. He had become generally more slowed up.

**ih106.**

First began to dement at the age of 51 years old, and was referred at 53. The family noticed when arriving home, no meals were ready. She became aggressive, losing her money and keys, and seemed unable to cope at work. She got lost on holiday, and appeared paranoid and confused when the family moved house.

The clinical diagnosis was of uncertain dementia type.

At the time of the first assessment she was 57 years old and in long-term hospital care. She presented as an agitated, distressed
lady, walking with a backward-bent posture, aided by two, taking small pigeon steps. She had twitchy movements, and was on treatment with tetrabenazine.

A CT scan done in November 1990, was normal, but a SPECT scan was consistent with Alzheimer's disease.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

No risk factors were identified.

Subsequently during the next year, the changes were of sudden bronchopneumonia and death, only two weeks after she was seen. She had had a grand mal fit a week before death. No post-mortem was done.

**ph109.**

First began to dement at the age of about 56 years old, when he had to give up work. He had been on medication for epilepsy for some time. His wife felt he had deteriorated, especially after a myocardial infarct, 8 years previously.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment he was 67 years old, and in long-term hospital care. He was a frail, elderly-looking man, unable to communicate, but able to smile. He had jerky twitches (of the face and limbs), especially when he was touched. At that time he could just walk with two.

His wife had felt unable to accept help, as she felt he would not want it.
A CT scan result done in 1984, showed widespread cortical atrophy.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Subsequently after a year, although physically stable, he remained very disabled. When seen, he was very drowsy and chair-bound.

First began to dement aged 55 years old, and was referred at the age of 63. The family noticed he was tending to forget arrangements, and gradually his difficulties increased. He felt as if people were trying to take his home, and was unsure of his wife being his wife. He had episodes of confusion, transient expressive dysphasia and possible limb weakness. At the age of 64 years old, he complained of blurred vision and headaches, and was experiencing hallucinations.

The clinical diagnosis was of uncertain dementia type, Lewy Body or Alzheimer's dementia.

At the time of the first assessment he was 65 years old, and in long-term care. He was on Aspirin treatment.

A CT scan done in November 1992, was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors included a family history, as his mother had had dementia from her mid 60's. He had a possible period of heavy alcohol consumption for 5 years, but no details were available.
Possible vascular aetiology was suggested by a possible past myocardial infarction and a strong family history of MI.

First began to dement at the age of 62 years old. Initially he had an accident at home and was subsequently not able to look after himself and went into long-term care. He also had a diagnosis of Parkinson’s, depression and normal pressure hydrocephalus (NPH).

The clinical diagnosis was of an Alcohol-related dementia.

At the time of the first assessment, he was 64 years old and living in a nursing home. He was on Madopar and Aspirin.

A CT scan done in May 1995, revealed evidence of a lacunar infarct and was consistent with NPH.

He met the DSM3R criteria for severe Alcohol-related dementia.

Risk factors were: a possible stroke; a family history that a brother had had "fluid on the brain" and sister went "senile" prior to her death. But limited information was available on each. There was a history of heavy alcohol consumption, of 29 units /day, over 10 years.

Subsequently during the next year, there was a gradual deterioration, with reduced mobility, and reduced ability to eat and swallow. He seemed less willing, or able to communicate, and his mood was lower. He was admitted to hospital on 27/4/95, with a stroke and secondary fitting. On 17/5/95 he was discharged back to the nursing home and died there on 24/5/95. No post-mortem was done.
First began to dement aged about 63 years old. The family noticed he had been depressed in 1989, and appeared not to be coping at work, nor sleeping well. When he was 64 years old, he had a possible small stroke. Despite a course of anti-depressants, the problem worsened, and by 1994 he was a heavy burden for his wife to care for.

The clinical diagnosis was of presenile dementia, uncertain type, mixed Alzheimer's and MID.

At the time of the first assessment he was 69 years old, and in long-term hospital care. He presented as a small, rotund gentleman, walking slowly, constantly wandering and unable to communicate. The fairly sudden onset and fast progression to a severe level of impairment was striking. He was on anti-depressant treatment.

The CT scan done in January 1991, was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

The risk factors included: a possible stroke when he was 64 years old; and a history of having been a boxer.

Subsequently during the year, the changes were gradual, and he was speaking little if at all. He was slower on his feet, but still active, and had increased tone on neurological examination. Mild orofacial dyskinesia was also present.

First began to dement aged about 56 years old and was referred at the age of 60. The family noticed in 1989, he was forgetful and
by 1993, when he was 60 years old, he was following his wife constantly, engaging himself with purposeless activity. He had developed incontinence too. Other notable features were his depression and insight (early on in the illness) and subsequent mood changes. He had then assumed an overwhelming placidity. He had suffered from Neuroleptic Malignant Syndrome in 1993.

The clinical diagnosis was of presenile-onset dementia, of uncertain type.

At the time of the first assessment he was 61 years old, and in long-term hospital care. He presented as a severely demented and easily agitated man, whose mobility was excellent. He tended to laugh every so often, for no apparent reason, but was unable to establish communication.

No scan result was available.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

The risk factors included a history of possible stroke (date uncertain); and a family history of his mother having had dementia and dying in her 70's.

Subsequently during the next year, the changes were of a continued gradual deterioration, but nil specific. He remained extremely mobile. The neurological examination was limited as he tended to avoid any attempts to be examined.

First began to dement at the age of about 63 years old, and was referred at the age of 65. The family noticed she was repeating questions, and becoming increasingly forgetful, putting things in the wrong places and losing things. By the next year she was
confusing the day and night and swearing (which was out of character for her). Other notable features were that in 1990, she had fallen and had had a head injury. Since then, her mobility and general level of functioning, had been worse. The involvement of services, early on in the illness, had been very patchy, and was complicated by the spouse's own depressive illness.

The clinical diagnosis was of Multi-infarct dementia.

At the time of the first assessment she was 71 years old, and in a nursing home. She presented as a small, quiet lady, bent over in her chair and walking with assistance, with a stooped gait and small steps. She was on treatment for epilepsy and on Aspirin.

No scan report was available.

She met the DSM3R criteria for severe Multi-infarct dementia.

Risk factors included a family history, of her brother developing dementia in his early 70's. Also, the head injury in 1990.

Subsequently during the next year, the changes were minimal. At the examination, she was very drowsy, occasionally mumbling, yawning and picking her nose. Her mobility had also deteriorated.

Was first noticed by his family to have cognitive problems at the age of about 48 years old.

The clinical diagnosis was of an Alcohol-related dementia.

At the time of the first assessment he was 53 years old. At the time he was living at home with his wife, who found his angry outbursts difficult to deal with. She was also drinking heavily. He
presented as a young-looking man, with a reasonable social facade, stating that "there's nothing wrong with me, I'm wasting your time". One notable feature was a history of epilepsy for which he was on treatment.

No scan result was available.

He met the DSM3R criteria for moderate Alcohol-related dementia.

The risk factors included: a possible stroke; a head injury in 1954, with loss of consciousness and a right frontal fracture; a family history of his mother having had senile dementia; a past occupation as a plumber; a heavy alcohol history of 5 units daily over a four year period at least.

Subsequently over the next year, the changes were of a continued and slow decline.

**ml126.**

First began to dement at the age of about 57 years old. The family noticed very subtle changes, like her having difficulty making sandwiches. She occasionally lost her sense of time, and her memory gradually deteriorated. She found handling money difficult, and would misplace things.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment she was 62 years old and in long-term hospital care. She presented as a small, docile lady, with a slow, stiffened gait, and no spontaneity. She was on Warfarin after a deep venous thrombosis.

A CT scan result (date uncertain), showed a moderate degree of generalised atrophy, especially of the temporal/ frontal lobes.
She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

No potential risk factors were identified.

Subsequently during the year, the changes were of a continued gradual decline. She deteriorated in her physical health due to cancer of the breast and died of widespread disease in September 1995.

First began to dement at the age of 55 years old, and was referred at 61. The family noticed objects were misplaced, and she had difficulty working the kettle, and had to be accompanied home on occasions. There was a deterioration in her housework, and she became muddled when cooking. Her memory, reading and writing worsened.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment she was 66 years old and in long-term hospital care. She presented as a frail woman, who was unable to communicate, and was grimacing and twitching continuously.

Her husband recalled how he would get frustrated with her and then feel bad, since she was ill. He, like many other carers, emphasised the difficulty in accepting long-term care.

The result of a CT scan done in October 1986, showed mild generalised atrophy.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.
The only identifiable risk factor was of possible past hypertension.

Subsequently during the next year, the changes were of a continued deterioration, with worsening mobility being the most apparent change (since many other features were already at the worst level). There was also marked worsening of bilateral arm contractures, and her face appeared asymmetrical. She was agitated and apparently distressed by any attempt at examination.

First began to dement at the age of about 63 years old, when her friend noticed a deterioration in her whilst on holiday. She was getting mixed up with dates and leaving her luggage behind.

The clinical diagnosis was of presenile dementia, uncertain type.

At the first assessment she was 71 years old and in a nursing home. She presented as a quiet lady, incapable of verbal communication, who was constantly chewing and had a pill rolling tremor of her right hand. She wandered about constantly and slowly.

A CT scan done in November 1986, was normal.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

There was no known history available from anyone who had known her premorbidly.

Subsequently during the next year, the changes were of a gradual deterioration and slowing-up.
First began to dement aged 59 years old, and was referred at 63. In about 1987, her memory began to deteriorate, and there were problems at work. She believed her money was being stolen, and she was forgetting and hiding things. In 1991 she had other paranoid beliefs and low mood. Apart from her memory loss, there were signs of dyspraxia.

The clinical diagnosis was of uncertain dementia type, Alzheimer's or MID dementia.

At the time of the first assessment, she was 65 years old. She was living on her own at home, with the support of two close friends. She presented as a dishevelled-looking, vague, but pleasant lady, with weakness of her right arm, resembling an old stroke. She was unable to cook for herself properly, and wasn't coping with the telephone. The CPN was contacted.

A CT scan done in November 1991, showed general atrophy.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

Apart from a possible infarct, there were no obvious risk factors.

The gradual deterioration continued, but she was still at home with home help, nurse, club attendance and CPN follow-up. Testing revealed a marked further decline in her praxic skills. She couldn't pull her pants up and believed her parents were still alive, but appeared cheerful and superficially appropriate.
First began to dement aged 56 years old. The family noticed that two days after an eye operation, he had "funny turns" every few weeks, when he was confused and unpredictable, disorientated, and needing to be fed and clothed. These would last a few days, and became less frequent with time. When assessed at the hospital, there was evidence of nominal aphasia, poor short-term memory, perseveration, apraxia, acalculia and lability. Other notable features were a history of Insulin Dependent Diabetes Mellitus for 16 years. He also bred exotic birds.

At the time of the first assessment he was 58 and living at home.

A CT scan (date uncertain), was normal.

He did not meet the criteria for DSM3R dementia.

Risk factors included: cardiovascular factors; possible TIA or stroke underlying the (acute) confusional episodes; and there was also a reported head injury.

Subsequently during the next year, the changes were of a deterioration in health, and his subsequent death 9/12 later. On the death certificate was Hepato-Renal Syndrome, cirrhosis, and respiratory tract infection.

Since this was only a possible case after the first assessment, and required a re-test, and since this was not possible, the case has to be excluded.

First began to dement at the age of about 55 years old, and was referred at the age of 62. The family noticed that in 1981, when he went off sick, he had lost confidence driving his bus. His
routine went, and his mood changed rapidly from placid to argumentative. In 1984, he was diagnosed as having an anxiety neurosis and by 1988, when he was 61, probable Alzheimer's Disease. He had non-fluent dysphasia, naming difficulties, dyspraxia, disorientation and poor memory. By 1990, he was becoming aggressive and increasingly difficult to manage because of his violent outbursts.

The clinical diagnosis was of presenile dementia, uncertain type, likely Alzheimer's dementia.

At the time of the first assessment he was 67 years old, and in long-term care. He presented as a small, skinny man with a beard. This was significant because any attempt at shaving was too distressing an ordeal for all concerned. He intermittently became extremely agitated at being examined and began shouting. A blood test was impossible. He kept up a constant, incoherent chant. He remained very mobile and was constantly moving about. His gait appeared to be abnormal with tiny shuffling steps.

A CT scan done in September 1988, showed moderate cortical atrophy.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

The only identifiable risk factor was a mild head injury in 1978, after which he had concussion.

Subsequently during the next year, the changes were minimal. The family noticed subtle defects in being able to hold a cup, and remembering to eat. His gait was slower.
First began to dement at the age of 48 years old, and was referred at the age of 52.

The family noticed in 1988, he tended to repeat himself and was generally more apathetic and tended to forget things. He seemed unable to follow simple instructions, and was generally more irritable, and had a disturbed sleep pattern. He crashed the car. He tended to ask his wife everything and couldn't manage his work. A course of anti-depressants were tried. The impairments became more noticeable, with dysphasia and dyspraxia.

The clinical diagnosis was of uncertain type, possible mixed Alzheimer's/Multi-infarct dementia.

At the time of the first assessment he was 54 years old, and was living at home with his wife and daughters, who were in their early 20's. He presented as a cheerful, slightly overweight man, with severe cognitive impairments, especially of nominal dysphasia, and with visual disorientation.

A CT scan done in April 1992, revealed general cerebral atrophy and a possible right parietal lobe infarct.

He met the DSM3R criteria for moderate Alzheimer's/Multi-infarct dementia, McKhann possible.

Risk factors included: hypertension (and treatment for this with enalapril); and a family history of a paternal grandmother with Parkinson's disease and a paternal aunt with late-onset memory failure.

Subsequently during the next year, the changes were of a continued decline, with marked visual disorientation, nominal aphasia and dependency on his wife's presence. He did not want
to attend any clubs, and had no insight into his being unwell, although seemed frustrated by not being able to communicate. He was needing increased supervision with the activities of daily living. He had a chatty manner and was able to make the occasional joke.

**im145.**

First began to dement at the age of about 55 years old, and was referred at the age of 57. The family noticed in 1990 a gradual deterioration in her short-term memory, and by 1992 a marked difficulty with visuo-spatial tasks and perseveration of speech. She was getting confused at her work as a telephonist. When her mother died in 1992, it was originally thought she was depressed, but then the clinical picture began to emerge.

The clinical diagnosis was of Alzheimer's dementia.

At the time of her first assessment, she was 58 years old. At the time she was living at home with her husband, and would be left alone at home for much of the day. She presented as a small, gentle, pleasant lady with a degree of expressive and receptive aphasia. At both assessments she was participating in the tacrine trial.

A SPECT scan done in November 1992 showed reduced flow in the frontal and temporal regions. A CT scan was reported as normal.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

No risk factors were identified.

Subsequently during the next year, the changes were gradual, and she would attempt to maintain a conversation, but have no
ability to actually keep to the topic in any meaningful way. Her husband also reported her to be hallucinating and deluded, and to have become more labile and slightly more hostile. She had a habit of rolling lavatory paper, picking at her hands, and repeatedly washing the dishes.

First began to dement at the age of about 59 years old and was referred at 60. The family noticed in 1990, she seemed stressed at a time when her father was unwell, but it was her failing memory that caused the family concern. She was forgetting the shopping, appointments, numbers and names. She needed increasing help with her finances, and gradually required more supervision at home. By 1993 she was disorientated during the day, and waking early. There was then a marked deterioration. She had been treated for childhood epilepsy with Phenobarbitone, and had been on the Tacrine trial.

The clinical diagnosis was of uncertain dementia type.

At the time of the first assessment she was 62 years old, and in a nursing home. She presented as a pleasant lady of medium build, who displayed mild mouth twitches. Her gait was of unsteady, slow, small steps.

No CT scan was available.

The patient met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors included the history of an uncle developing Parkinson's in his 80's and a great uncle with a possible dementia.
Subsequently during the next year, the changes were of a general decline. Some new neurological features had developed by the second examination.

**gm149.**

First began to dement at the age of about 44 years old. The family noticed she was repeating questions and appeared forgetful. The clinical diagnosis was of Korsakoff's Psychosis, secondary to alcohol abuse.

At the time of the first assessment she was 45 years old and inappropriately placed in an acute hospital ward. She presented as a young woman, with no neurological abnormalities and a reasonably intact social facade. However, severe behavioural problems were reported by the nursing staff. Other notable features included incidents of self harm in association with severe personality change, as a result of Korsakoff's Psychosis.

She met the DSM3R criteria for moderate Alcohol-related dementia.

The only risk factor identified was an uncertain amount of alcohol in the past.

Subsequently during the year, the changes were of only a minor type. In some respects she appeared to be improved slightly in her memory and orientation, but her aggressive outbursts were more marked. The staff reported no significant changes in other areas.

**mm151.**

First began to dement at the age of 59 years old, and was referred at 62. The family noticed her memory was impaired, and she was disorientated. She would become forgetful when out
shopping, and get lost. She was prone to mood swings and forgot how to use her key. Her husband was drinking heavily, and this hindered the involvement of the services. However, she did attend day care.

The clinical diagnosis was of dementia of uncertain type.

At the first assessment she was 68 years old, and in long-term care, where she had been admitted with pneumonia. She was on Aspirin.

A CT scan done in 1988, was normal.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors were: 2 MI's, 1979 and 1984; and a family history. Her own mother had died at 72 from a stroke and was said to be demented, and an uncle was in hospital with memory problems.

She died under two months after the first assessment. On the death certificate was bronchopneumonia, but no post-mortem was done. Clinically, a stroke had been queried at some time before death.

jm154.

First began to dement aged 53 years old, and was referred to the memory clinic at 55. In 1991, she was forgetting what had been said and having made arrangements, and was repeating herself. By 1994, a course of anti-depressants was tried, but she did not complete the course. She had to stop her work in the bank, as she was getting muddled, and had difficulty with new procedures. She was tearful and frustrated with the situation.

The clinical diagnosis was of a possible dementia.
At the first assessment she was 56, and living an independent life at home with her husband, and was still driving. She established good rapport, and was socially skilled with normal judgement, and ability to discuss the problem rationally.

A CT scan done in March 1994, was normal

She met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

There was a family history, as her mother had had dementia in her 70's.

Subsequently during the next year, she felt that there had been a decline and was very distressed by the effect on her life. She was reported to be irritable and weepy, blaming herself for things and low in mood, with some degree of hopelessness at the situation. There were no problems with the activities of daily living.

The diagnosis would need to be confirmed in due course.

First began to dement at the age of about 65 years old. The family noticed he had memory lapses, confusion, disorientation, and was losing things. He had a degree of dysphasia and dyspraxia and seemed more irritable. He was less hygienic and unable to use household appliances. There had been an extremely rapid decline in his functioning.

The clinical diagnosis was of possible Alcohol-related or vascular dementia.
At the time of the first assessment, he was 66 years old and in long-term hospital care. He presented as a man with severe aphasia and apraxia, and reduced concentration span.

A CT scan done in October 1994, revealed general atrophy.

He met the DSM3R criteria for severe Alcohol-related/Alzheimer's/MID dementia, McKhann possible.

Risk factors included: history of hypertension; cessation of heavy alcohol consumption in 1993, of 10 pints a day over a 20 year period; and a family history of his mother and two aunts, having been reported as confused.

Subsequently during the next year, he declined more, and was transferred to a long-stay old age psychiatry bed. He had to be moved with a hoist, and could not support himself standing, and his speech was much reduced, to semi-formed words. He barely communicated, and appeared to be rather twitchy, but with a very strong hand grip. He occasionally slapped the side of his chair.

First began to dement at the age of about 47 years old, and was referred at 52. In 1985 after an operation on a bladder papilloma, his speech was stuttery, and he could not do his time sheets, or manage simple maths and had a pessimistic attitude. By 1987 his memory was worse, and he had problems tying his tie and writing. He was aware himself of becoming slower, and poor concentration, and the family noted a personality change. By 1993, he was disorientated, and had marked tremor and involuntary movements. He had the sensation of pins and needles and electric shocks in his legs. At this time he was stressed at his work as a plumber. He had had an Orchidectomy and radiotherapy in 1979.
The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment he was 57 years old and in long term hospital care. He presented as a tall, stooped man with a shuffling Parkinsonian gait and tremor.

His wife had found it very hard when he went into long-term care, although she had been under a huge strain previously, with the burden of washing and his constant wandering. She also described the difficulty of their teenage son in dealing with the illness.

A CT scan done in October 1988, was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable. The illness was clinically very like Lewy Body dementia, as he had features of this, including severe Parkinsonism.

Subsequently during the next year, the changes were of a continued deterioration, with weight loss. There was loss of activity, agitation and marked worsening of the jerky movements.

First began to dement aged about 56 years old, and was referred aged 57. The family noticed she was losing her keys and purse and forgetting how to cook. She needed help doing things and was wandering and saying odd things. She was unmotivated and became restless, and her short-term memory deteriorated.

The clinical diagnosis was of Alzheimer's dementia.
At the time of the first assessment she was 65 years old and in long-term care, where she had been for five years. She presented as a completely unresponsive, bed-bound lady.

A CT scan done in 1985, had revealed diffuse cerebral atrophy.

She fulfilled the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

The main risk factor appeared to be a family history, as an aunt had had a moderate dementia at the age of 60.

Subsequently during the next year, the changes were minimal, but of a continued deterioration. There was an increase in her myoclonic jerks and an occasional grand-mal seizure occurred. By the second assessment, she was completely bed-ridden but physically stable.

**mm164.**

First began to dement aged 52 years old, and was referred at the age of 54. Friends and neighbours had become concerned. At the time, her mother was in a nursing home with senile memory loss.

The clinical diagnosis was of an uncertain type of dementia.

At the time of her first assessment she was 58 years old, and was on a long-stay ward where she had been admitted from a nursing home about 7 months before. She had been in the nursing home for about 4 years in total. A history of possible TIA's was given.

A CT scan done in August 1990, showed general atrophy and slight ventricular enlargement.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.
An identified risk factor was her mother having a dementia.

Subsequently during the next 6 months, she was very unsettled and hyperactive. She would push the furniture over and shout. She had severe extrapyramidal side effects, and this was exacerbated by neuroleptics. She had severe rigidity, hyperextension of the neck and difficulty swallowing. She died on 25/11/94, but no post-mortem was carried out.

First began to dement at the age of about 59 years old. The family noticed her becoming forgetful about past events, and also how to do things around the house. She appeared anxious, weepy, and unconfident, and did not want to be left alone. Her sleep pattern became disturbed.

The diagnosis was of a possible presenile dementia.

At the time of the first assessment, she was 59 years old and was living at home with her husband. She presented as an active lady, with a reasonable social facade and cognitive defects apparent on testing, but no abnormal neurological signs.

A CT scan done in January 1994, was normal.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

There was a history of possibly heavy alcohol consumption. She had kept this hidden from her husband. There were no other identifiable risk factors.

Subsequently during the next year, there was a rapid and dramatic worsening of her state, putting considerable strain on
her husband. He was negotiating the possibility of respite care for her. The main changes had been during the four months before re-assessment. She appeared to be more shakey, distant, with reduced comprehension and ability to communicate. She looked anxious and performed extremely badly on testing.

**mm169.**

Was first noticed to have memory problems aged about 61 years old. She had a diagnosis of severe rheumatoid arthritis and in 1989, had a fairy acute episode where she appeared agitated, confused, disinhibited and odd. For example, she placed fresh flowers in the bin and pilfered objects. Her concentration and memory appeared bad at the time, and some memory deficit persisted afterwards.

The clinical diagnosis was of a possible dementia.

At the time of the first assessment, she was 64 years old, and living at home with her husband. She presented as a severely disabled, pleasant lady, with memory impairment. She was socially intact, with no real evidence of personality deterioration. She was on anti-depressant medication.

No scan was available.

She did not meet the DSM3R criteria for dementia. She was therefore in the possible group, for re-assessment at follow-up.

Subsequently during the next year, the changes were of a deterioration of her physical health, and she had an attack of shingles which also affected her left eye badly. Her arthritis was also worse, and yet there was no obvious worsening of her behavioural or cognitive state. She was excluded from the study.
First began to dement at the age of 54 years old, and was referred at 60.

The family noticed her memory and concentration worsening. She was not as well turned out, and the quality of the housework deteriorated. She went through a phase of buying vitamin tablets and health magazines, perhaps sensing something was wrong. She left many aide memoires around. The first four years were of a slow deterioration, followed by a fairly rapid deterioration, with the last four years or so being of minimal change. She had been treated for Hashimoto's Disease with Thyroxine.

The clinical diagnosis was of presenile dementia, of uncertain type.

At the time of the first assessment, she was 64 years old. She lived at home with her husband, with respite every 8 weeks, and day hospital attendance. She presented as a very active lady, and it was very hard to examine her, as she was constantly on the move, laughing to herself and babbling nonsense. No eye contact was established.

A CT scan done in 1988, showed atrophy.

She met the DSM3R criteria for moderate Alzheimer's / MID dementia, McKhann possible.

The only identifiable risk factor was hypertension.

Subsequently during the year, she had several bad falls. She had head staples for this, and then she wore a crash helmet. Her expression was worried.
First began to dement at the age of 54 years old, and was referred aged 58. When he was about 50, he broke his shoulder and jaw in a fall. By the late 1980's, his memory impairment was more obvious, and there was concern for his physical and mental state. He had low mood, poor appetite, weight loss and apathy.

The clinical diagnosis was of Alcohol-related cognitive impairment.

At the time of his first assessment, he was 58 years old and living at home with his wife. He presented as a man with a broad-based gait.

A CT scan done in January 1993, showed atrophy of cerebrum and cerebellum.

He met the DSM3R criteria for mild Alcohol-related dementia.

Risk factors included: a past history of head injury; and alcohol consumption of 50 units weekly for 3 years.

Subsequently during the year, the changes were of a continued overall decline. He deteriorated fairly suddenly about three months prior to his death, becoming incontinent, irrational and less able to walk. His wife reported only moderate alcohol consumption. He was admitted to hospital with alcoholic liver disease, and encephalopathy, probably precipitated by sepsis, and died in March 1995. No post-mortem was done.

First began to dement at the age of 52 years old, and was referred aged 57 years, in about 1988. The family noticed that in 1984, she had seemed unhappy to be left alone, and had
difficulty remembering words, saying "thingummy" instead. By 1986, her personnel hygiene was worse, and her ability to cook and do the housework reduced. By 1987 she was progressively more disorganised.

The clinical diagnosis was of presenile dementia of uncertain type.

At the time of the first assessment, she was 63 years old and in long-term hospital care. She presented as a tall lady, who walked with small steps and repeated phrases like "don't do that". She had late-onset Diabetes Mellitus which was diet-controlled. The dementia had been of long, slow progression.

No scan result was available.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Subsequently during the next year, the changes were severe. She was extremely aggressive, hitting out and shouting, whilst maintaining a cold stare during the assessment. She was also hyperactive, and required periods of restraint, as well as continuing on a large dose of neuroleptics. Her speech was more incoherent, and the extrapyramidal signs more evident, though she was able to take large steps on walking. There were also the emergence of abnormal movements (pelvic thrusting and mouth twitching), and marked primitive reflexes.

First began to dement at the age of about 51 years old, and was referred at the age of 60. His wife gave up her work in 1984, because she was worried about him, especially after a holiday. He was diagnosed aged 52, after which there was a progressive deterioration. It was taking him hours to fill in a cheque. His
personality had changed, and he seemed anxious, withdrawn and fatigued and seemed to forget instructions. He was panicky and seemed less able to cope generally. Gradually, over the next four years, he became unable to do household chores, and did odd things like putting newspapers down the lavatory. He was inappropriate with strangers, and incontinent of urine. Once he had taken his hands off the wheel when driving, and had sold the family car for scrap.

The clinical diagnosis was of Alzheimer's disease.

At the first assessment he was 63, and living in long-term care in hospital.

A CT scan done in 1988, was normal.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors were: a head injury in 1984; a family history of an aunt and grandmother on the maternal side, and an aunt on the paternal side, having had dementia. He had worked in a slaughter house as one job.

Subsequently during the next year, his mobility became severely restricted. He only tended to move his arms, and had become very hypertonic, with an arched back. Twitchy, jerking movements were apparent. He had been treated with Madopar for his hypertonicity, with limited effect.

ao182.

First began to dement at the age of about 56 years old, and was referred at 60. Her brother described a gradual onset to her problems, at a time when she was drinking heavily. She was unable to cope at home, and by 1991 had to be admitted to a
nursing home. In 1993, she had a severe dysphasia, was restless and disoriented, had poor self care, and was wandering. She could not be looked after in the nursing home and was transferred to long-stay hospital care.

The clinical diagnosis was of early-onset dementia, of uncertain type, with features of Alcohol-related, Alzheimer's and MID.

At the time of the first assessment, she was 64 years old and presented as a placid lady, who tended to pick her dress up as she walked. She laughed inappropriately too. Her gait was fairly normal, but there was loss of arm swing, and she listed over to the right.

A CT scan result (date uncertain), showed general atrophy.

She met the DSM3R criteria for severe Alcohol / Alzheimer's / MID dementia, McKhann possible.

Risk factors included: a history of hypertension; an ECG-diagnosed MI; a family history. Her mother had dementia and died at 76, after an MI, and a maternal grandmother was said to have been demented and wandering. She had also dunk alcohol heavily, an unspecified amount for about four years.

Subsequently during the next year, the changes were of a gradual decline, and a possible stroke, after which she became less active. There were apparently some visuo-perceptual difficulties, like getting stuck behind a chair, or in a corner.

go184.

First began to dement at the age of about 53 years old, and was referred at 59. The family noticed in 1983, she was forgetting where she had put things, and sometimes drifted off in conversations. She tended to wander, and was unable to do
certain things. She was forgetting recipes, and her handwriting changed. In 1985, she was seen by her doctor because of anxiety, but by 1988, the memory problems were evident.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment, she was 64, and was in long-term hospital care. She also had a history of diet-controlled Diabetes Mellitus and hypothyroidism.

A CT scan done in June 1988, revealed general cortical atrophy.

She met the DSM3R criteria for severe Alzheimer's / MID dementia, McKhann possible.

One risk factor was a history of hypertension.

Subsequently, she developed jerkiness and epileptiform seizures. Baclofen did not appear to help her increasing rigidity. She was very contracted, whimpering, with a blank expression, blinking occasionally.

First began to dement at the age of about 55 years old, and was referred at 62. The family noticed that in 1981, she was gradually forgetting where she had put things and what she had said. By 1986, she was much less able to do everyday activities. Also of note was a history of a nervous breakdown in 1969, and previous heavy alcohol and Sodium Amytal abuse. There was also a query of her having had a TIA in 1977. She had diet-controlled late-onset Diabetes Mellitus.

The clinical diagnosis was of a possible dementia, Alcohol-related or MID.
At both assessments, she was living in a nursing home. At the first assessment, she was 67 years old, and presented as an elderly-looking, quiet lady, who had a reasonable social facade. She was rather frail, and was in bed for a rest in the afternoon. She listed to the left when walking, because of an old hip fracture, and had some fluctuating neurological signs. Her cognitive ability was slightly patchy.

No scan was available.

She did not meet the DSM3R criteria for dementia.

Risk factors included: a history of hypertension; TIA's; past heavy alcohol use of 15 units daily for 15 years.

Subsequently during the next year, the changes were of some deterioration according to the nursing staff. Occasional bizarre behaviour, pilfering and urinary incontinence was reported, especially at night.

There was no clear deterioration by the second assessment.

mo188.

Began to dement aged about 53 years old, and was referred at 57. Not much detail was available, but the subtle changes began in the early 1980's after she had had a mild stroke in 1981. After this she was on Aspirin. She also had diet-controlled Diabetes Mellitus.

The clinical diagnosis was of Alzheimer's / MID.

At the time of the first assessment, she was 67 years old and in long-term hospital care. She presented as a small, frail lady, in a chair.
Her husband admitted that coping with her aggression had been hard.

A CT scan done in 1981, showed an old infarct.

She met the DSM3R criteria for severe Alzheimer's / MID dementia, McKhann possible.

Risk factors included: stroke; hypertension; and in July 1991 (during the illness ) a head injury.

Subsequently during the next year, she became bed-bound. Her eyes did not appear to focus, but were able to follow objects, and she occasionally raised her eyebrows. She would push her tongue forward. She appeared very anxious, and was occasionally distressed by being examined. She had mild jerky movements, especially in her lower limbs, and had extreme flexion. There was hypertonicity and hyperreflexia.

First began to dement aged about 59 years old, and was referred at 61. The family noticed in 1986, she was asking her daughter to manage thing such as the money, when they were out. In 1988 when she was 61, her memory was obviously impaired. The family noted her mood had been low since a Cholecystectomy operation.

The clinical diagnosis was of possible MID.

At the first assessment she was 67 years old and in long-term care. She presented as an anxious, chair-bound lady, who was very fidgety, with twitchy legs and continuous oro-facial sucking, and a fixed right arm contracture. Generally, she had less movement on her left side. There was also the possible diagnosis of Parkinson's Disease.
Her daughters felt that there had been great difficulty in the professionals coming to a diagnosis.

A CT scan done in May 1988, showed nil focal.

She met the DSM3R criteria for severe MID.

Risk factors included: a history of stroke; hypertension; and a family history of her mother having had an early-onset form of possible MID. She had died of a stroke at the age of 72.

There were no real changes over the year, and it was reported that nor had there been, over the past 3 years.

First began to dement at the age of 56 years old, and was referred at 58. The family noticed in 1990, she was having difficulties at meals e.g. laying the table, and timing food preparation. She had problems writing, lighting the fire and sequencing actions. She was mislaying things, which she would accuse others of stealing. She would leave the door open, her bag in odd places, and had dysphasia. By 1994 she was aggressive and agitated. Other notable features were an extensive vascular history, of Ischaemic Heart Disease (IHD) since the 1970's (femoral-popliteal vein bypass, balloon angiography of the lower aorta, intermittent claudication, abdominal claudication and an aortic mesenteric graft (in 1989).

The clinical diagnosis was of uncertain type, Alzheimer's (by the scan) and MID (from the past medical history).

At the time of the first assessment she was 60 years old, and at home with her husband. There was good input from sitters,
occasionally overnight. She presented as a restless and rather aphasic lady. She was on anti-depressant treatment.

A CT scan done in March 1993, showed marked cerebral atrophy, especially of the dominant parietal-occipital lobe.

She met the DSM3R criteria for moderate Alzheimer's / MID dementia, McKhann possible.

Risk factors included: HI in 1960 (cycling accident); and those for MID as above.

During the following year, there was a rapid decline and she became much more aggressive, abusive and irritable, and was also violent towards herself. She started having convulsions with increasing frequency, causing her to fall. After one, there was a reported personality change. She became more incoherent, lost weight, and looked much older. Occasionally she seemed more lucid and would say she wished she was dead. Day care and nursing home placement failed and she was admitted to long-stay care.

By the second assessment she met the DSM3R criteria for severe dementia. She was constantly on the go, dysphasic and not eating. She was rather irritable and constantly mumbling nonsensical phrases, in an annoyed manner. She had marked myoclonic movements and some extra-pyramidal features.

First began to dement at the age of about 46 years old, and was referred at the age of 48. The family noticed in 1986, she was shopping inappropriately, and her spelling was poor. She was reluctant to go to see the doctor. By 1987, the diagnosis had been made, and she had nominal dysphasia and poor short-term memory, and was unable to cook or shop, and her social skills
deteriorated. By 1989, she was disorientated and dyslexic, and displayed frontal euphoria, disinhibition and indifference. Her husband had already given up work.

The clinical diagnosis was of Alzheimer's or Pick's Disease.

At the time of the first assessment she was 52 years old and in long-term hospital care, where she had been admitted in a hyperactive state in 1991. She and presented as a gaunt lady with staring eyes. She had severe bruxism and a severely contracted right hand.

A CT scan done in March 1987, showed atrophy of the temporal and left parietal lobes. A SPECT in June 1989 showed severe atrophy especially of the left frontal lobe.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

There was a strong family history, as a maternal uncle and her mother had had autopsy-proven Alzheimer's.

Subsequently during the next year, the changes were of a gradual deterioration, with a possible minor stroke, leaving right-sided weakness for a week or so. She was generally less active, and only walking when continuously prompted to do so.

**jp195.**

First began to dement at the age of about 54 years old. He was made redundant in 1981 and began acting oddly, and became absent-minded. On one occasion he was found crawling on the floor. A stroke and depression were queried. His memory continued to deteriorate, and he became extremely anxious. He had been investigated for headaches in 1979.
The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment he was 67 years old, and in long-term care. He presented as a man with constant oro-facial grimacing, and small, generalised, writhing twitchy movements. He was unable to support himself and walk. Occasionally he made a roaring sound. There were some extra-pyramidal features, and he was sensitive to neuroleptics.

A CT scan done in 1987, was consistent with Alzheimer's disease and showed moderate cortical atrophy.

He met the DSM3R criteria for severe Alzheimer's dementia. McKhann probable.

No risk factors were identified.

Subsequently during the next year, the changes were of a continued decline. He looked weary and wasted, and chewed his hand, and displayed other examples of hyperorality.

**jr200.**

First began to dement at the age of about 57 years old, and was referred at the age of 61. The family noticed in 1986, that the diary she kept had signs of the illness onset. In 1988 the first contact with the hospital was made and by 1993, she had stopped communicating.

The clinical diagnosis was of Alzheimer's dementia.

At the first assessment she was 65 years old and in long-term care, where she had been since 1992.

She presented as a small lady, with a docile manner, occasionally murmuring a word and tightly gripping any nearby objects.
Her son said he found her previous aggressive behaviour and repetitiveness hard to deal with, as well as seeing her own distress at the situation.

No scan report was available.

She met the DSM3R criteria for severe Alzheimer's / Multi-infarct dementia, McKhann possible.

Risk factors included: a previous stroke; past history of hypertension; and a family history of a brother developing Parkinson's and being confused in his 70's.

Subsequently during the next year, the changes were of a gradual continued decline, with the nursing staff now having to use a hoist to move her, as she was chair-bound.

First began to dement at the age of about 63 years old, and was referred at 64. The family noticed in 1988, his voice was becoming a whisper and in 1989 he was gazing into space and not able to count properly. His writing was scribbly and he was generally vague. In 1990 he was having problems with excessive salivation, and his confidence and memory were poor. He was having word-finding difficulties, and found numerical manipulations hard. The deterioration continued, and by 1991 there was evidence of constructional problems, and reduced ability to drive or play golf.

The clinical diagnosis was of uncertain type, Alzheimer's/MID. Associated Parkinsonism and visual hallucinations raised the possibility of Lewy Body dementia.
At the time of the first assessment, he was nearly 69, and at home. He presented as a very docile man, who spoke with a whisper and had minimal responses. He was on Paroxetine, Bedrofluazide, Aspirin, Madopar and L-Dopa. He was not keen on attending the day hospital and his wife felt more help at night would be useful.

CT scans from June 1990 and March 1991, were normal.

He met the DSM3R criteria for moderate Alzheimer's dementia, McKhann possible.


Subsequently during the next year, he greatly deteriorated, and by the second assessment was bed-ridden in long-term hospital care. No cognitive testing was possible. He had contracted hands, and his legs and feet were flexed. He had jerky movements of his limbs and a mild tremor. He appeared to be watching things about him, and occasionally mouthed a word. He would clutch at nearby things. His severity rating was now severe.

\textit{ir203}.

First began to dement at the age of about 57 years old. The family noticed in 1992, when MID was queried, she was depressed and tearful. After a stroke, she became slightly dysphasic and labile. She was admitted to long-term care, as she was asking strangers into the house, and falling out of her chair.

The clinical diagnosis was MID.

At the time of the first assessment, she was 60 years old and in a nursing home. She presented as a slightly dishevelled, tearful lady, in a wheelchair. She constantly asked what day it was, and when her daughter would visit. She was on anti-depressants,
anti-epileptics, and heart medication (including Amlodipine, Frusemide, Digoxin, Aspirin, Lisinopril). She also had diet-controlled Diabetes Mellitus.

Her daughter found her mother's lability and questioning difficult. She felt it had been hard for her brother to do some of the intimate caring when her mother had been at home.

No scan was available.

She met the DSM3R criteria for severe MID.

Risk factors were: a history of stroke; TIA's; hypertension; IHD; possible past heavy alcohol consumption; a possible family history as her mother's sister had been reported as having poor memory, in her 80's.

Subsequently during the next year, she was moved to a different nursing home, and had had her left leg amputated. She had some depressive delusions and possible nocturnal hallucinations. Otherwise, no real changes were apparent.

First began to dement at the age of 57 years old, and was referred at the age of 60. The family noticed in 1983, he was different after his Triple Bypass operation and had memory problems, irrational behaviour, and was tending to get lost and was generally slower. He had a tendency to hoard stones in his pockets and store them in the garden.

The clinical diagnosis was of dementia, uncertain type, Alzheimer's or MID.

At the time of the first assessment he was 68 years old and living at home with his wife. He presented as a very docile, but
unresponsive man. Other notable features were that his wife felt there had been big changes after he had had Quinsey's about three years before. He was diabetic and treated with Glipizide.

His wife described feeling "run into the ground", and found his inappropriate urinating particularly difficult to deal with.

No scan result was available.

He met the DSM3R criteria for severe Alzheimer's / MID dementia, McKhann possible.

There was a family history as his mother, who died at 68, was said to be confused prior to her final stroke. His father had died of a stroke at 69, and his brother had hypertension. Also, a cousin had had a dementia. He had been abroad in India, and had also had a possible stroke. It had begun when he was 53, and he had had Parkinsonian features. Other risk factors for the subject were: a HI aged 11 years old; and vascular risks included angina and bypass surgery in 1957 and 1983.

Subsequently during the next year, the changes were of gradual deterioration, and he became unable to use the lavatory for urination. He was admitted to long term care in September 1995. He seemed very content and relaxed.

ir212.

First began to dement at the age of about 62 years old, and was referred at 64. The family noticed memory problems, insidious in onset but then fairly stable. Other notable features were a past history of depression and Poliomyelitis.

The clinical diagnosis was of a possible dementia of uncertain type.
At the time of the first assessment she was 69 years old, and was living at home independently. She presented as a pleasant, wheelchair-bound lady, with only memory impairment. Otherwise she was not confused, and apparently able to remember important events.

No scan result was available.

She did not meet the DSM3R criteria for dementia.

Subsequently during the next year, the changes were of severe health problems, as she was admitted to hospital with pancreatitis in July. Complications followed and she was seen at the rehabilitation hospital in February 1996. Apart from a spell of delirium during her illness, the nurses reported only occasional mild disorientation, but of a fluctuating nature. She still did not meet the criteria for dementia.

First began to dement at the age of about 56 years old, and was referred at 58. The family noticed that in 1987, he was struggling at work, increasingly forgetful and low in mood. He was forgetting names, and that he had done various things. He was made redundant in 1988. After that, his writing deteriorated and his general interest declined and he was sleeping much more. By 1990 he had poor memory, was disorientated, inactive and irritable, with poor self care.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment he was 63 years old and in long-term care. He presented as a very docile, chair-bound man. He had occasional jerky movements, and his mouth was open. His hands were very contracted, and he had very little spontaneous
movement. He was treated with Carbamazepine, and the introduction of baclofen appeared to help his rigidity.

His wife had found his going into hospital very hard. She seemed to have found appropriate supports and was coping and attended a group.

A CT scan done in 1990, showed generalised atrophy. Normal pressure hydrocephalus was queried, and enlarged lateral and 3rd ventricles seen.

He met the DSM3R criteria for severe Alzheimer's dementia, McKhann probable.

Risk factors included: a possible stroke; a possible HI; possible past alcohol abuse (he had worked in brewery); and a possible family history of his father becoming confused aged 82, and his mother having died at 59 of a myocardial infarction.

Subsequently during the year, he deteriorated after a chest infection. Dysphagia became a problem.

**ds219.**

First began to dement at the age of about 43 years old, and was referred at the age of 44. The family noticed that in 1992, he had memory problems and Lofepramine did not appear to help. He had impaired concentration and was reluctant to accept the diagnosis, or to stop driving. He was on a Tacrine trial for a while. He found it difficult to think things through, and was stressed at work with reduced confidence. He stopped work in 1993.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment he was 45 years old and was living at home with his wife and four teenage girls. He presented
as a somewhat gaunt man, with a rather vacant expression, who tended to perseverate on clinical testing. He was intermittently very low in mood despite the treatment with Lofepramine, and could in no way accept his diagnosis.

His wife described poor follow-up at the clinic, and difficulty coping with his verbal aggression and moodiness.

A SPECT scan done in June 1993, revealed bilaterally reduced temporo-parietal uptake, consistent with a diagnosis of Alzheimer's disease.

He met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

Risk factors included a family history, as his father had developed a presenile dementia in his 50's. There was also the possible history of a head injury in his youth.

Subsequently during the year, the changes were of a continued deterioration and a decline on cognitive testing. He now had nominal aphasia, and some difficulty dressing.

rs221.

First began to dement aged about 52 years old, and was referred at 57. The family noticed in 1986 onwards, he was increasingly forgetful and not coping at work, as he became tearful and indecisive.

The clinical diagnosis was of Alzheimer's dementia.

At the first assessment he was 60 years old and presented as a cheerful, chatty but dysphasic man. At that time he lived with his wife at home.
A CT scan (date uncertain), was reported as normal.

He met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

Subsequently during the year, the changes were of a severe deterioration. Parkinsonism was marked. Behaviour included wandering, and the door was therefore locked. He was taking off his clothes inappropriately, and constantly fidgeting, moving and touching objects. He appeared anxious and irritable, and muttered in whispers.

First began to dement aged about 61 years old, and was referred at 62. The family noticed that in 1991, just after his son's death, he was very low in mood while on holiday. In 1993 the memory deterioration was obvious, with difficulties in speech and persistent low mood.

The diagnosis was of likely Alzheimer's dementia.

At the time of the first assessment he was 64 years old, and living at home with his wife. At the time seen, he was going into his office for a couple of hours a day, and was on the Lazabemide study, and an anti-depressant.

A CT scan done in August 1993, showed enlarged ventricles, with a normal MRI scan, and NPH excluded.

He met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

Risk factors included a family history as his father had died at 78 with a dementia associated with alcohol. His mother died at 81,
apparently demented, and a maternal aunt died at 88 with mild Parkinson's.

He was not seen at the second assessment, due to family stress and the family's belief that his own reaction to testing would be unfavourable. During the next year, his daughter reported rapid deterioration. His gait was apparently slow and stooped, and he had stopped work and golf in the summer of 1995. His speech was worse, with general confusion more apparent. He was reported to be more irritable and upset about his state, but unable to communicate clearly. Contact with the hospital was over but the GP contact was excellent. He was refusing day club attendance. A health visitor and CPN were involved, and companion sitters were just about to begin visiting.

ks225.

First began to dement at the age of about 57 years old, and was referred at the age of 63. The family noticed in 1985 she gave up her work and at 61 (in 1989) she had difficulty making a bacon sandwich. She also had features of dysphasia, poor concentration, disorientation, poor memory and praxic difficulties, such as with dressing.

The clinical diagnosis was of possible dementia, MID or Alcohol-related.

At the time of the first assessment she was 66 years old and in long-term care. She was very distressed in appearance. At that time she was on Trazodone. Parkinsonian features had improved and these may have been drug-induced. She was on treatment for Non-Insulin Dependent Diabetes Mellitus, which she had had since 1988. There was also a history of two previous pulmonary emboli, in 1978 and 1980.
Her husband reported that her previous attendance at a day club had been invaluable, enabling him to go to work part time and so relieve financial difficulties.

A scan result in May 1992 had shown a possible infarct, as the right appeared hyper-perfused. There was nil focal otherwise, but some atrophy.

She met the DSM3R criteria for severe Alzheimer / MID / Alcohol-related dementia, McKhann possible.

Risk factors included: a likely stroke, January 1994; a family history of her mother having died of MID aged 84; and past heavy alcohol consumption, in 1960's, 20 units daily for about 10 years.

Subsequently during the next year, the changes were great. Following increasing unsteadiness, she had a fall in June and never got back on feet. She died in June 1995, and no post-mortem was done, but bronchopneumonia was recorded as the cause of death.

ms227.

First began to dement aged 63 years old, and was referred at 65. The family noticed in 1989, she was getting lost locally, seemed to lose her interest in things and had poor memory for recent events. She was laughing and humming during the night, and was repetitive and got lax in her housework and cooking. Whilst out, she would publically change her underwear after episodes of incontinence, and give money away. By 1991, she had emotional blunting, reduced drive and disturbed sleep. By 1992, she was mute and unable to feed herself. Her husband had not felt he wanted more help, although it had been a worry for him when he was still working. He had to be persuaded to allow her into long-term care.
The clinical diagnosis was of Alzheimer's or Pick's Disease.

At the time of the first assessment she was 68 years old, and in long term care. She presented as a frail, vacant-looking lady with twitchy movements. Her left hand was beginning to contract and her face slightly drooped on the left side. She was expressionless and silent, but appeared perturbed. She was on anti-depressant treatment with Trazodone.

A CT scan done in October 1991, showed dilated ventricles, especially of the frontal system. This was consistent with a diagnosis of Pick's Disease.

She met the DSM3R criteria for severe Alzheimer's dementia, McKhann possible.

Risk factors included: a history of hypertension; a family history of a maternal aunt and mother who had apparently demented in their 60's.

Subsequently during the next year, the changes were of continued deterioration. By the second assessment she was in bed all day, but getting up for meals. Her gait was unsteady, with clipping heels, no arm swing, but a reasonable stride, and she tended to list over. She stared at things, stroked the nurse's arm, and occasionally got startled. She was rigid, and the hand contracture was much more severe. There was pill-rolling tremor of her right hand.

**ss228.**

Was first noted to have some memory deficit when he was admitted to hospital for alcohol-related problems, at the age of 57 years old. The diagnosis was of possible cognitive decline,
secondarily to the alcohol abuse, of 90 units weekly over a period of about 20 years.

At the first assessment he lived an his own, and was 57, presenting as a plethoric man in his late 50's, living independently but with mild memory deficits. He continued drinking.

No scan was available.

He did not meet the DSM3R criteria for dementia.

A year later he was seen again, with his wife who had been living back with him. She described his memory as worsening, and that he occasionally got lost, and self-inflicted superficial lacerations whilst drunk. The drinking caused problems with the neighbours on occasions too. There was no real decline evident on testing.

as229.

First began to dement at the age of about 62 years old and was referred at 65. The family noticed in 1988 or earlier, her memory was gradually getting worse and in 1990 after her husband died, she sat around doing very little, not recognising people, and having problems cooking. She began to wander and by 1992 the situation had worsened. In 1959 and 1975 she had had operations, as a possible subarachnoid haemorrhage had been investigated, and an inoperable parieto-occipital arterio-venous malformation had been found. She was also on Phenytoin for epilepsy.

The clinical diagnosis was of possible MID.

At the time of the first assessment, she was 68 years old and in a nursing home. She presented as a pleasant lady who walked slowly, with a shuffling, small-stepped gait and stiff legs, and
knew her way around. There was slight weakness on her right side.

No scan was available.

She met the DSM3R criteria for moderate MID dementia.

Risk factors included strokes from 1958 onward.

Subsequently during the next year, she had a period of low mood, and was treated with anti-depressants, and had considerable insight: "its sad not being able to do the things I used to".

ms230.

First began to dement at the age of about 64 years old, and was referred at the age of 65. The family noticed in 1991, she was leaving taps and the cooker on, and was repetitive. In 1992, she was mixing up the knives and forks and appeared depressed. Her sleep was poor, and her overall state varied, but gradually declined. By 1993, involuntary movements were noticed.

The clinical diagnosis was uncertain type, Alzheimer's or MID.

At the time of the first assessment she was 68 years old, and had just gone into respite care, pending nursing home placement. She was on Prozac, Aspirin and Sodium Valproate for epilepsy.

Her husband was very distressed at such a rapid and devastating decline in her.

A CT scan done in July 1992, showed right frontal infarction, possibly lacunar type, with no haemorrhagic or expanding complications.
She met the DSM3R criteria for severe dementia, Alzheimer's/MID, McKhann possible.

Risk factors included: a possible stroke; and a familial history, of her father having had a stroke in his 70's, and both grandmothers being confused in their 90's.

Subsequently during the next year, she was transferred to a nursing home, shortly after she was seen. Her speech and mobility had declined. The nursing staff described occasional petit-mal episodes where she would stare into space. She had sustained a fractured shoulder due to a fall, during one of these episodes.

She occasionally said a word like thankyou (on primitive reflex testing) or "oh no", laughed or cried, and made blowing noises through her lips. She was chair-bound, with a urinary catheter in. Her arms appeared floppy, and occasionally twitched.

First began to dement at the age of about 63 years old, and was referred at 65. Her husband noticed in about 1989, she was wandering and dishevelled in appearance. She was aware that something was wrong. Her domestic performance gradually declined, and patchy defects became apparent in her cognitive abilities. In 1991, she was accusing her husband of having an affair, and became increasingly paranoid and unmanageable.

The clinical diagnosis was of MID, although Alzheimer's disease was queried.

At the time of the first assessment, she was 68 years old and in long-term hospital care, where she had been since 1992. She presented as a quiet, thin, reasonably alert woman. She had no real ability to establish rapport at the meeting. She appeared to
be easily startled, and was annoyed at the neurological examination I performed, exclaiming "stop it!". She walked with a Parkinsonian gait, small steps, stooping over and with no arm swing. She held her hands to her face at times, as if distressed.

Her husband avoided visiting as he found it too distressing.

A CT scan done in October 1990, showed a degree of cerebral atrophy.

She met the DSM3R criteria for severe Alzheimer's / MID dementia, McKhann possible.

Risk factors included a stroke reported in 1986 and a history of hypertension.

Subsequently during the next year, there was a mild degree of gradual decline, especially manifest by reduced mobility and worsening eyesight.

is234.

First began to dement at the age of 54 years old, and was referred at 56. The family noticed in 1987 his handy work was taking him longer. By 1991, his speech was slow, and he was having difficulties such as re-wiring a plug, or doing his buttons, and remembering things. By 1993 he was panicky, and suffering from visual hallucinations and delusions. The decline was rapid. He had been on Tacrine.

The clinical diagnosis was of dementia of uncertain type, Alzheimer's/MID/Lewy Body. Features suggestive of Lewy Body dementia were: Parkinsonism; hallucinations; neuroleptic sensitivity; fluctuations. Other features were more suggestive of MID, such as: marked depression and insight; personality
preservation at the start; nocturnal confusion; somatic concerns; a facial droop; and increased blood pressure.

At the time of the first assessment, he was 61 years old, and in long-term care. He presented as an agitated man, who attempted to throw himself out of his chair. No blood sample was possible.

A CT scan (date uncertain) showed no abnormality.

He met the DSM3R criteria for severe Alzheimer's/MID dementia, McKhann possible.

Risk factors included: a history of hypertension; a family history of his father having died at 81, of dementia; a possible head injury; and a possible alcohol history.

Subsequently during the next year, the changes were of continued deterioration. He made constant groaning, gurgly noises, and at times appeared amused. His fingers were beginning to contract. There was an overall change from a picture of being sad, irritable and agitated to anxious, lacking reactivity and retarded.

First began to dement at the age of 54 years old, when he was found to have some cognitive impairment when admitted to hospital with a delusional belief. He was followed up as he was felt to have a possible presenile dementia of uncertain type. He also had severe respiratory problems and had previously worked in a slaughter house. His father had had Parkinson's Disease in his 60's.

At the first assessment he was 55 years old, and living at home, essentially independently, with another tenant who was rarely in. A CPN was involved too. He presented as a slightly overweight
man, with a good level of self care, but rather a flat and expressionless affect and slow responses. He was on antidepressant medication with Amitriptyline. His cognitive deficits were patchy.

A CT scan done in November 1993, was apparently normal. An MRI scan done in May 1994, showed some non-specific white opacities and a little atrophy.

He did not meet the DSM3R criteria for dementia, and so was placed in the possible group for review after the year.

At follow-up he was not markedly different, and was still functioning independently at home. The CPN reported that his mental state was fairly stable and that his main problems were due to his chest. He still did not meet the DSM3R criteria for dementia.

**ms239.**

First began to dement at the age of about 58 years old, and was referred at 63. The family noticed in 1983, she was making mistakes with the cooking and forgetting messages. In 1987 she was anxious and more muddled.

The clinical diagnosis was of a possible presenile dementia.

At the time of the first assessment, she was 69 years old and living at home with her husband, with gradually increasing respites. She presented as a slender woman in her late 60's, with inappropriate laughter and clear speech, but often nonsensical replies to questions. She was not tolerant of any examination.

No scan was available.
She met the DSM3R criteria for moderate Alzheimer's / MID dementia, McKhann possible.

Risk factors included: hypertension, for which she was on Frusemide and Enalapril; and a family history of her mother having died in her 60's of an accident, and apparently incontinent and putting things in odd places.

Subsequently during the next year, the changes were of mild deterioration. She was reported to be more irritable, but occasionally able to say something appropriate. She tended to mix her drinks with her food, and was using a spoon and fork messily. There were features suggestive of the Kluver-Bucy Syndrome, including hyperorality, and constantly touching objects. The assessment of gait was difficult as she had an old hip fracture.

ws240.

Was first noted to have cognitive difficulties on an admission to hospital when he was 46 years old. The clinical diagnosis was of KP or alcohol-related cognitive impairment.

At the time of the first assessment he was 47 years old, and living in land-lady supported accommodation. He presented as a friendly, socially-skilled man in his late 40's. He had patchy cognitive deficits, but nothing causing loss of independence. He was still drinking about 6 -12 pints daily, and raised blood pressure was noted and reported to his GP.

No scan result was available.

He did not meet the DSM3R criteria for dementia.

The alcohol history was of 30 units daily for 30 years. There was also a reported head injury, but the timing of this uncertain.
Subsequently during the next year, there were no real changes. He still did not meet the DSM3R criteria for dementia.

First began to dement at the age of about 58 years old, and was referred at about the same time. The family noticed in 1991, he was under pressure at work and his memory and concentration were poor. He was falling asleep a lot, and waking at 3am, and mislaying things. He would forget how to drive, and seemed very shakey. He was having difficulty finishing sentences.

The clinical diagnosis was Parkinson's-related, possibly subcortical dementia.

At the time of the first assessment he was 61 years old, and living at home with his wife, with respite admissions. He was on L-Dopa and Sinemet for his Parkinson's Disease. As with a Lewy Body dementia, fluctuations were reported.

No scan result was available.

He met the DSM3R criteria for moderate Alzheimer's dementia, McKhann possible.

Risk factors for a subcortical dementia included his Parkinson's disease. He also had a history of hypertension.

At the second assessment, he was unable to do the cognitive tests. He appeared very stiff, needing prompting to bend before sitting. He had a glazed, fixed face, with little eye contact, and had mild oro-facial dyskinesia. He occasionally pointed at the floor. He had a slight tremor, and was rather twitchy. He paused before answering, but his responses were unclear. The severity rating was now severe.
First began to dement at the age of about 60 years old. His vision and balance had deteriorated, and he was appearing more confused and was having problems with his memory. There were some psychotic symptoms - including paranoid beliefs and visual hallucinations. In 1989, he had had a cyst removed from his right frontal lobe, and both before and after this, he has suffered from headaches and hallucinations. He became moody and irritable. By 1991 he was agitated, wandering and aggressive. There was a past medical history of a fronto-craniotomy in 1975, finding chiasmic arachnoiditis and a possible aneurysm. In 1985 he was found to be hypertensive.

The clinical diagnosis was of presenile dementia of uncertain type.

At the time of the first assessment he was 67 years old, and in long term hospital care. He presented as a large, rather gentle, slow man, with marked Parkinsonian features. He had distinctive craniotomy scars. He was on treatment with Atenolol, Nifedipine and Glyceryl Trinitrate. Some features were like a Lewy Body dementia: hallucinations; fluctuations; and Parkinsonism.

A CT scan in 1989 and March 1991, showed a moderate degree of atrophy.

He met the DSM3R criteria for severe Alzheimer's/MID dementia, McKhann possible.

Risk factors were the two brain operations in 1975 and 1989, and a history of hypertension and angina.

During the year there was a continuous decline.
First began to dement at the age of about 61 years old. The family noticed in 1990 she was forgetful and unconfident, irritable and moody. She would often weep, and generally became worse in the evenings. She retired about this time. She was disorientated, her speech deteriorated, and she became physically aggressive.

The clinical diagnosis was of MID.

At the time of the first assessment, she was 65 years old and in long-term hospital care. She presented as a tall, thin, stooped lady. She had oro-facial dyskinesia, and a gait with fast, small steps, which was stiff and flat-footed. She appeared anxious and frail. She was on antidepressant treatment.

A CT scan done in February 1993, showed general cerebral atrophy, but small lesions could not be excluded.

She met the DSM3R criteria for severe Alzheimer's/MID dementia.

Risk factors included: a possible stroke; history of hypertension; and a family history of her mother dying at 80 with senile dementia and her sister dying in her 60's of dementia.

Subsequently during the next year, she became increasingly frail. She appeared quiet, raising her eyebrows every so often, open-mouthed, but now without obvious oro-facial dyskinesia.

Was first noted to be increasingly forgetful, and to have reduced concentration, at the age of 50 years old, and was referred at 51.
The clinical diagnosis was uncertain, but an alcohol-related impairment was felt most likely from the history.

At the first assessment she was 53 years old, living at home with her ex-husband. She presented as a serious lady, with some patchy cognitive deficits. She was on Amitriptyline and had a past history of depression since 1965.

In 1993, a CT scan had revealed a little cerebral atrophy.

She did not meet the DSM3R criteria for dementia.

Risk factors included: a head injury in 1980; and an uncertain alcohol history.

Subsequently during the year, there were no real changes reported by the couple. She still did not conclusively meet the dementia criteria.

First began to dement at the age of about 63 years old, and was referred at the age of 65. The family noticed in 1991, he tended to get lost in conversation, and was gradually not answering when spoken to. He had had a possible slight stroke. He would forget he had been to the lavatory, and became confused on occasions, like when trying to get out of the car. He was also making accusations and beginning to become dysphasic. Other notable features were a past sensitivity to Haloperidol. The onset of the illness had been extremely fast and the decline very rapid.

The clinical diagnosis was of a dementia of uncertain type, Alzheimer's or MID, also described as a 'rare cerebral neurodegeneration, progressive focal cortical atrophy'.
At the time of the first assessment he was 66 years old and in long-term care. He presented as a severely affected man. By the second assessment, he was immobile, markedly hypertonic, and incapable of communication. He was on Aspirin and Frusemide.

A CT done in August 1992, revealed mild hydrocephalus with mild ventricular enlargement. A SPECT scan done in May 1993, showed involvement of the left temporal and temporo-parietal cortex, with clear asymmetry and diffuse atrophy.

He met the DSM3R criteria for severe Alzheimer's / MID dementia, McKhann possible.

There was a risk factor of a possible past stroke.

During the next year before the second assessment, the changes were of a continued decline.

\textbf{jw258.}

First began to dement at the age of about 51 years old, and was referred at 53. The family noticed in 1991, he was unable to set the clock. The family wondered if his problem was due to overwork. His short-term memory worsened, and he was unable to remember times, dates or calculate the snooker scores. There was a striking family history of five deaf siblings, one of whom died of an MI at 49, and his mother dying of a stroke at 52.

The clinical diagnosis was of an uncertain type, Alcohol-related or Alzheimer's.

At the time of the first assessment he was 54 years old and at home with his wife and teenage daughter. He presented as a quiet man, who was rather slow in his movements and had a sad, vacant air. He found the cognitive testing trying and wrote: "I am tired".
His wife was very strained, and described getting help as a struggle at each step, and money as short. Their teenage daughter was finding it hard to cope with the illness.

A CT scan done in December 1992, showed mild atrophy.

He met the DSM3R criteria for moderate Alcohol-related / Alzheimer's dementia, McKhann possible.

Risk factors were: alcohol, currently 2 units daily, and 9 years ago, 70 per week; and a history of having been a boxer.

Subsequently during the year, the changes were of deterioration. Now he was unable to care for himself, more aggressive and had disturbed sleep. Since December 1994, small strokes had been reported, and he was now on Aspirin.

gw259.

First began to dement at the age of about 44 years old, and was referred at 52. The family noticed in the early 1980's, he was getting lazy, lacked confidence and had a type of nervous breakdown. He was aggressive, had poor memory and problems with recognition, and appeared apathetic and socially withdrawn. He seemed aware of the problem and had said "There is something happening to me".

The clinical diagnosis was of uncertain dementia type, atypical, with frontal lobe involvement, possibly Alzheimer's or Pick's Disease.

At the time of the first assessment he was 58 years old, and was living with his wife at home. He presented as a placid and contented man.
A CT scan done in 1989, showed cerebral and cerebellar atrophy.

He met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

Risk factors included: a family history of a maternal uncle who had dementia in his late 60's, had a stroke and died at 76; and a possible head injury when in a road accident some years before.

Subsequently during the year, the changes were of gradual decline. His mobility was worse, with a shuffling, stuttering gait. There was occasionally a shaking stereotypy of his arm. He was now doubly incontinent, and slightly more aggressive, tending to grit his teeth. He would repeat "oh Christ", "tea and toast" and laugh inappropriately. He remained at home, spending much time in bed, and unable to open doors.

First began to dement aged about 58 years old, and was referred at 62. The family noticed in 1987 she was very different whilst on holiday, having become quiet and reserved. In 1989 her memory was poor, and by 1992 she appeared distracted, disinhibited, and tended to mislay objects. She was careless, clumsy and restless.

The clinical picture was of uncertain dementia type, with frontal features.

At the time of the first assessment, she was 65 years old and living at home with her husband. She presented as a rather deaf lady who chewed her teeth continuously, and perseverated. She was disinhibited in manner: burping loudly; wanting to kiss me - chasing me round the room and needed restraining; and she cheated in the CAMCOG. It was impossible to do a proper neurological assessment or take blood.
A CT scan done in 1992, June showed an old tempo-lateral infarct, with moderate cerebral atrophy.

She met the DSM3R criteria for moderate Alzheimer's / MID dementia, McKhann possible.

Risk factors included: a stroke; and a possible family history, as an uncle had some behavioural disturbance and was admitted to hospital.

Subsequently during the next year, the changes were of deterioration, as she was admitted to long-term care by September 1995. Her husband had had to lock her in at home, and she had climbed out of a window. She constantly wanted to be out at the shops, at odd times and would get lost. By the second assessment, the severity rating had increased to severe. She was only able to emit a strained, grunting outbreath. She was sometimes reported to be very restless, and at other times drowsy. Sometimes she was able to walk unaided, but other times required two helpers. She still displayed oro-facial dyskinesia, other rhythmic movements and a slight tremor.

**rw272.**

First began to dement at the age of 52 years old, and was referred at 59. The family noticed in 1983, something was wrong. The family thought this was because of his redundancy and the pressure of having a teenage son. The onset was insidious, with moderate cognitive impairment, disorientation and poor memory. In 1990 episodes of confusion were noted.

The clinical diagnosis was of slowly progressive Alzheimer's dementia.
At the first assessment he was 63 years old, and living at home with his wife and 13 year old son. He presented as a quiet man, with cognitive decline, who was sensitive to his own deficits. At the first visit, he was on tacrine.

His wife was very frustrated and sad. His 84 year old mother was also involved in his care.

A CT scan done in May 1993, showed frontal and temporal atrophy.

He met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

Risk factors included a family history of a paternal aunt, who had been demented for two years before dying in her 70's.

Subsequently during the next year, the changes were of a continued gradual deterioration. He could not be left alone, and was unable to do household things. He needed prompting to change his clothes, and his conversation was not logical. He was markedly worse after a holiday to Canada. He had a degree of insight and was depressed. His numerical skills were worse and he was slightly irritable and more paranoid. He was unmotivated and required prompting for most tasks. He had been putting things in odd places. His wife also reported that he was restless at night and losing his way to the bedroom. At the second assessment, he had lost weight, and was worse on cognitive testing. He did not have any neurological signs, apart from a slight tremor.

**mw274.**

First began to dement at the age of about 59 years old, and was referred at 61. The family noticed in 1991 after her husband died, she was not able to cope. In 1992 she became confused with
a urinary tract infection, and collapsed at her daughter's home. In 1993 she was diagnosed as having "mini-strokes". There was also a history of having had a pacemaker insertion, and mitral valve replacement.

The clinical diagnosis was of MID.

At the time of the first assessment she was 62 years old, and in long-term care. She presented as a very deaf lady, who could not speak coherently. She walked with a small-stepped, shuffling gait and appeared rather Parkinsonian. She was on cardiac drugs and anti-epileptic medication.

No scan was available.

She met the DSM3R criteria for severe MID dementia.

Risk factors included: a stroke; and the vascular history as above.

Subsequently during the next year, the changes were of increasing distress and worse mobility. In August she had an episode of atrial fibrillation, leading to her deterioration and death on 2/8/95. No PM was done.

jy276.

Was first thought to have cognitive problems, at the age of 65 years old. In February 1993, she was noted to have a degree of disorientation and memory loss.

The clinical diagnosis was of alcohol-related cognitive decline.

At the first presentation she was 66 years old, and living at home, with daily home help and lunch club attendance. She was on Aspirin and Frusemide.
No scan was available.

She did not meet any of the DSM3R criteria for dementia.

Risk factors included: high blood pressure; and an uncertain alcohol history.

By the second assessment, she was in a nursing home, with a high level of independence. She had been transferred there because of continued drinking and not caring for herself, and having been found out in the street. Early on in the nursing home, some aggression had been reported towards her visiting family, and a fellow resident, but this settled. She had been admitted to hospital because of a chest infection, and on returning, for the next few weeks, she was behaving very oddly. For example, giggling, hiding, singing to herself, or sticking out her tongue at people. However this had settled, and she was very lucid and relaxed at the interview. She had stopped drinking by then. She still did not meet the criteria for dementia.

He first began to dement at the age of 57 years old, and was referred at 58. The family noticed that he could not remember where he had put things and was not coping at work. By 1993 the problem with his memory had worsened. Anti-depressants were tried.

The clinical diagnosis was of Alzheimer's disease.

At the time of the first assessment he was 58 years old, and living at home with his wife. He presented as a pleasant but anxious man, with a good social facade. The difficulties he had with the cognitive testing caused him frustration, but he did not have insight into the fact that he was unwell.
A CT scan done January 1994, was normal.

He met the DSM3R criteria for mild Alzheimer's dementia, McKhann probable.

Risk factors were: a family history of his mother and maternal aunt having had Alzheimer's in their 80's; and possible alcohol overuse in the past, but no definite history.

Subsequently during the next year, the changes were of a continued decline and slowing down. His gait was becoming shuffly. He now met the criteria for moderate dementia. He was attending a day centre. His wife described that it was not possible to leave him at home alone, as he would leave taps on and doors open. His speech was becoming worse, and he was more easily irritated. He had some ideas that his possessions were being hidden and would put things away in the wrong places. He was no longer able to tell the time.

First began to dement aged about 55 years old. The family noticed in 1982, that his short-term memory was worse and he was more easily upset, and not managing his job. Parkinsonism had also been noticed by then.

The clinical diagnosis was of Alzheimer's dementia.

At the time of the first assessment he was 68 years old, and living at home with his wife. He presented as a pleasant, communicative man, with insight.

A CT scan done in February 1983, showed ventricular dilatation greater than cerebral atrophy, but not normal pressure hydrocephalus.
He met the DSM3R criteria for moderate Alzheimer's / Alcohol-related dementia, McKhann possible.

Risk factors included a family history of his mother having had Alzheimer's dementia in her 60's with movement problems, (a post-mortem had been done). An aunt had also been affected. He also had a history of boxing and an uncertain alcohol history, of 10 units daily for 9 years.

Subsequently during the next year there were no marked changes.

**jh283.**

First began to dement at the age of about 63 years old, and was referred at the same time. The family noticed in 1994, he was neglecting himself and his memory seemed worse. His house was dirty, with food left to rot. Other notable features were that he had had a pacemaker for heart block, peripheral vascular disease, hypertension and gout. He had had a perforated duodenal ulcer, which had been treated by vagotomy and a polya gastrectomy.

The clinical diagnosis was of uncertain dementia type, possible MID or Alcohol-related.

At the time of the first assessment he was 64 years old and living at home, independently but struggling. He was on Allopurinol, Frusemide, Lisinopril and Thiamine.

A CT scan done in October 1993 showed nil focal, but increased sulci over the convexity, suggesting a degree of atrophy.

He just met the DSM3R criteria for mild Alcohol-related dementia.

Risk factors included: hypertension and the vascular history as above; head injury from a motorcycle accident in the 1960's; and
a history of heavy alcohol consumption, 63 units weekly over 3 years, possibly still drinking an uncertain amount.

Subsequently during the next year, the changes were of a deterioration of his physical health, according to the CPN. He had died on 5/5/95, in hospital, of acute-on-chronic hepatic failure, renal, respiratory and cardiac shock. The PM found: 1. Alcoholic hepatitis, submassive hepatic infarction, and pancreatitis. 2. Myocardial hypertrophy, coronary atherosclerosis and biventricular dilation. 3. Pulmonary oedema. A standard CNS examination was done and showed a brain of 1392g, with no obvious abnormality, with the internal and vertebral arteries patent and normal, and the brain normal externally and on sectioning. The arteries at the base of the brain in normal configuration and with moderate patchy atheroma.

First began to dement at the age of about 60 years old, and was referred when he was 62. The family noticed he was forgetful and repetitive in his behaviour and questioning. By 1993, there was a noticeable deterioration of his personal hygiene and appearance. He tended to get lost when out driving and seemed ill at ease in social situations. He started shop lifting, and things worsened and he became increasingly irritable. By 1994, his lack of response and motivation was obvious, with a lack of drive and interest in things.

The clinical diagnosis was of presenile dementia, uncertain type, possibly MID or Alzheimer's.

At the time of the first assessment, he was 63 years old, and living at home with his wife. He presented as a young-looking, socially pleasant man, with some obvious memory problems. He was on Aspirin treatment. His son described him as being
constantly repetitive, stubborn and irritable. His wife was ill with terminal cancer.

A CT scan done in October 1993, showed focal atrophy of the right temporal lobe, and a possible old infarct.

He met the DSM3R criteria for moderate Alzheimer's / MID, McKhann possible.

Risk factors included a possible stroke.

Subsequently during the next year, he continued to deteriorate. After his wife's death, he had phoned his son constantly, and his son had had to take him to work with him sometimes, so the son would know where he was. He would spend a lot of time in bed. He had stopped any activities at home apart from making a cup of tea. The son's main concern was his father's constant wandering in the neighbourhood which was putting him at risk. At the second assessment, he had a good social facade, but a slight childish joviality about him, at one point nearly getting up to leave.

First began to dement at the age of 41 years old, when the family were on holiday, and she suddenly became confused and disorientated.

The clinical diagnosis was of uncertain dementia type, possibly Pick's Disease.

At the first assessment she was 42, and living at home with her husband and two teenage sons. She presented as an extremely anxious lady, who was alerted by sounds outside the room, and cried when her husband went to fetch the tea, as if she did not know what was happening.
A CT scan done in September 1994 was normal but an MRI (also repeated in March 1995) showed atrophy of the left cerebral hemisphere.

She met the DSM3R criteria for moderate Alzheimer's dementia, McKhann probable.

No risk factors were identified.

Subsequently during the next year, she continued to have limited capabilities, and ability to cope, but was slightly better, and seemed less anxious. A small degree of fluctuation was reported. Her husband described how she did not fully integrate into the family anymore, and preferred to go to bed very early. She had some understanding of her illness, which made her depressed. She had limited capacity for discussion, initiation or incentive. The cooking was done with the carer, and she needed to be told what to do, or ask if she should do this and that. At the second assessment, she still appeared timid and insecure, and from time to time in the interview, seemed expressionless and socially awkward. The testing revealed no marked memory problems, but subtle praxic ones. Her gait was unsteady and there was an occasional mild twitch of her right little finger.
The Relatives, Carers and Service Provision.

Much has been written on this subject, and the purpose of this chapter is not to review the literature, but comment on the issues in the light of this study.

Context.

In presenile dementia, there are various unique factors which make the situation for the person with dementia, and those associated with them, different from dementia occurring at a later stage of life. The person is still likely to be working when the disease process begins, and this may lead to problems at work. The spouse is also still likely to be working, and the role of being a carer has to be combined, or take over from this. Changing roles, restricted social lives, and sexual needs are important issues. There may well be a young family, and the impact of the emotional changes for them need to be considered. The younger-onset forms of dementia will effect people whose physical health is still strong, and whose activity levels are higher than more elderly people. There is the associated emotional stress of coming to terms with curtailed expectations at a relatively early age.

Experience of the Study.

The issues impacting on the relatives became of great relevance during the study, as individual stories were revealed during the interviews. The distress of relatives made many visits emotionally charged. The second assessment provided an opportunity to ask some relevant and more structured questions to document this area of enquiry.

The additional questions at the second assessment were asked to establish the needs of the carers seen, both currently and retrospectively, and the sense of satisfaction of their experience with the health service. The use of services by the group at the second assessment is given in the Results. The burden of care, (financial, emotional and physical), was enquired
into, and a note kept of any mental health problems arising in the carers. The Carer Stress Index was included, see Method: Battery. Thus, some qualitative and quantitative description was obtained. The carers were all at different points in coming to terms with the illness, and the data collected has to take into account the context of when the issues were relevant, and the current whereabouts of each subject.

The study was wide-ranging in its areas of interest, and this particular area of enquiry was not detailed. A further, more specific study would be required to gather better data in this area.

The Lothian Health Care initiative to create better service provision for this group of patients, has meant the possibility of using results of the study to back arguments, as to the real service needs and wishes of those seen.

Qualitative Impressions From the Carer Interviews.

A whole range of different reactions in dealing with a relative with dementia, was elicited. As mentioned, in part this was due to the stage that the illness was at for each individual. Also it was coloured by the personalities involved and the family dynamics and other factors. There were situations in which a spouse would try to maintain absolute control over the person with dementia, perhaps in an effort not to feel overwhelmed by the chaos caused by the illness. Some spouses found themselves, even years after admission of the partner into long-term care, visiting twice daily, and exhausted and depressed. Their whole lives revolved around the hospital or nursing home. Other spouses seemed at the other extreme, detached and even unable to admit there was a problem. The coping strategy of denial, could mean that inadequate supervision and care is given. Thus reactions ranged from the over- to the under-involved.

Some relatives described feeling disloyal when speaking about the person, and would feel guilty if they got irritated with them. Many carers commented on how difficult it had been to accept long-term care. One daughter said it was a process of
gradually letting go, similar to working through a bereavement, only the person involved was still alive. She felt it difficult to know whether her presence was still appreciated by her mother, and described the guilt associated with deciding not to continue to visit her in long-term care.

Early presenting features were another area of interest, when discussing the illness with the relatives. This is a difficult area in which to gain accurate data, because of the limitations of recall. Again, a prospective study would be required to document more fully such issues. Accounts of personal experience of early-onset dementia, such as by Friel McGowin (1993), led to the possibility of some of the group having kept diaries or accounts themselves. On enquiry, one such account came to light and an extract is given here. This lady (go184) was working as a teacher at the onset of her illness. The spelling and layout is as found in the original.

To Hell and Back Again.
Break Down.

Teaching 7/8 years old. Towards end of 3rd Term - all or almost was lost. Unruly children - boys that was. Things went from bad to worse. Strain on me was enormous, trying to keep calm, trying to teach, trying to forget incessant head aches. Discipline eroding every day. Life was a struggle to cope - I often said to myself that I knew I wasn't coping enough. My poor husband got most of the brunt of my worries but never complained and was always there with his shoulder for me to cry on. I knew that I could not take much more but as it was near the end of the summer holiday I thought I could carry one regardless. (Exhausted every day.) looked awful - big black bags around my eyes - strained - sometimes I hardly recognised myself in the mirror. However the situation had been noticed, and under another pretence I was called to have a talk. Kindly but brutally I was told that I was not coping - and that I was ill. I agreed and said
that it was not all my fault only. They insisted that I was ill and the situation was was my fault entirely and suggested I should see a doctor - which I had already done. Of course I cried, I don't know how I ever walked home. The flood opened and I cried and cried and howled and howled. Next day I tried very hard to be normal but it was difficult and often time and time again tears were pouring down my face. At one stage the pain of it all was enormous and althow the light was on for me it was pitch black and long swords, 2 gold and 2 silver were hanging above me. I really saw this - I was hurting, hurting, hurting. And as I write this down I can't keep back the tears again. Later on that long night I felt as if someone was chopping up my shoulders. My eyes were bothering me - seemed to be cloudy just above my eyes - then realised this was all part of the stress and strain that I had been through.

Another area of interest in interviewing the relatives was their participation in groups for carers. Very few had been, or were, involved in this way. Several reasons became apparent for this, one being the impossibility of taking the time off caring to attend. The second reason was the preference to spend time out with friends, and the third reason was a dislike of group settings. The attitude was sometimes expressed that a relative had no wish to tell others what was in store, or dig up their own pain. A more individualised counselling service could be of more help for some.

The carer's satisfaction with the help received from the health service varied from one case to the next, but roughly only a half were satisfied. There are however a multiplicity of reasons, both objective and subjective, which influence an individual's perception of satisfaction. Objective factors included the actual availability of appropriate services at the relevant time. More subjective reasons were the individual carer's personality and tolerance of caring, and their involvement and relationship with the subject. The perspective could change with time too.
These are some of the comments of the carers, watching their relative's decline, and losing someone who was physically still present. Some of them were currently caring, and others were remembering their experience retrospectively:

"There is no light at the end of the tunnel."
"It is a living bereavement."
"It's a living death."
"It's like watching someone slowly dying."
"She missed out on the good years."
"I have no life."
"It's like living in a limbo, I can't live my life. I feel run into the ground."
"I can't move on, even 'though he's in hospital now."
"It's become a house of silence."
"It's a very lonely illness."

Some of the comments describe the person with dementia:

"It's like he's a baby again."
"There's an emptiness about her."
"There's a lost look in his eyes."
"There is a vacant look about her."

And one person with insight into their illness said:

"It's like falling into a black hole and losing sight of the daylight."

The Perception of Need and Acceptance of Help.

Related to the satisfaction with the help on offer, is the perception of need for help and acceptance of it. When is help accepted? Some carers seem to soldier on, bound by a sense of loyalty, love and duty, beyond a point which appears good for their own well-being. Is it the role of the health professional to take over responsibility in such cases, with relatives who appear unable to ask for help? But acceptance of help comes not only on the part of the carer, but also from the person with dementia. For example, the situation of a middle-aged subject with dementia, refusing to attend a day centre with elderly people, was not an uncommon scenario.
It is a complex interaction of factors as to who needs, and who benefits from various services. It would be useful to understand these better in order to provide a more appropriate service. For example, work has been done on the value of day clubs as an alternative to day hospitals (Currie et al 1995).

Another area of importance, is the understanding of the decisions involved in admission to long-term care. Juva et al (1994), studied the functional decline and mortality after a one year follow-up study, of 93 demented elderly subjects in Finland. The appearance of incontinence, and other recorded risk factors (age, degree of dementia and mobility) did not seem to predispose to institutionalisation. Subjective factors, such as caretaker's burden, probably have a greater influence on the ending of home care. There are factors operating in both the subject (such as the illness severity, and behavioural disturbance), and the carer (such as poor health, exhaustion, resentment and exasperation), that make admission to long-term care the outcome. If research was able to identify factors amenable to change, could long-term care ever be avoided, and would this be in everyone's best interest?

Financial Burden.

Because of the sometimes lengthy progression of the disease, it is possibly without equal, in terms of the financial and emotional toll it puts on those who have to care. Alzheimer's Disease as a major area of care expenditure, is discussed by Gray and Fenn (1993). Dementia has been said to be the most expensive neurological condition, when community care costs are included. Part of this cost falls on the relatives.

Infact, when enquired into, few relatives reported that they were put under financial strain by the illness. However, disruption and added costs were numerous. Apart from the obvious potential loss of income, either or both the subject's and the carer's, other loss of finance could be subtle. A subject could, before the illness was diagnosed, have been increasingly irresponsible with money. Another situation given by a carer,
was that because of the need to constantly supervise, supermarket shopping was impossible and corner-shop shopping became expensive. One husband found he had to buy new clothes for his wife as she became larger, due to her overeating.

**Identified Needs.**

Sperlinger and Furst (1994), reviewed the service experiences of people with presenile dementia in London. 15 carers were interviewed. The results from this study represent a far wider group of carers.

More education and explanation of the illness, was one thing that the relatives felt was needed, and was not adequately provided at the time they required it. Several comments specifically related to the way that the diagnosis was made and given. As described in the Introduction: Epidemiological Issues, there can be a lengthy period of uncertainty at the beginning of the illness, when the person with the problem will try to cover up, and the family will try to explain away the difficulties. The diagnosis is therefore delayed. The changes in ability to work, and strains in relationships, are seldom recognised as symptoms early on. An article by Rice and Warner (1994), discusses the issues of breaking the bad news and what to tell patients with dementia about their illness, and the issues involved in giving information about the diagnosis and prognosis. Information and explanation is required in an ongoing way too. Several of the carers in the sample, whose relatives had a diagnosis of Alzheimer's Disease, told me that it had been explained to them that this was due to mini-strokes.

Apart from practical help and information, more counselling and support facilities would have been appreciated. The major sources of support were family, friends, staff in the long-term care facilities and General Practitioners. Sometimes however, the hospitals were criticised for not involving the carer enough. For some people with insight in the early stages of their illness, some supportive work would also have been appreciated.
Sitter services were in great demand. Additional features suggested, were that the sitters should be known to the families, possibly via a day centre, and with nursing qualifications when required. The hours of the service should extend to cover evenings and weekends, and be specific to enable the carer the optimise their free time.

Respite care facility appeared to be lacking. Activities in most nursing home and long-term care facilities were few, and carers felt this to be another target for improvement.

Any of the sample who mentioned out-patient contact, found it to be an infrequent check-up, of no practical value to them. Even after a diagnosis, some people appeared to have fallen through the net and were lost to any suitable follow-up. One spouse described that apart from a quick outpatient review every six months, there was no attempt at developing the care input required at home, as problems arose. Considering the difficulty of many carers to seek help, this leaves the onus far too much on them.

The role of a co-ordinating out-patient memory clinic could avoid such problems in follow-up. The role of the General Practitioner is reinforced by Newens et al (1994b). They emphasise the need for continuity of follow-up, counselling, support and co-ordination of community care. In terms of other health professionals, the role of the Community Psychiatric Nurse in the dementia service has been discussed by Spear and Herzberg (1995).

Study Results Pertinent to the Carers.

Only a few items from the data set, relevant to carer needs, have been highlighted in the Results section. A couple of points are mentioned here.

The work of Burns et al (1990b), illustrated the high level of non-cognitive features which are encountered in Alzheimer's Disease, and the impact these have on the carers. The use of the MOUSEPAD in this study, intended to describe such
profiles for the group of people with presenile dementia, and serves to illustrate the burden on carers in a very real way. For example, from the first assessment, 44% of the sample of 126 cases seen had exhibited an aggressive behaviour of some form, at some stage of the illness. Such items should also be looked at more critically, and evaluated according to where the subject was, at the time of the most disturbed behaviour, and who the carer was at that time. Knowledge of the duration and progression of the behavioural disturbances, describes the carer's burden more accurately.

About a half of the sample seen were in long-term care, and over half of these subjects had been there for over 3 years. The prolonged nature of such a 'living bereavement' on the relatives is difficult to imagine. Likewise, the long duration of symptoms in some cases, means the continued strain of witnessing a slow deterioration. Of the 126 cases seen, the majority had had a duration of between 3 and 9 years since the diagnosis had been made.
Protocol.

Contents.

Page: 

I. Letters of contact.

130-132. i) To doctor, with protocol.
(basically the same for hospital consultant and GP)

133-134. ii) To relative, with information sheet.
(revised if sent to the person with dementia, with an adapted information sheet).

135. II. Consent form.

136. III. Letter of thanks.

IV. First Assessment.
(The following parts of the interview: CAMDEX, CAPE, CORNELL, MOUSPAD, NART and Webster are not included, but can be found in the respective manuals).

137. i) Individual Assessment Overview.

138-141. ii) Case Record Data.

142-146. iii) Data Sheet.
Section H of the CAMDEX: interview with patient's relative or other informant.

147. iv) Behavioural front sheet.
CAPE-BRS.

148. CORNELL.

MOUSEPAD.

149-151. v) Cognitive front sheet.
Section B of the CAMDEX: Cognitive Examination.

NART (+/- Schonnel).

Section D of the CAMDEX: Physical Examination.

152-154. vi) Brief Neurological Examination.

vii) Physical and Neurological Coding Sheet.
Webster Scale.

V. Second Assessment.
(The following parts of the interview: CAMDEX, CAPE, CORNELL, MOUSPAD, NART, Webster and
Carer Stress Index are not included, but can be found in the respective manuals).

155. **i) Individual Overview, Assessment 2.**

156-157. **ii) Data Sheet 2.**
First part of Section H of the CAMDEX: interview with patient's relative or other informant.
Behavioural front sheet, (as for first)
CAPE-BRS.
CORNELL.
MOUSEPAD.

158. **iii) Cognitive front sheet 2.**
Section B of the CAMDEX: Cognitive Examination.
NART (+/- Schonnel).
Section D of the CAMDEX: Physical Examination.
Brief Neurological Examination, (as for first).
Physical and Neurological Coding Sheet, (as for first).
Webster Scale.

**VI. Forms for Control Bloods.**

159-160. **Scheme and consent form.**
Mini-mental state test (not included here).
I, i). Letter to doctor.

University of Edinburgh,
Department of Psychiatry
The Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh
EH10 5HF

Telephone No.031-447 2011
Ext.4781

Date

Dear

I am currently starting a study of patients with presenile dementia (of various aetiologies) on a three year Wellcome Research Training Fellowship, based here at the University Department of Psychiatry.

The study will involve patients with a diagnosis of presenile dementia of all aetiologies. I am aware that in some cases this is a preliminary diagnosis which may initially be based on a clinical presentation of memory deficit or cognitive impairment. In some instances this may herald the onset of a progressive decline, whilst in others the problem may appear to resolve. I am keen to follow up the cases I have identified and have included the name of your patient

I am writing to ask for your agreement in my approaching the family/carer for their cooperation in the study. I have enclosed a copy of the study protocol for your information and would be very pleased to discuss anything further with you.

I look forward to hearing from you,
Yours Sincerely,

Dr. Kirstie Woodburn.
Wellcome Research Fellow.
Protocol for Presenile dementia study.

Dr. Kirstie Woodburn, Wellcome Research Fellow.
(Ethics approval granted July 1993.)

Study Aim.
To study a population of patients with presenile dementia of all aetiologies, to describe the clinical profiles of each and the patterns of decline which occur, together with any genetic characterisation possible.

Population Studied.
The population of live patients with presenile dementia has been obtained from the Lothian Psychiatric Case Register. Subjects were diagnosed between 1988 and the end of 1993 as having an apparent dementing process, whatever the aetiology (including Alzheimer's/ Multi-infarct/ Huntington's and Alcohol-related) and include both inpatients and outpatients. In addition some cases have been obtained from the Neurology Department at the Western General Hospital and also from St. John's and Bangour Village Hospital. Each set of case notes has been reviewed and checked for the diagnosis of an apparent dementing process.

Patient Contact.
Having identified each individual suitable for the study, the consultant responsible in each case will be approached for their approval of contact being made with the patient. The General Practitioner will also be contacted and their cooperation requested.

The next of kin will then be contacted, firstly by telephone if possible and subsequently sent an information sheet by post. With their agreement, an appointment for an initial assessment would be made. At this meeting the standard consent form would be completed.

Clinical Data Collection.
The collection of clinical data could involve a home visit or clinic appointment at the Royal Edinburgh Hospital, depending on the convenience to the patient and carer.
Clinical data will be collected from the informant/next of kin, with regard to the course of the disease, the family history, past medical history and personal history of relevance. The main carer would be interviewed to provide a behavioural assessment, using the behavioural scale of the Clifton Assessment Procedure for the Elderly (CAPE), and another semi-structured interview. Each patient will have a routine physical examination and a thorough neurological examination including the Webster Scale and primitive reflex testing. Neuropsychological testing will be done using the CAMCOG section of the Cambridge examination for Mental Disorders of the Elderly Examination (CAMDEX).

Diagnostic investigations will have been completed in the majority of cases.

At the assessment interview, 40mls of blood will be taken and kept in freezer storage in anticipation of the molecular studies.

**Follow up.**
After one year, the carers and patients will be seen again and enquiry made into the course of the illness with a repeat of the behavioural, neurological and neuropsychological examination made.

In the event of a patient dying during the course of the study it is hoped that whenever possible, a neuropathological examination will be performed.

**Kirstie Woodburn.**
**January 1994.**

University of Edinburgh,
Department of Psychiatry
The Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh
EH10 5HF

Telephone No.031-447 2011
Ext.4781

Date

Dear

I am a doctor with an interest in memory problems which begin before the age of 65 years, and my work is a research project aimed at a better understanding of these conditions. A greater understanding will help towards finding effective therapy.

Your doctor has suggested that I write to you, as you are the closest relative of . Because of memory problems, it is likely that I would need to speak to you, in your capacity as the , rather than to your , about past history and current problems.

Perhaps I could suggest that we arrange to meet so I can tell you more about the project and you can ask me questions. I can come to see you at home at a time that suits you, or if more convenient, you may prefer to meet with me at the hospital.

Please will you phone and let me know, at the number given above, and if I am out, please leave me a message.

I have enclosed an information sheet for you, and I look forward to hearing from you.

Yours Sincerely,

Dr. Kirstie Woodburn.

Wellcome Research Fellow.
Memory Study: Relative's Information Sheet.

The aim of the study is to gain a greater understanding of the types of dementing illness which begin in early adulthood or middle age. Your relative may have such a disease and has been selected to help in this work. As your relative may not be able to give agreement themselves to taking part, it is important to explain to you what the study involves, in order that you may or may not consent on his or her behalf.

At the initial assessment, we would like to obtain information from you as to your relative's current and past health details. At this time, a general check of your relative's health will be made, and if any of the routine tests which are part of their basic hospital care have not been completed, we will be able to do these. With a short questionnaire, the level of your relative's current memory difficulties will be assessed. A sample of blood will be taken, which will be used to study any possible cause for the condition by looking at their genetic make-up.

At the end of about one year from the first visit, we would like to review any changes in your relative's health and will ask to see you again.

Your agreement for your relative to take part in this study would be greatly appreciated. However, if you feel at all uneasy about it, we will be happy to discuss things again. There is no need to agree unless you wish to, and if at any time you want to withdraw agreement, this will not in any way affect the normal care arrangements which you already have with the doctor. The assessment itself will be as brief and stress-free as possible, and would not be of an unpleasant nature. The information obtained would all be treated in utter confidence, and the results of any tests only made available if they had any importance for treatment purposes.

Dr. Kirstie Woodburn.
II. Consent Form.

A Study of Memory Loss and Related Conditions.

Further information is available from:
Dr. Kirstie Woodburn
University Department of Psychiatry
The Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh.
EH10 5HF

Telephone Number: 031-447 2011 Ext.4781.

Your General Practitioner will be informed of your participation in this study and will be advised of any clinically significant information that comes to light.

I agree to participate/ to the subject participating * in this study.

I have read this Consent Form and the Subject Information Sheet and had the opportunity to ask questions on them.

I understand that I am/ the subject is* under no obligation to take part in this study and a decision not to participate will not alter the treatment I/ the Subject* would normally receive.

I understand that I have/ the subject has* the right to withdraw for this study at any stage.

I understand that this is non-therapeutic research from which I/the subject* cannot expect to derive any benefit.

Signature of Subject/ or Guardian.*

Name of Subject.................................................................

Signature of
Investigator..................................................Date..............................

* Delete as appropriate.
III. Letter of thanks.

Department Of Psychiatry
The University Of Edinburgh
Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh EH10 5HF

Tel 031 447 2011 Ext. 4781

Date

Dear

Thankyou very much indeed for agreeing to help me with my study, and for sparing the time to talk with me. As you know, I plan to get in touch with you again in about a year's time to ask a few more questions. Meanwhile with my thanks and best wishes,

Yours Sincerely,

Dr.Kirstie Woodburn.
### IV. i. Individual Overview For First Assessment.

**Name:**

<table>
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<tr>
<th>Assessment</th>
<th>Date. Part 1</th>
<th>With whom.</th>
<th>Where.</th>
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<td>Data sheet.</td>
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<td>Blood Sample.</td>
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<td>Thanks</td>
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</table>

**Included or not (if not, why):**

**DSM3R Diagnosis:**
IV. ii. Case Record Data.

YES/NO/POSSIBLE. Date done:

Where notes are / Volumes used:

**Patient**
Name:.......................... REH No........... Study No..........

D.O.B:....................... Age(yrs):.............M/F:............... Nationality...........
(Current) (0/1) (British=0; Other=2)

Address:..........................Tel.No:...........
(home or ward)

**Informant**
Name:.......................... Age............ M/F:...........

Relationship: ....... Address Of Contact:............. Tel.No:.............

Relationship Code:
spouse=0; sibling=1; child=2; parent=3; other(specify)=4.

**Next Of Kin**
Name:.......................... Age............ M/F:...........

Relationship: ....... Address Of Contact:............. Tel.No:.............

**G.P**
Name:........................................

Address Of Contact:................................Tel.No:.............

**Consultant**
Name:........................................

Hospital
Address:..................................Tel.No:.............

**Diagnosis:**
REH Referral Diagnosis: ............ Date: ............ Age: ....

DSM3R/Feighner:........................................
Other Information:........................................
Last Date Of Contact/place discharged to:
Any other useful contacts (e.g. CPN or day placements/respite care):

Investigations.
Note any abnormalities or relevant findings and date (m/y) of test.

Bloods:

U&F...........................................................................................................

LFT...........................................................................................................

FBC...........................................................................................................

ESR..........................................................................................................

VDRL/TPHA..............................................................................................

TFT...........................................................................................................

B12&Folate..............................................................................................

Glucose....................................................................................................

Other (e.g. HIV)......................................................................................

X-RAY.....................................................................................................

ECG...........................................................................................................

EEG...........................................................................................................

L.P.............................................................................................................

CT (or MRI/SPECT)................................................................................

OTHER include cognitive testing/neurological examination etc...........
Additional Note Detail.

Onset/ Presenting Symptoms/ Date:
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Past Medical or Psychiatric History / Treatment / Head injury / Alcohol / Smoking :
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Family History:
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Social History:

Development ........................................................................................................................................
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Education ........................................................................................................................................
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Occupation ........................................................................................................................................
........................................................................................................................................
Marriage/Children

Social Circumstances

Risk Factors:

Units ETOH (if known):
IV. iii. MEMORY STUDY DATA SHEET
(See CAMDEX part II.)

Patient Name: ..................................... Study No. ..............

D.O.B.:.......................... M/F........... Age in years now: ..............

Interview Date:.............. Interviewer: K. Woodburn.

Informant (and reliability if relevant):...........................................

Place of interview with informant:...........................................

Patient current supports and attendances:...................................

(Where not asked/not applicable = 8, where don’t know = 9)

A) ONSET/PRESENTING SYMPTOMS.

1. When was first hospital contact?........................CODE ..............

Code: <1year=0  1-2year=1  2-3year=2  >3year=3

2. What was the main presenting feature of the illness?

   Code: ...........

   CODE:
   Memory loss / disorientation=0.
   Mood change / personality change=1.
   Movement disorder=2.
   Other=3.

3. What is the most difficult behaviour to cope with?

B) MEDICAL HISTORY.

Current Health.

1. Does current treatment include neuroleptics?

   CODE............................

   Code: No = 0  Yes = 1  Doesn’t know = 9
2 a) Current physical health O.K.? 
CODE: .............................................
Code:  No = 0    Yes = 1  Doesn't know = 9

(describe fully. Any: Hypertension/ Diabetes/Parkinson's/ MS/ Tumour, etc)

2 b) Currently attending non-dementia related hospital clinic? 
CODE: .............................................Code:  No = 0  Yes = 1  Doesn't Know = 9

(Specify reason and clinic)

3. Is vision (+/- glasses) O.K.? CODE: .................................
Code:  No = 0  and specify  Yes = 1  Doesn't know = 9

4. Is
a) hearing (+/- aid) O.K.? CODE: .................................
Code:  No = 0  and specify  Yes = 1  Doesn't know = 9

b) speech/language O.K.? CODE: .................................
Code:  No = 0  and specify  Yes = 1  Doesn't know = 9

5. Is mobility O.K.? CODE: .................................
Code:  No = 0  and specify  Yes = 1  Doesn't know = 9

6. Additional Cerebro-vascular symptoms. 
CODE:  No = 0  Yes = 1  and specify  Doesn't know = 9
a) Are headaches a problem?
CODE: ............................................................................

b) Is dizziness a problem?
CODE: ............................................................................

7. Additional Neurological symptoms
Code:  No = 0  Yes = 1  Don't know = 9

Are there episodes of brief, shock-like movements noticed on a regular basis?
CODE: ............................................................................
Past History.
8. Additional Alcohol History: Only if required after Section H.
a) Any history of alcohol abuse?
CODE: .................................................................
CODE: No = 0    Yes = 1    Don't know = 9
Detail: ............................................................................
Current problem? CODE: ......................

b) What was the most (in units) on a regular basis?


c) Length of time of heavy pattern of drinking (state when began and ended) .................................................................


d) Complications:
i) Psychiatric (e.g. fits/ D.T's). .................................................................
ii) Physical (e.g. liver/ neurology) .................................................................
iii) Social (e.g. family/ job/ driving/ law) .................................................................

C) Family History.

Ages and causes of death of any relatives (note overleaf)
Check: Parents/ Siblings/ Grandparents/ Aunts/ Uncles/ Cousins.
Any relatives with dementia specifically diagnosed?
Note other movement disorders.

D) Social History.

1. Marital status. Code: ..................................................
   Code:  
   Single=0             Widowed=3.  
   Married=1.           Not applicable/ not asked=8  
   Divorced/ Separated=2.        Doesn't know=9

2. Spouse's age in years ...............................................  
   Any relevant information: .................................................................
3. (Number of children)........................................
Any relevant information.................................................................

4. Patient living with Code:........................................
CODE: Alone=0. Spouse =1. Other family=2. Other (including hospital) =3.

5. Any stated birth difficulty or incident?
Code:........................................
Code: No = 0 Yes = 1 Don't know =9
Give details. ..............................................................................................

6. Any developmental difficulties?
Code:........................................
Code: No = 0 Yes = 1 Don't know =9
Give details. ..............................................................................................

7. Number of years in full time education? ......................

8. Academic record. Code:........................................
Code: Nil = 0 Leaving Certificate = 1 Lowers/Highers/Grades = 2
Uni/CollDeg/Dipl =3

9. The highest occupational level achieved by the patient
Code: (according to OPCS statistics)..............................................................

10. The highest occupational level achieved by the spouse
(or father if unmarried).
Code: (according to OPCS statistics)..............................................................

E) Risk Factors.

1. Any exposure to industrial poisons(e.g.Pb/Al etc)?
Code:..........
If yes give details. ..............................................................................................

________________________________________________________
2. Previous work with animal products (e.g. on a farm/worked with animal tissue)? Code: ...........................................
If yes give details................................................................................................................................

3. Any significant foreign travel? Code: ..........................
If yes, state when and where.................................................................

If yes, give details...................................................................................

5. Has the patient any dietary restrictions? Code: ..........
If yes give details...................................................................................

6. Has the individual ever had contact with another suffering from a dementing illness (or other neurological disorder)? Code:......................
If yes give details..................................................................................

7. Has the patient ever received donated human tissue (include blood transfusion, certain eye operations etc)? Code:............................
If yes state what and when....................................................................

V. iv. Behavioural Front Sheet.

Patient's Name:...................  Study No.:......
Date:...............  Interviewer: K. Woodburn.

Informant
Name:...........................................................................
Address:...........................................................................

How was interview conducted?  
Face to Face 1
Telephone 2

Relationship of informant to subject  
Spouse 1
Sibling 2
Sister/Bro-in-law 3
Son/Daughter 4
Son/Dau-in-law 5
Friend 6
Caretaker/warden 7
Other(specify) 8

Roughly how often seen?  
Lives with 1
Daily 2
>1/week 3
Weekly 4
Monthly 5
Yearly 6

Subject's age at present: .........................

Resident at present: .........................

(Current health, including eyesight and hearing etc and treatment are specified in demographic data).

1. MOUSPAD.
2. CAPE.
3. CORNELL.

Memory Study
Assessment No. .......

Name:..................... Study No.:..............
Date:............... Interviewer: K. Woodburn.

Age at present:

Resident at present:

Testing completed:
If not, specify reason(include visual/auditory/speech impairments):

(Current health and treatment documented in data sheet)

1. NART, Error score
   (____) Premorbid IQ
   (____)

2. CAMCOG, Total
   (____)
IV. vi. Memory Study.
Brief Neurological Assessment

Name of Patient: Study No.: Examiner: K. Woodburn Date:

N.B. (Where untestable code: 0, don't know: 9.)

**Face, Pupils**

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**Reaction to light:**

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<td>Yes/No</td>
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<td>3.</td>
<td><strong>Right</strong></td>
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**Reaction to accommodation:**

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<td>Yes/No</td>
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**Eye Movements.**

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<td>7.</td>
<td><strong>Nystagmus</strong></td>
<td>Yes/No</td>
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**Mouth Movements.**

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**Orbicularis Oculi.**

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<td>9.</td>
<td><strong>Left</strong></td>
<td><strong>Normal/Weak</strong></td>
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<td>10.</td>
<td><strong>Right</strong></td>
<td><strong>Normal/Weak</strong></td>
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**Visual Fields.**

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**Fundoscopy.** (If abnormal specify below)

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<td>Limbs.</td>
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<td>Tone.</td>
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<td>14.</td>
<td>U.L.</td>
<td>Left</td>
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<td>15.</td>
<td>U.L.</td>
<td>Right</td>
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<td>16.</td>
<td>L.L.</td>
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<td>If present UM/LM</td>
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<td>20.</td>
<td>U.L. Right</td>
<td>Absent/Present</td>
</tr>
<tr>
<td>21.</td>
<td></td>
<td>If present UM/LM</td>
</tr>
<tr>
<td>22.</td>
<td>L.L. Left</td>
<td>Absent/Present</td>
</tr>
<tr>
<td>23.</td>
<td></td>
<td>If present UM/LM</td>
</tr>
<tr>
<td>24.</td>
<td>L.L. Right</td>
<td>Absent/Present</td>
</tr>
<tr>
<td>25.</td>
<td></td>
<td>If present UM/LM</td>
</tr>
<tr>
<td></td>
<td>Co-ordination.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Upper limbs: Finger-Nose Test.</td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>L</td>
<td>Norm/Equiv/Abnorm</td>
</tr>
<tr>
<td>27.</td>
<td>R</td>
<td>Norm/Equiv/Abnorm</td>
</tr>
<tr>
<td></td>
<td>Upper limbs: Hand-Tapping Test.</td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>L</td>
<td>Norm/Equiv/Abnorm</td>
</tr>
<tr>
<td>29.</td>
<td>R</td>
<td>Norm/Equiv/Abnorm</td>
</tr>
<tr>
<td></td>
<td>Lower limbs: Heel-Shin Test.</td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>L</td>
<td>Norm/Equiv/Abnorm</td>
</tr>
<tr>
<td>31.</td>
<td>R</td>
<td>Norm/Equiv/Abnorm</td>
</tr>
<tr>
<td></td>
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<td></td>
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<tr>
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<tr>
<td><strong>Tendon Jerks.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Upper Limbs.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Biceps</td>
<td>R</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>33.</td>
<td>L</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>34. Supinator</td>
<td>R</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>35.</td>
<td>L</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>36. Triceps</td>
<td>R</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>37.</td>
<td>L</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td><strong>Lower Limbs.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Knee</td>
<td>L</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>39.</td>
<td>R</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>40. Ankle</td>
<td>L</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>41.</td>
<td>R</td>
<td>Dec/Norm/Inc</td>
</tr>
<tr>
<td>42. Plantar</td>
<td>L</td>
<td>Flex/Ext/Equiv</td>
</tr>
<tr>
<td>43.</td>
<td>R</td>
<td>Flex/Ext/Equiv</td>
</tr>
<tr>
<td><strong>Gait.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44.</td>
<td></td>
<td>Normal/Equiv/Abn</td>
</tr>
</tbody>
</table>

(If abnormal, describe..................)
IV. vii. Memory Study.
Physical and Neurological Examination Coding Sheet.

Name: ................................................................. Study No: .................................................................
Current Age: .................................................. Where seen: .................................................................
Examiner: K. Woodburn Date: .................................................................

Any assessment problems? .................................................................
(State if part not done or don't know and why........Code 8 or 9)

Cardiovascular System:
1. Pulse Rate (beats per minute) ............................................
   Rhythm (regular = 0, irreg = 1) ......................

   BP
   Systolic ..................................................
   Diastolic ..................................................
   (BP to be recorded with the subject sitting with the forearm resting on a horizontal surface after 5 minutes rest).

Respiratory: (Shortness of breath at rest)
Respiration (Normal = 0, Abnormal = 1) ......................

2. Abdominal System: (Normal = 0, Abnormal = 1) .................

Miscellaneous:
3. Tongue. (Normal = 0, Atrophic = 1) ..................

4. Teeth (Own = 0, False = 1) ........................................

   Eyesight
   Glasses worn (No = 0, Yes = 1) ................................
   Vision with glasses: (Unable to see materials or instructions in booklet)
   (Normal = 0, slightly impaired = 1, very impaired = 2) ...........
Hearing
Hearing aid worn  (No = 0, Yes = 1) ........................................................................

Hearing with aid: (Can hear well or with difficulty e.g needs raised voice) ..........
(Normal = 0, slightly impaired = 1, very impaired = 2)

Mobility
(Normal/ unaided = 0, needs aid = 1, needs person = 2, chair/ bed bound =3) ...........

Physical disability interfering with manual task,
e.g. unable to hold pen to write. (No = 0, Yes = 1).................................

Neurological System: (all in BNE: Q's here not in CAM "D")

5. Eyes:
a) Pupil response to light (Normal = 0, Abnormal = 1) ........
b) Pupil equality (Normal = 0, Abnormal = 1) .................................
c) Optic fundi (Normal = 0, Abnormal = 1) ......................................

6. Face:
Face symmetry(Normal = 0, Abnormal = 1) ..................................

Limbs:
7. Tone in limbs (Normal = 0, abnormal = 1) .................................
Tremor (Absent =0, mild = 1, severe = 2) ........................................
(Mild = present but causes no difficulty with dressing or eating or gait).

8. Handedness (Right = 0, Left = 1) ...........................................

9. Primitive Reflexes:  (Absent = 0, present = 1)
a) Hoffmann  ......................
b) Grasp  ............................
c) Palmo-Mental ............................

d) Jaw ............................

e) Snout ............................

f) Glabellar ............................

g) Sucking ............................

10. Myoclonus (Absent = 0, Present = 1) ...........................................

(During the examination, including cognitive testing, were there any episodes of brief shock-like movements noticed?)

11. Were there any unusual spontaneous involuntary movements of the face/ trunk/ upper or lower limbs noticed during the assessment? (No = 0, Yes = 1) ..............

12. Webster Score (Out of 24) ..............................
V. i. Individual Overview Assessment 2.

Name: ________________________________

Study No.: (P) Date: __________________________

Contact with relatives: __________________________

Data: __________________________

Behavioural assessment: __________________________

Cognitive assessment:

Previous NART = __________________________
Needs Schonnel? = __________________________
Previous CAMCOG = __________________________
Needs 2nd? = __________________________

Neurological: __________________________

Blood: __________________________

Previous amount = __________________________
Needs extra = __________________________

Spouse for control? = __________________________
Consent&done? = __________________________

PM Views: __________________________

Discussed at 1? = __________________________
Current attitude = __________________________

Thankyou: __________________________

Time after 1st? = __________________________
V. ii. MEMORY STUDY DATA SHEET 2.

NAME: ________________________  STUDY NO.: ________________________
DATE: ________________________  AGE: ________________________
INFORMANT: __________________  WHERE: ________________________

1. Where subject is now? (any change since last seen)

Patient living with. (code)
CODE: Alone=0. Spouse=1. Other family=2. Other(incl.hospital)=3.
Dead=4.

2. Any major changes? CODE: (0 = no, 1 = yes):

   i) Subject:

CODE: 3ia 3ib 3ic
0 = none, 1 = home care, 2 = day centre, 3 = long term, 4 = other, 5 = respite.

ii) Carer:

CODE: 3iia 3iib 3iic
0 = none, 1 = contact + Alzheimer Disease Society, 2 = carer group, 3 = other.

4. If in Long-term care
   a) when admitted to LTC?
   CODE: 0 = <1 yr, 1 = 1-2 yr, 2 = 2-3 yr, 3 = >3 yr.
   b) why admitted to LTC?
   CODE: 0 = behaviour, 1 = physical care, 2 = carer problem, 3 = other.

5. Feelings about the services provided and satisfaction

CODE: ________________________
CODE: 0 = no, 1 = yes.

   a) Physical:
b) Social:
c) Emotional:
d) Financial:

**CODE, most important:**
CODE: 0 = a, 1 = b, 2 = c, 3 = d.

7. Treatment check list (for diag.). List in full
   Code, 0 = no, 1 = yes, 9 = don't know
   a). Aspirin.
   b). Anti hypertensive/heart
   c). Anti diabetic
   d). Antidepressant
   e). Neuroleptic
   f). Past sensitivity to neuroleptics?

8. Changes in: Code, 0 = no, 1 = mild, 2 = moderate, 3 = severe.
   1.a). Vision
   1b). Hearing
   1c). Speech
   1d). Mobility
   1e). Myoclonus
   1f). Health
   1*). Headaches
   1*). Dizziness
   2g). Feeding
   2g2). Dysphagia:
   2h). Dressing
   2i). Soiling
   3i). Personality
   3k). Memory
   3l). Thinking
   3m). Mood
   3n). Paranoia
   3o). Sleep
   3p). CVA
   3q). MI

9. Check on H
   worse night time? .......... step-wise or gradual? ..........

10. Alcohol Consumption (any added info)
    Code current (0 = no, 1 = yes):

11. Any personal account available?
V. iii. Cognitive Testing Front Sheet.2.

Name: .......................  Study No.: ...............  
Date: ...............  Interviewer: K. Woodburn.

Age at present:

Resident at present:

Testing completed:  
If not, specify reason(include visual/auditory/speech impairments):

-----------------------------------------------------------------------------------------------------------------------------------

(Current health and treatment documented in data sheet)

1. NART.  
If initial score < 40, need a Schonnel.

2. CAMCOG.  
If initial score unable or 0, not repeated.
VI. Forms for Control Bloods.

Scheme for normal control subjects for genetic studies, Feb 1995.

CODE NO: DATE: WHERE:

NAME: DOB: AGE:

M/F: NATIONALITY:

ADDRESS: TEL.NO:

OCCUPATION (if none, please state father's occupation):

AGE LEFT SCHOOL/COLLEGE:

ANY PAST/CURRENT MENTAL HEALTH PROBLEMS:

ANY FAMILY HISTORY OF PSYCHIATRIC ILLNESS: Yes/No. ..............
(if so, please state briefly, overleaf, for 1st degree relatives only,
e.g. parents, sibs, children):

ANY PAST/CURRENT GENERAL HEALTH PROBLEMS:
(If so specify overleaf, e.g. high blood pressure etc.):

APPROXIMATE ALCOHOL CONSUMPTION WEEKLY:

CURRENT MEDICATION:

PAST MEDICATION:

Score on MMSE (if older than 45): .................

Any other comments, reasons for exclusion etc. PTO.
VI. Consent Form.
For Control Blood.

I agree to participate in this study which has been explained to me by
........................................................................................................
and I have been given the opportunity to ask questions.

It has been explained to me that some of the blood sample will be stored on a long term basis and may be made available to other workers in the field.

I understand that I have the right to withdraw from the study at any stage. I understand that this is non-therapeutic research from which I cannot expect to derive any benefit.

Signature of subject:............................................................................

Signature of investigator:........................................................................

Date:.................................................................................................
### Glossary of Abbreviations.

#### A.

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td><strong>aa.</strong></td>
<td>Amino acid. Amino acids are the building blocks of protein. There are twenty common ones. The details of how the genetic message on DNA is translated into a peptide sequence, can be found in Weatherall (1991).</td>
</tr>
<tr>
<td><strong>AβP.</strong></td>
<td>(also known as βA4 or βA4a) Amyloid β peptide. This is found in plaques and vascular deposits in Alzheimer's Disease. Its abnormal metabolism from the larger amyloid precursor protein, and deposition, is either a central pathogenic event, or the result of another process.</td>
</tr>
<tr>
<td><strong>ACh.</strong></td>
<td>Acetylcholine. This is a neurotransmitter. The enzymes related to it have been shown to be greatly reduced in the brains of AD sufferers.</td>
</tr>
<tr>
<td><strong>ACT.</strong></td>
<td>α1-antichymotrypsin. This is a serine protease inhibitor, encoded for on chromosome 14.</td>
</tr>
<tr>
<td><strong>AD.</strong></td>
<td>Alzheimer's Disease. Also referred to as Alzheimer's Dementia, Alzheimer's disease or Alzheimer's dementia.</td>
</tr>
<tr>
<td><strong>ADDTC.</strong></td>
<td>State of California Alzheimer's Disease Diagnostic and Treatment Centre.</td>
</tr>
<tr>
<td><strong>AIDS.</strong></td>
<td>Acquired Immune Deficiency Syndrome.</td>
</tr>
</tbody>
</table>
Al. Aluminium.

AMTS. Abbreviated Mental Test Score. (See neurocognitive assessment.)

Ap. Apathy subscore of CAPE-BRS.

APOE. (occasionally referred to as ApoE.) Apolipoprotein E. This protein plays a role in nerve development and repair. The three common allele, ε2, ε3, ε4, have a major impact on cholesterol levels in the serum, and are highly correlated with the risk of atherosclerosis and cardiovascular disease.

APOEε4. (occasionally referred to as E4, e4 or ε4). Apolipoprotein E, ε4 allele. This has been found to be a genetic risk factor for Alzheimer's Disease.

APOEε2. (also referred to as E2, e2 or ε2). Apolipoprotein E, ε2 allele.

APP. Amyloid Precursor Protein. The gene encoding this protein is found on chromosome 21. The transcript of the gene is sometimes referred to as APP770, as it is made of 770 amino acids.

B. βA4 or βA4a. see AβP.

bp. Base pair. The structure of DNA is of two chains of nucleotide bases, wrapped around
each other. Each pair of bases can be described as a base pair.

**BEHAVE-AD.** Scale for rating behavioural pathology in Alzheimer's Disease. (See behavioural assessment.)

**BNE.** Brief Neurological Examination. (See neurological assessment.)

**BP.** Blood pressure.

**BSE.** Bovine Spongiform Encephalopathy. Also known as Mad Cow Disease, this represents a bovine form of prion disease.

**B12.** Vitamin B12. Deficiency of this vitamin has been associated with a number of psychiatric disturbances, including progressive dementia. It is therefore important to identify and treat it at the earliest opportunity before irreversible structural changes occur in the brain.

**c-fos.** This is a cellular oncogene, which is encoded for on chromosome 14. It was a potential candidate for linkage with Alzheimer's Disease, but this has been refuted.

**Cd.** Communication difficulty subscore of CAPE-BRS.

**chAT.** Choline acetyl transferase, enzyme which makes Ach.
<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>CAA</td>
<td>Congophilic amyloid (or βA4a) angiopathy. A genetic condition characterised by haemorrhagic stroke.</td>
</tr>
<tr>
<td>CAMDEX</td>
<td>Cambridge Assessment of Mental Disorders in the Elderly Examination. (See global assessment.)</td>
</tr>
<tr>
<td>CAMCOG</td>
<td>Cognitive Assessment in the CAMDEX. (See neurocognitive assessment.)</td>
</tr>
<tr>
<td>CAPE</td>
<td>Clifton Assessment Procedure for the Elderly. (See behavioural assessment.)</td>
</tr>
<tr>
<td>CAPE-BRS</td>
<td>Behavioural rating scale of the CAPE. (See behavioural assessment.)</td>
</tr>
<tr>
<td>CERAD</td>
<td>Consortium to Establish a Registry for Alzheimer's Disease. (See global assessment.)</td>
</tr>
<tr>
<td>CJD</td>
<td>Creutzfeldt-Jacob Disease, or Jakob-Creutzfeldt Disease. This is a human form of a spongiform encephalopathy, or prion disease.</td>
</tr>
<tr>
<td>CPN</td>
<td>Community Psychiatric Nurse.</td>
</tr>
<tr>
<td>CSDD</td>
<td>Cornell Scale for Depression in Dementia. (See mood assessment.)</td>
</tr>
<tr>
<td>CSF</td>
<td>Cerebro-spinal fluid.</td>
</tr>
<tr>
<td>CSI</td>
<td>Carer Stress index. (See carer strain assessment.)</td>
</tr>
<tr>
<td>CT scan</td>
<td>Computerised Tomographic scan.</td>
</tr>
</tbody>
</table>
CVA. Cerebro-vascular accident, or stroke.

Cytochrome P450 This is an enzyme family which catalyzes detoxification reactions.

CYP2D6. Cytochrome P450 Debrisoquine 4-hydroxylase. The B allele of the gene for this protein, has been found to be a risk factor for Parkinson's Disease.

CYP2D6B. Represents the mutant B allele, of the CYP2D6 gene.


19q12. Locus on C19, q representing the long arm, position 12.


D. DLBD. Diffuse Lewy Body Dementia. In this condition, the Lewy Body inclusion bodies, appear more widely spread in the brains of patients with dementia without predominant Parkinsonism. (See LBD.)
DNA. Deoxyribonucleic acid. Genetic information is stored in the nucleus of cells as DNA, packaged up into 23 pairs of chromosomes. The two ends of the strand are known as the 5 prime (5') and 3 prime (3') ends.

There are four bases:

A. Adenine.
C. Cytosine.
G. Guanine.
T. Thymine.

cDNA. DNA consists of two chains of nucleotide bases wrapped around each other. Each is the complementary DNA of the other strand.

mtDNA. Mitochondrial DNA.

nDNA. Nuclear DNA.

DS. Down's Syndrome, Trisomy 21.

DSM3R. Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition Revised. (See criteria.)

E.

EDTA. Ethylenediaminetetra-acetic acid. Once the blood was taken, it was stored in EDTA tubes.

EOAD. Early Onset Alzheimer's Disease.

EPS. Extrapyramidal signs. Parkinsonian features of rigidity, tremor, hypokinesia etc.
EPSE. Extrapyramidal side effects, usually caused by neuroleptic medication.

ETC. Electron Transport Chain, involved in the process of Oxidative Phosphorylation. This is the mechanism of the cell's energy production, by the reduction of ADP to ATP, using the high reducing potential of an electron, and producing water from oxygen.

E5-1. Presenilin II, or STM2. The gene encoding this protein has been found on chromosome 1.

F. Familial Alzheimer's Disease.

G. Glyceraldehyde-3-phosphate dehydrogenase, is a key enzyme in glycolysis.

GMSS. Geriatric Mental State Schedule. (See global assessment.)

GP. General Practitioner.

GSS. Gerstmann-Straussler-Sheinker Syndrome. This is another human spongiform encephalopathy, or prion disease.

GTN. Glycerl Trinitrate. This is used in the treatment and prophylaxis of angina.
**H.**

**HCHWA-Dutch.** Hereditary Cerebral Haemorrhage with Amyloidosis of the Dutch type. This is a rare genetic disorder, with severe β-amyloid deposition in the cerebral blood vessels.

**HC.** (also referred to as HD) Huntington's Disease or Chorea. The key features of this condition are choreiform movements and dementia.

**HI.** Head Injury.

**HLA-A2.** Histocompatibility antigen HLA-A2. This has been reported to confer susceptibility to early-onset sporadic Alzheimer's Disease in men.

**HSPA2.** This is a heat shock protein which is encoded for on chromosome 14 and was a potential candidate for linkage to Alzheimer's Disease, but this has been refuted.

**HSP.** Hereditary Spastic Paraparesis. A rare genetic condition, see case study ic63.

**HV.** Health Visitor.

**I.**

**ICD** International Classification of Disease

<table>
<thead>
<tr>
<th>ICD9</th>
<th>9th revision.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICD10</td>
<td>10th revision.</td>
</tr>
</tbody>
</table>

**IHD.** Ischaemic Heart Disease.

**IT15.** Interesting Transcript 15, the transcript of the HD gene.
Kluver-Bucy Syndrome. Removal of the temporal lobes in monkeys, has led to a cluster of clinical signs. These are of placidity, strong oral tendencies in examining available objects, tendencies to attend and react to every visual stimulus, and an increase in sexual behaviour. In humans this manifests as: visual agnostic difficulties; hyperorality; hyperphagia; hypermetamorphosis; apathy and dullness.

Korsakoff's Psychosis. This is an amnestic condition, which can result from damage to the posterior hypothalamus and nearby midline structures. The commonest cause for lesions is thiamine deficiency, as a sequel to Wernicke's encephalopathy, usually the result of chronic alcoholism.

Low density lipoprotein. Lipid molecules (triglycerides, phospholipid and cholesterol), are combined with specific apoproteins to form lipoproteins which are released into the blood. LDL transport triglyceride to muscles and other tissues as a source of energy, or to fat depots for storage.

Lewy Body Dementia. Lewy bodies are intracytoplasmic eosinophilic neuronal inclusions. The term Lewy Body disease, can be applied to idiopathic Parkinson's disease, in which there is predominant subcortical pathology and motor impairment, and patients in which subcortical and cortical Lewy Bodies are associated with variable combination of cognitive impairment, psychiatric symptoms and extrapyramidal features, (LBD).
LPCR. Lothian Psychiatric Case Register. (See ascertainment of sample.)

LTC. Long Term Care.

M.

MCV. Mean Cell Volume. This provides a measure of the average size of red blood cells. The MCV increases with vitamin B12 deficiency.

MD. Myotonic Dystrophy.

MI. Myocardial Infarction.

MID. Multi-infarct dementia.

MMSE. Mini-Mental State Examination. (See neurocognitive assessment.)

MOUSEPAD. Manchester and Oxford University ScalE for Psychopathology in Alzheimer's Disease. (See behavioural and psychopathological assessment.)

MRC. Medical Research Council.

MRC-BMU. Medical Research Council-Brain Metabolic Unit.

MRI scan. Magnetic Resonance Imaging scan.

N.

NAC. Non-amyloid component proteins of the plaques found in Alzheimer's Disease. These are also known as synucleins.
NACP (also known as synuclein α) The precursor protein of the non-amyloid component of Alzheimer's Disease β amyloid.

NART. National Adult Reading Test. (See neurocognitive assessment.)

NHS. National Health Service.

NINCDS. National Institute of Neurological and Communicative Disorders and Stroke.

NINCDS-ADRDA. NINCDS-Alzheimer's Disease and Related Disorders Association criteria for Alzheimer's, also known as McKhann criteria.

NINDS-AIREN. National Institute of Neurological Disorders and Stroke - Association Internationale pour la Recherche et L'Enseignement en Neurosciences, vascular dementia criteria.

NMDA. N-methyl-D-aspartic acid. The NMDA receptor, is an excitatory amino acid receptor, for glutamate.

NPH. Normal Pressure Hydrocephalus.

O. Office of Population Censuses and Surveys. This includes a classification of occupations, according to socio-economic group (class I-V).

ORE. Open Reading Frame. This is a region of DNA, a 'frame' consisting exclusively of nucleotide triplets that represent amino acids.

PBE. Present Behavioural Examination. (See behavioural assessment.)
PCR. Polymerase Chain Reaction. This technique allows the amplification of any short DNA sequence.

Pd. Physical Disability subscore of CAPE-BRS.

PDAT. Presenile Dementia of the Alzheimer's Type.

PDC. Guam Parkinson's Dementia Complex. Amyotrophic lateral sclerosis and a related condition, characterised by Parkinsonism and progressive dementia (PDC), occur in the indigenous Chamorro population of Guam in the Western Pacific.

PM. Post-Mortem.

PrP. The Prion Protein weighs approximately 27-30 kd. The Prion Gene, encoded on the short arm of chromosome 20 in man, is a single copy gene of simple structure and organisation.

PrPsc. The abnormal isoform of the prion protein.

PSD. Presenile Dementia.

PSP. Progressive Supranuclear Palsy. This unusual progressive neurological disorder, shows ocular, motor and mental features. There is supranuclear paralysis of external ocular movements, particularly in the vertical plane, dysarthria, pseudobulbar palsy, dystonic rigidity of the neck and trunk, and dementia.

R. RAGE. Rating of Aggressive Behaviour in the Elderly. (See behavioural assessment.)
**REPDS.** Revised Elderly Persons Disability Scale. (See global assessment.)

**RE.** Restriction Endonuclease. Enzyme which cuts DNA. See below.

**RFLP.** Restriction Fragment Length Polymorphism. Restriction endonucleases cut DNA at specific sites. The resulting fragments of DNA will vary in size according to the enzyme used. The fragments are therefore a form of genetic finger-printing.

**RNA.** Ribonucleic acid. The information contained in DNA, is transported from the nuclei of cells to their cytoplasm, by means of a type of messenger, which is complementary to the DNA from which it is transcribed.

**mRNA.** The messenger RNA molecules.

**RSS.** Relative Stress Scale. (See carer strain assessment.)

**S.**

**S182.** Presenilin I. The gene encoding this protein has been found on chromosome 14.

**SBMA.** Spinal and Bulbar Muscular Atrophy. Neurodegenerative condition, whose underlying mechanism is a triplet repeat expansion.

**SCAI.** Spinocerebellar Ataxia type I. Neurodegenerative condition, whose underlying mechanism is a triplet repeat expansion.

**sel-12.** Gene from C.elegans, similar to S182. sel = supressor and/or enhancer of lin-12, which is a receptor for intercellular signals, specifying cell fate.
**Sd.**  Social disruption or disturbance subscore of CAPE-BRS.

**SDAT.**  Senile Dementia of the Alzheimer's Type.

**SDLT.**  Senile Dementia of the Lewy Body Type.

**SGRS.**  Stockton Geriatric Rating Scale. (See behavioural assessment.)

**SOD.**  Superoxide Dismutase. This enzyme is the natural defence against free oxygen radicals which destroy neurons.

**spe-4.**  Gene from *C. elegans*, encoding SPE4, a protein required for spermatogenesis. It has some homology with S182.

**SPECT scan**  Single Photon Emission Computerised Tomographic scan.

**SRO.**  (also see PSP.) Steele-Richardson Syndrome.

**STM2.**  Presenilin II, or E5-1. The second seven-transmembrane gene/protein associated with Alzheimer's Disease. The gene encoding this protein has been found on chromosome 1.

**T.**

**TIA.**  Transient Ischaemic Attack.

**TFGB3.**  Transforming growth factor β 3 subunit. This is encoded for on chromosome 14 and was a potential candidate for linkage with Alzheimer's Disease, but this has been refuted.

**TFT's.**  Thyroid Function tests.
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>TREF</td>
<td>Triplet Repeat Expansion. Repeating triplet of nucleotides in DNA. This is the molecular mechanism underlying Huntington's Disease.</td>
</tr>
<tr>
<td>V.</td>
<td>Venereal Disease Research Laboratory test, which screens for syphilis.</td>
</tr>
<tr>
<td>VDRL</td>
<td>Venereal Disease Research Laboratory test, which screens for syphilis.</td>
</tr>
<tr>
<td>VLDL</td>
<td>Very Low Density Lipoproteins. These are converted by lipoprotein lipase in the blood to low density lipoproteins. (Also see LDL.)</td>
</tr>
<tr>
<td>VLDL-R</td>
<td>Very Low Density Lipoprotein Receptor. There has been a report of this as a genetic risk factor associated with sporadic Alzheimer's Disease.</td>
</tr>
<tr>
<td>W.</td>
<td>Wechsler Adult Intelligence Scale.</td>
</tr>
<tr>
<td>WAIS</td>
<td>Wechsler Adult Intelligence Scale.</td>
</tr>
<tr>
<td>WAIS-R</td>
<td>Wechsler Adult Intelligence Scale, Revised.</td>
</tr>
<tr>
<td>Y.</td>
<td>Yeast Artificial Chromosome. YACs are cloning vectors, which enable entire chromosomes to be taken apart and put together.</td>
</tr>
</tbody>
</table>
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