VI,1 Male, aged 5. Primary school pupil. (Affected).

Interviewed with family and tested. Poor at retaining more than one instruction at a time. Speech delay (few single words other than ‘mama’ and ‘dada’ at two years, short phrases at 2 years six months. Speech therapy provided.

Now occasional word finding difficulties and reported ‘poor auditory memory’ on previous informal clinical assessment. Social difficulties mixing with other children. Behavioural difficulties relating to aggression and mixing with other children and school related difficulties prompting referral for psychiatric assessment. Rivermead screen: Story recall Immediate 3.22%, Story recall delayed 0%, Face recognition 100%, Picture recognition 100%

VI,2 Female, aged 2. (Unknown).

No difficulties reported.

V,6 Female, aged 29. (Affected).

Interviewed and tested. As quoted directly “words are the only problem. They do not seem to mean anything to me”. “When watching a documentary on TV, I can remember visually what I have seen but I cannot remember what has been spoken…. They [words] do not stick in my head”. “When I go on holiday I can picture the place, but if someone asked me the name of that place, I can’t remember’. “I have a very poor general knowledge”. “When I read a book I cannot remember what it is about”. “It stops me having conversations with people, it stops me feeling independent”

Rivermead BMT during interview: Story recall Immediate 11.2%, Story recall delayed 4.8%, Face recognition 100%, Picture recognition 90%.

V,7 Male, aged 31. (Affected).

Interviewed and tested. As quoted directly “Memory is a chore”. Needs to employ very complex mnemonics to remember one word e.g. to associate a word with a number, colour or a place. For example to remember the name, Rebecca, V,7 codes this as “6 or 18 which can also be 9(1+8) feels like dark red”. Necessity for items to always be in the same order when memorising them. He creates ‘tags’ for words in a word list for example such as for the first word “one=gun=all or nothing= black or white”. These tags are created to “prevent this memory field of information collapsing”.

Asked casually to recall the phone number 750305, gave the response “three-quarters red” that translates as 750/1000 (three quarters), Peugot 305 [car], Ferrari [is a red car].


Interviewed with family and tested. Reported being poor at recalling information from conversations and in the classroom. History of speech delay resulting in speech and language therapy. Needs identified from speech and language report ‘difficulty learning and retaining word meanings’, ‘has difficulties remembering when sentence length increases’. Special needs provision up to the age of 4
years. Known in the family as ‘shy’ and ‘withdrawn’. Poor school attendance. Some social difficulties mixing with other children, and concern about ‘blank responses’ and ‘extremely slow processing of ideas’ at school.

**V,9 Female, aged 12. Secondary School Pupil. (Suspected Affected).**

Interviewed with family. Specific Language Impairment. Speech and Language delay (few details provided). School refusal / phobia. Socially withdrawn and does not mix with other children. Poor academic attainment.

**V,10 Male, aged 13. Secondary School Pupil. (Suspected Affected).**

Interviewed with family. Myalgic encephalomyelitis (ME). Diagnosed with Dyslexia. Academic Difficulties. Long periods of school absenteeism. Difficulty remembering the content of books, lessons and conversations. If someone reads out loud to him he reports “I don’t take any of it in…. there’s no point reading books because I don’t remember”

Rivermead screen: Story recall Immediate 19%, Story recall delayed 21.4%, Face recognition 100%, Picture recognition 100%. Not tested on standardised measures of Intelligence and Memory.

**V,11 Male, aged 10. Primary School Pupil. (Unknown).**

Not interviewed and no report of difficulties by family members. Not tested.

**V,12 Female, aged 19. (Unaffected).**

Interviewed with family and no reported difficulties currently. Mild language delay in childhood- did not speak at all until 18 months. Single words at 22 months. Studying for higher degree. Partially tested on standardised measures of memory and found to be within (or above) normative range – scores shown in S3a.

**V,13 Female, aged 12. Secondary School Pupil. (Unaffected).**

Interviewed with family and no reported difficulties. Partially tested on standardised measures of memory and found to be within normative range for all scores – scores shown in S3a.

**IV,6 Female, aged 51. (Affected).**

Interviewed and tested. As quoted directly: “I know what has happened but I can’t put it into words”. “I can visualise experiences but can’t put them into words”. “I want to say a word and I can’t remember it…I sort of see it in my mind but only the beginning of the word and when it’s said I can recognise it”. “The police stopped me on the road on the way to my mothers and asked me where I was going… I couldn’t remember [articulate] my mother’s address”

**IV, 8 Female, aged 38. (Affected).**

Interviewed and tested. Observation and reports indicate she cannot retain content of conversation. Could not give researchers directions to her house because she couldn’t remember road names, even the road next to where she lived. As quoted directly: “Sometimes I’ve got a fantastic idea in my head but if I try to speak it, it will go. I can’t find it. It’s like losing something, losing your way and having to retrace your steps to find it” When reading a book “if I was asked what I’ve just read I would ‘black out’. When listening to people talking “A thing comes over me. I hear him saying things to me but they’re not going in. You just don’t take anything in” History of academic difficulties and language delay. Diagnosed as dyslexic in childhood.
IV,10  **Female, aged 48. (Affected)**

Interviewed and tested. As quoted directly: “Words just go out of my head”. Reports forgetting what she has heard ‘almost as soon as she has heard it’. Had academic difficulties as a child and was given special reading lessons. Awarded a distinction at College for her practical work in teenage years, but could not sit written exams due to poor memory.

IV,11  **Male, aged 39. (Suspected Affected)**

Interviewed with no reported difficulties at interview, later reports being “extremely bad at remembering names and can’t put a face to a name either”. Not tested.

IV,13  **Female, aged 49. (Unaffected).**

Interviewed with no reported difficulties. Partially tested using standardised measure of memory only: scores found to be within (or above) normative range—scores shown in S3a.

III,7  **Female, aged 75. (Affected).**

Interviewed and tested. As quoted directly: “People use a lot of words I don’t know the meaning of… my husband uses words I don’t understand”. “It’s very hard [to remember] with names and words”. “To remember names I have to go through the letters of the alphabet”. Anxiety from memory difficulties and feeling ‘stupid’ impacts ability to socialise and causes anxiety.

III,8  **Female, aged 78. (Suspected Affected).**

Not interviewed and not tested. Reported as using “the wrong words for the wrong thing, and commonly used the word thingamajig instead”. Does not read, and has difficulty remembering the names of plants; specific words such as ‘cyclamen’ – she could look at the plant and remember sick, then, gradually remember ‘Cyclamen’.

III,10  **Male, aged 76. (Unknown).**

Not interviewed and not tested.