

# Understanding Early Signs of Dementia

## A Patients and Carers Perspective



By capturing some of the pre-conscious, intangible, emotional elements of everyday speech, it is possible to detect the onset of dementia (and other degenerative diseases for that matter) much earlier than is possible than by merely using tangible conscious feedback mechanisms.

## Background

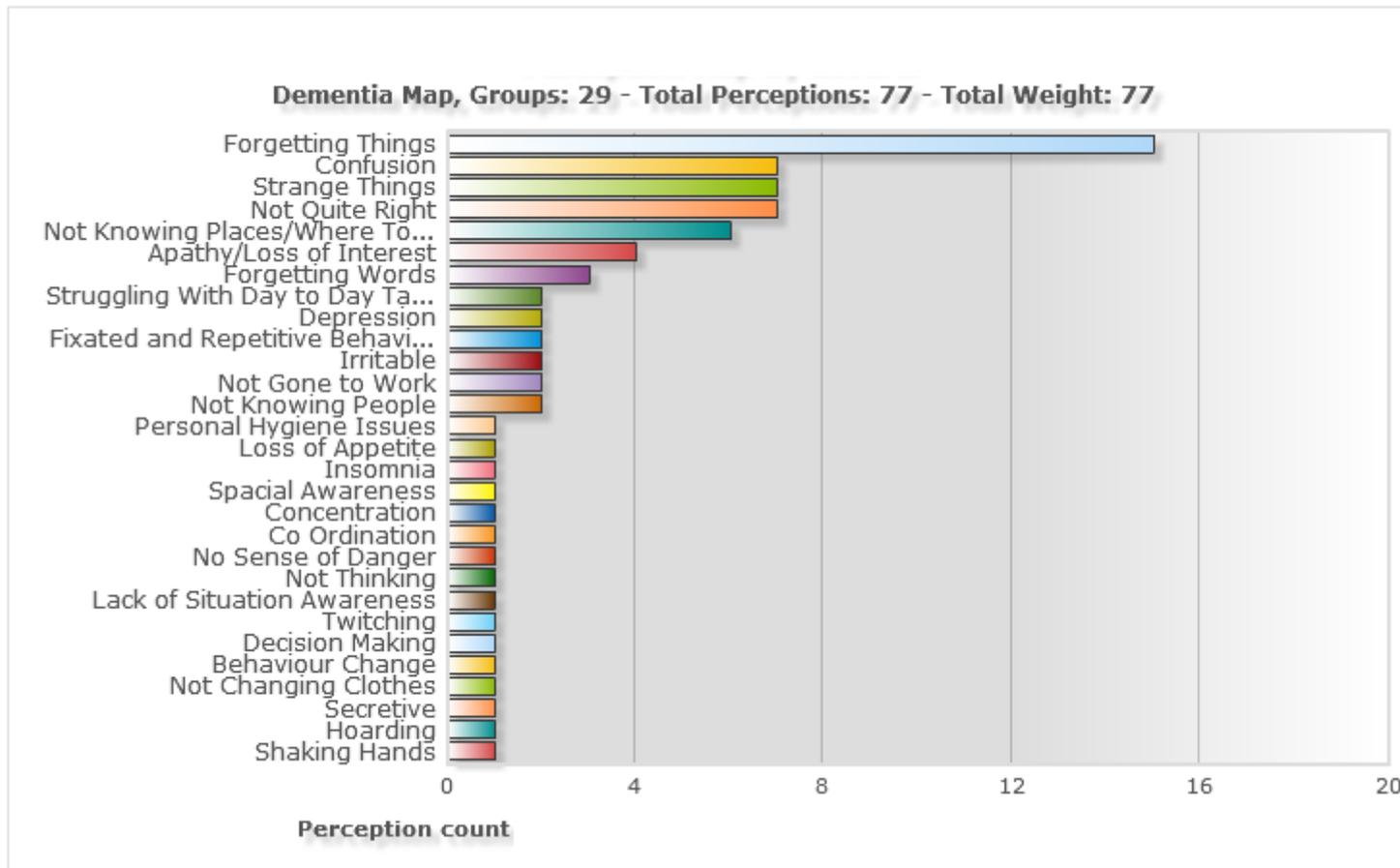
We heard of the poor national dementia diagnosis rates 35%-70% [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

We love a difficult problem to solve, and couldn't resist analysing sufferers and carers real experiences of dementia, that's what we do, analyse peoples thoughts views and experiences. So we collected, processed and analysed 47 online stories of "dementia experiences," that's 11,900 words in 195 separate paragraphs.

## Our Conclusions

- The time between first signs of dementia and making a GP appointment is many months, sometimes years with the benefit of hindsight this is recognised by authors, they were simply not aware of the symptoms of dementia.
- There are very early signs of dementia that are **not just memory related**; indeed they may even precede recognised memory problems. Partners, family and carers may well be the first to spot these very early signs, sometimes these signs appear years before a GP appointment, let alone a diagnosis!

The chart below maps 77 experiences that appear early in the narrative at a stage we called 1<sup>st</sup> sensed. Many of the symptoms are behavioural changes, noticed by friends, family and work colleagues.



Akumen believe there is one real early pattern whereby the patient or carer says the following;

“I first sensed/noticed something wasn’t quite right”

This is followed by he/she started to do “strange things”

The phrase not quite right does not appear at all after the stage 1<sup>st</sup> Sensed.

**Please Note:** Whist the dementia stories were very rich in explaining the dementia experience, they were not reliably placed in a chronological order by the authors.

## So What!

The benefits of early diagnosis are well documented; the earlier treatment starts the better and the less costly this disease is to society.

We believe soliciting the experiences of patients recently diagnosed with dementia in an open but chronological format would reveal more early indicators and patterns of dementia experience other than **just** memory. We can already see that a chronological dementia experience map would help identify where on the dementia continuum sufferers are, for example we do not see paranoia appear as a symptom until at least midway between first sensed and GP appointment.

This would be crucial knowledge, pertinent to raising the awareness of dementia and reducing the gap between first recognising something is “not quite right” and making that GP appointment.

Akumen specialise in analysing the qualitative experiences of people in volume, our experience of processing and analysing over 25,000 experiences is that patient’s, customer’s, frontline staff collectively have the answers to many problems, we believe this is one of them.

## So what’s next?

We are looking to find clinical partners and funds to further this qualitative research, and increase the knowledge, awareness and early diagnosis of dementia. We are confident 50-100 interviews with sufferers and carers will rigorously define a chronological dementia map of symptoms that could become an early onset dementia diagnosis app.

Please contact Paul Howarth on [paul@akumen.co.uk](mailto:paul@akumen.co.uk) or phone 07870 276147 if you would like to discuss this initial research



***You deserve to be better informed!***