

Freedom of Information – Response – 27182

Please find attached a pdf document detailing our FOI request. For ease, I have also pasted the content of the request into the body of this email below:

I am writing to request information under the Freedom of Information Act 2000 regarding individuals with young onset dementia (defined as individuals of any age who first experienced symptoms of dementia under the age of 65 and then received a formal diagnosis) within your local authority area.

Please provide the following information, using the most recent available data (preferably as of 14 April 2026 where possible).

Where data specific to young onset dementia as defined above is not held, please provide the closest available proxy (for example, individuals under 65 with a dementia diagnosis and note the proxy that has been used).

Questions

1. Does your authority routinely record young onset dementia as a distinct category within its data systems? (Yes/No)

A - No - For the purpose of the rest of this FOI, we will treat young onset dementia to be anyone with a dementia classification who is under 65.

2. How many specialist young onset dementia services are currently commissioned or available within your local authority area?

A – None.

3. Does your authority have a specific commissioning strategy, policy, or guidance for supporting individuals with young onset dementia? (Yes/No) If yes, please provide a copy or summary.

A - [Suffolk Dementia Strategy 2024-2029](#) references support to young onset dementia but not specific strategy focused on young onset.

4. If yes, does your authority have specific criteria or guidance for determining appropriate care settings for individuals with young onset dementia, including age-appropriate or specialist provision? (Yes/No)

A – No.

5. How many individuals are known to your authority with young onset dementia?

A – 117

6. How many of these individuals are currently receiving local authority-funded care and support?

7. Please break down the proportions of those in receipt of local-authority funded care and support with young onset dementia by age:

Age band % of total
 Under 40
 40-44
 45-49
 50-54
 55-59
 60-64
 65-69
 70+

Age band	% of total
Under 40	0%
40-44	0%
45-49	6%
50-54	7%
55-59	31%
60-64	56%
65-69	0%
70+	0%

- In the most recent full financial year:
 - o how many individuals under the age of 65 have you identified who qualify for support?
 - o how many individuals with young onset dementia did you start to provide a service for?

A – The number of those who had a service within the year is 80.

8. Do you cost packages for individuals with young onset dementia internally or externally?

A – Where appropriate, a personal budget to meet an adult’s care and support needs is allocated following a care and support assessment by Adult Social Care.

9. Of those receiving care, please provide a breakdown by service type (if recorded):
- o Residential care (please specify if service is predominately older person or working age adult)
 - o Nursing care (please specify if service is predominately older person or working age adult)

- o Specialist young onset dementia services*
- o Supported living*
- o Home care / domiciliary care*
- o Other (please specify)*

A –

Service	Number of people
Adult Placement Scheme	<5
Community Support Services	<5
Day Services	6
Direct Payments	5
Extra Care Housing	<5
Home Care and Support	22
Nursing Care	<5
Residential Care	19
Supported Housing	<5
Wellbeing Visits	<5

Please note that some individuals may be receiving support from multiple service types.

Counts fewer than five (<5) have been suppressed to prevent the potential identification of individuals.

10. The average weekly cost of care for individuals with young onset dementia (if available).

A – £1,310.66

11. The number of individuals with young onset dementia placed outside your local authority area, and the total annual spend on these placements (if available).

A –

Total Individuals	9
Total Annual Cost	£915,828.13

