Figures from the national Dementia Care and Support Register for 2017

Fact sheet 1 – Background characteristics of people with dementia
ACKNOWLEDGEMENTS

Figures from the national Dementia Care and Support Register for 2017. Fact sheet 1 – Background characteristics of people with dementia

Authors
Carola Döpp, Nivel
Iris van der Heide, Nivel
Marianne Heins, Nivel
Karlijn Joling, Amsterdam UMC (VUmc)
Robert Verheij, Nivel
Anneke Francke, Nivel

ADVISORS
Marco Blom, Alzheimer Nederland
Julie Meerveld, Alzheimer Nederland
Karlijn Kwint, Vilans
Margreet Reitsma, Vilans
Pieter Roel, Ministry of Health, Welfare and Sport (until 1 January 2020)
Valentin Neevel, Dutch Ministry of Health, Welfare and Sport (after 1 January 2020)


© March 2020 Nivel, Postbus 1568, 3500 BN UTRECHT (NL)

This publication has been produced as part of the programme called Dementiezorg voor elkaar (Dementia care for each other), a cooperative project involving Nivel, Vilans, Movisie, Pharos and the Trimbos Institute.

If you have any questions about this report, please contact the project leader Carola Döpp (c.dopp@nivel.nl).
INTRODUCTION

The average age of the population of the Netherlands will continue to rise over the coming years. Hand in hand with that ageing, the number of people with dementia will increase dramatically. One of the preconditions for being able to keep providing good care to people with dementia and those close to them is getting a clear picture of the care and support needed. What care and support do these people use? And where do they get it? Basic information like this is a prerequisite for being able to learn and improve.
WHAT IS THE DEMENTIA CARE AND SUPPORT REGISTER?

1. A source of information giving a picture of the use of care and support by people with dementia and their cohabiting partners.

2. It aims to provide a picture and then start a discussion about the quality of care and support.

3. Uses existing data. With NO extra recording burden.

4. A long-term source of information used for publishing annual figures and trends about the uptake of care and support by people with dementia and their partners.

5. Data is at the individual level and stored in the secure environment of Statistics Netherlands.
This fact sheet is about the background characteristics of people affected by dementia. All the information is based on the latest available data, in this case from 2017. To help put the information in the right context, details are also given for comparative purposes about the background characteristics of people aged 65-plus in the general population. The fact sheet contains the following:

1. Characteristics of people with dementia nationwide figures for 2017
   - Which people with dementia does the Register contain information about?
   - Age & gender
   - Immigration background & civil status
   - Income
   - Death and place of death

2. Characteristics of people with dementia regional figures for 2017
   - Age & gender
   - Immigration background
   - Civil status
   - Income
   - Place of death

3. Methodological underpinning & FAQs
1. Background characteristics of people with dementia
   Nationwide figures for 2017
WHICH PEOPLE WITH DEMENTIA DOES THE REGISTER CONTAIN INFORMATION ABOUT?

The diagram below shows how many people and cohabiting partners the Dementia Care and Support Register contained details of in 2017.

It is estimated that 280,000 people are living with dementia in the Netherlands (figures from the Dutch Alzheimer's Association) of whom about 180,000 (64%) are known.

The Dementia Care and Support Register contains details of 178,741 people who had dementia in 2017 and 56,079 cohabiting partners.

This dataset has been produced using existing data sources. For a more detailed explanation, see page 23.
AGE AND GENDER OF PEOPLE WITH DEMENTIA – 2017
The baseline date for all characteristics is 1 January 2017

65 per cent of the people with dementia were female. That is 10 per cent more than in the group of people aged 65-plus in the Dutch population as a whole, of whom 55 per cent were women. People with dementia were 81 years old on average in 2017. Figure 1 gives the distribution in the various age categories.

Figure 1. Breakdown of people with dementia by age (in percentages)
Among people with dementia, the percentage with an immigrant background was the same as among those aged 65+ in the general population. In both cases, the group aged 65+ comprised 10% with immigration backgrounds from the western world and 4% from elsewhere (CBS Statline).

Many people with dementia live in care institutions (38%). Among the elderly population (65+) as a whole, that figure was just 4% in 2017 (CBS Statline). 24% of people with dementia live alone, as opposed to 31% of people aged 65+ in the general population.
The average annual income of people aged 65+ was 28,000 euros in 2017 (CBS Statline). For 55 to 84 per cent of people with dementia, the annual income was below that.

Nine per cent of people with dementia had annual incomes of 10,000 euros or less. These people are living below the poverty line, which was defined as 1040 euros a month or less in 2017 (Statistics Netherlands, 2018). Some 2.3% of all people aged 65+ were below the poverty line in 2017 (CBS Statline).
20% of people with dementia in 2017 died during that year.

Place of death of people with dementia

- Home: 8%
- Hospital: 8%
- Care institution: 82%

Top 5 causes of death
Primary cause of death of people with dementia who died in 2017

1. Dementia: 39%
2. Stroke, not specified as a haemorrhage or infarction: 5%
3. Cardiac failure: 4%
4. Unspecified fall: 3%
5. Parkinson's disease: 3%
2. Background characteristics of people with dementia
Care Administration Region figures for 2017
The average age of people with dementia varied across the various regions from 79 to 83.

The majority of people with dementia were women in all regions, at percentages ranging from 62 to 67 per cent.

The percentage of young people with dementia varied across the regions from 4 to 11 per cent.

Five regions with the highest proportion of younger people (ages 40-65) with dementia

1 Amsterdam 11%
2 Haaglanden 11%
3 Drenthe 10%
4 Zuid-Hollandse Eilanden 10%
5 Zuid-Limburg 9.5%

Dementia at younger ages

The national figures show that 7.4% of the people who had dementia in 2017 were aged between 40 and 65. The percentage of younger people with dementia varied across the regions from 4 to 11 per cent of the total group with dementia.

The care administration regions with the highest percentages are given in the table on the left.
The percentage of people with non-western immigrant backgrounds was between 1 and 5 per cent of the overall group of people with dementia in most regions. The care administration regions on the right are the exceptions.

Regions with a high percentage of non-western immigrant backgrounds among people with dementia

1) Amsterdam Care Administration Region - 20%
2) Haaglanden Care Administration Region - 15%
3) Rotterdam Care Administration Region - 14%

The percentage of people with non-western immigrant backgrounds was highest in Amsterdam.
Figure 5. Residential situation of people with dementia as at 1 January 2017 (% per category)
There is a lot of variation between care administration regions regarding the residential situation of people with dementia.

The highest proportion of people with dementia who lived at home (75%) was in Zuidoost-Brabant, which therefore also had the lowest figure for care institutions (25%).

People with dementia living alone

Nationwide, 24% of people with dementia were living alone. Regionally, it varied between 18 and 36 per cent in 2017.

The percentage of single people with dementia was highest in 2017 in Amsterdam (36%) and Rotterdam (31%).
INCOMES OF PEOPLE WITH DEMENTIA – REGIONS IN 2017

Care administration regions with the highest proportion of people with dementia living below the poverty line (€1040 a month or less)

<table>
<thead>
<tr>
<th>Rank</th>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Amsterdam</td>
<td>13%</td>
</tr>
<tr>
<td>2</td>
<td>Rotterdam</td>
<td>12%</td>
</tr>
<tr>
<td>3</td>
<td>Groningen</td>
<td>10%</td>
</tr>
<tr>
<td>4</td>
<td>Haaglanden</td>
<td>10%</td>
</tr>
<tr>
<td>5</td>
<td>Arnhem</td>
<td>10%</td>
</tr>
<tr>
<td>6</td>
<td>‘t Gooi</td>
<td>10%</td>
</tr>
</tbody>
</table>

6 to 13 per cent of people with dementia were living below the poverty line. This percentage was lowest in Zuidoost-Brabant and highest in Amsterdam.

In all the regions, the largest group of people with dementia (37-57%) had annual incomes between 10,000 and 20,000 euros.

People aged 65+ in the general population

- 2.3 per cent were living below the poverty line.
- Average annual income 28,000 euros (see also page 10)
PLACE OF DEATH OF PEOPLE WITH DEMENTIA – REGIONS IN 2017

The majority of people with dementia who died in 2017 passed away in a care institution. Very few people (6-10%) died at home.

<table>
<thead>
<tr>
<th>CARE ADMINISTRATION REGION</th>
<th>= at home</th>
<th>= hospital</th>
<th>= care institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘t Gooi</td>
<td>9%</td>
<td>6%</td>
<td>84%</td>
</tr>
<tr>
<td>Amstelrland and De Meerlenden</td>
<td>7%</td>
<td>10%</td>
<td>82%</td>
</tr>
<tr>
<td>Amsterdam</td>
<td>9%</td>
<td>12%</td>
<td>78%</td>
</tr>
<tr>
<td>Apeldoorn/Zutphen</td>
<td>7%</td>
<td>7%</td>
<td>84%</td>
</tr>
<tr>
<td>Arnhem</td>
<td>8%</td>
<td>8%</td>
<td>82%</td>
</tr>
<tr>
<td>Drenthe</td>
<td>7%</td>
<td>7%</td>
<td>84%</td>
</tr>
<tr>
<td>Flevoland</td>
<td>7%</td>
<td>8%</td>
<td>83%</td>
</tr>
<tr>
<td>Friesland</td>
<td>8%</td>
<td>6%</td>
<td>85%</td>
</tr>
<tr>
<td>Groningen</td>
<td>8%</td>
<td>5%</td>
<td>85%</td>
</tr>
<tr>
<td>Haaglanden</td>
<td>9%</td>
<td>9%</td>
<td>78%</td>
</tr>
<tr>
<td>Kennemerland</td>
<td>9%</td>
<td>11%</td>
<td>78%</td>
</tr>
<tr>
<td>Midden-Brabant</td>
<td>10%</td>
<td>9%</td>
<td>80%</td>
</tr>
<tr>
<td>Midden-Holland</td>
<td>7%</td>
<td>7%</td>
<td>85%</td>
</tr>
<tr>
<td>Midden-IJssel</td>
<td>7%</td>
<td>6%</td>
<td>85%</td>
</tr>
<tr>
<td>Nijmegen</td>
<td>10%</td>
<td>8%</td>
<td>82%</td>
</tr>
<tr>
<td>Noord &amp; Midden-Limburg</td>
<td>10%</td>
<td>11%</td>
<td>78%</td>
</tr>
<tr>
<td>Noord-Holland Noord</td>
<td>11%</td>
<td>7%</td>
<td>81%</td>
</tr>
<tr>
<td>Noordoost-Brabant</td>
<td>10%</td>
<td>9%</td>
<td>80%</td>
</tr>
<tr>
<td>Rotterdam</td>
<td>7%</td>
<td>9%</td>
<td>83%</td>
</tr>
<tr>
<td>Twente</td>
<td>7%</td>
<td>6%</td>
<td>86%</td>
</tr>
<tr>
<td>Utrecht</td>
<td>8%</td>
<td>8%</td>
<td>84%</td>
</tr>
<tr>
<td>Waardenland</td>
<td>7%</td>
<td>7%</td>
<td>85%</td>
</tr>
<tr>
<td>West-Brabant</td>
<td>8%</td>
<td>7%</td>
<td>82%</td>
</tr>
<tr>
<td>Westland Schieland Delfland</td>
<td>6%</td>
<td>8%</td>
<td>84%</td>
</tr>
<tr>
<td>Zaanstreek/Waterland</td>
<td>8%</td>
<td>11%</td>
<td>79%</td>
</tr>
<tr>
<td>Zeeland</td>
<td>7%</td>
<td>6%</td>
<td>84%</td>
</tr>
<tr>
<td>Zuid-Holland Noord</td>
<td>9%</td>
<td>6%</td>
<td>85%</td>
</tr>
<tr>
<td>Zuid-Hollandse Eilanden</td>
<td>9%</td>
<td>7%</td>
<td>83%</td>
</tr>
<tr>
<td>Zuid-Limburg</td>
<td>7%</td>
<td>10%</td>
<td>82%</td>
</tr>
<tr>
<td>Zuidoost-Brabant</td>
<td>10%</td>
<td>10%</td>
<td>78%</td>
</tr>
<tr>
<td>Zwolle</td>
<td>10%</td>
<td>6%</td>
<td>80%</td>
</tr>
</tbody>
</table>

The percentages do not always add up to 100%. The remaining percentage fell in the category ‘other’.
3. Methodological underpinning & FAQs
1. What is the Dementia Care and Support Register?

The Dementia Care and Support Register is a unique source of information with data about the uptake of care and support for people with dementia. The purpose of the register is to help improve care and support for people with dementia and those close to them.

The register contains data from various existing sources that are linked together at the level of the individual. The register thus lets us obtain a picture of the care pathways that people with dementia progress through and of trends in the utilisation of care through the years. In the longer term, data about the quality of care and support will be added.

Based on the register, information is periodically issued about the uptake of care and support at the national and regional levels obtained by coupling existing data sources together. Policy-makers, interest groups, managers and coordinators of dementia networks can use this information to start discussions with regional and/or national partners about the quality of care and support for people with dementia and those close to them. Are people getting the right care? And are they getting it in the right place? What can we do to make sure that people receive relevant support at the correct moment and at the correct location?

Under certain conditions, researchers will in the longer term also be able to use the data from the register for research that benefits the quality of care and support for people with dementia.

The register uses datasets that are already available and therefore does NOT create any additional administrative burden. The data is collated and coupled together in a secure environment at Statistics Netherlands that complies with the applicable privacy legislation.
Data from existing sources on the use of care and support by people with dementia

- Background characteristics People with dementia
- Background characteristics co-habiting partners
- GP care
- Hospital admissions
- Medication provision
- Long-term care
- Provisions under the Social Support Act

Optimizing clinical practice
Fact sheets
2. How are people with dementia selected?

Various existing datasets are used for selecting data for inclusion in the register from people who have dementia. This fact sheet covers the year 2017, which is the data that was available for analysis as at the end of 2019. The register contains data about people who had dementia in 2017. These people were selected on the basis of them meeting at least one of the criteria described in the table below.

<table>
<thead>
<tr>
<th>Selection criteria</th>
<th>Data file</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis code ICPC P70 (dementia)</td>
<td>Nivel Zorgregistraties (NZR) for GPs and GP units. All available years up to and including 2017 were used for locating people with dementia.</td>
</tr>
<tr>
<td>ICD 10 diagnosis codes, specifically: F00 (Alzheimer dementia) F01 (vascular dementia) F02 (dementia as an aspect of another condition) F03 (unspecified dementia)</td>
<td>Landelijke Basisregistratie Ziekenhuiszorg (Dutch Hospital Data). Files from 2014 onwards have been used for locating people with dementia.</td>
</tr>
<tr>
<td>Medication code (ATC code) N06D (anti-dementia medication).</td>
<td>Medicines files (Statistics Netherlands), files from 2008 up to and including 2017 were used for locating people with dementia. NZR for GPs and GP centres: all years through to 2017 were used for locating people with dementia.</td>
</tr>
<tr>
<td>Indication for care package level ZZP 5 VV – VV (sheltered housing with intensive dementia care) and/or psychogeriatrics as the predominant reason for an indication under the Long-Term Care Act and/or psychogeriatrics as a secondary reason for an indication under the Long-Term Care Act.</td>
<td>File about the uptake of care under the Long-Term Care Act, based on data from the Care Needs Assessment Centre (CIZ). The years 2015 through 2017 were used for locating people with dementia.</td>
</tr>
</tbody>
</table>

People aged under 40 were excluded because dementia generally only occurs from age 40 onwards. People who have a ZZP7 indication (meaning they need very intensive care and supervision) has not been used as a criterion for selecting people with dementia as there is a chance of them having a psychiatric condition rather than dementia.
3. How many people with dementia were details found of in the various files?

The table below shows how many people with dementia were found using each of the datasets. These are people who had dementia in 2017. Because some people will be present in more than one file, the third column gives the percentage of unique individuals with dementia that each dataset has contributed to the total.

<table>
<thead>
<tr>
<th>Source file (owner)</th>
<th>Number of people identified from each file</th>
<th>Cumulative number</th>
<th>Cumulative percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-Term Care Act file (CIZ, Care Needs Assessment Centre)</td>
<td>125,513</td>
<td>125,513</td>
<td>70.2</td>
</tr>
<tr>
<td>Medicine file (Statistics Netherlands)</td>
<td>70,023</td>
<td>166,713</td>
<td>93.3</td>
</tr>
<tr>
<td>National Basic Hospital Records (DHD)</td>
<td>36,605</td>
<td>174,888</td>
<td>97.8</td>
</tr>
<tr>
<td>Nivel Zorgregistraties for general practitioners</td>
<td>10,095</td>
<td>178,472</td>
<td>99.8</td>
</tr>
<tr>
<td>Nivel Zorgregistraties for general practitioner units</td>
<td>1,608</td>
<td>178,741</td>
<td>100</td>
</tr>
</tbody>
</table>

4. Is the data used in the register representative?

The data from Nivel Zorgregistraties is representative for the entire Dutch population as regards age and gender. There was GP data for 2017 for 10% of the Dutch population and there were details about the GP units for 58% of the Dutch population.

The other datasets contained information about the entire Dutch population. As an illustration: the dataset for hospital admissions contains details of ALL day admissions, clinical admissions and ‘long-term observations without overnight stays’ at all general and university hospitals in the Netherlands.
5. Which people does the register NOT contain details of?

The register does not contain details of every individual with dementia. There are two reasons for this:
- Some people with dementia are not yet receiving any care or support from professionals and can therefore not yet be found in the files used. These are for example people who are still in or have not yet reached the phase of not being quite right any more.
- People who only receive care or support from a professional whose details have not been included in the register will also be missed, such as GP practices that do not take part in Nivel Zorgregistraties, for instance.

6. What datasets were used for analysing the background characteristics?

**Gender, age, residential situation and immigration background**
To give a picture of the various characteristics of the group of people who have dementia, various files from Statistics Netherlands are used containing personal details and household details, based on the Municipal Population Register.

**Income**
To obtain a picture of the incomes of the group of people with dementia, the Statistics Netherlands dataset on standardized incomes was used. This is the disposable income (the net amount that a household can spend per year), corrected for the size and composition of the household.

**Death and place of death**
For people with dementia who died in 2017, the death statistics from Statistics Netherlands were used. The cause of death statistics from Statistics Netherlands were used for determining the location of death and the top five causes of death for the 36,070 people with dementia who died in 2017.
7. How were the care administration regions determined that people with dementia belong to?

There were 31 care administration regions in 2017. Every care administration office has a defined catchment area. People with dementia are allocated to a specific region on the basis of the four digits of their postcode. The postcodes of people with dementia were determined using files from Statistics Netherlands, based in turn on data from the Municipal Population Register (GBA).

8. Why does the register contain data on fewer people than the Vektis study?

Vektis (2019) found 256,000 people who had dementia in 2017. The register contains data about 178,741 people with dementia in 2017. This difference is largely explained by the fact that there are differences in the criteria used for finding people with dementia in the datasets.

The key differences are:
- The Vektis study also selected people with a mild cognitive impairment or memory problems. These people were not included in the register because we do not know if they developed dementia.
- The register also did not include a selection criterion of receiving district-based care covered by code 1035 (care for the vulnerable elderly and the chronically sick for longer than 3 months – psychogeriatric / psychiatric).