

European Carers' Report 2018

*Carers' experiences of diagnosis
in five European countries*



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1. Introduction

This report presents the findings of a study conducted in 2017 by Alzheimer Europe (AE), Bangor University and five AE member organisations on the important topic of the diagnosis of dementia. The study set out to better understand the experiences of informal carers of receiving a diagnosis of dementia across five European countries.

In 2006, AE had carried out a survey about carers' experiences of diagnosis. Since then there have been a lot

of changes in policy and practice affecting diagnosis. Many European countries have developed and implemented national dementia strategies or plans, several of which have addressed the topic of diagnosis. In 2017, we therefore decided to revisit the survey in order to explore some new topics, as well as better understand how these changes may have affected carers' experiences of diagnosis.

1.1. Alzheimer Europe's 2006 survey on carers' experiences of diagnosis

The 2006 survey involved a total of 1181 informal carers from five European countries: France, Germany, Poland, Spain and the UK (Scotland).¹ The survey revealed several important challenges in the process of receiving a diagnosis of dementia and highlighted important gaps in the information, care and support received by carers at the time of diagnosis. Some of the key findings of this survey included:¹

- the most frequent symptom which prompted help seeking was memory/confusion (81%), however difficulties with activities of daily living and behaviour that challenges were also very frequently reported by carers and experienced as more difficult to cope with than cognitive symptoms
- many people (67%) had been diagnosed with dementia for at least two years when the survey was conducted. At the time of the survey 8% were in the mild stage of dementia. The diagnosis had been made either at a GP/primary care practice (31%) or in a hospital (31%). Two-thirds of the people with dementia had

been informed of their diagnosis (64%), but there were important differences between countries, and in Spain only 23% of people with dementia had been informed of their diagnosis

- the majority of carers felt that the provision of information on all aspects of dementia was inadequate: 19% of carers received no information at the time of diagnosis; 66% received no information on disease progression; 59% were not informed about the existence of an Alzheimer's association; and 82% were given no information about available services. Satisfaction with the information received was relatively high: the average response from all respondents was 3.5 (1 indicating 'not satisfied at all' and 5 'very satisfied'); this was much lower in Spain (2.7). Almost half of the carers (46%) would have liked more information on disease progression and services
- across all countries, 35% of carers used home support and 45% day care services, but several services were not available and often carers had to pay for the services

1.2. Other relevant literature

Current estimates suggest that over 9 million European citizens (EU28) may have dementia.² Despite a great deal of policy development and research efforts on diagnosis, many people with dementia will never receive a diagnosis, will receive it too late or will not be adequately supported. An accurate and timely diagnosis is crucial for people with dementia and their families. The diagnosis, whilst a critical stage, is not the end of the journey. It should be accompanied by provision of timely and adequate information, care and support.

The time before diagnosis and the experience of being diagnosed and receiving the diagnosis can be quite challenging for some people with dementia and their families. Regardless of the experience of diagnosis, it should come at the right time. Often, carers and people with dementia feel that diagnosis took too long or/and was made too late. A survey carried out in 2005 in six European countries ("Facing dementia survey")³ revealed that it took, on average, two years and two months to get a diagnosis (i.e. from first symptoms to diagnosis), with relevant differences between countries (ranging from 10 months in Germany to 32 months in the UK).

The concept of timely diagnosis takes into consideration the "right time" for the individual, as opposed to its chronological sense⁴. An emerging body of literature has outlined the benefits of a timely diagnosis of dementia, including that diagnosis is a right and most people wish to know it. Timely diagnosis can help people plan for their future, make advance care plans, start treatments and/or gain access to care, support and research. Diagnosis may also

have psychological benefits for people with dementia and their families, as it can put an end to uncertainties.^{5,6} The potential negative impact of diagnosis on people with dementia has also been investigated and is particularly relevant in the absence of a cure or more effective treatments for dementia. The potential impact of the diagnosis may also depend to some extent on how and by whom it is communicated.

Most people with dementia want to be told their diagnosis in a clear, straightforward way.^{7,8,9,10} Family carers and health professionals have often argued against disclosing the diagnosis of dementia to the person on the grounds that knowing the diagnosis may cause them psychological harm. The disclosure of the diagnosis to the person is one of the most difficult areas in dementia management.¹¹ Whilst the person may feel initially upset and shocked, these feelings may lessen after a period of time and it may help the person to better understand the condition, attach meaning to his/her experiences, find ways of coping with the disease and plan for his/her future.¹⁰

Diagnosis without adequate support may not be as helpful.^{12,13} Following a diagnosis of dementia, people with dementia and their families should be provided with appropriate information and support.¹⁴ The provision of high-quality information is essential for helping the individual adjust to dementia and for facilitating access to adequate support and services. Lack of information or information received in a "haphazard" fashion may hinder access to relevant services.^{15,16}

2. Methodology

2.1. Purpose, conduct and financing of the study

The main aim of the study was to investigate the experiences of informal carers of receiving a diagnosis of dementia across five European countries. The study was carried out jointly by Bangor University (Wales, UK), AE (Luxembourg) and five AE's member organisations: the Czech Alzheimer Society (Czech Republic), Alzheimer Society of Finland (Finland), Federazione Alzheimer Italia (Italy), Alzheimer Nederland (the Netherlands) and Alzheimer Scotland (Scotland, UK).

Main contributors:*

- Bangor University
 - Bob Woods (academic lead)
- Alzheimer Europe
 - Jean Georges
 - Ana Diaz

- Czech Alzheimer Society
 - Martina Mátlová
- Alzheimer Society of Finland
 - Eila Okkonen
 - Anna Salmi
- Federazione Alzheimer Italia
 - Mario Possenti
 - Francesca Arosio
- Alzheimer Nederland
 - Wendy Werkman
 - Susanne van den Buuse
- Alzheimer Scotland
 - Lindsay Kinnaïrd

The survey was conducted in the Czech Republic, Finland, Italy, the Netherlands and the UK (Scotland) and was made possible thanks to an educational grant from Roche to Alzheimer Europe.



2.2. Data collection

The data were collected using a survey collectively developed by the study authors, using as a basis the format of the AE's 2006 carers survey, with revisions and additions to address the aims of the current study.

The final questionnaire included 57 questions and addressed the following topics: demographics of the carer and person with dementia; the symptoms that were experienced and prompted help-seeking; the pathway through

* The full list of people who have contributed to this work can be found in the acknowledgements section at the end of this report.

the diagnostic process; the experience of the diagnostic process; support and information offered at the time of diagnosis; emotions experienced immediately after the diagnosis and subsequently; and the carers' experience of their community as "dementia friendly".

The questionnaire was drafted in English and professionally translated from English into Czech, Dutch, Finnish and Italian, and the translations verified by a process of back translation and rechecking against the English version. An online version of the survey in each of the five languages was created on the Bristol Online Survey platform, and a paper version also made available.

The link to the online survey was distributed through the participating national Alzheimer's associations (e.g. e-mail, social media and newsletters) and the paper version made available on request or mailed out according to local circumstances. The paper version was not used in the

Netherlands. The different online versions of the survey were live between February and July 2017, with differences between countries in the time needed for recruitment (e.g. Finland finished the recruitment in around a week whereas some other countries, such as the Czech Republic and the UK (Scotland), needed a little over two months). Information about the survey and links to the national online surveys were also disseminated through Alzheimer Europe's electronic newsletter.

To be able to take part in the study, the person had to be currently supporting or providing care to a family member or friend who had received a diagnosis of dementia. Both the respondent and the person with dementia had to be resident in one of the five participating countries.

Ethical approval was given by Bangor University Healthcare Sciences Ethics Committee.

2.3. Data analysis

The main statistical analysis was carried out by Bangor University using a statistical software package (IBM SPSS Statistics 25). This involved a descriptive analysis of the whole sample as well as of findings from each individual country, and, when appropriate, some cross-country comparisons.

In this report, the overall findings for all the questions included in the survey are reported. The national findings are only presented to highlight relevant differences between countries. In addition to this report, two academic articles are planned for publication in international peer-reviewed journals which will examine in detail factors associated with timely diagnosis and post-diagnostic support.

3. Who took part in the study?

3.1. Demographic information of the carers

A total of 1409 carers participated in the survey. Of those, 212 lived in the Czech Republic, 363 in Finland, 339 in Italy, 268 in the Netherlands and 227 in the UK (Scotland). The majority of the participants completed the survey online (83.4%).

The demographic characteristics of the carers are as follows:

- more than two-thirds were female
- the median age was 57
 - carers in Finland and the Netherlands were slightly older with a median age of 62
- around half of the carers (52.6%) were adult children and a bit more than a third (35.6%) were spouses
 - the Czech Republic and Italy were the countries with the lowest percentages of spouses completing the survey (18% and 21.6% respectively). The Netherlands had the highest percentage of carers who were spouses (53.7%)
- three-quarters of the carers (73%) identified themselves as being the main carer or sharing this role with another person(s) on an equal basis
- the sample was in general quite highly educated, around half of the carers had completed tertiary education (college, university or equivalent)
 - the Netherlands and the UK (Scotland) had the highest proportion of carers who had completed tertiary education (75.7% and 69.8% respectively)
- the majority of carers were in paid employment (44%) or retired (36%). 8% of carers claimed not to be able to work due to the carer role
 - in Finland only 2.2% of the carers felt they could not work due to this role, whereas in the UK (Scotland), 15.6% said they were not in paid employment due to be caring for a person with dementia

Figure 1: Gender of carers (n=1393)

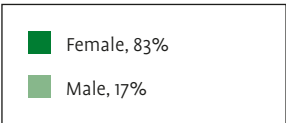
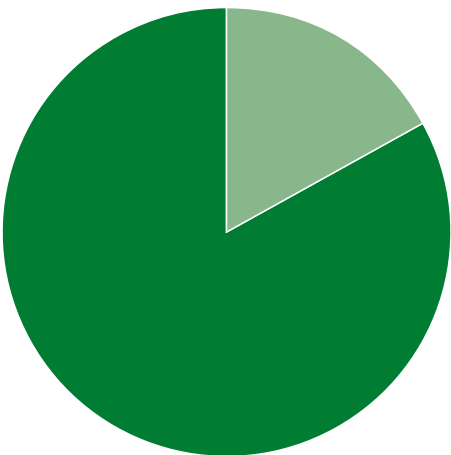


Figure 2: Relationship of the carer to the person with dementia (n=1404)

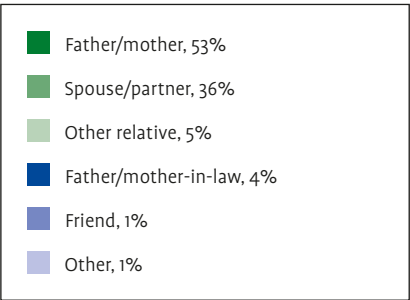
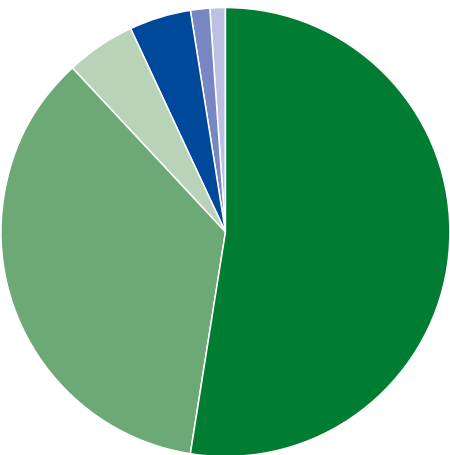


Figure 3: Role as carer (n=1405)

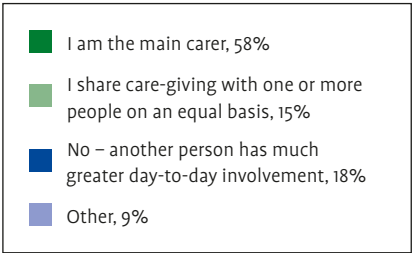
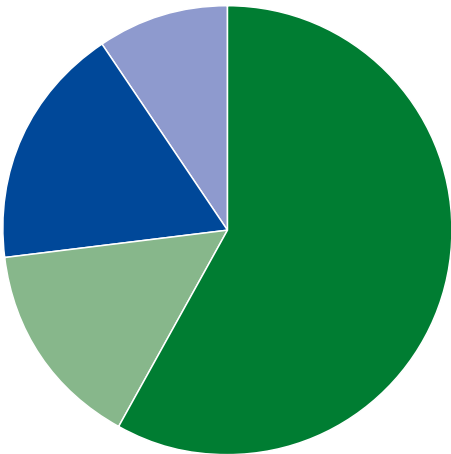


Figure 4: Level of education (n=1403)

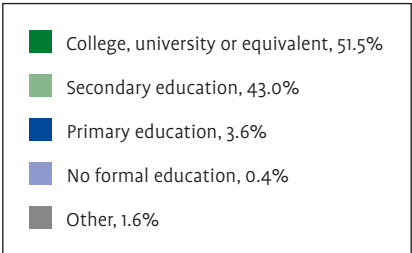
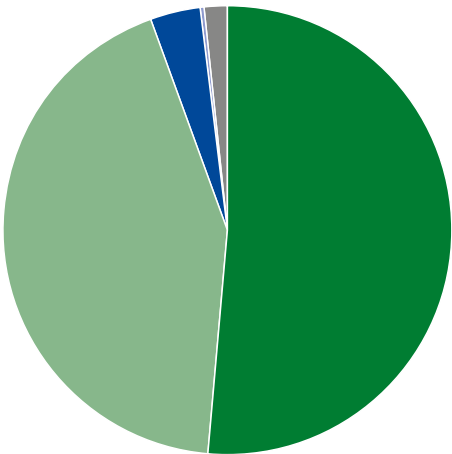


Figure 5: Employment status (n=1402)

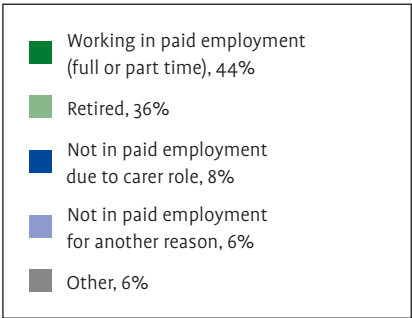
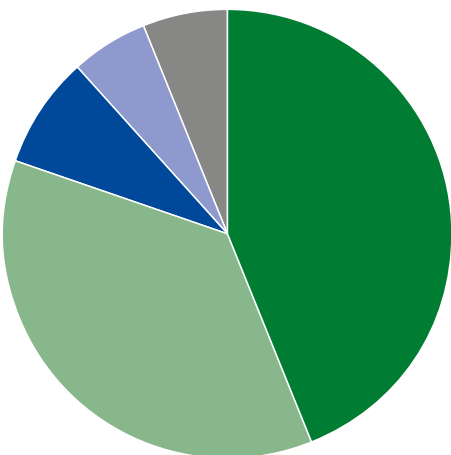


Table 1: Summary of demographic characteristics of carers by country

		Total n=1409	Czech Republic n=212	Finland n=363	Italy n=339	Netherlands n=268	UK (Scotland) n=227
Gender (n=1393)	% female	82.80%	82.90%	86.90%	80.30%	75.80%	88.40%
Median age (n=1400)	Years	57	57	62	50	62	57
Education (n=1403)	Secondary	43.0%	43.9%	46.4%	66.2%	21.3%	27.6%
	Tertiary	51.5%	49.5%	43.9%	29.4%	75.7%	69.8%
Main carer? (n=1405)	Yes	58.1%	49.5%	57.2%	51.3%	66.0%	68.1%
	Shared equally with other(s)	15.0%	19.30%	13.8%	19.0%	12.7%	9.7%
Relationship to person with dementia (n=1404)	Spouse	35.6%	18.0%	41.2%	21.6%	53.7%	42.7%
	Adult child	52.6%	62.1%	50.8%	64.8%	38.4%	45.8%

3.2. Demographic information of people with dementia

The demographic characteristics of the people with dementia are as follows:

- the median age was 77
 - people with dementia in the Czech Republic and Italy were slightly older (median age 82)
- around two-thirds (61%) of the people with dementia were female
 - this was not the case in the UK (Scotland) where there were slightly more men than women with dementia (53.1% and 46.9% respectively)
- the majority had completed secondary (42%) or primary education (26%)
 - more people with dementia in the Netherlands and in the UK (Scotland), had been to college/university (41.4% and 34.4% respectively)
- in relation to living arrangements, at the time of the diagnosis, the majority of people with dementia were living at home either with a carer (67%) or alone (30%); a very small proportion (0.4%) was at that point in time in residential care. Currently (i.e. at the time of completing the survey), whilst an important percentage were living in the community, fewer people were living alone (13.6%) and more had moved into a care home (22%)
 - the proportion of people living in residential care was particularly high in the Netherlands (36.9%)

Figure 6: Gender (n=1395)

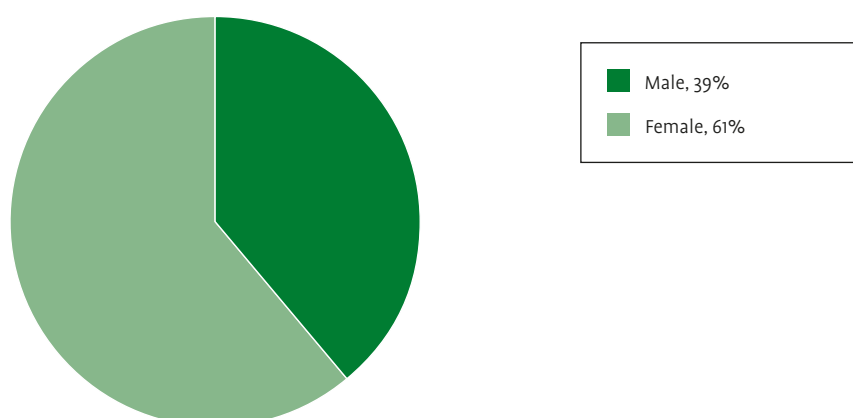


Figure 7: Education (n=1404)

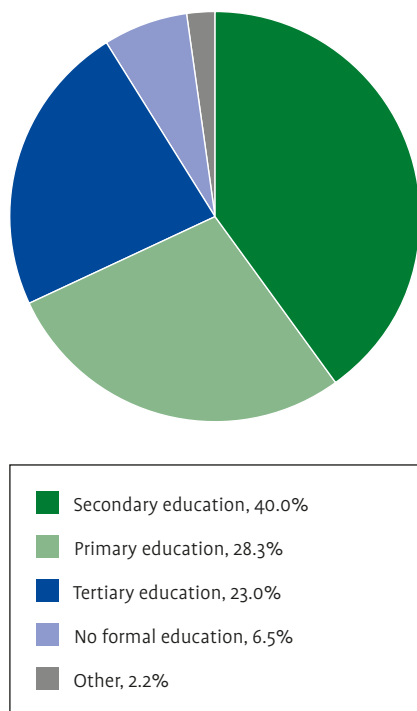


Figure 8: Living arrangements at diagnosis (n=1402)

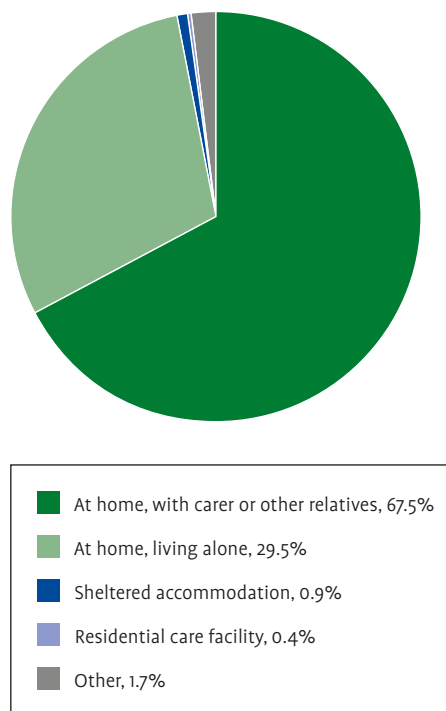


Figure 9: Current living arrangements (n=1407)

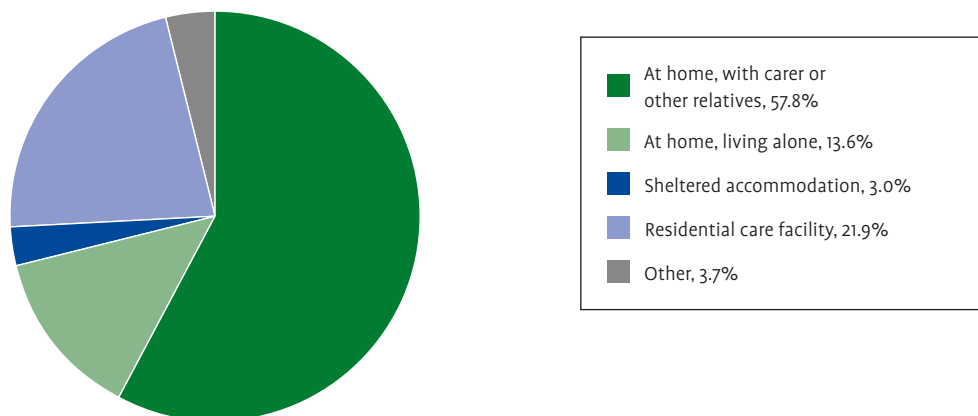


Table 2: Summary of demographic characteristics of people with dementia by country

		Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Gender (n=1395)	% female	60.4%	68.4%	55.6%	73.9%	57.4%	46.9%
Median age (n=1399)	Years	77	82	77	82	77	77
Living arrangements now (n=1407)	Living at home	13.6%	10.4%	21.8%	13.4%	5.0%	16.3%
	Residential care	22%	28.9%	19.0%	12.1%	36.9%	17.2%
Education (n=1404)	Primary	28.3%	23.8%	35.5%	45.5%	22.4%	2.2%
	Secondary	40%	47.6%	26.7%	41.7%	34.0%	59.0%
	Tertiary	23%	20.5%	17.6%	8.0%	41.4%	34.4%

4. Results

4.1. First indications that something was wrong and seeking help

Carers were asked:

1. What were the first indications they had noticed that something was wrong
2. What had first prompted them to actively seek help

For each question, there was an identical list of 36 items related to the following categories: difficulties with memory and attention; difficulties with activities of daily living; difficulties with mobility; difficulties with communication/speech/social activities; difficulties with mood and behaviour.

The results showed that:

- “memory/confusion” was reported by the vast majority of participants (87.6%) as the first indication that something was wrong
- this was followed by “difficulties finding belongings” and “difficulties following a conversation” which were mentioned by more than half of the carers (59 and 56.2% respectively)
- “difficulties with financial activities”, “depression”, “personality changes” and “difficulties travelling outside of the house” were also frequently mentioned (by around 40% of the carers)
- the same answers (and in the same order) were reported when carers were asked about the difficulties which prompted them to seek help

Table 3 shows the most recurrent difficulties which were mentioned by carers, i.e. all items which were mentioned as a first indicator or as a difficulty which prompted seeking help by at least 30% of the participating carers.

Table 3: Difficulties mentioned as first indicator and which prompted seeking help

		First indicators (n=1409)	Prompted seeking help (n=1409)
Difficulties with memory and attention	Memory/confusion	87.6%	83%
	Concentration/attention	37%	29.7%
Difficulties with activities of daily living	Finding belongings	59%	50.4%
	Financial activities	45.9%	36.1%
	Using the telephone	38.3%	30.2%
	Cooking	36.9%	30.2%
	Shopping	31.7%	26.9%
Difficulties with mobility	Travelling outside home	43.2%	42.2%
	Driving a vehicle	37%	33.4%
Difficulties with communication/ speech/social activities	Following a conversation	56.2%	52.1%
	Hobbies/interests	36.1%	27.6%
Difficulties with mood and behaviour	Depression/low mood	41.9%	39.1%
	Personality changes/mood	41%	39%
	Social withdrawal	34.5%	30.3%
	Irritability	33.4%	29.7%
	Lack of energy/apathy	32.6%	30%

4.2. The journey to diagnosis

4.2.1. Overall timeframe

The overall mean length of time between problems being noticed and the diagnosis being made was 2.1 years (n=1242). This was shorter in Italy and the Czech Republic where the mean length of time was 1.6 years. Carers in the Netherlands reported the highest mean length of time (2.6 years).

Taking into account the relationship, gender and education of both the carer and the person with dementia, it took longer to have the diagnosis when the carer was a woman and when the person with dementia was a man. On the other hand, with regard to education, it took longer in the

case of more educated people with dementia and carers. In-law relatives tended to report shorter timeframes for receiving the diagnosis.

Considering the year when the diagnosis was provided, those receiving a diagnosis in 2006 and 2007 seemed to have experienced the shortest length of time between problems being noticed and the diagnosis being made. However, these figures should be viewed with great caution as in some years (e.g. 2006, 2005) very few people in the sample were diagnosed (see table 8 for details of number of people diagnosed by year).

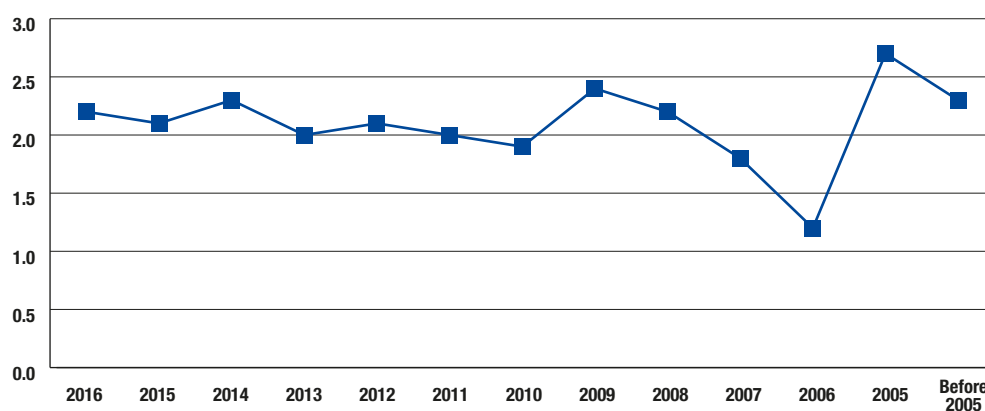
Table 4: Overall mean length of time by country

	Mean length of time (years)	N
Czech Republic	1.6	185
Finland	2.2	332
Italy	1.6	265
Netherlands	2.6	255
UK (Scotland)	2.5	205
Total	2.1	1242

Table 5: Length of time by gender, education and relationship (in years)

	Carer		Person with dementia	
	Mean length of time	N	Mean length of time	N
Gender				
Male	1.8	222	2.4	500
Female	2.2	1010	1.9	732
Education				
No formal education	1.1	5	2.3	79
Primary education	1.8	38	1.8	336
Secondary education	1.9	517	2.0	494
Tertiary education	2.4	658	2.6	302
Relationship				
Spouse/partner	2.2	465		
Father/mother	2.1	638		
Father-in-law/mother-in-law	1.9	57		

Figure 10: Mean length of time for diagnosis (n=1232)



4.2.2. Specific timeframes

More specifically, the length of time between the person noticing that something was wrong and seeking help and between seeking help and the diagnosis being commenced tended to be quite long. In nearly half of the cases (46.7%), it took more than a year to seek help and in 21.5% of the cases, it took more than a year to commence diagnosis.

Where help was sought from a general practitioner (GP), the timeframe before then seeing a specialist appeared quicker. More than three-quarters of the carers (79.3%) reported that the person with dementia had the first visit with the

specialist doctor or service within 6 months of the first visit to their GP (i.e. “a month or less” or “1 to 6 months”).

The Czech Republic and Italy had the fewest people reporting that it took a year or more at each of the three timeframes (i.e. between changes being noticed and help being sought, between seeking help and assessment being commenced and between GP visit and specialist visit). In the Netherlands, whilst the length of time between seeking help and assessment commencing, and between GP visit and specialist visit seemed shorter, the time between changes being noticed and help being sought was the longest.

Figure 11: Comparison of timeframes

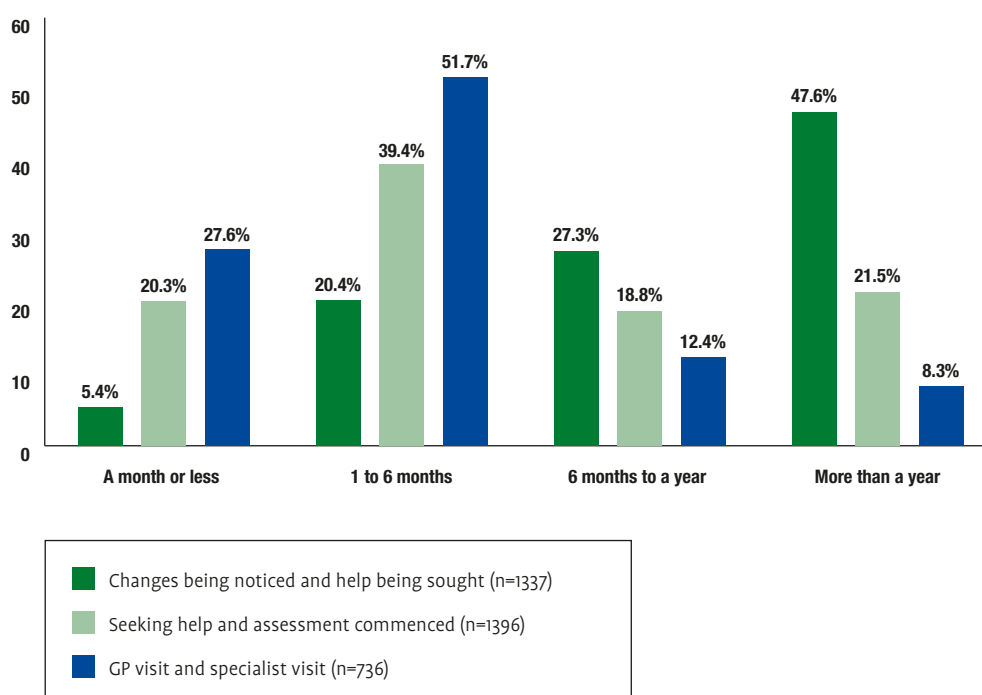
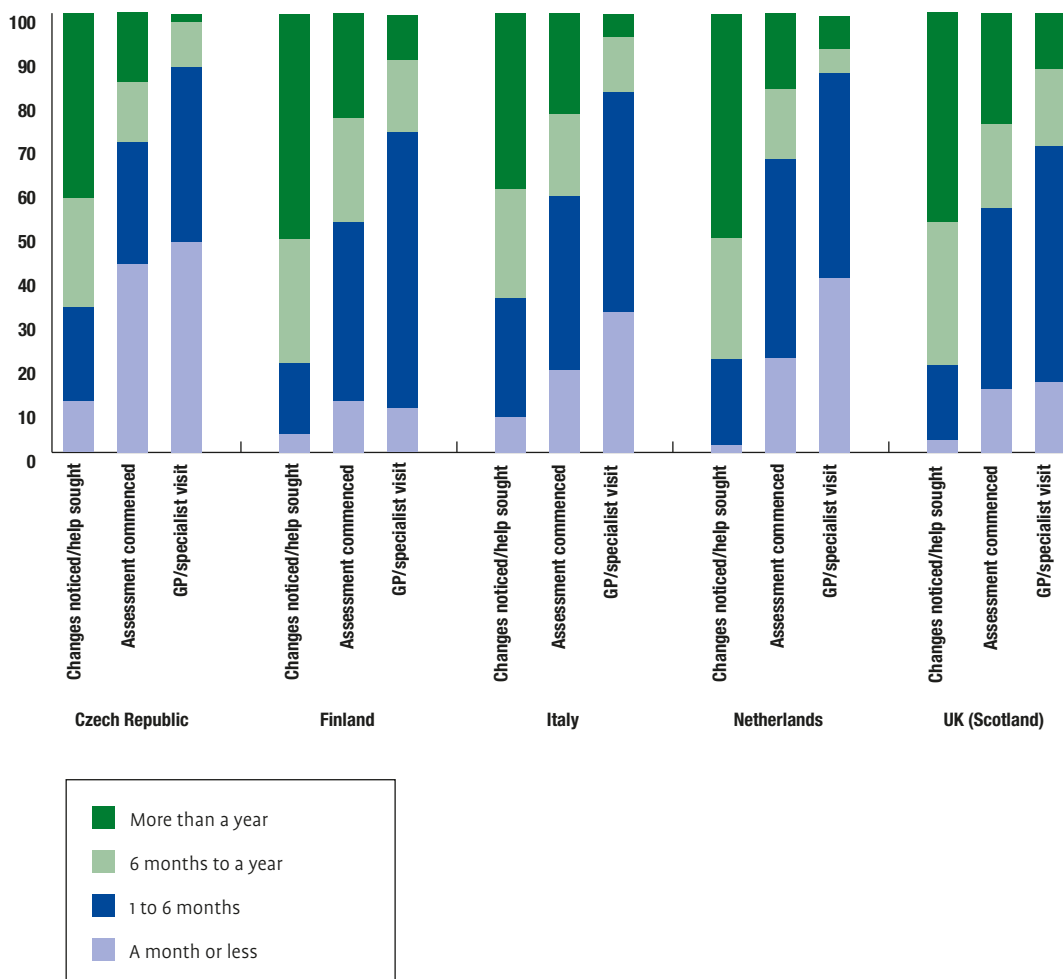


Figure 12: Comparison of timeframes by country



4.2.3. Who was involved?

The professional from whom carers had most often first sought help was the GP. In the UK (Scotland), the Netherlands and Finland, a high proportion of carers had sought help in this way (83.9%, 78.4 and 57.3% respectively). In the Czech Republic and Italy, several carers had also sought help from memory clinics, outpatient service in hospitals or private clinics.

Likewise, when carers were asked whether they had got a referral from the GP, this was the case for the majority of the carers in the UK (Scotland) and the Netherlands, and less frequent in the other countries.

In more than half of the cases (64%), a family member (this could be the person completing the survey or another family member) had made the decision to seek help in this

way. In Italy and the Czech Republic, this was more common (e.g. 83.6% and 68.4% respectively). In only 4% of cases, the person with dementia had decided him/herself to seek help for diagnosis. However, in more than a quarter of cases (27%), carers reported that the person with dementia and the carer had made this decision together. In the Czech Republic and Italy, fewer carers reported having made this decision jointly (21.3% and 12.5% respectively).

In the majority of cases (58.9%) the diagnosis was made in a memory clinic or at an outpatient service in hospital. This was followed by GP/primary care practice where 16.9% of the people with dementia were first diagnosed and a private clinic (12.7%). People living in Finland, the Czech Republic and in the UK (Scotland) were more often diagnosed in primary care (24.6%, 19.6% and 19.5% respectively), whilst Italy had the highest proportion of people being diagnosed in a private clinic (26.1%).

Figure 13: Where person sought help first
(n=1336)

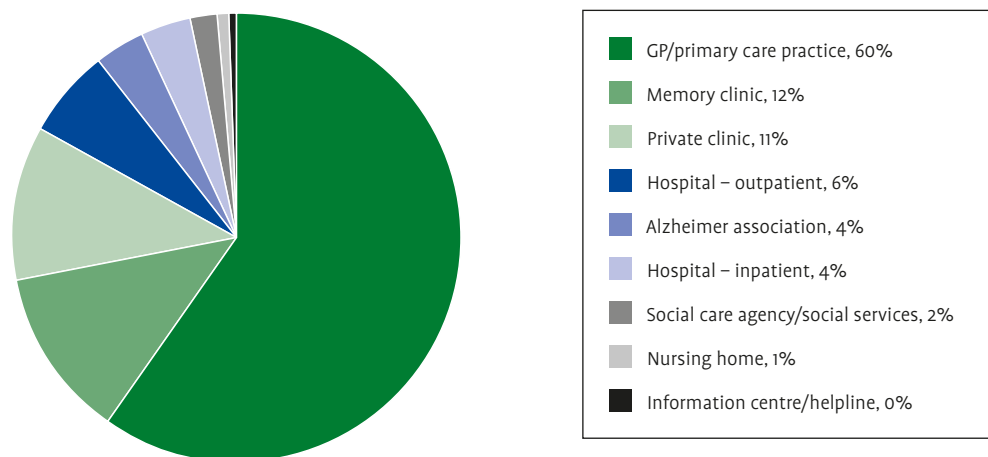


Figure 14: Who made the decision to seek help
(n=1400)

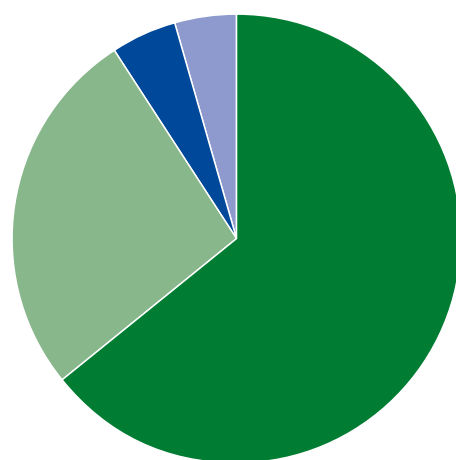


Figure 15: Where the diagnosis was made
(n=1392)

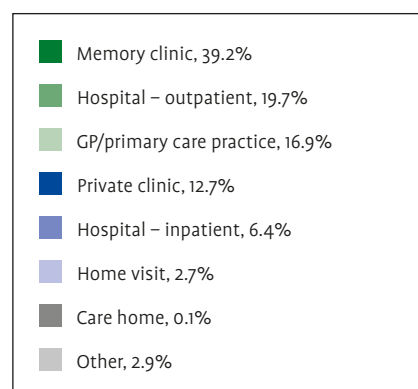
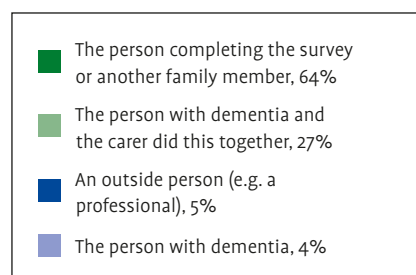
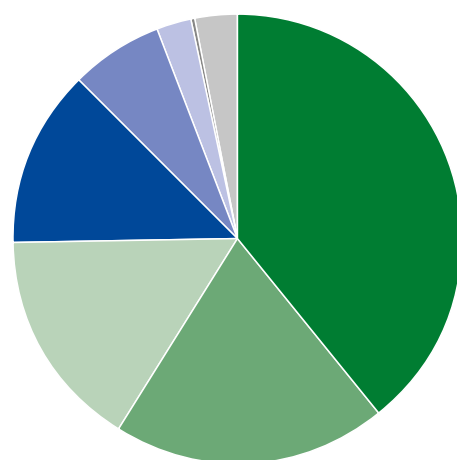


Table 6: Comparison by country

		Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Mean length of time (years)		2.1	1.6	2.2	1.6	2.6	2.5
Who made decision (n=1402)	Carer/family member	64%	68.7%	54.1%	73.6%	59.4%	52.7%
	Jointly	27%	21.3%	31.5%	12.5%	30.8%	39.8%
Where diagnosis was made (n=1402)	Primary care/GP	16.9%	19.6%	24.6%	6.2%	10.1%	19.5%
	Memory clinic	39.2%	29.7%	47%	43.3%	34.3%	33.6%
	Hospital – outpatient	19.7%	18.2%	4.7%	16.6%	33.6%	32.7%
	Private clinic	12.7%	12.9%	16.3%	26.1%	0.4%	1.3%

4.3. The diagnosis

4.3.1. Assessments carried out

The majority of the carers reported memory tests as part of the assessment (89.6%) and around two-thirds referred to an interview with the person with dementia and to brain scans (76.3% and 73.2% respectively). An interview with a carer was slightly less frequent (66.5%), and less than half of the carers referred to physical examinations (44.3%) or blood tests (39%). Having a visit at home (11.6%) or lumbar puncture (8.3%) was rarely mentioned.

The Czech Republic was the country where, overall, fewer assessments had been carried out. In particular, the number of people who reported a brain scan as part of the assessment was much lower than in the other countries (55.9% vs. 70.5%, 73.7% and 84.3% reported in the other countries). In the Netherlands, on the other hand, carers reported the highest proportion (18.3%) of people with dementia having a lumbar puncture as part of the diagnostic assessment.

Figure 16: Assessments carried out (n=1409)

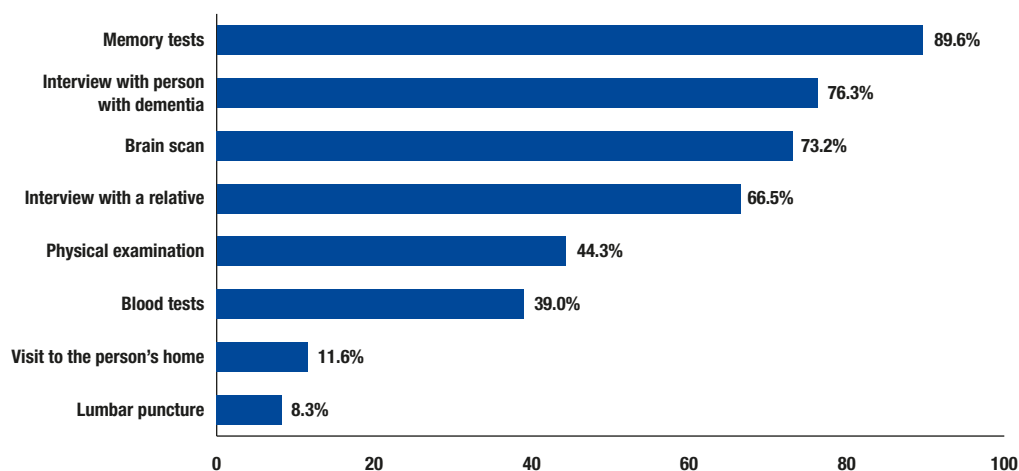


Table 7: Assessments reportedly carried out by country

	Total (n=1409)	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Memory tests	89.60%	78.70%	92.80%	87.90%	92.20%	93.90%
Interview with person with dementia	76.30%	62.60%	78.20%	86.70%	72.00%	75.90%
Brain scan	73.20%	55.90%	84.30%	73.70%	70.50%	73.70%
Interview with a relative	66.50%	65.40%	66.10%	69.60%	63.80%	66.70%
Physical examination	44.30%	42.70%	64.20%	38.10%	46.30%	21.10%
Blood tests	39%	22.30%	47.70%	43.70%	41.80%	30.70%
Visit to the person's home	11.60%	7.10%	11.80%	2.40%	16.00%	24.10%
Lumbar puncture	8.30%	5.20%	8.50%	6.50%	18.30%	1.80%

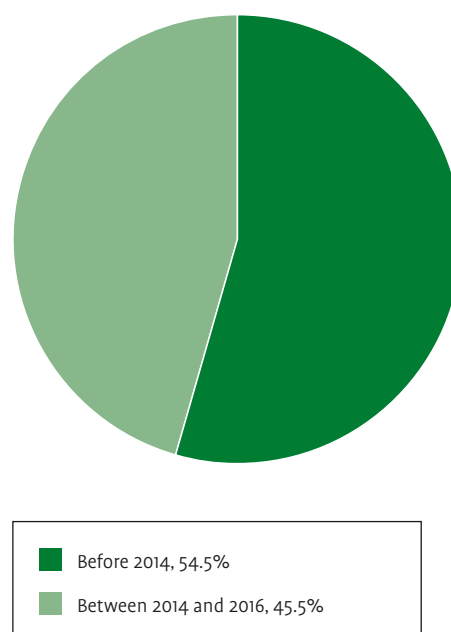
4.3.2. Year when diagnosis was made

Table 8 shows the year when the person received the diagnosis of dementia. In almost half of the cases (45.5%) the diagnosis was quite recent (i.e. had been made in the three years prior to the survey – between 2014 and 2016).

Table 8: Year of diagnosis (n=1392)

	N	%
2016	206	14.8
2015	237	17.1
2014	190	13.6
2013	200	14.4
2012	151	10.8
2011	101	7.3
2010	106	7.6
2009	67	4.8
2008	38	2.7
2007	24	1.7
2006	12	0.9
2005	13	0.9
Before 2005	47	3.4

Figure 17: Year of diagnosis (n=1392)



4.3.3. Condition diagnosed prior to dementia and type of dementia

Another diagnosis had been made before the diagnosis of dementia in about a quarter of cases (25%). Of these people (n=353), the most common conditions diagnosed before dementia were depression and mild cognitive impairment (28% and 25% respectively). Depression was particularly high in the UK (Scotland) (44%).

In relation to the diagnosis, more than half (55%) received a diagnosis of Alzheimer's disease. This was followed by a diagnosis of vascular and mixed dementia (both 11%). 12% of the carers referred simply to a diagnosis of "dementia". The proportion of people with Frontotemporal dementia (FTD) and dementia with Lewy bodies (DLB) was very small (5% and 2% respectively). The number of people diagnosed with vascular dementia was higher in the UK (Scotland) than in any other country.

Figure 18: Condition before diagnosis (n=353)

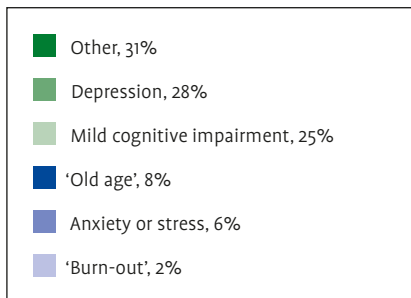
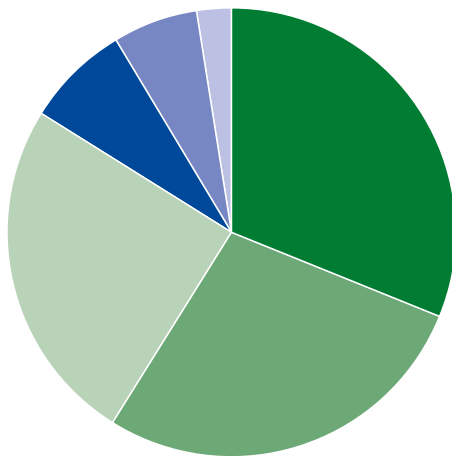
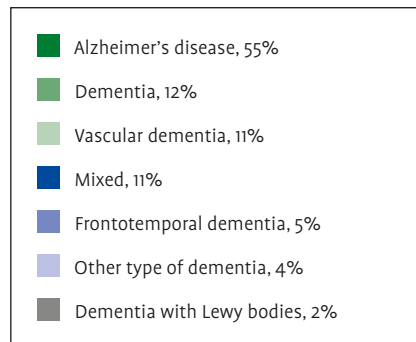
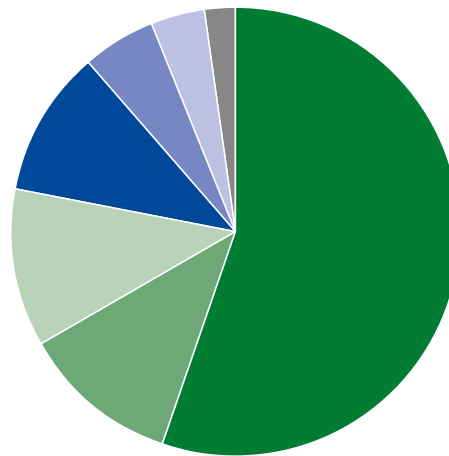


Figure 19: Type of dementia diagnosed (n=1340)



4.3.4. Severity and timeliness of diagnosis

At the time of diagnosis, according to the doctor who made the diagnosis, around half of people were at a mild stage of dementia (53%), around a third (36%) at moderate and 4% at severe stage. A small proportion (7%) had mild cognitive impairment.

In terms of the timeliness of the diagnosis, only a very small minority of carers (1%) felt the diagnosis had been made too soon. Slightly over half of the carers (53%) felt the diagnosis should have been made earlier and 46% reported that the diagnosis was made at the right time.

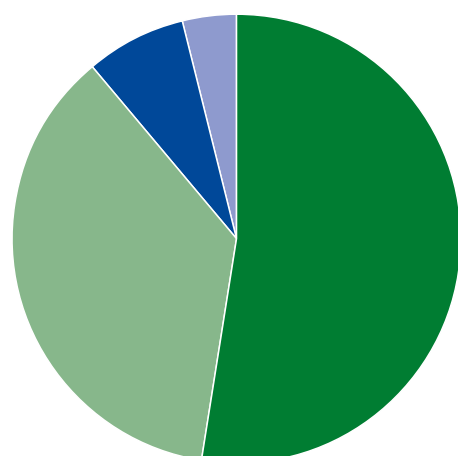
Overall, carers of people diagnosed at later stages tended to feel more often that the diagnosis should have been made earlier and vice versa, carers of people at milder stages felt more often that the diagnosis was timely. Still, of those diagnosed at mild stages, a significant proportion (41.5%) would have preferred an earlier diagnosis.

In the Netherlands, more carers reported that the diagnosis was timely. In Italy and the Czech Republic, more carers reported that the diagnosis should have been made earlier.

Carers who reported that the diagnosis should have been made earlier (n=655) were asked about the reasons for the delay of diagnosis. The most frequently mentioned reasons can be grouped together in four categories: factors relating to the person with dementia; factors relating to carers; factors relating to the healthcare professional; and factors relating to the system. Table 10 provides details for each category.

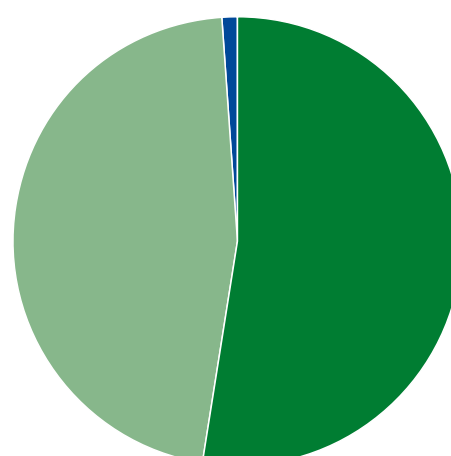
Not being aware of dementia and attributing the symptoms to old age were reasons which were frequently given in Italy and the Czech Republic. The person with dementia not wanting to seek help tended to be more common in Finland and the Netherlands. The professional not considering anything was wrong and the long time for referral or diagnosis were more frequent in the UK (Scotland).

Figure 20: Stage (n=1148)



- Mild cognitive impairment, 7%
- Mild dementia, 53%
- Moderate dementia, 36%
- Advanced dementia, 4%

Figure 21: Carers' perception of timeliness of diagnosis (n=1243)



- It would have been better if the diagnosis had been made earlier, 53%
- The diagnosis was made at the right time, 46%
- The diagnosis was made too soon, 1%

Table 9: Comparison of severity of dementia as diagnosed by doctor and perceived timeliness

Carers' perception of timeliness	At the time of diagnosis, which stage or severity of dementia did the doctor say the person was in? (n=964)		
	Mild dementia	Moderate dementia	Severe dementia
Too early	0.7%	0.3%	0.0%
Right time	57.7%	31.7%	26.1%
Too late	41.5%	67.9%	73.8%

Figure 22: Perception of timeliness of diagnosis by country (n=1163)

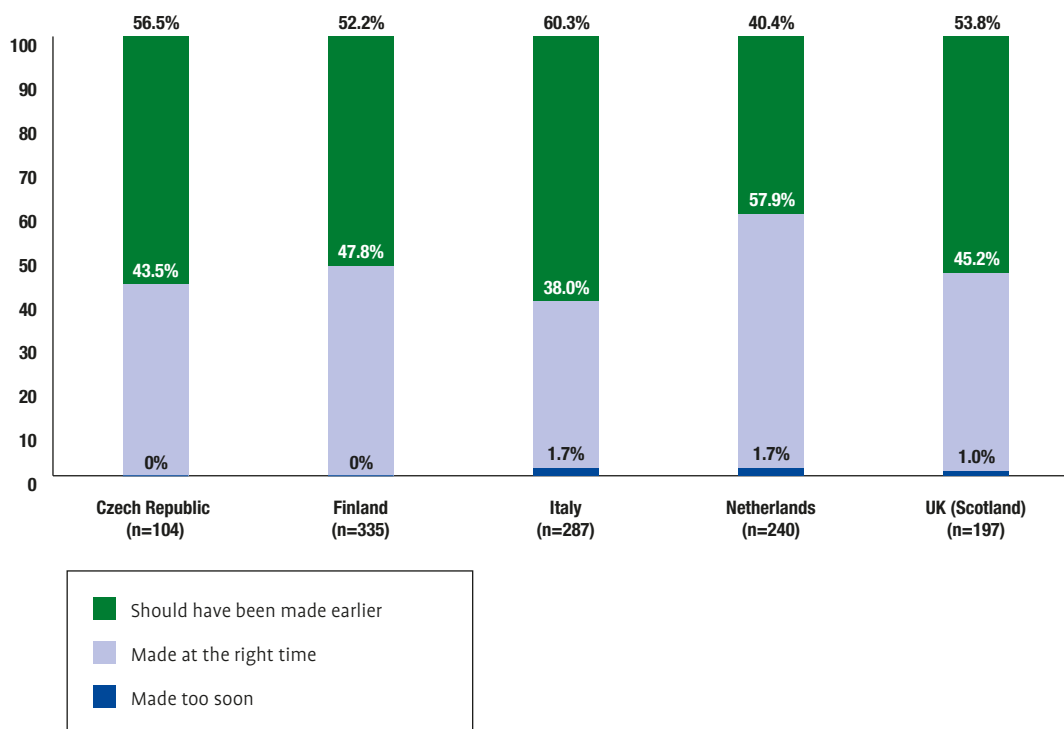


Table 10: Factors for delay of diagnosis (n=655)

	%
Factors relating to the carer (i.e. the carer thought it was just old age or was not aware of dementia)	40.9%
Factors relating to the healthcare professional (i.e. first professional seen did not consider that anything was wrong or suggested it would not be worthwhile pursuing diagnosis)	39.5%
Factors relating to the person with dementia (i.e. person with dementia refused to seek help)	37.8%
Factors relating to the system (i.e. referral or assessment took a long time)	25%

4.3.5. Disclosure of diagnosis

To the person with dementia

The diagnosis was shared with the person with dementia in the great majority of cases, either by a healthcare professional (72.4%) or by another person (7.5%). However, 20% of the people with dementia in this study were not informed of their diagnosis. This proportion was much higher in Italy where 59.3% of the people with dementia were not informed of their diagnosis.

In only a small proportion of cases did this reflect the expressed wish of the person with dementia (10% of the 282 who were not informed). The other reasons for non-disclosure fell into 4 main categories: not wishing to upset the person; the person would not understand or was not aware; the family thought it unnecessary; and the doctor advised against telling the person.

When the diagnosis was shared with the person with dementia, in the majority of cases, this was communicated by a geriatrician (30%) or a neurologist (29%). In 9% of the cases, the GP was the professional informing the person about the diagnosis. A carer was present in the meeting in almost all the cases (89%).

To the carer

The great majority of carers completing the survey were informed about the diagnosis of dementia by a healthcare professional (84.5%) and in a meeting where the person with dementia was also present (75.4%). In Italy and the Czech Republic, the person with dementia was present in the meeting less often (person with dementia present in 56.3% of the cases in Italy and 63.4% in Czech Republic).

Figure 23: Diagnosis shared with person with dementia by country (n=1400)

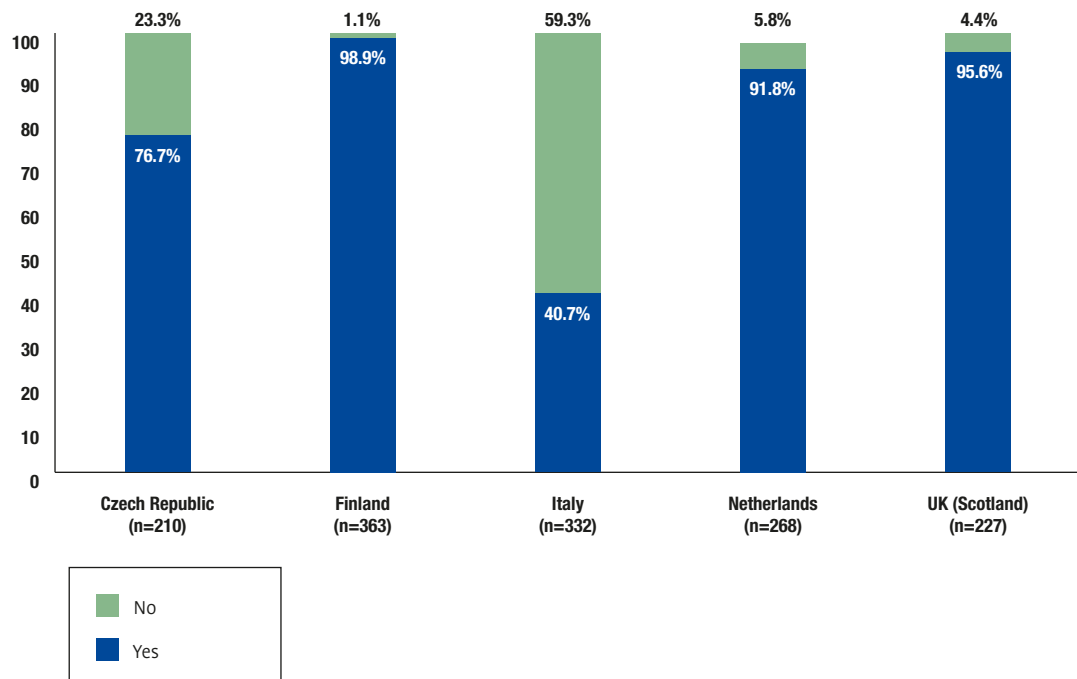
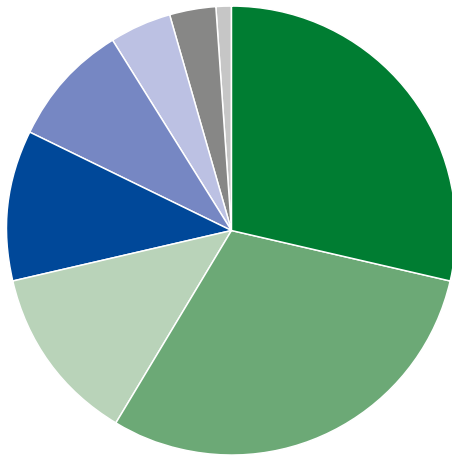
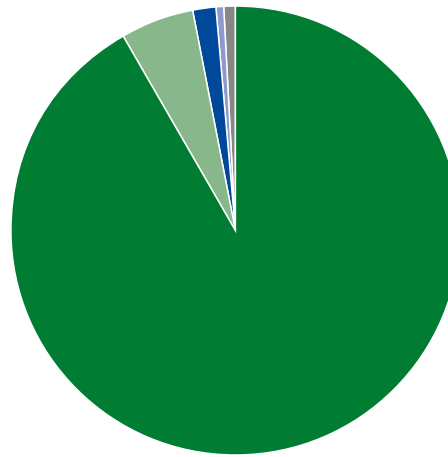


Figure 24: Professional who disclosed diagnosis (n=958)



■ Neurologist, 29%
 ■ Geriatrician, 30%
 ■ Psychiatrist, 13%
 ■ Hospital doctor, 11%
 ■ GP, 9%
 ■ Psychologist/neuropsychologist, 4%
 ■ Psycho geriatrician, 3%
 ■ Psychiatric nurse, 1%

Figure 25: How the diagnosis was communicated (n=988)



■ In a meeting with the carer or another relative present, 92%
 ■ In a meeting without the carer or other relative present, 5%
 ■ By letter, 0.5%
 ■ By telephone, 0.5%
 ■ Other, 2%

Table 11: Disclosure to carers

	Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Informed by a healthcare professional (n=1400)	84.5%	81.4%	79.3%	90.7%	88.4%	81.7%
In a meeting where person with dementia was present (n=1180)	75.4%	63.4%	91.3%	56.3%	85.7%	79.8%

4.3.6. Quality of the disclosure

In relation to the quality of the disclosure of diagnosis, ratings for the disclosure to the person with dementia and the disclosure to the carer were, for the majority of the items, very similar, and in both cases the general perception of the disclosure was quite positive:

- around three-quarters felt that the doctor was well prepared (72.7% and 70%) and had explained everything clearly to the person with dementia and carer (80.9% and 75.1%)
- the specific diagnosis (i.e. not vague terms such as forgetfulness or memory problems) was stated in the majority of the cases (79.3% in case of disclosure to person with dementia and 81% for carer)
- in 63.7% of cases, it was felt that the doctor had established a good relationship with the person and in 62% with the carer

However, some aspects may need further attention. In the case of the disclosure to the person with dementia:

- in around half of the cases (53.2%), the person with dementia was not asked prior to the diagnosis whether they wanted to know the diagnosis or who they would have liked to be involved in the process (52.6%)
- one in five carers (22.6%) felt that during the meeting the doctor had mainly spoken to him/her
- around a quarter of the carers (27.8%) felt the person with dementia had not understood the diagnosis

In the disclosure to the carer:

- more than half of the carers (56%) felt the doctor did not give them an opportunity to speak to him/her without the person with dementia present
- in the case of the disclosure to the carers, many carers felt that the meeting was too short (47.2%), however this was less often the case for the disclosure to the person with dementia (20.9%)
- in many cases (40.1%) a written summary of the meeting was not provided

Table 12: Quality of disclosure

	Total (N)	Strongly disagree (%)	Disagree (%)	Neither agree or disagree (%)	Agree (%)	Strongly agree (%)
The person with dementia was asked if he/she wanted to know the diagnosis before it was made	694	26.6%	26.6%	20.6%	16.8%	9.5%
The person with dementia was asked who else should be involved before the diagnosis was made	711	26.4%	26.2%	19.4%	18.6%	9.4%
The doctor gave the carer an opportunity to speak to him/her without the person with dementia present	718	26.3%	29.7%	10.7%	21%	12.3%
During the meeting the doctor mainly spoke to the carer	729	15.6%	39.6%	22.1%	17%	5.6%
In your opinion, the person with dementia understood the diagnosis	731	10.8%	17%	18.3%	36.7%	17.2%
The doctor sharing the diagnosis explained everything clearly						
Disclosure to the person with dementia	733	4.2%	7.1%	7.8%	44.2%	36.7%
Disclosure to the carer	1047	4.1%	9.1%	11.7%	46.6%	28.5%
The meeting was too short						
Disclosure to the person with dementia	715	15.9%	37.2%	26%	14.3%	6.6%
Disclosure to the carer	1018	5.6%	19.8%	27.3%	33.1%	14.1%
There was plenty of opportunity to ask questions						
Disclosure to the person with dementia	721	5.4%	11.2%	17.3%	46.5%	19.6%
Disclosure to the carer	1014	5.4%	17%	18.1%	42%	17.5%
The doctor established a good relationship with						
Disclosure to the person with dementia	731	6.6%	11.5%	18.3%	37.8%	25.9%
Disclosure to the carer	1039	7.1%	11.2%	19.7%	39%	23%
The specific diagnosis was stated						
Disclosure to the person with dementia	724	4.7	8.0	8.0	43.9	35.4
Disclosure to the carer	1027	3.6%	6.5%	8.9%	50.5%	30.5%
The doctor was well prepared for the meeting and had all the information needed						
Disclosure to the person with dementia	728	3.8%	7.4%	16.1%	45.1%	27.6%
Disclosure to the carer	1022	3.9%	8.3%	17.7%	45%	25%
A clear written summary of the meeting was provided						
Disclosure to the person with dementia	725	19.7%	20.4%	13.8%	29.4%	16.7%
Disclosure to the carer	1037	16.4%	20.6%	11.3%	34.5%	17.2%
Clear arrangements were made for further contact and follow-up						
Disclosure to the person with dementia	729	10.3%	13.4%	16.7%	37.6%	21.9%
Disclosure to the carer	1032	8.9%	11.6%	15.1%	40.8%	23.5%

4.3.7. Reactions to diagnosis

The findings show the diversity of emotions and reactions which carers and people with dementia may feel at the time of diagnosis and after some time. The top three reactions from carers at the time of diagnosis were: worry, uncertainty and sadness (74%, 43.2% and 38.5% respectively). Two-thirds of the carers (74%) reported feeling worried about the future at the time of diagnosis.

At the time of the survey, worry about the future continued to be the most frequently reported emotion, but fewer carers reported this (58.2%). Also, at the time of the survey, acceptance was reported by almost half of carers (46.4%) and resignation by almost a quarter of the carers (24%). Feeling “unconcerned” was at the bottom of the list at both times (0.7% at both times).

The carers reported the same three reactions from people with dementia at the time of diagnosis (i.e. uncertainty, worry, sadness). However whilst these were the most frequently mentioned, they were only reported in around

one-third of the cases (30%, 29.2% and 28% respectively). At present, sadness continues to be common (23.7%). The other most common reactions from people with dementia, were unconcerned and acceptance (both reported by around 20% of carers).

On the other hand, feelings of relief, which were reported by several carers at the time of diagnosis (22.9%) seemed to be less important in the case of people with dementia, and this feeling was only reported for 4.6% of people with dementia at the time of diagnosis and 1.3% at present.

Whilst both groups may have felt worried and concerned at the time of diagnosis, it appeared people with dementia's feelings had then evolved more to acceptance or being unconcerned. Sadness was reported as an important emotion for carers and people with dementia both at the time of diagnosis and at present. Higher levels of acceptance were reported for both groups at present.

Table 13: Reactions to diagnosis

Carers					
Time of diagnosis (n=1409)			Now (1409)		
Reaction	Frequency	%	Reaction	Frequency	%
Worried about the future	1042	74.0	Worried about the future	820	58.2
Uncertain about the implications	608	43.2	Acceptance	654	46.4
Sad/depressed	543	38.5	Sad/depressed	487	34.6
Mixed feelings/ ambivalence	420	29.8	Resignation	338	24.0
Acceptance	366	26.0	Mixed feelings/ ambivalence	323	22.9
Relief	323	22.9	Uncertain about the implications	303	21.5
Shock	241	17.1	Reassured	177	12.6
Despair	217	15.4	Despair	175	12.4
Anger	170	12.1	Relief	133	9.4
Reassured	140	9.9	Anger	118	8.4
Disbelief	128	9.1	Optimism	60	4.3
Resignation	127	9.0	Shock	39	2.8
Panic	122	8.7	Disbelief	38	2.7
Optimism	43	3.1	Panic	31	2.2
Unconcerned	10	0.7	Unconcerned	10	0.7

People with dementia					
Time of diagnosis (n=1184)			Now (1409)		
Reaction	Frequency	%	Reaction	Frequency	%
Uncertain about the implications	355	30.0	Sad/depressed	290	23.7
Worried about the future	346	29.2	Unconcerned	250	20.4
Sad/depressed	332	28.0	Acceptance	249	20.3
Mixed feelings/ ambivalence	326	27.5	Mixed feelings/ ambivalence	238	19.4
Disbelief	293	24.7	Worried about the future	235	19.2
Unconcerned	220	18.6	Uncertain about the implications	221	18.1
Acceptance	168	14.2	Resignation	207	16.9
Shock	168	14.2	Disbelief	125	10.2
Despair	123	10.4	Anger	102	8.3
Anger	139	11.7	Despair	96	7.8
Resignation	98	8.3	Reassured	78	6.4
Panic	92	7.8	Panic	47	3.8
Relief	54	4.6	Optimism	44	3.6
Optimism	42	3.5	Shock	23	1.9
Reassured	37	3.1	Relief	16	1.3

4.4. Post-diagnostic support and treatment

4.4.1. Information received, satisfaction and information which carers would have liked at the time of diagnosis

More than a quarter of people with dementia (27.9%) and almost a fifth of carers (19.9%) did not receive any type of information at the time of diagnosis. When carers and people with dementia did receive information, overall, this seemed to be more often related to medical aspects (i.e. drug treatments, 56% in the case of carers and 47.3% of people with dementia; dementia 48.4% of carers and 35.1% of people with dementia; disease progression 38.4% of carers and 21.1% of people with dementia). Carers also seemed to have often received information about Alzheimer organisations and practical advice about coping and living well with dementia (38% and 35.1%). Only around a quarter of the carers received information on available services, support groups and healthy lifestyles (27%, 26% and 26%). For all types of information, people with dementia received information less often than carers. Information about taking part in research and advance care planning were particularly low in both cases (i.e. carers 13.8% and 15.3% and people with dementia 7.5% and 7.6% respectively).

Overall, carers were quite satisfied with the information received. The average response from all respondents was 3.5 (on a scale from 1 to 5, with 1 indicating 'very dissatisfied' and 5 'very satisfied'). Carers were particularly satisfied with the information received about Alzheimer organisations (3.83), driving (3.79) and prevention e.g. healthy lifestyle to reduce rate of further decline (3.58).

51.1% of carers would have liked to have received information on practical advice about coping and living well with dementia, 46% on available services and 40.2% on disease progression. Reported needs about information on care allowances, legal rights/issues and existing help/support groups were also considerably high (39.2%, 38.1% and 37.8% respectively).

Table 14 shows detailed information about the information that carers and people with dementia received at

the time of diagnosis, the carers' satisfaction with the information received and information they would have liked to have received. It has to be kept in mind that the sample was recruited via Alzheimer associations, so perhaps this had an impact on the type of information which they received.

In the Czech Republic and Italy, the top three types of information for which carers had received information were drug treatments, disease progression and dementia. In Finland, the Netherlands and the UK (Scotland), several carers had also received information on other psycho-social aspects (Alzheimer organisations or help/support groups).

In the Czech Republic, Finland and UK (Scotland), at least 25% of carers had received information for eight types of information and in the case of the Italian carers, at least 25% had received information for nine different types of information. In the Netherlands, this was only the case for five types of information (see Table 16). Overall, carers in Finland and the Netherlands were the most satisfied with the information received (both average score 3.8). Satisfaction with information on driving in these two countries was particularly high (4.11 and 4.03 respectively). Carers in Italy were less happy with all types of information received. With the exception of medical information (dementia, drugs and progression) and information on Alzheimer associations, the satisfaction with all other types of information was below 3. In Italy, satisfaction with information received on advance care planning, information on legal rights and services was particularly low (mean: 1.94, 2.38 and 2.39 respectively).

People with dementia living in Italy were also less likely to receive any type of information compared with all the other countries (see table 17), and almost half of the Italian people with dementia (49%) had received no information at all. On the other hand, people with dementia in Finland were more likely to receive all different types of information. In Finland, there were six types of information which at least 25% of the people with dementia had received; this was the case for four types of information in the Netherlands and UK (Scotland), three types of information in the Czech Republic and one in Italy.

Table 14: Information received, satisfaction and information they would have liked

	Carers			PWD
	Received (n=1409)	Satisfaction (1 to 5)**	Would have liked (n=1409)	Received (n=1409)
Dementia	48.4%	3.48	16%	35.1%
Disease progression	38.4%	3.44	40.2%	21.4%
Drug treatments	56%	3.56	21.8%	47.3%
Alzheimer organisations	38%	3.83	29.5%	17.6%
Other help/support groups available	26%	3.53	37.8%	15.2%
Services available	27%	3.38	46%	15.9%
Healthy lifestyle to reduce rate of further decline	26.2%	3.58	25%	21.1%
Practical advice about coping and living well with dementia	35.1%	3.44	51.1%	20%
Care allowances, welfare and finance issues	29%	3.51	39.2%	13.5%
Legal rights and issues	20.9%	3.32	38.1%	7.9%
Advance care planning	15.3%	3.29	26.5%	7.6%
Driving	19.7%	3.79	7.8%	18.8%
Taking part in research studies	13.8%	3.36	19.9%	7.5%
No information provided	19.9%	N.A.	N.A.	27.9%

* Top three results in **bold**

** This question was only answered by carers who have received the type of information considered. Satisfaction was measured in a scale from 1 to 5, 1 indicating that the person was 'very dissatisfied' and 5 'very satisfied'

Table 15: Top three types of information received by carers

	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Dementia	59.7%	59.5%	51.0%		32.5%
Disease progression	63.5%		52.8%		
Drug treatments	70.6%	58.4%	71.1%	38.4%	36.8%
Alzheimer organisations		42.4%		42.9%	39.9%
Available help/support groups				36.6%	

Table 16: Type of information received by carers (n=1409, *column in blue*) and satisfaction (S), by country

	CR	CR (S)	F	F (S)	I	I (S)	N	N (S)	UK-S	UK-S (S)
Average satisfaction with information received		3.6		3.8		2.8		3.8		3.5
Type of information										
Dementia	59.7%	3.63	59.5%	3.73	51.0%	3.11	34.7%	3.58	32.5%	3.22
Disease progression	63.5%	3.70	36.9%	3.66	52.8%	3.03	20.1%	3.76	17.5%	3.30
Drug treatments	70.6%	3.64	58.4%	3.89	71.1%	3.16	38.4%	3.63	36.8%	3.61
Alzheimer organisations	38.9%	3.82	42.4%	4.07	27.4%	3.39	42.9%	3.97	39.9%	3.70
Other help/support groups available	19%	3.73	23.4%	3.78	23.3%	2.84	36.6%	3.70	28.1%	3.66
Services available	37.9%	3.71	27.5%	3.70	28.0%	2.39	17.5%	3.91	25.9%	3.53
Healthy lifestyle to reduce rate of further decline	32.7%	3.61	30.3%	3.96	31.3%	2.92	16.4%	3.95	17.5%	3.80
Practical advice about coping and living well with dementia	49.3%	3.70	29.8%	3.77	42.5%	2.78	25.4%	3.84	30.7%	3.51
Care allowances, welfare and finance issues	50.2%	3.80	29.2%	3.85	29.8%	2.57	9.3%	3.88	31.1%	3.77
Legal rights and issues	23.2%	3.41	22.9%	3.69	26.5%	2.38	4.5%	4.08	26.3%	3.98
Advance planning	21.8%	3.41	21.8%	3.96	15.6%	1.94	3%	3.75	13.2%	3.60
Driving	13.7%	3.79	21.8%	4.11	19.8%	2.96	22.4%	4.03	18.9%	3.84
Taking part in research studies	11.4%	3.46	10.5%	3.82	19.2%	2.52	15.7%	3.95	11.0%	3.76
No information provided	10.0%	N.A.	16.5%	N.A.	24.8%	N.A.	20.1%	N.A.	26.8%	N.A.

* Information received by at least 25% of carers in bold

Table 17: Type of information received by people with dementia by country (n=1409)

	People with dementia				
	CR	F	I	N	UK-S
Dementia	35.1%	54.5%	18.6%	34%	30.3%
Disease progression	28.9%	35%	10%	15.7%	16.2%
Drug treatments	65.9%	68%	31.3%	33.2%	37.3%
Alzheimer organisations	11.8%	25.9%	3.8%	20.9%	26.3%
Other help/support groups available	5.2%	16.5%	2.9%	28%	25.4%
Services available	16.6%	22.6%	5.3%	18.3%	17.5%
Healthy lifestyle to reduce rate of further decline	22.3%	32.8%	13.3%	19.8%	14.5%
Practical advice about coping and living well with dementia	21.8%	24%	13.3%	20.1%	21.9%
Care allowances, welfare and finance issues	24.6%	21.8%	3.5%	3%	17.1%
Legal rights and issues	4.7%	13.2%	2.1%	2.2%	18%
Advance planning	10.9%	16.3%	0%	1.5%	9.2%
Driving	13.7%	26.7%	5.9%	26.5%	21.1%
Taking part in research studies	5.7%	8.3%	2.4%	13.4%	8.3%
No information provided	19.4%	14.0%	49%	23.5%	31.6%
No information provided	10.0%	16.5%	24.8%	20.1%	N.A.

* Information received by at least 25% of people with dementia **in bold**

4.4.2. Information for which carers took action

There were differences in the extent to which carers took action based on the information they had received. Overall, the most frequently reported actions related to drug treatments (63.3%). This was particularly high in Finland, the Czech Republic and Italy, where around three-quarters of carers acted on information received (76.9%, 73.9% and 73.2%). The second most commonly reported action related to financial matters, which was reported by over half the

carers (54.1%), and nearly three-quarters (73.7%) in the UK (Scotland). This was followed by joining an Alzheimer organisation (41.8%), which was reported by around half the carers in Finland, the Netherlands and the UK (Scotland) (56.2%, 49.6% and 48.2% respectively), and by a quarter in the Czech Republic and Italy (27.5% and 25.1%). One-fifth of carers (20.2%) reported taking action on advance planning following information received at the time of diagnosis. Less than 10% of the carers reported that the person with dementia had taken part in research (9.5%). This ranged from 5.3% in Italy to 13.8% in the Netherlands.

Table 18: Actions taken (n=1409)

	Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Finances e.g. making arrangements for the management of the finances of the person with dementia in the future	54.1%	55.5%	52.3%	37.2%	60.1%	73.7%
Advance care planning	20.2%	16.6%	19.8%	2.7%	43.7%	22.8%
Preventing disease progression e.g. the person with dementia exercised more	25.9%	21.8%	29.2%	24.5%	30.2%	21.5%
Other help/support groups e.g. joining a carers support group	25.2%	16.6%	22.9%	22.1%	28.0%	38.2%
Research studies/clinical trials e.g. the person with dementia took part in a research study	9.5%	6.2%	11.0%	5.3%	13.8%	11.4%
Drug treatments e.g. the person with dementia commenced an anti-dementia drug	63.3%	73.9%	76.9%	73.2%	38.4%	46.5%
Alzheimer association e.g. joining the association	41.8%	27.5%	56.2%	25.1%	49.3%	48.2%
Services available e.g. the carer and/or the person used at last one new service	36.1%	41.2%	36.6%	21.5%	49.6%	36.4%
Did not act on any of the advice given	3.7%	9.5%	1.1%	2.4%	4.5%	3.5%

* Top three results in bold

4.4.3. Sources of information

Almost all carers used some source of information to keep up-to-date with issues related to dementia; only 2.2% of them reported that they didn't use any source of information at all for this purpose. The most popular sources of information were the Internet (64.2%) and Alzheimer's associations (60.3%). In the Czech Republic and Italy, fewer carers reported the Alzheimer association as a main source of information (36% and 48.1% respectively). Also, around a third of carers used specific dementia literature (35.7%) and newspapers, journals or magazines (33%) to keep informed. Overall, healthcare professionals (HCPs) were slightly less often the source of information used by carers, however

among HCPs, GPs were mentioned as a source of information by almost a quarter of the carers (23.6%). Amongst the other HCPs important differences exist within the countries. In the UK (Scotland), carers referred to any HCP less frequently as a source of information. In other countries, the HCPs who were more frequently considered a source of information included:

- neurologists: Italy (33.6%) and Czech Republic (19.4%)
- geriatricians: Finland (30.3%) and Italy (20.9%)
- psychiatrists: Czech Republic (27.5%)
- memory nurses: Finland (24.8%)
- care managers: Netherlands (55.2%)

Table 19: Sources of information (n=1409)

	Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
GP/primary care physician	23.6%	21.3%	28.9%	20.4%	24.3%	21.5%
Neurologist	16.3%	19.4%	12.1%	33.6%	10.4%	0.9%
Geriatrician	17.8%	4.7%	30.3%	20.9%	22.4%	0.0%
Psychogeriatrician	2.4%	5.7%	0.3%	NA	NA	2.6%
Psychiatrist	6.7%	27.5%	0.8%	4.4%	1.9%	6.1%
Psychiatric nurse/memory nurse	14.2%	2.8%	24.8%	NA	10.4%	12.3%
Care manager	22.2%	3.8%	16.5%	NA	55.2%	9.6%
Community nurse	12.1%	3.3%	17.4%	NA	14.9%	8.3%
Alzheimer association	60.3%	36.0%	64.5%	48.1%	77.2%	74.1%
The internet	64.2%	72.0%	64.2%	64.3%	63.4%	57.5%
TV/radio	25.1%	19.9%	35.0%	15.3%	29.1%	24.1%
Newspapers/journals/magazines	33.0%	30.3%	39.7%	22.4%	42.2%	29.8%
Specific dementia literature	35.7%	46.4%	28.9%	32.4%	41.4%	34.6%
Other	4.6%	4.3%	2.5%	4.1%	6.3%	7.0%
None	2.2%	0.9%	1.9%	3.2%	0.4%	4.4%

* Top three results in bold

4.4.4. Services and support

Carers were asked to consider an extensive list of potential supports that might be offered and used in the six months following diagnosis. Overall, the number of services offered to carers was relatively low: only five of the 22 supports suggested in the list were reported to be offered to more than 15% of the carers.

One in five carers (20.9%) were offered a contact with a named person or service who could assist them with signposting services or whom they could contact as needed. The other two services more frequently offered were day care (19.2%) and dementia cafés (18.7%). Overall, a relatively small percentage of people were offered services linked to social activities and creative activities (e.g. befrienders 10.9%, creative activities 9.7% and other group activities 12.7%) and even less, activities or services related to cognitive stimulation, reminiscence or memory training (10.8%, 6.2% and 8.6% respectively).

Likewise, contact with a named person and day care were among the services which were most often used in the six months following diagnosis (32.5% and 22.9% respectively). Assessment of the needs of the person with dementia was also relatively high (23.3%).

For almost all services, a third or more of carers would have liked to have used the service, but did not receive information about it (with the exception of home and day care which were slightly lower i.e. 27.8% and 29%). Half of the carers (50.9%) were not offered an assessment of their own needs, but would have liked to have used this service, and in 44.6% of the cases, the carers would have liked an assessment of the needs of the person with dementia. Also, several carers would have liked counselling or emotional support for the person with dementia (44.6%).

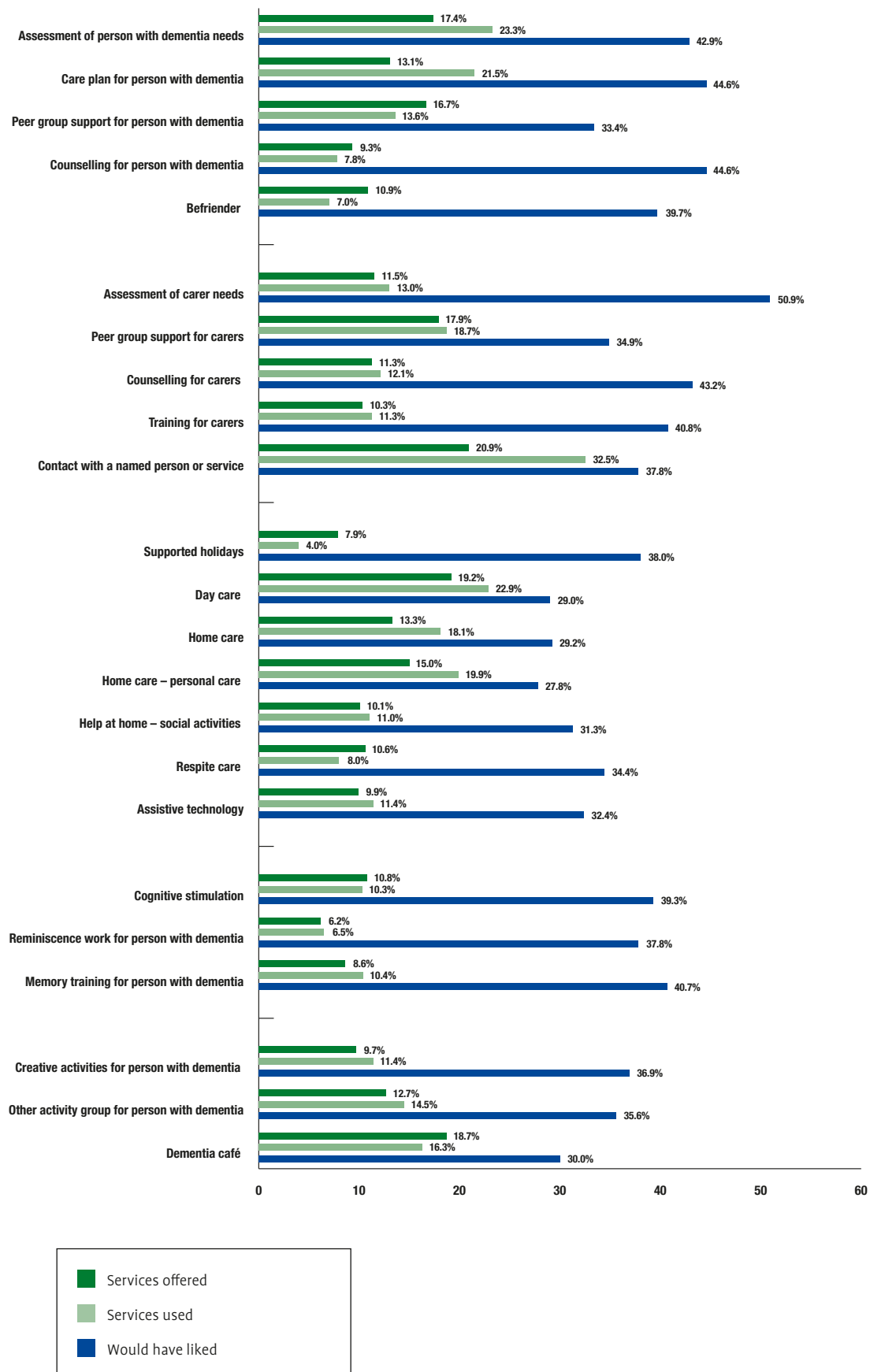
Carers in Italy were offered any kind of service/support less frequently. The usage of services/support was especially high in the Netherlands (60%) and the UK (Scotland) (42%) and very low in Italy (10%). An assessment of the needs of the person with dementia was reported by around a quarter of carers (23.3%), and was again least common in Italy (7%). A similar picture emerged regarding a care plan for the person with dementia, which was reported by one in five carers; low rates were reported in Italy (9%) and the Czech Republic (6%). Day care was used by half of the carers in the Netherlands, but by only 11% in Italy. Counselling or emotional support for the person with dementia and carer and training/education courses for carers were requested by a substantial number of carers in Italy and in the UK (Scotland). Carers from Italy appeared more likely to report unmet needs in relation to post-diagnostic support.

Table 20: Services and support (n=1409)

	Service offered	Service used	Would have liked
Person with dementia			
Assessment of needs	17.4%	23.3%	42.9%
Care plan	13.1%	21.5%	44.6%
Peer group support	16.7%	13.6%	33.4%
Counselling/emotional support for person with dementia	9.3%	7.8%	44.6%
Carer			
Assessment of needs	11.5%	13.0%	50.9%
Peer group support	17.9%	18.7%	34.9%
Counselling/emotional support	11.3%	12.1%	43.2%
Training/education course	10.3%	11.3%	40.8%
Contact with a named person or service (signposting to services or contact as needed)	20.9%	32.5%	37.8%
Befriender – supportive/social visits from a volunteer	10.9%	7.0%	39.7%
Supported holidays	7.9%	4.0%	38.0%
Day care	19.2%	22.9%	29.0%
Home care	13.3%	18.1%	29.2%
Home care – help with personal care	15.0%	19.9%	27.8%
Help at home – paid worker visits for social and other activities with person with dementia, such as outings etc.	10.1%	11.0%	31.3%
Respite care	10.6%	8.0%	34.4%
Assistive technology	9.9%	11.4%	32.4%
Cognitive stimulation	10.8%	10.3%	39.3%
Reminiscence work for person with dementia	6.2%	6.5%	37.8%
Memory aids/memory training for person with dementia	8.6%	10.4%	40.7%
Creative activities for person with dementia – music, art etc.	9.7%	11.4%	36.9%
Other activity group for person with dementia – exercise, social activity, outings etc.	12.7%	14.5%	35.6%
Dementia café	18.7%	16.3%	30.0%

* Top three results in bold

Figure 26: Services offered, services used and services the person would have liked (n=1409)



4.4.5. Anti-dementia drugs*

Of the four currently approved anti-dementia drugs,** overall, donepezil was the most frequently prescribed drug (27.7%) and galantamine the least (6.8%). This was not the case in Italy and the Netherlands, where fewer people were

prescribed donepezil (1.5% in the Netherlands and 17.6% in Italy) and were more frequently prescribed a different anti-dementia drug (e.g. memantine in Italy and galantamine in the Netherlands). In the Netherlands, almost half of the people with dementia (46.6%) had not been prescribed any of the four anti-dementia drugs.

Table 21: Anti-dementia drugs prescribed

	Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
	n=1391	n=207	n=358	n=336	n=266	n=224
Donepezil	27.7%	40.1%	40.8%	17.6%	1.5%	41.7%
Rivastigmine	13.7%	6.3%	15.6%	21.4%	15.4%	3.6%
Galantamine	6.8%	0%	6.1%	2.4%	16.5%	9%
Memantine	14.6%	21.7%	16.5%	22.3%	3%	7.2%
None of the above drugs prescribed	20.2%	11.6%	4.7%	16.7%	46.6%	26.9%

4.5. Carers' perceptions of the friendliness of their community

4.5.1. Diagnosis shared with other people

In the majority of the cases, the carer or the person with dementia shared the diagnosis with other people. Only 2.1% said that no-one else knew about the diagnosis. In 83.2% of cases, they had shared the diagnosis with close family members and in around half of the cases with close friends of the carer (56.9%) and/or of the person with dementia (56.8%).

In all countries, close family members were the people with whom the carer or person with dementia had most often shared the diagnosis. In Italy, close friends of either the person with dementia or the carer were told less often about the diagnosis than in other countries (38.3% and 31.9% respectively). Neighbours were told less often about the diagnosis in the Czech Republic and Italy (29.4% and 37.5%).

* In the Czech Republic, Finland and Italy, it was decided to include in the question the generic and the trade name(s) of each anti-dementia drug. In the Netherlands and in the UK (Scotland), it was decided to only use the generic name of each anti-dementia drug (i.e. donepezil, rivastigmine, galantamine, memantine). Differences exist between countries in relation to the national guidelines for prescription and reimbursement of these drugs.

** There are currently two classes of drug approved, cholinesterase inhibitors (donepezil, rivastigmine and galantamine) and the N-methyl-D-aspartate receptor (NMDA) receptor antagonist, memantine.

Figure 27: Who else the carer or person with dementia has told (n=1409)

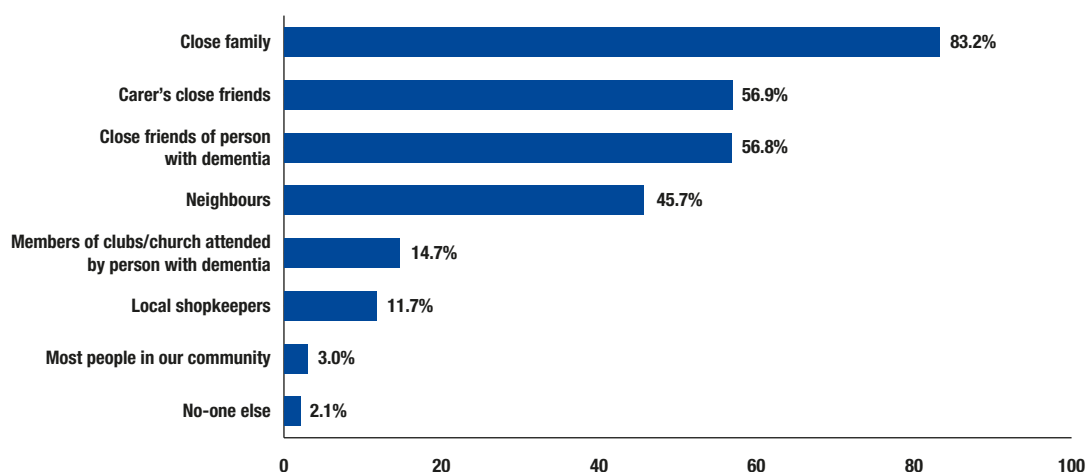


Table 22: Who else the carer or the person with dementia has told: comparison by country (n=1409)

	Total	Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
Close family	83.2%	87.2%	94.8%	76.1%	80.2%	75.0%
Carer's own close friends	56.9%	49.3%	75.8%	31.9%	58.6%	69.3%
Close friends of person with dementia	56.8%	50.7%	69.1%	38.3%	62.7%	63.2%
Neighbours	45.7%	29.4%	47.1%	37.5%	53.7%	61.4%
Members of clubs/churches attended by person with dementia	14.7%	4.3%	11.0%	8.6%	19.8%	33.3%
Local shopkeepers	11.7%	6.2%	5.5%	13.6%	14.9%	20.2%
Most people in our community	3.0%	1.9%	3.6%	0.6%	6.0%	3.1%
No-one else	2.1%	1.4%	0.6%	1.2%	7.5%	0.4%

4.5.2. Perceptions of the community

Table 23 shows the level of agreement or disagreement of carers with a number of statements in relation to their community. 67.6% of the carers felt that, since the diagnosis, the person with dementia had not been able to carry on with most of his/her previous community activities and roles. However, several carers still felt that the person with dementia was valued and respected by other people (59.2%), continued to have an important role in his/her family (57.8%) and was still part of the community in which he/she lived (43.8%). More than half of the carers (56.8%) felt that caring for a person with dementia often made them feel lonely. Perceptions about others were unclear, as 47.8% felt that people tended to stay away once they knew someone had dementia. However, 45.8% felt that

once people knew that the person they were caring for had dementia, they went out of their way to be helpful and friendly.

Table 24 shows selected answers for all the different statements by country. Italy was the country where the fewest number of people felt that the person with dementia had not been able to continue with previous community activities and roles since the diagnosis. However, the majority of carers in Italy (56.6%) did not agree with the statement about people in their community being aware of dementia and three-quarters of the carers felt lonely (75.6%). In Finland, more carers felt the person with dementia was still part of the community where they lived (56.9%) and of their family (73%). In the UK (Scotland), most carers (64.3%) felt the person with dementia was still valued and respected.

Table 23: Perceptions of the community

	N	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The person I care for has been able to carry on with most of his/her previous community activities and roles since the diagnosis	1325	34.5%	33.1%	11.1%	15.8%	5.5%
Most people in our community are aware of dementia and know of its effects	1330	12.4%	26.0%	24.3%	31.1%	6.2%
People tend to stay away once they know someone has dementia	1336	7.7%	18.6%	25.8%	33.7%	14.1%
There are places I avoid because they are not tolerant of people with dementia	1315	18.4%	30.7%	26.2%	18.5%	6.2%
Caring for a person with dementia often makes me feel lonely	1340	9.2%	16.8%	17.2%	31.8%	25.0%
Once people know that the person I care for has dementia, they go out of their way to be helpful and friendly	1327	5.7%	12.1%	36.3%	38.1%	7.7%
The person I care for is still part of the community in which he/she lives	1319	17.7%	20.8%	17.7%	33.3%	10.5%
The person I care for continues to have an important role in his/her family	1334	9.7%	15.1%	17.4%	35.5%	22.3%
The person is still valued and respected by other people	1337	6.6%	10.3%	23.9%	39.9%	19.3%

Table 24: Selected statements by country

		Czech Republic	Finland	Italy	Netherlands	UK (Scotland)
The person I care for has been able to carry on with most of his/her previous community activities and roles since the diagnosis	Disagree and strongly disagree	72.8%	61.6%	59.9%	81.4%	66.4%
Most people in our community are aware of dementia and know of its effects	Disagree and strongly disagree	33.8%	30.8%	56.6%	31.1%	38.3%
People tend to stay away once they know someone has dementia	Agree and strongly agree	46.9%	40.7%	53.6%	50.9%	48.0%
There are places I avoid because they are not tolerant of people with dementia	Agree and strongly agree	29.9%	19.2%	31.5%	18.9%	26.4%
Caring for a person with dementia often makes me feel lonely	Agree and strongly agree	42.5%	51.9%	75.6%	44.2%	66.1%
Once people know that the person I care for has dementia, they go out of their way to be helpful and friendly	Agree and strongly agree	51.3%	39.7%	45.8%	47.7%	48.2%
The person I care for is still part of the community in which he/she lives	Agree and strongly agree	49.2%	56.9%	34.0%	37.5%	39.2%
The person I care for continues to have an important role in his/her family	Agree and strongly agree	43.1%	73.0%	46.4%	58.9%	62.1%
The person is still valued and respected by other people	Agree and strongly agree	58.5%	50.3%	59.5%	58.5%	64.3%

5. Conclusions

Diagnosis is critical for people with dementia and their families. This survey has looked at the experiences of receiving a diagnosis of dementia of 1409 informal carers in five European countries. These people are relatives, friends or neighbours currently providing care and support to a person with dementia. The overall conclusion of this study is that whilst some aspects relating to diagnosis may be improving, we could not identify a clear change in the last decade in the experience of diagnosis of dementia and post-diagnostic support is still a major issue across Europe. Another important finding relates to key differences in the experience of diagnosis and post-diagnostic support across countries in Europe.

The most common first indication that something was wrong and which prompted the person to seek help was related to memory problems/confusion. This is the same finding that was reported in the survey conducted by AE in 2006.¹ However, as in 2006, the survey highlighted that other difficulties, such as difficulties with activities of daily living, communication and issues related to mobility (e.g. travelling, driving) were also frequently experienced and often reported as difficulties which triggered help-seeking. This is important as dementia is often most frequently portrayed as a memory condition. Consequently, this should be taken into account when raising awareness about dementia and promoting timely diagnosis.

The findings also suggested that it took an average of 2.1 years to receive a diagnosis. This is almost the same figure that was reported in a similar study in 2005 ("Facing dementia study").³ No relevant differences in this time-frame were apparent in the most recent years; overall, if anything, diagnosis tended to take longer. Differences also exist across the countries surveyed. The findings showed that it often takes a long period of time for people to first seek help after noticing the first symptoms. The Czech Republic seemed to perform particularly well in this area, and several carers had a very short period of time for commencing assessments and visiting the specialist. GPs continue to be the healthcare professionals from whom carers first seek help. Nevertheless, this decision to seek help was made by the person with dementia alone in a relatively small number of cases.

In 2006, as many people were diagnosed in hospital as were diagnosed by their GP; this no longer seems to be the case. The diagnosis is now more frequently made in

a memory clinic or outpatient service of a hospital. Only a small proportion were diagnosed by the GP. Most carers reported that the person with dementia had undergone memory tests, interviews and brain scans. As would be expected, lumbar punctures were less common, however these were slightly more frequent in the Netherlands. The number of people with dementia in the Czech Republic who had a brain scan was much lower than in any other country.

An important number of carers reported that the person had been diagnosed with another condition prior to dementia. This is something that people with dementia and carers often refer to and can be very distressing. Depression was one of the most common conditions with which people with dementia were diagnosed prior to diagnosis.

The majority of people had received a diagnosis within the past five years prior to completing the survey. An important and positive finding is that two-thirds had been diagnosed at early stages (mild dementia or MCI) and only 4% had received the diagnosis at advanced stages. However, many carers felt the diagnosis had been made too late. This was more frequent as the severity of dementia increased. Carers in the Netherlands tended to feel that the diagnosis had been more timely. Some of the main factors identified as delaying the diagnosis seemed to be related to the lack of awareness and education about dementia, and the way dementia is perceived.

One in five people with dementia were not informed about their diagnosis. In this respect, very important differences exist across countries. In Italy in particular this was a major issue. In only a few cases this reflected the expressed wish of the person with dementia. A positive finding is that when diagnosis is disclosed, carers seemed to be satisfied with how it had been disclosed. Important aspects included the feeling that the doctor was well prepared, had explained everything clearly and had established a good relationship with the person with dementia. However, aspects which were not covered so well were the involvement of the person prior to diagnosis and determining their preferences for the disclosure.

Diagnosis can be a life-changing experience. The majority of carers were worried about the future, and many carers and people with dementia felt sad at the time of diagnosis. After some time however, while many continued to feel

sad, other more positive feelings such as acceptance also emerged. Additionally, negative feelings tended to be less prevalent after a period of time.

One of the main gaps highlighted in the 2006 survey was that many carers (19%) had not received any type of information at the time of diagnosis. This finding was identical in 2017: once again, 19% of the carers reported that they had not received any information. In the case of people with dementia this percentage was even higher. The majority received information regarding medical aspects and pharmacological treatment, but information on psychosocial aspects was very often missing. Information about taking part in research was the type of information which fewest carers received. The provision of information about available services was also relatively low. Despite this, almost every carer reported using different sources of information to keep up-to-date on dementia, especially the Internet. Furthermore, the role of the Alzheimer associations in providing information was very important.

The survey has emphasised several unmet needs in the provision of information and access to services and support. The need for information on coping and living well with dementia and the need for available services was particularly high. Several carers did not have access to an assessment of their own needs, a care plan for the person with dementia or access to counselling services, but would have liked to have used these services.

The majority of the carers had shared the diagnosis with other people. This tended to be close family and (to a lesser extent) close friends. Many carers felt that the person with dementia was still valued and respected by others, particularly within their own families. Fewer people had shared the diagnosis with others in their communities, and carers often felt that after the diagnosis the person with dementia was no longer able to carry on with community activities and roles. Loneliness due to their role as a carer was frequently reported.

In conclusion, the time to receive a diagnosis has not substantially changed in the last years, however people now seem to be more often diagnosed in a specialist service; in many cases the diagnostic work-up included brain scans. A few more people were informed of their diagnosis now than in 2006, however whilst this is a common practice in some countries, it is still not the norm in others. Many positive aspects of the process of disclosure were raised, but the involvement of the person with dementia was often still lacking. In most countries, post-diagnostic

support and care still require a good deal of improvement. Greater involvement of the person with dementia in the full diagnostic process is very much needed. Every person with dementia should be given the opportunity to decide whether they would like to know the diagnosis and who should take part in this process. Several carers still experience unmet needs with regard to information and support during the diagnostic process and afterwards. Sadness and loneliness among carers should be further addressed. Communities are changing, and hopefully becoming more inclusive of people with dementia. However, further work on raising awareness and making communities a better place for people with dementia and their carers is needed.

The findings have also highlighted important differences in the experience of diagnosis based on the country where a person lives. Italy and the Czech Republic had the shortest times for diagnosis, and people with dementia in Italy had good access to diagnostic tests. However, these countries need better involvement of people with dementia in the diagnostic process, as several did not know about their condition and had received little or no information. Additionally awareness of dementia among the general public is lacking in Italy. Finland, the Netherlands and the UK (Scotland) were particularly good at disclosing the diagnosis to people with dementia. In general, carers seemed more open to sharing the diagnosis with other members of the community. However, there is still room for improvement in the post-diagnostic support offered to carers and people with dementia. Information on relevant aspects such as advance care planning, legal rights, driving and in particular, opportunities to take part in research should be further addressed.

This study had several limitations which should be considered and which may have had an impact on the findings. Some of the more significant limitations relate to the way in which the sample was recruited (e.g. via Alzheimer associations, online). Overall, many participants were adult children and the majority of the carers and of people with dementia were well educated. This may indicate that the people completing the survey were among the "most privileged" carers, so the situation of other carers may be even worse.

The following testimonials from people with dementia and supporters from AE's European Working Group of People with Dementia (EWGPWD)* show how, despite difficulties in obtaining a diagnosis and dealing with the impact, it is still possible to live well with dementia and contribute to family life and society in different ways.

* For information about the EWGPWD, please see <https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia>

Helen Rochford-Brennan. Chair of the EWGPWD (Ireland)



My diagnosis came after a number of years of wondering what was wrong with me. At work the in-tray was not moving, I found myself at a Board meeting struggling for words. I thought I was losing my mind. In one sense my diagnosis brought relief as

the symptoms of dementia were frightening. But after meeting with the doctor I had to drive home over 60 miles and wondered how I was going to tell my husband and son. I had no leaflet, no advice. I went to Dr Google and

scared myself. I don't remember the conversation with my family but I do remember the pain. The only way I can describe those first few months was heartbreak ... as there is no cause or cure, there were and are many dark nights. But my early diagnosis put me (the person with dementia) in control. My diagnosis led me to cognitive rehabilitation therapy, research through Trinity College and The Irish Dementia Working Group (supported by the Alzheimer Society of Ireland). I am now Chair of the European Working Group of People with Dementia.

“Through my strategies, I have learned how to live exceptionally well in my new life, my life with Alzheimer’s”

This journey has allowed me to find my voice and a purpose filling the void left by leaving paid employment. Because I received an early diagnosis I have been able to employ strategies to live well and if necessary learn new skills. I use my phone now more than ever before. I use white boards, ipad my computer and many notes to myself. Through my strategies I have learned how to live exceptionally well in my new life, my life with Alzheimer's. Having a diagnosis and sharing that diagnosis with family and friends mean I have a community of support; people in my life who know I have dementia. This is preferable to stumbling in the dark worrying about me. I advocate for each person having a right to diagnosis but it is important to acknowledge that not all diagnoses are equal.

Petri Lampinen. Member of the EWGPWD (Finland)

My name is Petri I am from Finland. Thinking about the early stages of my dementia is still very difficult for me: my whole personality started to change, I started to drink, I couldn't control myself, I was carefree, impulsive and grumpy. I received a diagnosis of Frontotemporal dementia (FTD) at the age of 52. I couldn't believe that I had dementia, nobody in my family has had dementia so this was all new to me. Before the diagnosis of FTD I was diagnosed with depression. This is not unusual for people with dementia. Also, FTD is very rare in Finland and this made the diagnosis even more difficult. As doctors believed I had depression, I was prescribed medication which made my symptoms worse. Problems with my short-term memory and changes in my personality increased and I had to spend some time in a psychiatric ward. The psychiatrist there realised I didn't have depression and suspected I could have FTD. I had to have several tests and scans such as CT, MRI, SPECT and EEGs, I also had a spinal tap, blood test, memory tests... Several doctors were taking care of me, but they did not talk enough to each other. No one seemed to know what was happening to me.

Eventually, thanks to a psychiatric nurse, I found a doctor at the University Hospital where, after more tests and research, I was diagnosed with FTD. Waiting for the diagnosis was a very hard time for me and my family, I sometimes wonder how we managed to survive this. Getting the diagnosis was difficult but also a very big relief for me and my family. It helped me to understand my symptoms and what could help me. I gave up driving as I felt it was no longer safe and drinking alcohol as I could not control myself.

Since the diagnosis I have kept very active and have done occupational therapy and rehabilitation for dementia. I have a very positive attitude and I want to help other people. I collaborate with The Alzheimer Society of



Finland and I give speeches about young onset dementia to nurses. I think dementia has given me some gifts, which I will use for my own and other people's good for as long as I can.

“Waiting for the diagnosis was a very hard time for me and my family, I sometimes wonder how we managed to survive this”

Carol Hargreaves. Member of the EWGPWD (UK, Scotland)



I was in my work (managing a chain of book makers) and I started giving the cashiers jobs I should've been doing. Somehow I knew I couldn't cope. Then, the mini strokes started, but I didn't realise. Other people would notice a slight change in my face and my speech and tell me. Now if I'm tired or stressed my speech will still go funny. It's a reminder and it hits me, because I feel so well.

As I already had a diagnosis of bipolar, doctors put it down to that. I knew it wasn't. It was a really dark time. Eventually, the scans showed it was dementia. A psychologist that I'd never met before was called in and she said "I'm sorry

to tell you the scan has shown vascular dementia. We'll get you information but you've probably got a good six months so get your affairs in order". Nobody should be told they've got a serious illness alone. Then came the big book of information. I've never read it. No one ever explained or told my family. My family wrapped me up in cotton wool. They were told to watch me like a hawk.

Then, Susan (my Alzheimer Scotland outreach worker) came into my life. I joined the Scottish Dementia Working Group. I took the bull by the horns, and went in by myself. I love working in groups. I get a real buzz out of it. All I can say is I thought I'd be dead by now but life is so full. My whole life changed, from me having my son and step daughters, to moving into a flat on my own. There has been lot going on with family in the last few years and I was able to be there for them. Me and my sister have a fantastic relationship and we look after my mum together.

“ Nobody should be told they've got a serious illness alone ”

Jayne Goodrick (UK, Wales). Wife of Chris Roberts (Vice Chair of the EWGPWD)

When we received the diagnosis that my husband had dementia, we didn't realise that the whole family received the diagnosis, that it would affect us all. We were given the diagnosis, passed a few leaflets, and sent home. The silence was deafening. We didn't know who to turn to or where to go for information, for help, for solace. We each hit the internet separately, not wanting to upset the other, especially with what Dr Google told us. We had no hope.

What I would have found really helpful would have been speaking to other people in our situation, to show us that yes, the diagnosis is a blow, but that you can move on from that and continue to live your life, that you needn't become disengaged, disabled, or disempowered by the label. Yes, that may happen sooner, or later, but not at that moment in time.

Peer support was really what we needed. Advice on what there was on offer. What social services could do. What an occupational therapist did, and why they should be involved.

How to do a Lasting Power of Attorney. Practical things we could do which would give us back a sense of being in charge – being proactive, not passively waiting for the inevitable.

And having picked ourselves up, then information on the disease, the one specific to us (there are more than 200 different causes of dementia), what to expect, how to manage, how to adapt, how to keep myself well, as well as my husband. Practical advice, such as when we hit a problem, find out what is the problem and then how to overcome it. The best support we had in the beginning was a dementia support worker from the Alzheimer's Society. She told us what we needed to know, with honesty and tact, but she



'got it' as she was also living alongside dementia as her mum had a diagnosis. We were assigned a CPN (I had to google that – community psychiatric nurse), but I didn't understand why we needed a nurse, my husband didn't need nursing! Eventually, we worked our way around the health care and the social care systems, but it was more by trial and error than by design.

Things have changed now. There are carer courses offered by the Alzheimer Society that upskill you, and create a peer support network by default. In the UK there is a new national centre for carers of people with dementia being built 'Dementia Carers Count'. This will be that go to place for the information I needed at diagnosis; it will offer courses in what I would have benefited in learning from the start; and it will be there for when things progress and I am once again swimming in an unknown sea of confusion.

So things are changing. But not quickly enough.

“The best support we had in the beginning was a dementia support worker from the Alzheimer's Society. She told us what we needed to know, with honesty and tact”

6. Acknowledgements

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Alzheimer Europe A.S.B.L. • R.C.S. Luxembourg F2773 • 14, rue Dicks • L-1417 Luxembourg
Tel.: +352-29 79 70 • Fax: +352-29 79 72 • info@alzheimer-europe.org • www.alzheimer-europe.org
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