

# Dementia in Europe Yearbook 2014

National care pathways for people  
with dementia living at home





This Yearbook arises from the 2014 Work Plan of Alzheimer Europe, which has received funding from the European Union, in the framework of the Health Programme.

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## 1 Foreword



It gives me great pleasure to present this comparative report on care pathways for people with dementia living at home in Europe.

The pathways to get a diagnosis of dementia are complex and are likely to be multifactorial. Many people living with dementia in Europe are still not diagnosed, and often the diagnosis comes too late. Every person with dementia has the right to a high quality, timely diagnosis, if they so wish. There is now clear indication that people can live well with dementia. Nevertheless, without the right support and care this may not be possible. Getting the necessary support and care depends on several factors. Among them, availability and appropriateness are key, as are the informational aspects and the navigability of the complex health and care systems involved in the diagnosis and care of people with dementia.

This comparative report contains information on national policies and practices addressing different aspects of the timely diagnosis of dementia and of the post-diagnostic care and support available to individuals living with dementia in 30 European countries. The report outlines the main similarities and differences in the processes that people need to follow to be diagnosed and to access the support and care in these countries. It also highlights some of the gaps and main challenges that these individuals may experience. In doing so, the report shows that there is not always a single, linear pathway that may suit every person and every country.

The report is based on information provided and reviewed by Alzheimer Europe's member associations, to whom we are immensely grateful. Some external experts, from countries where Alzheimer Europe has no member, also helped compile the information. The names of all those who made it possible to produce the report are acknowledged at the back of the publication. I would also like to thank Ana Diaz, Project Officer of Alzheimer Europe, for having coordinated the data collection and for writing the comparative report.

We hope that this report will enable readers to gain an impression of the complexities of the different dementia care pathways which currently exist in Europe. We also hope that it can provide the basis for further discussion and development of care pathways in these countries.

**Jean Georges**  
*Executive Director*  
*Alzheimer Europe*



## 2 Introduction

### 2.1 Background to the report

This comparative report on national care pathways for people with dementia living at home has been produced as part of the 2014 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.

Decisions about the broad areas to be addressed were informed by a literature review on the topic. Agreement on the specific sections to be included for each area was reached in a meeting with 16 Alzheimer Europe (AE) member associations at the beginning of 2014. Based on this, a questionnaire was drafted and later reviewed by four members of the group. The final questionnaire was sent out to all AE members. In addition, in countries where AE has no member (i.e. Hungary, Latvia, Lithuania and Estonia), relevant informants were identified and invited to participate.

29 AE member associations and two external experts returned the questionnaires<sup>1</sup>. Questionnaires had been completed by the national organisation and, whenever necessary, with the aid of relevant national experts in the field of social policy, medicine and social support<sup>2</sup>. Organisations were contacted again when necessary to clarify certain issues and information was transferred into a database and analysed. The comparative report was sent to all participating organisations for final approval prior to publication.

In addition to this comparative report, a national report for each country has been produced. These national reports are available to the public on the Alzheimer Europe website (<http://www.alzheimer-europe.org>).

Table 1: Participating countries (N=30)

EU Member States (N=25 countries)			Non EU Member Countries (N=5 countries)	Countries contacted that did not participate
Austria	Germany	Poland	Jersey	<b>EU member states</b>
Belgium	Greece	Portugal	Monaco	Estonia
Bulgaria	Ireland	Romania	Norway	Hungary
Croatia	Italy	Slovenia	Switzerland	Slovakia
Cyprus	Latvia	Spain	Turkey	
Czech Republic	Lithuania	Sweden		<b>Non EU member</b>
Denmark	Luxembourg	UK		Iceland
Finland	Malta			
France	Netherlands			

### 2.2 Care pathways: definition and relevance

Care pathways chronologically pinpoint the key steps to be taken throughout a person's care journey (Irving and McGarigle, 2012). In the case of dementia, the term "care pathway" makes reference to how national systems seek to provide seamless care and treatment from the moment of detection and diagnosis of dementia to end of life. Also, the term refers to the experiences of people with dementia and their families with such care systems. In short, it describes the journey of a person from the time he/she experiences a memory concern (or other dementia-related symptom) to the time the person is assessed and given a diagnosis, and later, to the treatment and care that is available to the individual to help him/her live well with dementia.

<sup>1</sup> Two separate questionnaires were received from the Alzheimer's Society (UK) and Alzheimer Scotland. In the report, comments are provided on the basis of the UK including Scotland except when specified otherwise. In some sections, the information reported by Alzheimer Scotland is presented separately from the information reported by the Alzheimer's Society (UK). This approach is taken when the data reported by each differ substantially. The reader is warned when this approach is taken.

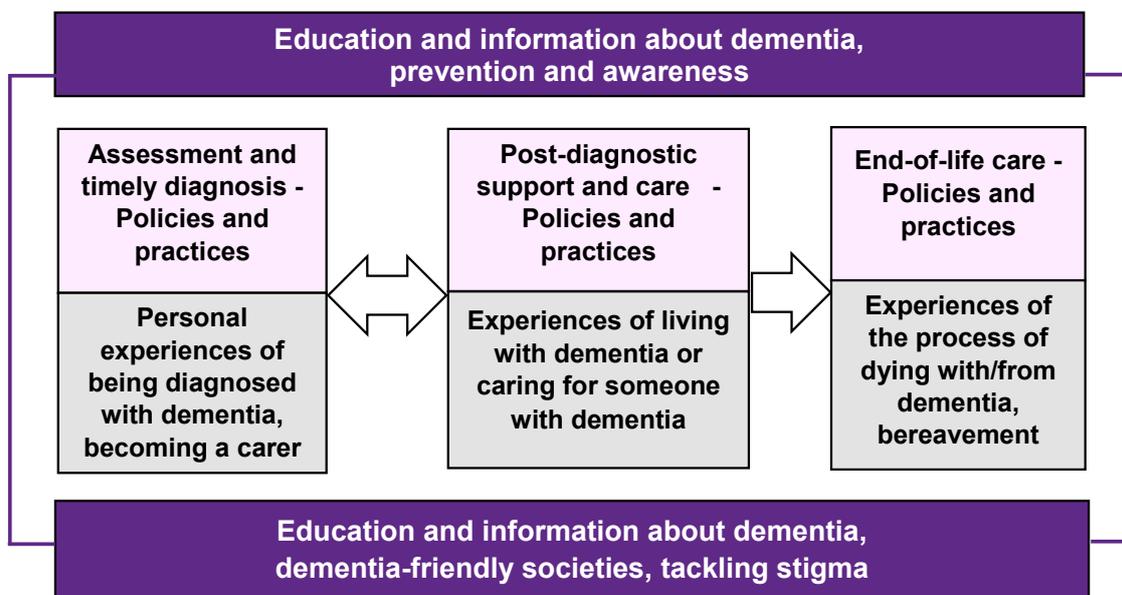
In the case of Belgium, the questionnaire was sent to the AE member "Ligue Nationale Alzheimer Liga". Two different questionnaires were received, one with reference to the Walloon region and Brussels (Ligue Alzheimer asbl) and another for the Flemish region (Alzheimer Liga Vlaanderen and Expertisecentrum Dementie Vlaanderen). When information differs an explanation is provided as to which region the information applies to.

<sup>2</sup> Please see the acknowledgements section of this report for further details of participants.

A key benefit of the care pathway approach is that it can improve the care of people with dementia, as care pathways should be based on the best available evidence. Another advantage is that it can be evaluated and may help to reduce inconsistencies and inequalities in health and care systems. In addition, it may help healthcare professionals and, people with dementia and their families, to understand better their roles and expectations. A main concern of using care pathways is the risk of reducing care to a set of pre-defined tasks and depersonalising care (de Luc, 2001). There is some consensus that care pathways should be person-centred and not rigidly applied.

Typical stages of care pathways in dementia include prevention and identification of symptoms, timely diagnosis, post-diagnostic support and care, and end-of-life care.

Diagram 1: Dementia care pathway



### 2.3 Layout of the report

This comparative report focuses on national care pathways for people with dementia living at home. Elements of the care pathway related to institutional care and end-of-life care, have not been reviewed.

Diagnosis is a critical stage of the journey of people with dementia and their families. Diagnosis is often referred to as the gateway to care as it may provide access to treatment and support and offers an opportunity to plan for the future. Section 3 of this comparative report, looks at the journeys of individuals from the time they start experiencing a cognitive change to the time they are formally diagnosed with dementia. It provides information about the national policies and practices addressing the timely diagnosis of dementia in the participating countries. It also attempts to gain a better understanding of what a person who is experiencing these cognitive changes needs to do in order to be assessed and diagnosed. It looks at the role of primary and secondary care and the interplay between them (i.e. referral pathways, communication and the ongoing management of people with dementia in the community). It also considers the role of the person with dementia in this process, with a particular focus on the disclosure of diagnosis to the person and information about the disease that the person will receive at the time of diagnosis. At the end of the section, the main barriers and challenges to the diagnosis of dementia are presented.

Whilst diagnosis is a crucial step, getting a diagnosis is only the first step in the dementia journey. The needs and experiences of receiving and living with a diagnosis of dementia are unique and complex. Section 4 of this comparative report looks at the support and care services that are in place to support people to live well with dementia. It provides an overview

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of how people with dementia and their families get to know about and access the psychosocial support and care available in their country. It covers aspects related to information provision and assessment of support and care needs at the time of diagnosis. Following this, it looks at the ongoing needs of people with dementia, how they navigate the system and the challenges or barriers they may face.



## 3 Journeys to diagnosis

### 3.1 Introduction

The delayed and missed diagnoses of dementia have received increasing attention due to the possible implications for harm and expense (Bradford et al., 2009). It is estimated that around half of the people living with dementia in Europe have never been diagnosed and, for those diagnosed, it will most likely happen when it is at a moderate stage (Brooker et al., 2013; Manthorpe et al., 2011). An emerging body of literature has outlined the benefits of an earlier and timely diagnosis of dementia, including that diagnosis is a right and most people wish to know it. It allows people to plan better for their future and to start treatments that may slow the disease progression. Diagnosis may also have psychological benefits for people with dementia and their families as it can be an end to uncertainties and may enable people to access relevant support and care (Brooker et al., 2013; Prince, Bryce and Ferri, 2011). The potential negative impact of diagnosis on people with dementia has also been investigated<sup>3</sup> and is particularly relevant in the absence of a cure or of more effective treatments for dementia. Over the last years, it has increasingly been suggested that the concept of “timely diagnosis” may be a more person-centred approach to diagnosis than “early”, as this implies the “right time” for the individual, as opposed to its chronological sense (Dhedhi, Swinglehurst and Russell, 2014). Efforts should therefore concentrate on a “speedy response to the first reported signs of changed behaviour and functioning in the patient” (De Lepeleire et al., 2008:569).

This section presents different aspects related to the diagnosis of dementia in 30 European countries<sup>4</sup>. The section starts by outlining how the diagnosis of dementia has been addressed at a national level in policy documents and the type of interventions that have been implemented to promote a timely diagnosis of dementia. The section then moves on to consider the different pathways to a diagnosis of dementia in the participating countries, with a focus on the role of primary and secondary care in diagnosing dementia and the interplay between them. The disclosure of diagnosis to people with dementia is then explored. The section also reviews the pharmacological treatment of dementia and approaches to the ongoing assessment of dementia in the participating countries. Finally, the section concludes with a brief description of the most relevant barriers and challenges to the timely diagnosis of dementia in these countries.

### 3.2 Promoting timely diagnosis

#### 3.2.1 National Policies: Addressing the diagnosis of dementia at a national level

With the exception of Latvia, all participating countries identified a national policy document (or national guideline) that addresses one or more aspects relating to the diagnosis of dementia in their country. In some cases, such a document was under development (Malta, Portugal) or was about to be implemented (Cyprus, Jersey).

Differences exist in relation to the national body that had issued the policy document or guideline. Almost half of the countries, referred to an “expert consensus statement” developed by an Alzheimer’s association (AA) or by a relevant professional body in the country (e.g. society of neurology or psychiatry, etc.). In 11 countries, this document was developed by a National Health Organisation or governmental body (for example, a National Dementia Strategy). In four cases (Belgium, Lithuania, Switzerland, UK), both an expert consensus statement and a policy document issued by a governmental body co-existed in the country.

<sup>3</sup> For example psychological distress, consequences of false positive diagnosis, stigma, risk of suicide, etc.

<sup>4</sup> Please note that for the UK, two separate questionnaires were received from the Alzheimer’s Society (UK) and Alzheimer Scotland. Comments in the report are provided on the basis of the UK, including Scotland, except when specified otherwise. The same applies to Belgium (Walloon region, Brussels and Flemish region). Comments in the report are provided on the basis of the whole country (Belgium) except when specified otherwise.

Figure 1: Type of national policies in all participating countries

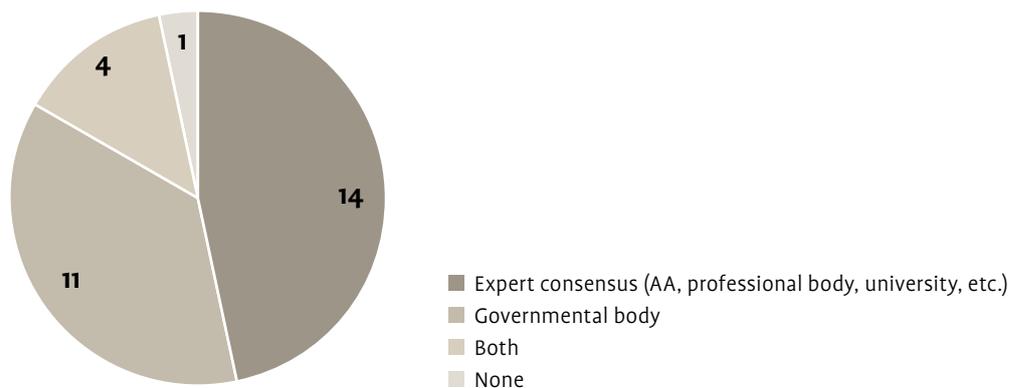


Table 2: Countries and type of national policy documents where diagnosis is addressed

	Expert consensus statement or (similar) developed by a relevant professional body or/and an Alzheimer's association	National policy document developed by a governmental body
Austria	X	
Belgium	X	X
Bulgaria	X	
Croatia	X	
Cyprus		X*
Czech Republic	X	
Denmark		X
Finland	X	
France		X
Germany	X	
Greece		X
Ireland	X	
Italy	X	
Jersey		X*
Lithuania	X	X
Luxembourg		X
Malta		X*
Monaco		X
Netherlands	X	
Norway		X
Poland	X	
Portugal		X*
Romania	X	
Slovenia	X	
Spain	X	
Sweden		X
Switzerland	X	
Turkey	X	
UK	X	X

\* Under development or to be implemented

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Relevant differences can be observed in the scope of these national policy documents. Table 3 shows topics related to diagnosis and the number of countries reporting that the topic was addressed in their national policy document. The diagnostic work-up is the topic most commonly addressed, whereas the expected times for a person to be assessed and the disclosure of diagnosis to the person are topics less likely to be covered in these national documents. Six countries<sup>5</sup> reported that all the topics were addressed in the national policy documents.

Table 3 – Topics addressed in the national policy document

Diagnostic work-up	22 <sup>6</sup>
Ongoing assessment of dementia (Follow-up)	20 <sup>7</sup>
Measures or interventions for the timely detection of dementia	17 <sup>8</sup>
Criteria for referral to a dementia specialist	15 <sup>9</sup>
Disclosure of diagnosis to the person and/or family	12 <sup>10</sup>
Expected times for a person to be assessed/diagnosed	8 <sup>11</sup>

### 3.2.2 Raising public and professional awareness and understanding about dementia

An important barrier to timely diagnosis of dementia seems to come from people with memory concerns and their families. They often have limited knowledge about the signs of dementia, identify dementia as part of normal ageing, have fears about the stigma attached to dementia, or do not know where to go or what to do when signs appear. From the point of view of the physician, time constraints, insufficient knowledge and skills to recognise or diagnose dementia, therapeutic nihilism and fear of harming the patient are often cited as barriers to a timely diagnosis of dementia (Cahill et al., 2008; Koch and Illiffe, 2010; Phillips, Pond and Goode, 2011; Vernooij-Dassen et al., 2008). There is some general agreement that increasing knowledge and decreasing the stigma relating to dementia may have a positive impact on people's help-seeking behaviour (Mukadam, Cooper and Livingston, 2013).

Participating countries were asked about educational or information campaigns to raise awareness about dementia in their country. Most countries (27 out of 30)<sup>12</sup> reported that such campaigns exist in their country. In several cases, this referred to campaigns organised by the voluntary sector (most often Alzheimer associations). According to the national organisation from Jersey, whilst campaigns had not been organised in the past, an awareness campaign was planned for the coming year.

These campaigns are different in scope and frequency, with a typical example being a campaign for raising awareness organised as part of World Alzheimer's Day (21<sup>st</sup> September), whilst other organisations reported organising campaigns or awareness activities regularly throughout the year.

#### **BOX 1: Campaigns: an example from Belgium (Flemish region)**

"Music for Life" is an example of a large scale solidarity campaign to raise awareness for dementia. A choir of people with dementia and their carers performed as the supporting act for a very popular band (Muse) at a concert in Antwerp, Belgium (December, 2012). The campaign was supported by a national broadcasting company (VRT: Flemish radio and television), other mass media and the Flemish government. The campaign had a great impact on the population of Flanders.

In 2013, there was another campaign to raise awareness, this time specifically on young onset dementia. Throughout the year, Flemish television regularly features movies that deal with dementia.

Several countries perceived interventions aiming at changing general practitioners' (GP) attitudes, or increasing their skills or knowledge, as relevant tools for promoting the timely diagnosis of dementia. For example, in Croatia, the family doctors' curriculum was reviewed in 2014, and education about Alzheimer's disease increased in order to raise awareness about timely diagnosis.

<sup>5</sup> Denmark, Finland, Greece, Netherlands, Scotland and Sweden.

<sup>6</sup> Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Lithuania, Luxembourg, Monaco, Netherlands, Poland, Romania, Spain, Scotland, Spain, Sweden and Switzerland.

<sup>7</sup> Austria, Bulgaria, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Lithuania, Luxembourg, Malta, Monaco, Netherlands, Norway, Poland, Scotland, Spain, Sweden and Switzerland.

<sup>8</sup> Austria, Belgium (Flemish region), Cyprus, Denmark, Finland, Germany, Greece, Jersey, Lithuania, Malta, Monaco, Netherlands, Norway, Poland, Sweden, Switzerland and UK.

<sup>9</sup> Austria, Bulgaria, Denmark, Finland, Greece, Lithuania, Monaco, Netherlands, Norway, Poland, Romania, Spain, Sweden, Switzerland and UK.

<sup>10</sup> Austria, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Netherlands, Scotland, Sweden and Switzerland.

<sup>11</sup> Cyprus, Denmark, Finland, Greece, Monaco, Netherlands, Scotland and Sweden.

<sup>12</sup> Countries where campaigns are not organised: Austria, Germany and Jersey.

Other countries<sup>13</sup> referred to training programmes about dementia that are available to GPs. In Belgium, the INAMI (National Institute for Health and Disability Insurance) has launched, in their e-learning programme for GPs, a dementia module that provides two hours of training on dementia. In Denmark, e-learning programmes are available to GPs and other health professionals. In Sweden, GPs and nurses can access training on providing information to concerned people about early signs of dementia. In Ireland, the Irish College of General Practitioners developed in 2011 a distance learning module on Alzheimer's disease for GPs (Cahill, O'Shea and Pierce, 2012).

Finally, Belgium, the Netherlands and the UK highlighted the positive impact that promoting dementia-friendly communities may have on the timely diagnosis of dementia in their country.

**BOX 2: Dementia-friendly communities: an example from the Netherlands**

Alzheimer Nederland has started campaigning for dementia-friendly communities to raise awareness on improving the daily lives of people with dementia among municipalities in the Netherlands. The aim is to improve the understanding of dementia and to inspire and encourage members of the community (e.g. police, shopkeepers, gyms, council workers, libraries, rotary club, etc.) to help in different ways. Currently, 80 out of the 403 existing municipalities in the Netherlands have started to develop some activities. On World Alzheimer's Day 2014, ten more municipalities signed a letter of intent with Alzheimer Nederland to improve the care of people with dementia at home and to delay institutionalisation. In other municipalities, shopkeepers have been trained in how to interact with people with dementia in their shops. DemenTalent is an example of these good practices.

*What is DemenTalent?*

DemenTalent looks at the "talents" of people with dementia. It involves people with mild and moderate dementia, between 53 and 75 years old who are motivated to participate in the community. We (the community) have to use their talents and give such talents a place within the communities. We make this happen by giving people with dementia a volunteer job in the community. We started at Radio Kootwijk in cooperation with the Forestry Commission (Staatsbos-beheer). Examples of the involvement of people with dementia include helping to maintain the countryside and helping to paint and clean different buildings in the community.

**3.2.3 Proactive approaches to assessment and diagnosis**

Another option to facilitate an earlier diagnosis of dementia is population-level dementia screening of all individuals who are over a certain age in primary care (Phillips et al., 2011). However, this practice is not currently recommended due to the risk of false positives and the consequent economic cost to the health system and distress for people wrongly diagnosed. Other proactive approaches to assessment and diagnosis include case-finding and incentivising diagnosis.

Participating organisations were asked whether GPs in their countries were given incentives that would encourage the timely diagnosis of dementia. Most of the participating countries believed there were no such measures in their country. Two examples of countries where incentives exist are the Netherlands and the UK.

**BOX 3: GP incentives: Dementia Enhanced Service and Quality and Outcomes Framework in the UK**

It is estimated that less than half of people with dementia receive a diagnosis and there are wide variations across the country (Alzheimer's Society, 2014).

The National Health Service England published plans for a new enhanced service "for take up by GPs as part of the GP contract to reward practices for having a proactive case finding approach to the assessment of patients who may be showing the early signs of dementia". The Dementia Enhanced Service, part of the Directed Enhanced Service (DES), is designed to "reward GP practices for undertaking a proactive approach to the timely assessment of patients who may be at risk of dementia". This means that the GP makes an "opportunistic offer of assessment" for dementia to a group of pre-defined patients that are considered to be at a higher risk of developing dementia. This applies to situations where the GP considers it clinically appropriate to make such an offer and where the patients agree to it.

In addition, the Quality and Outcomes Framework (QOF) is a voluntary incentive for GPs. It includes three indicators for dementia: DEM1 incentivises GPs to keep a register of people with dementia who use their practices, DEM2 relates to the percentage of people with dementia whose care has been reviewed in a face-to-face review during the year and DEM3

<sup>13</sup> For example Belgium, Denmark, Ireland, Italy, Norway and Sweden.

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is the number of newly diagnosed patients that had undergone a number of diagnostic tests – e.g. calcium, glucose, B12 and folate levels, etc. Only two of these indicators apply in Scotland (DEM2 and DEM3) and Wales (DEM1 and DEM2).

Participating countries were invited to describe any other interventions or policies that in their view, could positively impact on the timely diagnosis of dementia in their country. In Denmark and in the Netherlands, some municipalities organise yearly home visits to older people by a health professional. Similarly, in Finland, every year a different cohort of older adults is selected for a preventive home visit (e.g. all people that have turned a particular age). In these visits, among other health aspects, the person's cognitive functioning can be assessed. In Denmark, the person has to give consent for these visits and the person has to be 75 years old or over. Geographical variations in the provision of these visits were reported in Finland and in the Netherlands.

In Monaco, any person over the age of 60 can benefit from memory tests at the Gerontological Coordination Centre. In Turkey, some clinics offer check-up visits for older people where their mental health can be assessed; nevertheless, this practice is not available for the whole population.

Some countries referred to the opportunities for detecting dementia symptoms when the person presents to the health system for a different condition. In Scotland, ad hoc short-term localised initiatives had in the past offered memory screening widely, primarily to people over 65 who were presenting to the National Health Service to receive for example their annual flu inoculation. Similarly, in Denmark, after the age of 70, all driving licenses have to be renewed in the GP surgery; this testing includes two memory tests (word retrieval, watch drawing test). New certificates are needed at the age of 74 and every other year until the age of 80. After the age of 80, it has to be renewed every year. This may be another opportunity to identify signs of dementia in primary care.

In Sweden, some GPs offer online memory tests for people who are concerned about their memory. Printed information about how to seek help if a person is worried about his/her memory is also often available in primary care surgeries.

Some countries described programmes or initiatives run by the Alzheimer's association that are aimed at identifying symptoms of dementia or people at risk and to promote a timely diagnosis. Box 4 describes an example of these initiatives.

### **BOX 4: Brain health promotion in Finland**

The MEVA project (2011-2014) aims at making brain health promotion a permanent process in primary health care. Primary health care professionals are trained to identify people at increased risk of dementia with the help of the dementia risk score. In addition, participating health professionals and the project team will develop guidelines for lifestyle counselling. This project is coordinated by Pirkanmaan Muistiyhdistys ry (member of Alzheimer Society of Finland).

### **3.2.4 Structural factors**

In Latvia and in Romania, setting up a memory clinic in the country had importantly contributed towards the timely diagnosis of dementia. In Jersey, the health and social care is currently under reconfiguration and this was perceived as something that will ultimately contribute to the timely diagnosis of dementia in the country.

## **3.3 Getting a diagnosis: the referral pathway**

### **3.3.1 Dementia and primary care**

For most people their GP is the gateway to diagnosis. General practice is usually the first point of contact for people who have memory concerns and/or their families (Manthorpe, et al. 2011; Fox et al., 2013). Nevertheless, primary care is not the only place where concerns might be noticed or raised. People experiencing memory concerns may live in a long-term care facility or symptoms may be identified when receiving care in an acute setting (Brooker et al., 2013). The latter places will not be addressed in this report.

### 3.3.1.1 Gatekeeping role<sup>14</sup>

In around two thirds of the participating countries, GPs play a gatekeeping role in diagnosis<sup>15</sup>. Within the public health system, people who are experiencing memory changes do not have direct access to secondary care. They need a referral from their GP to get access to a specialist. Typically, in these cases the GP does an initial cognitive assessment and rules out other treatable conditions and then refers them for specialist assessment if dementia is suspected<sup>16</sup>.

In Poland, a referral is needed for neurologists and geriatricians but not for psychiatrists. In Switzerland, referrals to a memory clinic have to be made by a GP; nevertheless, for visiting a specialist doctor, sometimes self-referrals are acceptable.

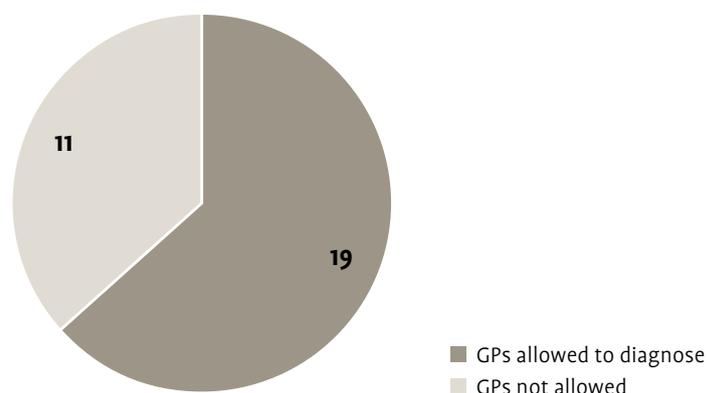
In nine of the participating countries<sup>17</sup>, within the public health system, people with memory concerns have the option to see the GP or to self-refer to a specialist.<sup>18</sup>

### 3.3.1.2 Can GPs diagnose dementia?

In almost two thirds of the participating countries<sup>19</sup> GPs are allowed to diagnose dementia. However, in five out of these 19 countries<sup>20</sup>, the national organisation stated that this is not a common practice or that GPs are encouraged to refer people with suspected dementia to a specialist service. A national survey in the Netherlands (2013) indicated that whilst GPs can diagnose, in practice only 7% of the diagnoses are made by a GP. In addition, whilst in some countries it is possible for the GP to diagnose, the person has to be seen by a specialist in certain situations, for example if anti-dementia medication is required or has to be reimbursed (e.g. Denmark).

In eleven of the participating countries<sup>21</sup>, GPs are not allowed to make a diagnosis of dementia. In these cases, if a person with memory complaints presents to their practice, the GP is expected to make the initial assessment and, if clinically necessary, to refer the person to a specialist.

Figure 2: Are GPs allowed to diagnose?



<sup>14</sup> In this section information from Cyprus is missing.

<sup>15</sup> Belgium (Flemish region), Bulgaria, Denmark, Finland, France, Ireland, Italy, Jersey, Latvia, Lithuania, Monaco, Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland and UK.

<sup>16</sup> In some countries, as for example Lithuania and Portugal, whilst a referral from a GP is required to access a specialist doctor in the public system, people with memory concerns can access a specialist doctor directly for a fee (private system).

<sup>17</sup> Austria, Belgium (Walloon region-Brussels), Croatia, Czech Republic, Germany, Greece, Luxembourg, Malta and Turkey.

<sup>18</sup> In some countries, e.g. Malta, people with memory concerns can also self-refer to a specialist in the private sector (apart from the public one).

<sup>19</sup> Austria, Croatia, Cyprus, Denmark, Finland, Germany, Greece, Ireland, Jersey, Latvia, Luxembourg, Malta, Netherlands, Norway, Poland, Sweden, Switzerland, Turkey and UK.

<sup>20</sup> Cyprus, Finland, Malta, Netherlands and UK

<sup>21</sup> Belgium, Bulgaria, Czech Republic, France, Italy, Lithuania, Monaco, Portugal, Romania, Slovenia and Spain.

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### 3.3.1.3 When does the GP diagnose?

Eight (out of 19)<sup>22</sup> countries did not respond to this question.

GPs' characteristics (i.e. level of clinical competency and specialism and attitude to diagnosis and referral)<sup>23</sup>, as well as, the stage at which dementia is diagnosed and the complexity of the condition<sup>24</sup>, are relevant factors that might determine if the person is diagnosed at primary or secondary care. Examples provided of people diagnosed in primary care, include very old or frail people, simple cases or people in advanced stages of dementia.

Conversely, the person is generally referred on to a specialist for the purpose of diagnosis if a differential diagnosis is needed; the person is younger than 65 years old; presents atypical symptoms, atypical progression, or other conditions that are considered as complex.

### 3.3.2 Secondary care: specialist doctors involved in diagnosing dementia

The key specialist doctors involved in the diagnosis of dementia are neurologists, psychiatrists (often old age psychiatrists -OAP- or neuropsychiatrists) and geriatricians. The literature suggests that the most common specialist doctors to diagnose dementia in Europe are neurologists (Brooker et al., 2013).

In most participating countries, neurologists, psychiatrists and geriatricians are equally qualified to diagnose dementia. The decision on which specialist to refer to may be based on the individual with memory concerns and/or the GP's preferences; availability and geographical location; type of dementia; or age of the person.

According to the national organisations in Bulgaria, Finland, Greece and Monaco, neurologists have a leading role in diagnosing dementia. In Belgium, Ireland and Norway, people with young onset dementia are typically diagnosed by a neurologist. In the UK, neurologists carry out brain scanning and can have a role in diagnosing if part of a multidisciplinary team. In Scotland, complex cases might be referred on to a neurologist.

OAPs and geriatricians have a leading role in diagnosis in the UK and Ireland. In these countries, existing memory clinics are, in their majority, consultant-led (either by an OAP or a geriatrician) (Cahill, O'Shea and Pierce, 2012).

In three countries (Bulgaria, Croatia, Cyprus), the OAP/psychiatrist is the specialist of choice for cases with predominant neuropsychiatric symptoms. In Croatia, a trend towards people with young onset dementia being diagnosed by an OAP has been observed.

Ten countries reported that there were no<sup>25</sup> or very few<sup>26</sup> geriatricians in their country. Where the geriatrician role exists, this specialist tends to diagnose when there are comorbidities or when the geriatrician is already treating the person for a different condition (Finland, Germany, Romania). In Lithuania, geriatricians can diagnose dementia but consultation with a psychiatrist or neurologist is required.

Finally, in 25 countries memory clinics (MC) or services that include a multi-disciplinary team (MDT) are also involved in the assessment and diagnosis of dementia. Whilst in some countries most individuals are seen in these clinics, in others, only the most complex cases, people younger than 65, people with mild cognitive impairment (MCI) and rare dementias are referred to such specialised services. See Table 4 for details.

Table 4: Frequency of people with suspected dementia referred to MC or MDT

Always or always if available:	Monaco, Bulgaria, Denmark, Finland, Ireland, Latvia, Portugal, Slovenia, Spain.
Complex cases:	Belgium, France, Germany, Jersey, Netherlands, Norway, Poland, Romania, Sweden, Switzerland, UK.
Information missing:	Austria, Croatia, Italy, Lithuania, Luxembourg.

<sup>22</sup> In this section, only the 19 countries where GPs are allowed to diagnosed are considered.

<sup>23</sup> UK and Ireland. <sup>24</sup> Croatia, Denmark, Poland, Scotland and Switzerland.

<sup>25</sup> Bulgaria, Croatia, Cyprus, Jersey, Portugal, Slovenia.

<sup>26</sup> Sweden, Latvia, Greece, Poland.

Diagram 2: Example of Pathway (I): Diagnosis at secondary care

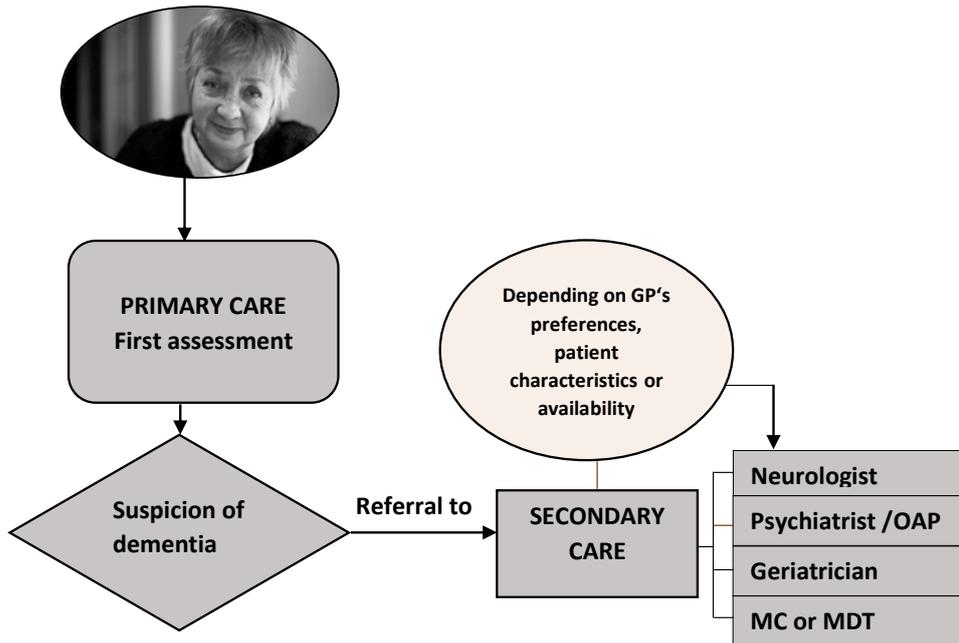


Diagram 3: Example of Pathway (II): Diagnosis either at primary or secondary care

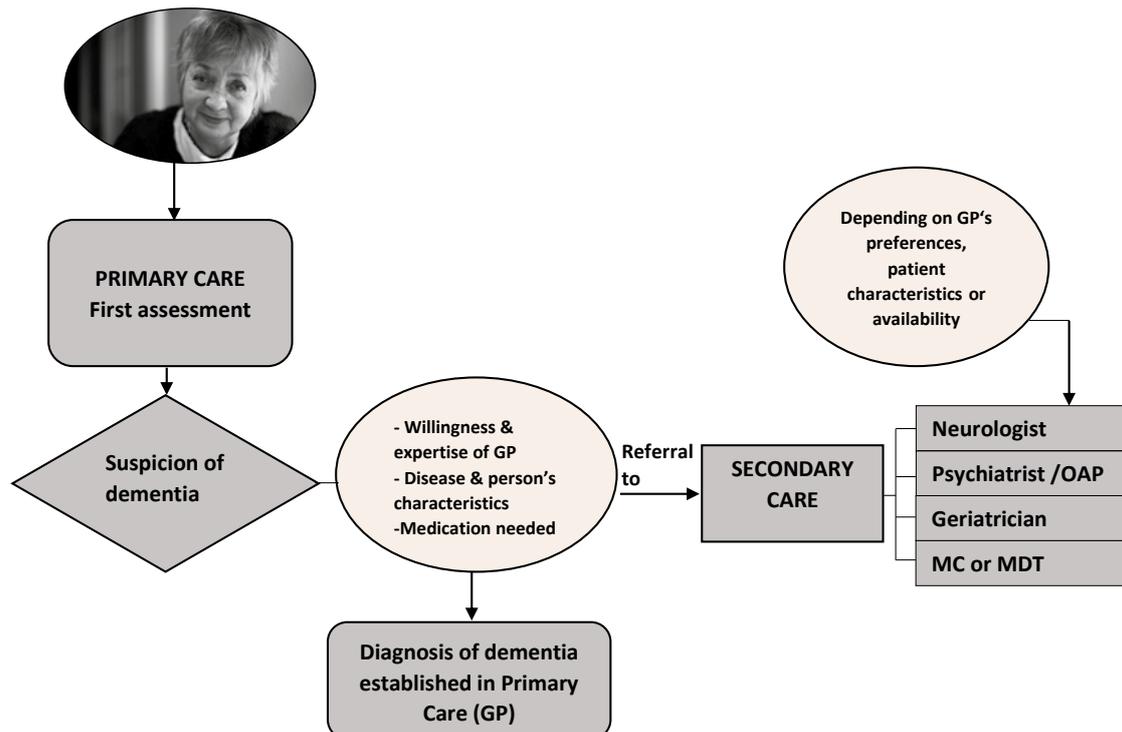
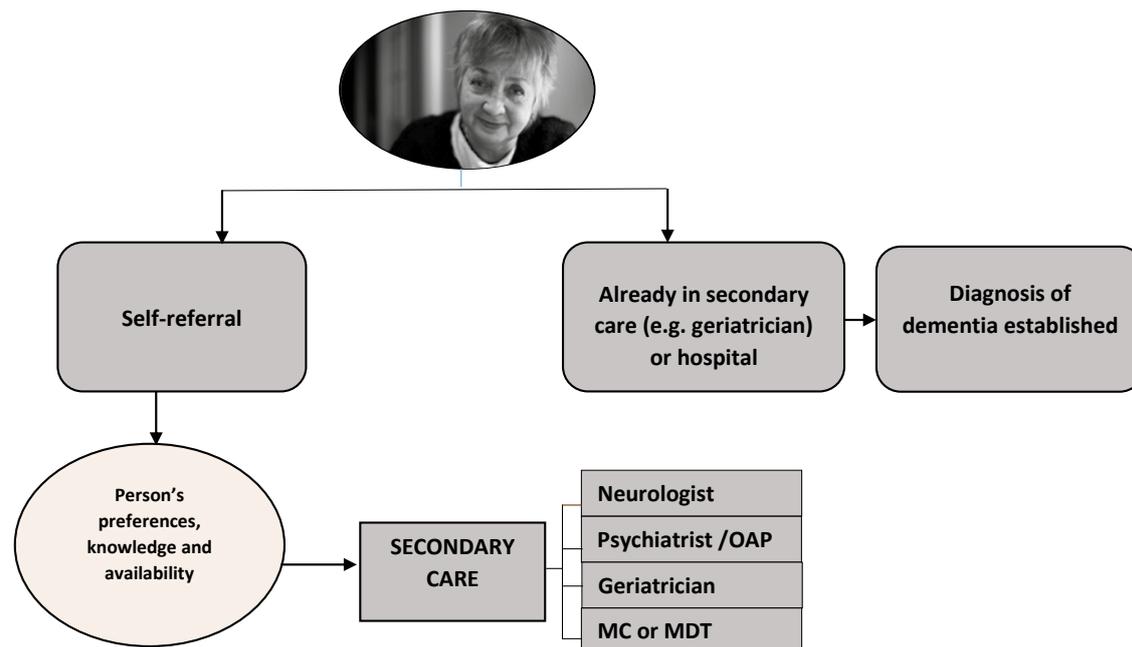


Diagram 4: Example of pathway (III): Diagnosis by self-referral or other health professionals



### 3.3.3 The primary-secondary care interface

Appropriate collaboration and communication between primary and secondary care have been identified as important elements of good quality care (Koch and Iliffe, 2010; Yaffe et al., 2008). In almost two thirds of the participating countries<sup>27</sup>, once the diagnosis has been established, the GP is routinely informed about the clinical diagnosis and, whenever appropriate, about the medical treatment. In some countries, information about the diagnosis is only routinely sent to the GP when the person is diagnosed in a hospital or memory clinic (Austria, Latvia). In Latvia, GPs of people diagnosed in an outpatient service can request this information to be sent to them.

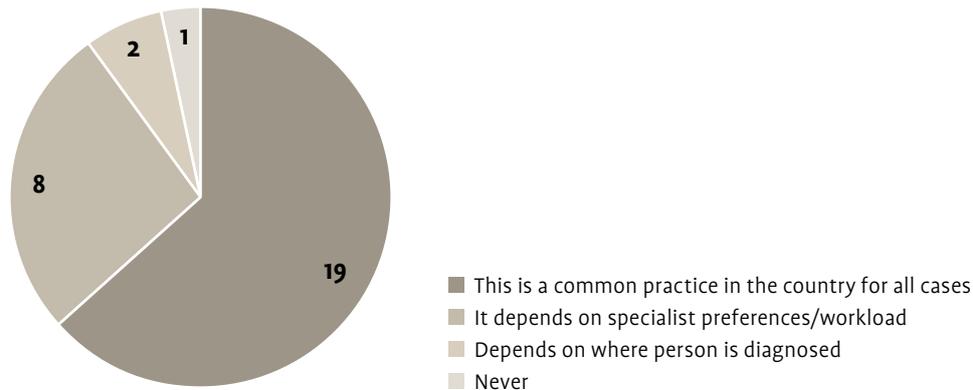
Eight participating countries<sup>28</sup> reported that this practice often depends on the specialist's own preferences or workload. In Bulgaria, GPs are not routinely informed by the specialist about the diagnosis and treatment of their patients.

The implementation of electronic medical records systems was pointed out as a factor contributing to the effective communication between primary and secondary care. Nevertheless, in some countries, such systems may not have been developed in the whole country (e.g. Poland). Another drawback, highlighted by Cyprus, is that in their country this only applies to people who are seen in primary and secondary care within the public system.

<sup>27</sup> Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Ireland, Jersey, Lithuania, Monaco, Netherlands, Norway, Romania, Spain, Sweden, Switzerland and UK.

<sup>28</sup> Greece, Italy, Luxembourg, Malta, Poland, Portugal, Slovenia and Turkey.

Figure 3: Feedback about diagnosis to GP



### 3.4 Disclosure of diagnosis

There is a growing body of literature suggesting that most people with dementia want to be told their diagnosis in a clear straightforward way (Dungen et al., 2014; Robinson et al., 2011; Mastwyk et al., 2014; Lee, Roen and Thornton, 2014). 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 psychological harm. In addition, several primary care physicians have reported that disclosure of the diagnosis to the person is one of the most difficult areas in dementia management (Illife et al., 2009). Nevertheless, it is now suggested that, whilst initially the person may feel upset and shocked, these feelings tend to subside after a period of time and in fact, diagnosis may help the person to better understand the condition, to attach meaning to his/her experiences and to find ways of coping with the disease (Lee et al., 2014). In addition, disclosure of diagnosis may help people to plan for their future, access treatment options and should be considered as a right. There is also evidence that, whilst some people with dementia will not be able to retain and recall their clinical diagnosis, often they will be able to retain other information provided about it (Manthorpe et al., 2011). A survey involving a large sample of carers in five European countries revealed that half of the carers felt that, at the time of diagnosis, they had received inadequate information on the disease, disease progression and drug treatments (Georges et al., 2008).

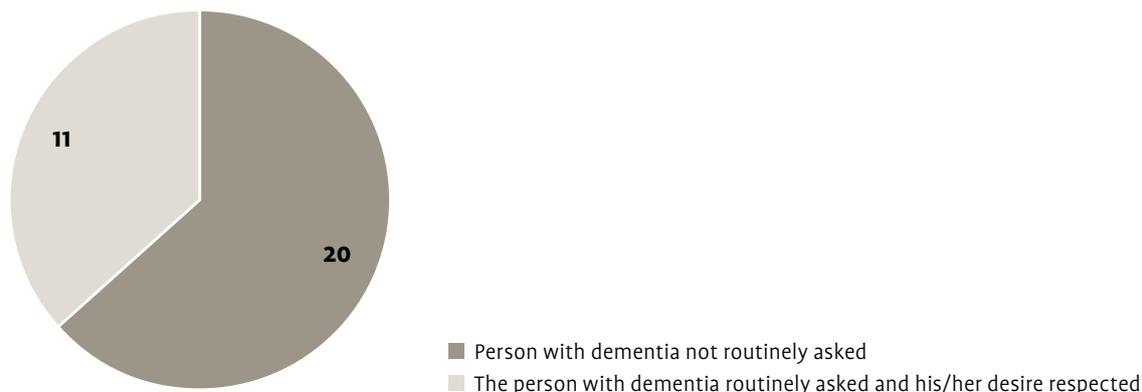
In eleven<sup>29</sup> countries, at the time of assessment, the person with dementia is routinely asked about his/her desire to know the diagnosis and his/her wishes are respected. In Denmark and Scotland, the family can only be informed about diagnosis if the person with dementia gives consent. In Belgium, according to the law on patients' rights, the individual should be consulted about his/her wishes. In some of these eleven countries<sup>30</sup>, it was pointed out that, often in practice, it was the doctor who ultimately decided to whom diagnosis should be disclosed.

<sup>29</sup> Belgium, Czech Republic, Denmark, Finland, France, Germany, Jersey, Netherlands, Scotland, Sweden and Switzerland. Please note that in the UK only Scotland reported this option.

<sup>30</sup> Czech Republic, France, Germany and Switzerland.

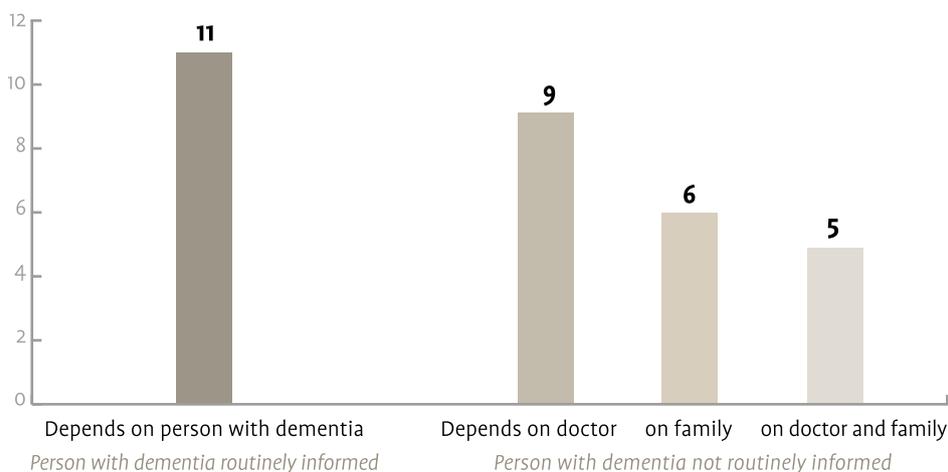
## National care pathways for people with dementia living at home

Figure 4: Person with dementia routinely informed about diagnosis<sup>31</sup>



Overall, in two thirds of the participating countries (20), the person with dementia is not routinely informed about his/her diagnosis. In these countries, disclosure of diagnosis to the person with dementia might depend on the family willingness (6)<sup>32</sup>, doctors' own criteria or preferences (9)<sup>33</sup> or a combination of both (5)<sup>34</sup>. Five countries<sup>35</sup> reported that when this decision is made by the doctor, it is most often the family who is informed.

Figure 5: To whom the diagnosis of dementia is disclosed



In most participating countries, the diagnosis of dementia is disclosed by the doctor who established the diagnosis. In Greece, it was pointed out that, in fact, it is often the family who discloses the diagnosis to the person with dementia.

Figure 6 shows the type of information that people with dementia and/or their families are more likely to receive, at the time of diagnosis, from the specialist doctor and GP<sup>36</sup>. Information about dementia, its prognosis and pharmacological treatment<sup>37</sup> seem to be systematically provided to people with dementia and/or their families by the specialist doctor. It is noteworthy that, around one third of the national organisations, pointed out that the information on availability of services and Alzheimer association contact details, are not systematically provided, and reported considerable variation in practices among clinicians in their country.

<sup>31</sup> Please note that the UK and Scotland provided different responses for this question.

<sup>32</sup> Bulgaria, Croatia, Greece, Ireland, Italy, and Slovenia.

<sup>33</sup> Cyprus, Luxembourg, Monaco, Norway, Poland, Portugal, Romania Turkey and UK (not Scotland).

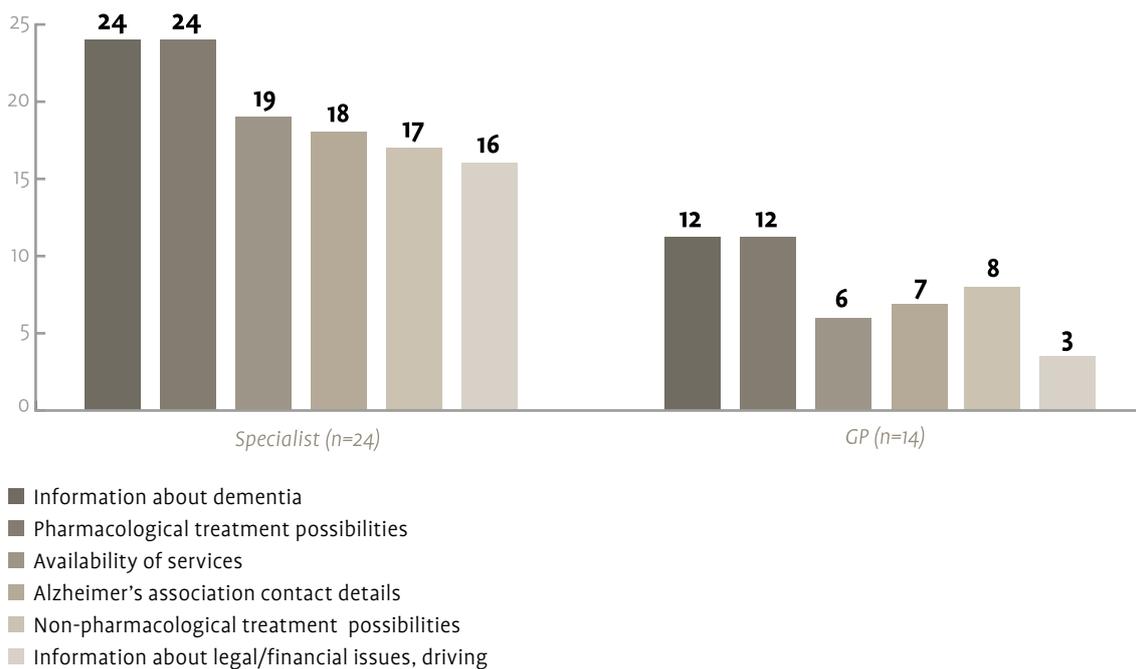
<sup>34</sup> Austria, Latvia, Lithuania, Malta and Spain.

<sup>35</sup> Malta, Latvia, Portugal, Poland and Turkey.

<sup>36</sup> Please note that the UK and Scotland provided different responses for this question.

<sup>37</sup> Six countries (Belgium, Ireland, Luxembourg, Spain, Sweden, and UK) left blank this question or felt practices in the country significantly varied and could not provide an answer. In the case of information provided by GPs, the number of missing responses increased noticeably (16). Many countries felt this question was not relevant for their country, as information is mainly provided by the specialist doctor, and the GP only provides information if requested by the person/family.

Figure 6: Information provided to people with dementia and/or family by doctor



### 3.5 Pharmacological treatment of dementia and ongoing review of anti-dementia medication

Dementia remains an incurable condition and its management requires both pharmacological and non-pharmacological (psychosocial) interventions (Farlow, Miller and Pejovic, 2008). Whilst the treatment of dementia remains a challenge, a number of drugs have been approved to treat some forms of dementia (mainly Alzheimer's disease).

Current available approved pharmacological treatments include three second generation cholinesterase inhibitors (ChEIs) – donepezil, rivastigmine and galantamine – and the NMDA (N-methyl-D-aspartate) receptor antagonist memantine. Other pharmacological therapies have also been investigated as treatments for dementia, nevertheless to date there is insufficient evidence to support their efficacy, and thus they are not recommended for routine use (Singh and O'Brien, 2009).

ChEIs are the mainstay of treatment for mild to moderate forms of Alzheimer's disease (AD) and memantine is the approved agent for the treatment of moderate to severe AD (Overshott and Burns, 2005; Lleo, Greenberg and Growdon, 2006; Farlow, Miller and Pejovic, 2008). To date, the added benefit of using combination therapy (memantine and ChEI) remains controversial (Howard et al., 2012).

#### 3.5.1 Access to anti-dementia drugs

##### 3.5.1.1 Availability of anti-dementia drugs

All participating countries reported that memantine is available in their country. The three ChEIs are available in 27 of the 30 participating countries. In Croatia and the Netherlands, two of the three ChEIs are available. In Latvia, only "ipidacrin" (a first generation ChEI) is available.

In terms of reimbursement of anti-dementia drugs, in 24 countries the four drugs can be reimbursed<sup>38</sup>. In addition, in the Netherlands, the three available drugs are reimbursed. In Latvia, none of the drugs are reimbursed. In Malta, only donepezil is reimbursed. In Croatia and Lithuania, two drugs are reimbursed (one ChEIs and memantine). In Poland, three out of the four drugs are reimbursed.

<sup>38</sup> Please note that the percentage of reimbursement can vary among countries. Please see Dementia in Europe Yearbook 2012 for further detail.

## National care pathways for people with dementia living at home

Table 5: Availability and reimbursement of anti-dementia drugs

Number of anti-dementia drugs	Availability	Reimbursement
0	-	Latvia
1	-	Malta
2	Latvia	Croatia, Lithuania
3	Croatia, Netherlands	Netherlands, Poland
4	All the other countries	All the other countries

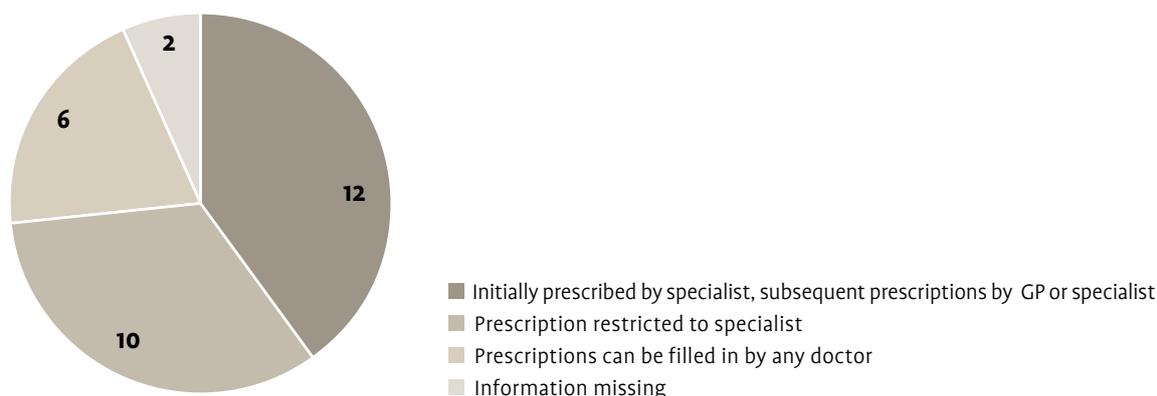
### 3.5.1.2 Prescribing doctor<sup>39</sup>

Twelve participating countries<sup>40</sup> described a model of shared care where treatment with ChEIs and memantine has to be initiated by a specialist and can be continued in primary care. In these countries, anti-dementia drugs are initially prescribed by a specialist and subsequent prescriptions may be written by the GP or the specialist.

In ten countries<sup>41</sup> all decisions regarding treatment (i.e. initiation, continuation, and discontinuation) should be taken by a specialist and only the specialist can prescribe the drugs. In some countries, such as Malta and Portugal, this only applies if reimbursement of the drug is required. In these cases, both initial and subsequent prescriptions have to be written by the specialist<sup>42</sup>. In Luxembourg, whilst not strictly limited to specialists, this is the most common practice.

Six participating countries<sup>43</sup> reported no restrictions regarding the doctor who can make decisions about treatment and prescribe the anti-dementia drugs. Consequently, in these countries any doctor (including GPs) can prescribe anti-dementia drugs at any time (i.e. both first and subsequent prescriptions).

Figure 7: Prescription of anti-dementia drugs



### 3.5.1.3 Severity of the disease and Mini Mental State Examination (MMSE)<sup>44</sup> limits<sup>45</sup>

In eighteen countries<sup>46</sup> the prescription of anti-dementia drugs is restricted by the severity of the disease, particularly if reimbursement is required. Typically, ChEIs are available to people in the mild to moderate stages of Alzheimer's disease and memantine to people in the severe stages<sup>47</sup> or moderate and severe<sup>48</sup>. In other countries, only people with specific upper or lower MMSE scores qualify for reimbursement of the drugs. Cut-off MMSE scores are not consistent through Europe<sup>49</sup>.

<sup>39</sup> Information about this section is missing for two countries (Bulgaria and Latvia).

<sup>40</sup> Austria, Croatia, Cyprus, Denmark, Finland, France, Greece, Italy, Netherlands, Turkey, UK and Lithuania.

<sup>41</sup> Belgium (Walloon region and Brussels), Czech Republic, Luxembourg, Malta, Monaco, Poland, Portugal, Romania, Slovenia and Spain.

<sup>42</sup> In Malta, as only donepezil can be reimbursed, the other three drugs can be initiated, continued and discontinued by any doctor.

<sup>43</sup> Germany, Ireland, Jersey, Norway, Sweden and Switzerland.

<sup>44</sup> The Mini Mental State Examination (MMSE) (Folstein et al., 1975) is a widely used and internationally validated screening test for cognitive impairment in older adults.

<sup>45</sup> Information about this section is missing for two countries (Bulgaria and Monaco).

<sup>46</sup> Austria, Belgium, Cyprus, Czech Republic, France, Germany, Italy, Luxembourg, Lithuania, Malta, Netherlands, Norway, Poland, Romania, Slovenia, Switzerland, Spain and UK.

<sup>47</sup> For example, in the UK; nevertheless, memantine can be also prescribed to people unable to tolerate ChEIs in the UK.

<sup>48</sup> For example in Germany and Lithuania.

<sup>49</sup> For detailed information on MMSE scores limits for each country, see the Dementia in Europe Yearbook 2012.

### 3.5.1.4 Generic version of the drugs

In several countries, the criteria for prescription described in the preceding sections only apply when reimbursement of the drug is required. Since generic (cheaper) version of these anti-dementia drugs are now available, clinicians may choose not to follow these criteria as cost is less of an issue.

### 3.5.2 Ongoing review of anti-dementia medication

There is some consensus in the literature that pharmacological treatment should be continued when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms (NICE, 2011). Participating countries were asked about the timing of patient medication reviews in their country, the professional that undertakes such reviews and discontinuation decision-making.

#### *Timeframes and doctor responsible for review of anti-dementia medication*

Typically, in most countries the drug is reviewed shortly<sup>50</sup> after prescription and then regularly, most often every six months or yearly. Whilst the timeframe for review is specifically set in some countries, others have considered that there is insufficient evidence to define an optimal review time, and that the individual should be monitored regularly, but that the specific timings for patient reviews should be addressed by the treating clinician<sup>51</sup>.

#### **BOX 5: National Institute for Health and Care Excellence - NICE 2011**

“(…) patients who continue on the drug should be reviewed regularly using cognitive, global, functional and behavioural assessment.”

Seven countries<sup>52</sup> reported that currently there are no specific guidelines for the timing of patients' reviews with decisions being made at the discretion of the treating doctor. According to the Dutch association, the timing of reviews will be addressed shortly in their country.

In Bulgaria, according to the national organisation, the medication is not routinely monitored.

The information about the doctor that monitors the anti-dementia medication has been already addressed in section 3.5.1.2 (see Figure 7).

#### 3.5.2.1 Discontinuation<sup>53</sup>

In the participating countries, by and large the decision to stop the anti-dementia medication is taken by the prescribing/ treating clinician. The national organisations from Croatia and the UK stated that the family may also, for different reasons, in some cases, take this decision.

In eight countries<sup>54</sup> the drug is no longer reimbursed and discontinued once the pre-defined low MMSE score is reached<sup>55</sup>. In Cyprus, state pharmacies have to be informed of the MMSE score of the person with dementia taking the drug every six months.

Other countries, such as France and the UK, have highlighted the risks of using the MMSE as a single criterion for continuation decision making and have framed this decision in a wider, but also more abstract, concept – i.e. “benefits are no longer evident” or “where the drug is considered to be having a worthwhile effect”. In the UK, it is recommended that in addition to the use of standardised scales, the “carer’s views on the patient’s condition at follow-up should be sought”. In a similar vein, in some countries<sup>56</sup> the drug is discontinued when it no longer benefits the person; and in Romania and Slovenia when the person is at the end stage of dementia.

<sup>50</sup> This first review can be after 1 month, after 3-4 months or after 6 months.

<sup>51</sup> For example Denmark, UK and France.

<sup>52</sup> Ireland, Latvia, Netherlands, Norway, Poland, Romania and Spain.

<sup>53</sup> Information is missing for six countries: Austria, Belgium, Bulgaria, Jersey, Monaco and Netherlands.

<sup>54</sup> Cyprus, Czech Republic, Italy, Luxembourg, Lithuania, Malta, Norway and Switzerland.

<sup>55</sup> In Lithuania the MMSE limits are applied for the discontinuation of ChEIs but not for memantine.

<sup>56</sup> Croatia, Denmark, Finland, Germany and Sweden.

### BOX 6

#### Haute Autorité de Santé - HAS France

“The discontinuation of medication should not be based exclusively on MMSE score, age or institutionalisation, but if benefits for the patient are no longer evident and taking into consideration the context on a case by case basis.”

#### National Institute for Health and Care Excellence - NICE UK

“The Committee recognised the difficulties of using MMSE score alone to assess the severity of Alzheimer’s disease and the response to AChE inhibitors. The Committee agreed that cognitive scales alone such as the MMSE are not always appropriate for assessing the severity of dementia.”

Finally, seven countries<sup>57</sup> reported that in the absence of guidelines in their country, clinicians are using their own discretion or clinical judgement on a case by case basis.

### 3.6 Ongoing assessment of dementia

One third of the countries<sup>58</sup> reported that the ongoing evaluation of dementia is most often done by the specialist doctor. In Malta, whilst there is no approved dementia protocol for follow-ups, following their diagnosis in a state-run hospital, individuals with dementia can be given a follow-up appointment by the specialist. This occasionally happens in the private sector as well, where the GP or specialist would advise the person with dementia to arrange for a follow-up visit in order to assess disease progression and medication.

In Bulgaria, most people with dementia are not followed up. Those who are prescribed and reimbursed an anti-dementia medication should be evaluated every six months, but there are important barriers for access, as there are only a few specialised centres in the country.

Almost two thirds of the participating countries<sup>59</sup> reported a mixed approach to the ongoing evaluation of dementia. In these countries, after diagnosis, and if appropriate, establishment of the medical treatment, some people with dementia are discharged from the specialist doctor and monitored in primary care (GPs) while others are monitored by the specialist.

Seven countries<sup>60</sup> reported that, if there is no change in the severity of the person’s condition, the specialist may discharge the patient from the service entirely into the care of the GP. In these countries the GP is the doctor that most often monitors the person with dementia. Cases considered as complex (e.g. people under the age of 65, patients with learning disabilities, behavioural and psychological symptoms of dementia [BPSD], special types of dementias, minority groups) are followed-up by the specialist doctor. The decision may be also dependent on the resources available to the specialist (Ireland, Slovenia, Switzerland).

In Austria, Poland, and Germany the person with dementia/family can decide where the person will be monitored. In Poland, people living in rural areas with limited access to resources often perceive the GP as the most convenient choice.

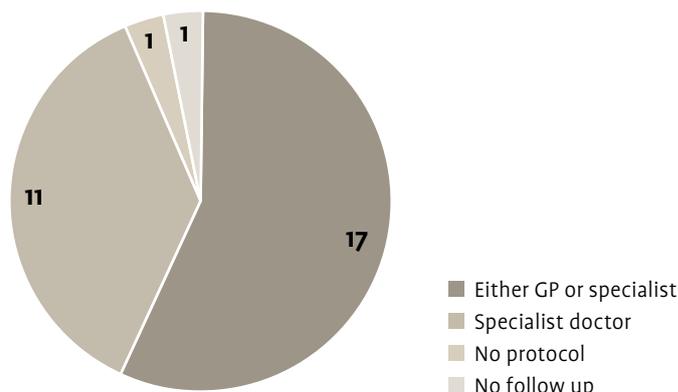
<sup>57</sup> Greece, Ireland, Latvia, Poland, Portugal, Spain and Turkey.

<sup>58</sup> Belgium (only Walloon region and Brussels), Croatia, Cyprus, Czech Republic, France, Latvia, Monaco, Portugal, Romania, Spain and Italy.

<sup>59</sup> Austria, Denmark, Finland, Germany, Greece, Ireland, Jersey, Lithuania, Luxembourg, Netherlands, Norway, Poland, Slovenia, Sweden, Switzerland, Turkey, UK. Also, in the Flemish part of Belgium.

<sup>60</sup> Denmark, Finland, Ireland, Netherlands, Norway, Slovenia and UK.

Figure 8: Doctor responsible for the ongoing assessment of dementia



In around half of the countries, people with dementia attend a follow-up visit one to three times a year (see Table 6). In Sweden, the National Board of Health and Welfare recommends that people with dementia should be followed up at least once a year, in Denmark a yearly visit with the GP is compulsory and, in Romania, a visit after six months is recommended.

People with young onset dementia, people with mild cognitive impairment, people presenting BPSD or rapid decline, or with limited social support, are likely to be monitored more often. In Belgium (Walloon region and Brussels), Greece, Poland and Turkey it was reported that the frequency of visits (if monitored by a specialist) may decrease in cases of severe dementia.

Table 6: Frequency of visits

1 to 3 visits per year	Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, France, Greece, Ireland, Italy, Portugal, Slovenia, Sweden, UK (not Scotland)
At the discretion of the doctor	Finland, Jersey, Lithuania, Luxembourg, Norway, Poland, Romania, Switzerland, Spain, Turkey
Decided with the person with dementia	Scotland
Missing	Germany, Malta, Netherlands, Latvia

### 3.7 Main barriers and challenges to diagnosis

Participating countries were invited to identify the main challenges and barriers that people with dementia and their families face in relation to the diagnosis of dementia in their country.

According to the participating countries, the most common barriers to the diagnosis of dementia are system-related (24 countries). Barriers related to primary care (GPs) were also identified in 16 countries. Finally, 15 countries highlighted one or more factors in relation with the person and/or society<sup>61</sup>.

In regards to the system-related barriers, the most commonly identified obstacle for the diagnosis of dementia is the lack of specialist doctors in the country and the long waiting lists to see a specialist doctor<sup>62</sup>.

Other relevant system-related factors included the variable provision<sup>63</sup> of and access to diagnostic services in the country<sup>63</sup>; and the lack of guidelines and of clear pathways before and after diagnosis that could assist health professionals in their decision-making and people with memory concerns and their families in navigating the system<sup>64</sup>.

<sup>61</sup> See table 7 for further detail about countries.

<sup>62</sup> Croatia, Bulgaria, Czech Republic, Denmark, Slovenia, Turkey, Cyprus, Finland, Italy, Germany, Portugal, Slovenia, Spain and UK.

<sup>63</sup> Austria, Belgium, Cyprus, Croatia, Finland, Lithuania, Sweden and UK.

<sup>64</sup> Belgium, Germany, Jersey, Lithuania, Luxembourg, Malta, Netherlands and Poland.

## National care pathways for people with dementia living at home

Training and expertise in recognising and managing dementia may be another relevant factor contributing to missed or delayed diagnosis. Finally, lack of awareness about dementia (among the public and GPs) and the social stigma attached to the disease were perceived as important obstacles to diagnosis.

Figure 9 shows all the reported challenges to the diagnosis of dementia and frequencies per topic, and Table 7 the countries that reported each barrier.

Figure 9: Main barriers to timely diagnosis

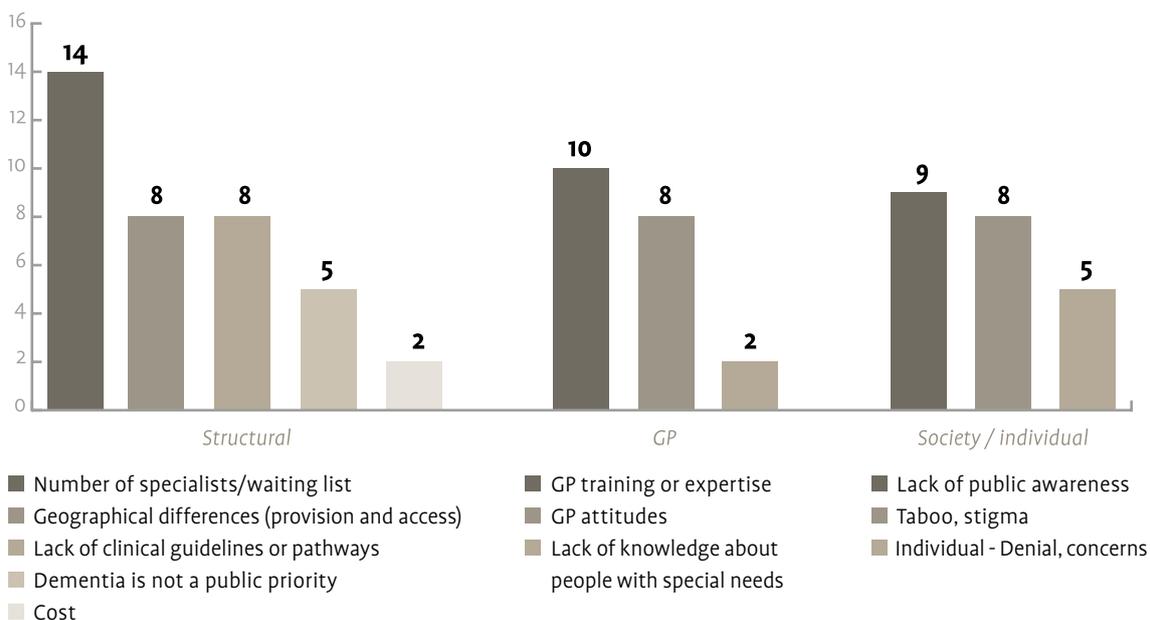


Table 7: Main barriers by country

STRUCTURAL (24 countries)		GP (16)		SOCIETY / INDIVIDUAL (15)	
Austria	Lithuania	Belgium	Portugal	Austria	Romania
Belgium (Walloon region & Brussels)	Luxembourg	Croatia	Romania	Belgium	Switzerland
Bulgaria	Netherlands	Denmark	Switzerland	Denmark	UK
Croatia	Malta	Finland	Turkey	Finland	
Cyprus	Poland	France	UK	Greece	
Czech Republic	Portugal	Germany		Ireland	
Denmark	Romania	Ireland		Jersey	
Finland	Slovenia	Malta		Lithuania	
Germany	Spain	Monaco		Malta	
Italy	Sweden	Netherlands		Monaco	
Jersey	Turkey	Norway		Poland	
Latvia	UK			Portugal	

### 3.8 Conclusions

This section has provided an overview of the different journeys to a diagnosis of dementia in 30 European countries. Relevant inequalities in regards to access to specialised care have been emphasised in the report. These inequalities include relevant differences between countries, but also make reference to large regional variations within individual countries in regards to the time and type of access to diagnostic services. This indicates that the place where the individual lives may have an important impact on the pathway to diagnosis and on the ongoing monitoring of dementia. Inequalities could also be due to the lack of clear and binding guidelines addressing the referral pathways to diagnosis and the ongoing assessment of dementia in many of these European countries. The reported information suggests that “subjective” factors, either related to the individual or to the doctor (e.g. attitudes, knowledge, etc.), often play a relevant role in the pathway that the individual will follow.

The report indicates that stigma and, a lack of information about dementia, are still perceived as relevant barriers to diagnosis in Europe. The information provided by the national organisations suggests that attempts have been made to raise awareness of dementia in Europe. Information campaigns are now widely organised in Europe and several initiatives (mostly local) to promote the timely diagnosis of dementia have been identified. Nevertheless, proactive approaches to the timely diagnosis of dementia are still not widely implemented and there is a great variation in their implementation between European countries.

In keeping with the international literature, this section has emphasised the pivotal role that GPs play in the diagnosis of dementia in Europe. Nevertheless, in several countries, irrespective of the complexity of dementia and of GPs’ skills, diagnosis and ongoing assessment of dementia are exclusively provided by specialist doctors.

The information provided by the national organisations indicates that most people with dementia might have access to pharmacological treatment of dementia, with most anti-dementia drugs now widely available. The availability of more affordable generic version of these drugs may have helped to tackle the inequalities in access to these drugs in some countries. However, guidelines about the ongoing review of medication and, in particular, of drug discontinuation, are still lacking. The report suggests that criteria for discontinuation and for reimbursement are often closely intertwined.

An issue of special concern is the limited involvement that people living with dementia may have in diagnosis. The information provided by the national organisations suggests that a number of people with dementia are still not routinely consulted about relevant decisions relating to their diagnosis, including their desire to be informed about their diagnosis.





## 4 Post-diagnostic support and care

### 4.1 Introduction

There is international consensus favouring the timely identification of dementia and for as many people as possible (Watts, Cheston and Moniz-Cook, 2013). Several advantages to the timely diagnosis of dementia have been reported and there is some evidence suggesting that with the appropriate support, living well with dementia is possible. Nevertheless, diagnosis without adequate support may not be as advantageous (Manthorpe et al., 2013; Watts et al., 2013). It is still not clear what services should be available to people with dementia after diagnosis (Watts et al., 2013).

This section outlines the pathways to post-diagnostic support and care for people living with dementia in 30 European countries<sup>65</sup>. Main topics addressed in this section include the information about psychosocial care and support provided to people with dementia at the time of diagnosis and key professionals involved in providing this information; and the assessment and ongoing review of care and support needs and the development of care plans. Aspects related to access to psychosocial support and the navigation of the care systems are also reviewed. The section concludes by identifying some of the most relevant barriers and challenges to post-diagnostic care and support in the participating countries.

### 4.2 Information pathways

Following a diagnosis of dementia, people with dementia and their relatives should be provided with appropriate information and support (Kelly and Szymczynska, 2012). The provision of high-quality information is essential for helping the individual adjust to dementia and to facilitate access to adequate support and services. Lack of information or information received in a “haphazard” fashion may hinder access to relevant services (Brodsky et al., 2005; Hansen et al., 2005).

A survey carried out in 2006 involving 1,000 carers from five European countries showed that carers often felt that the provision of information on all aspects of Alzheimer’s disease was inadequate (Georges et al., 2008). In this study, 19% of the participants received no information at the time of diagnosis, 59% were not informed about the existence of an Alzheimer’s association and 82% were given no information about available services. Likewise, other small-scale qualitative studies have shown that carers of people with dementia experience difficulties in gaining information about the support and services available to them (Robinson et al., 2009). When the quest for information is productive, it generates very positive feelings in the person and overall, people with dementia and their carers would welcome more information about available support in their local community (Georges et al., 2008; Innes, Szymczynska and Starket 2014; Robinson et al., 2009).

There is limited knowledge about the views of people with dementia on the type and nature of information they would wish to receive around the time of and after diagnostic disclosure (Manthorpe et al., 2011). Manthorpe and colleagues (2011) highlighted the need for tailored information that is “applicable to the current level of needs, rather than generic information covering a range of circumstances and levels of need” (Manthorpe et al., 2011:104).

The international literature suggests that the setting and format, as well as the time at which information is provided, are of critical importance, and that these are not always appropriate for people with dementia (Robinson et al., 2009; Innes, Szymczynska and Starket, 2014; Manthorpe et al., 2013). This body of research supports that “more time may be needed to address individual needs for information, and tailor advice in this process of ‘reflection and adaptation’, when immediate reactions to the diagnosis may have had a chance to evolve” (74:2013).

The relevance of information and advice to people with dementia and their families prior to, during, and after the diagnostic process is also highlighted in some of the national dementia strategies (Manthorpe et al., 2013). In the National Dementia Strategy for England, for instance, those who commission assessments services are expected to advise “on the immediate treatment, care and support that is needed for individuals with dementia and their carers, signposting individuals, to the appropriate services and resources”.

<sup>65</sup> Please note that the analysis of the data indicated that, for many aspects of the post-diagnostic support and care, the information from Scotland should be considered separately from the UK, as relevant differences were observed in the approach taken by each to post-diagnostic support and care. The reader is warned when Scotland is counted separately from the UK.

Participating countries were asked about the professionals or individuals who play a key role in providing information and advice about available psychosocial services, resources and entitlements to people newly diagnosed with dementia and their carers.

#### 4.2.1 Support worker role

In 13 countries<sup>66</sup> a support worker was identified as one of the main professionals providing this type of information to people with dementia and their families at the time of diagnosis. This role is often, but not in all countries, dementia specific. This support worker role receives different titles in these countries. In addition, it is not unusual to find different titles for this role within a single country (e.g. in Denmark, Finland and the UK). A detailed analysis of the exact function, role competencies and focus of support of each of these titles, and of the difference between them, was beyond the scope of this report.

##### **BOX 7: Inventory of titles of support workers in participating countries**

- Dementia adviser
- Dementia care managers
- Dementia case manager/Case manager
- Dementia coordinator/Memory coordinator
- Dementia practice coordinator
- Dementia counsellor
- Dementia navigator
- Dementia nurse
- Dementia support worker
- Dementia team
- Link worker
- Resource worker
- Pathway coordinator
- Admiral nurse
- Reference person on dementia
- Community care coordinator

In the majority of the countries, this role exists in the public sector<sup>67</sup> and in some countries also in the private and voluntary sector. These support workers also differ in regards to the organisation where they are based. In some cases, the support worker is based in the municipality, local authority or social services of the municipality (Denmark, Sweden, UK, Monaco), some are based in or linked to a health institution, e.g. memory clinic or GP surgery (Jersey, Norway), specialised network (France, Netherlands), the voluntary sector (Czech Republic, Ireland), or a combination of these (Finland, UK, Switzerland).

According to the Swiss Alzheimer association, this is a newly created role and not yet widely implemented in Switzerland. In some countries, the availability of this support worker varies across regions (Netherlands, Norway). In Sweden this role is not dementia specific (case manager) but some municipalities have provided dementia training to professionals in this role. In Monaco, the Gerontological Coordination Centre is a single desk for people over 60 and plays a key role in providing information and help to people with dementia. The centre also acts as the intermediate structure between the beneficiaries and the medical and social services.

In Denmark, at the time of diagnosis, the individual is offered to be contacted by the relevant person in the municipality for counselling. Similarly, in Scotland, all people newly diagnosed with dementia are entitled to a minimum of a year's worth of post-diagnostic support coordinated by a link worker. The post-diagnostic target is designed to give people time and space to access services and receive high quality support in a way that meets their individual needs over the course of a year. It recognises that a diagnosis of dementia can have a huge impact on individuals, carers and families and that coming to terms with a diagnosis and what it will mean for an individual and their loved ones can take time and expert support. GPs can refer people with dementia to these link workers or the person can self-refer his/her self.

<sup>66</sup> Belgium, Czech Republic, Denmark, Finland, France, Ireland, Jersey, Monaco, Netherlands, Norway, Sweden, Switzerland and UK.

<sup>67</sup> In some countries like Finland and the UK, this role is sometimes outsourced to the voluntary sector, i.e. to an Alzheimer's association.

## National care pathways for people with dementia living at home

Nevertheless, in other countries where this role exists, the person is not systematically contacted or referred to this professional. People with dementia and their family are expected to contact this professional if or when they need information.

### BOX 8:

#### Denmark

Denmark has educated dementia coordinators for the last 20 years. The dementia coordinator is a key person employed by the municipality, who is engaged in the organisation of the dementia effort. In addition to being an advisor to the person with dementia and his/her caregiver, the dementia coordinator also supervises colleagues and students; provides training; is stimulating and inspiring; coordinates efforts in relation to treatment and care; and is a key figure in the multi-sectorial cooperation in the field of dementia.

#### Norway

Dementia teams are based in the community and collaborate with GPs in identifying and assessing people with memory concerns. Also, these teams can participate in the follow-up of people with dementia. In Norway, about half of the 430 municipalities have a dementia team. A main challenge is the variation in service implementation and care provision in the country. Nevertheless, whilst not every municipality has a dementia team and the composition of these teams varies among the municipalities, the small size of the country contributes to the good organisation of the care and support provided to people with dementia in the country. Norway is currently developing new national standards for dementia care.

The relevance of this role is also addressed in other countries that have recently launched or that are now in the process of developing a National Dementia Strategy (e.g. Malta, Luxembourg). In these countries, this role may further develop in the near future.

### 4.2.2 GPs, specialists, social workers and community nurses

In more than two thirds of the participating countries (see Table 8), GPs and specialists provide information to their patients about available social support and care in the community. However, it was highlighted that often the information provided by doctors might depend on the doctor's knowledge and expertise or on the doctor's subjective evaluation of the situation and needs of the person with dementia and his/her family.

Social workers in the community seem to also play a relevant role in the provision of information to people with dementia in 18 countries (see Table 8), in particular information about social care and available services. Nevertheless this professional typically provides this information on demand, and too often this does not happen at the time of diagnosis.

Community nurses (not dementia specific) seem to be less often the providers of information about support at the time of diagnosis, with only seven countries reporting that this was a key professional for this type of information.

Table 8: Key professionals in the provision of information by country

Name of professional	Countries
Support worker	Belgium, Czech Republic, Denmark, Finland, France, Ireland, Jersey, Monaco, Netherlands, Norway, Sweden, Switzerland, UK.
GP	Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Jersey, Latvia, Lithuania, Luxembourg, Monaco, Netherlands, Norway, Poland, Portugal, Sweden, Slovenia, Switzerland, Turkey, UK (not Scotland).
Specialist doctor	Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Finland, Germany, Greece, Ireland, Italy, Jersey, Lithuania, Luxembourg, Monaco, Netherlands, Poland, Portugal, Romania, Sweden, Slovenia, Switzerland, Turkey, UK (not Scotland).
Social Worker	Austria, Belgium, Bulgaria, Croatia, Cyprus, France, Germany, Greece, Latvia, Lithuania, Monaco, Poland, Portugal, Slovenia, Spain, Sweden, Turkey, UK.
Community Nurse	Austria, Croatia, Cyprus, Ireland, Lithuania, Poland, UK.

### 4.2.3 Voluntary sector

Almost all national organisations identified the Alzheimer’s associations in their countries as relevant sources of information about social support and care at the time of diagnosis. The association itself, peer support groups organised by the association, or volunteers trained by them, are all different channels through which information can be provided.

## 4.3 Assessment of support and care needs at the time of diagnosis

Participating countries were asked if, at the time of diagnosis, an assessment of the care and support needs of the person with dementia was undertaken and if care plans were routinely offered to people with dementia.

### 4.3.1 Assessment of care and support needs

In eight countries this type of assessment is routinely offered to all people with dementia (see Table 9), but the most common situations reported were that this assessment was not provided at all (seven countries) or that it was only provided to certain individuals (16 countries). Examples of the latter include people in need of services people diagnosed in particular places such as a memory clinic, or living in particular areas of the country. See Figure 10 and Table 9 for further details.

Figure 10: Approach to the assessment of support and care needs<sup>68</sup>

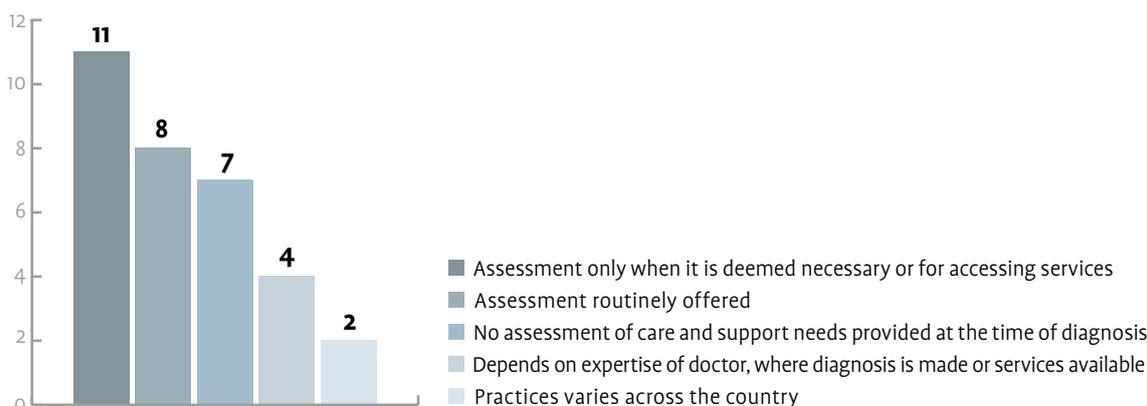


Table 9: Assessment of care and support needs at the time of diagnosis

No assessment of care and support needs provided at the time of diagnosis	Austria, Bulgaria, Czech Republic, Germany, Luxembourg, Malta, Portugal.
Assessment routinely offered to all individuals with dementia	Denmark, Finland, Jersey, Monaco, Netherlands, Slovenia, Sweden, Scotland.
Assessment offered when deemed necessary or for accessing services	Belgium, Croatia, Cyprus, France, Greece, Latvia, Lithuania, Spain, Switzerland, Turkey, UK (not Scotland).
Practices varies across the country	Italy, Norway.
Depends on expertise of doctor, where diagnosis is made or services available	Ireland, Poland, Romania, Switzerland.

<sup>68</sup> Please note that in this section the information provided by the Alzheimer’s Society and Alzheimer Scotland are presented separately.

### 4.3.2 Care plan<sup>69</sup>

In the eight countries where an assessment of care and support needs is routinely offered to people with dementia, a care plan is also developed. In six of these eight countries<sup>70</sup>, the care plan was described as the natural outcome of the assessment of care and support needs, and it is developed around the time of diagnosis. In Denmark and Sweden the care plan is only written once care needs arise. According to the Danish national association, a care plan in electronic form will be implemented in the coming years in Denmark. All professionals involved in the care of the individual with dementia will have access to the electronic care plan.

#### **BOX 9:**

##### **Cyprus**

The assessment is carried out by a multidisciplinary team consisting of a psychiatrist, a mental health community nurse and a mental health occupational therapist (OT). This team evaluates the psychosocial needs of the individual with dementia. The care plan is developed after the assessment. The psychiatrist is usually the care coordinator and either the OT or the nurse is the case manager, depending on the stage of dementia and type of problems.

##### **Monaco**

The care plan is developed within five days of the visit at home. It is developed by a multidisciplinary team with expertise in dementia care. This team includes social workers, nurses, a geriatrician and the coordinator of the Gerontological Coordination Centre. Following this, a social worker presents the care plan to the person with dementia and his/her family and explains to them the financial help available.

Seven further countries<sup>71</sup> reported that a care plan is offered when care needs arise, typically when the individual has to access or is attending a service. For example, people attending day care programmes or living in long-term care may be more likely to have a care plan than people living at home who are not using services.

In some countries<sup>72</sup> care plans are routinely offered to people with dementia with complex needs, as for example individuals with young onset dementia.

#### **BOX 10:**

##### **Germany**

It is not common in Germany to get a care plan at the beginning of the disease. But if the needs of the person increase and he/she needs to access formal care, a care plan will be developed.

##### **England and Wales**

A care plan should be made following an assessment of social care needs, following discharge from hospital or when a person goes into a care home. Once it is decided that the person has eligible needs, the local authority has a duty to provide sufficient support to ensure that these needs are met. The person who carried out the assessment should write a care or support plan. The care or support plan describes which services are to be provided. Any health and care professional who works with the person with dementia should be involved in care planning, as well as the individual themselves and their carer. The person with dementia or their carer should be given a copy of the care plan and the name of the person responsible for ensuring that services are provided (care manager). The care manager can be contacted if there are any difficulties.

In 11 countries<sup>73</sup>, care plans are not offered to people with dementia. Eight of these 11 countries are the same countries that do not offer assessment of care and support needs to people with dementia at the time of diagnosis<sup>74</sup>. Three countries (Croatia, Spain and Turkey) that reported that an assessment of needs was offered to people with complex psychosocial needs, do not offer a care plan.

<sup>69</sup> Please note that Scotland is counted separately from the UK in this section.

<sup>70</sup> Finland, Jersey, Monaco, Netherlands, Slovenia and Scotland.

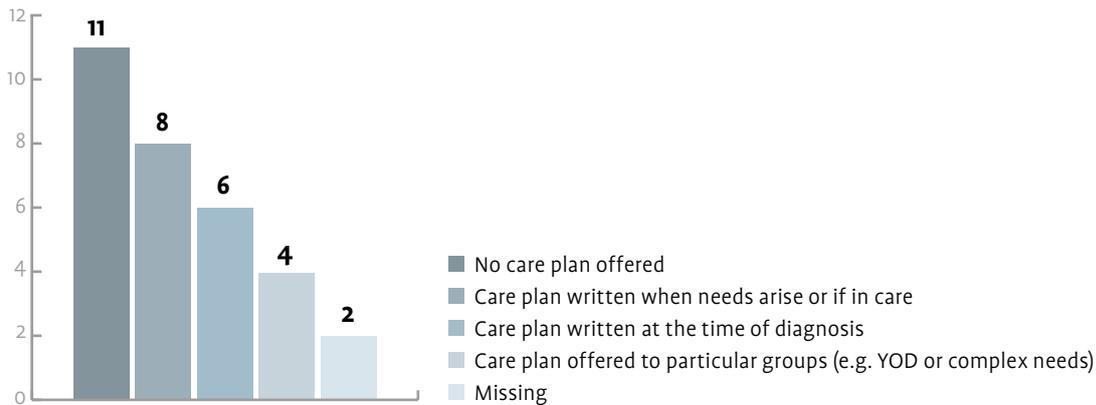
<sup>71</sup> Belgium (Walloon region and Brussels), France, Germany, Greece, Ireland, Poland and UK (not Scotland).

<sup>72</sup> Norway, Romania and Flemish region in Belgium.

<sup>73</sup> Austria, Bulgaria, Croatia, Czech Republic, Latvia, Lithuania, Luxembourg, Malta, Portugal, Spain and Turkey.

<sup>74</sup> Nevertheless in some of these countries, e.g. Malta, Switzerland – care plans will be offered once the National Dementia Strategy is fully implemented.

Figure 11: Care plan offered to people with dementia?<sup>75</sup>



#### 4.4 Psychosocial interventions

There is growing evidence supporting the value of psychosocial interventions for treating people with dementia (Moniz-Cook et al., 2011; Vasse et al., 2012). Psychosocial interventions can benefit people with any type of dementia and may have a positive effect on different areas including cognition, neuropsychiatric symptoms and quality of life. In addition, psychosocial interventions rarely cause serious side effects. Examples include interventions for cognitive and sensory stimulation (cognitive stimulation therapy, reminiscence, aromatherapy, massage, Snoezelen, etc.), interventions that address emotional aspects of dementia (education about dementia, counselling, etc.) and interventions that enhance social engagement.

##### 4.4.1 Interventions for cognitive and sensory stimulation<sup>76</sup>

The majority of the participating countries (27)<sup>77</sup> reported that these interventions<sup>78</sup> are available in their country. Nevertheless, around half of these countries reported that these are organised in day care centres or long-term care institutions and mainly aimed to people attending such centres. Also, often these interventions are offered by the Alzheimer organisations to their members. Seven national organisations<sup>79</sup> reported that these interventions can be also provided by the private sector in their country.

Typically, to gain information about or access to these interventions, people with dementia have to contact directly the organisation or institution organising the intervention. The Monaco Alzheimer association reported that these interventions are offered to the person at the time of diagnosis and recommended, when necessary, in the care plan. In the Netherlands and in Scotland, the support worker could help the individual with dementia to gain relevant information and access.

Overall, there are important local variations in the criteria for accessing such therapeutic interventions, as criteria are mainly dependent on the particular organisation or institution organising the intervention. In the UK and in Germany, some therapies with reimbursement require certain criteria to be met (e.g. a clinical diagnosis of dementia, a doctor's referral, etc.). Often no specific criteria need to be fulfilled to access these interventions when they are offered by the Alzheimer's association<sup>80</sup> or if they are accessed privately.

<sup>75</sup> Italy left blank this question.

<sup>76</sup> Austria left blank this question.

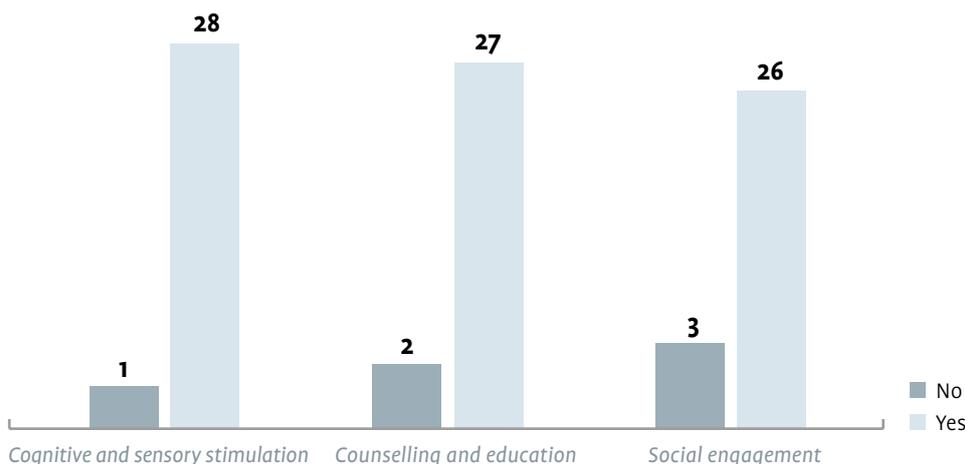
<sup>77</sup> Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Jersey, Latvia, Lithuania, Luxembourg, Malta, Monaco, Netherlands, Norway, Poland, Portugal, Romania, Spain, Sweden, Switzerland, Turkey and UK.

<sup>78</sup> For example reminiscence, reality orientation therapy, aromatherapy, massage, Snoezelen, etc.

<sup>79</sup> Latvia, Germany, Portugal, Sweden, Switzerland, Turkey and UK.

<sup>80</sup> Apart from being a member.

Figure 12: Availability of psychosocial interventions



### 4.4.2 Education and counselling<sup>81</sup>

In almost all participating countries (28)<sup>82</sup>, people with dementia can benefit from interventions that provide education about dementia, counselling or psychological support.

Around half of the participating countries<sup>83</sup>, reported that these interventions are offered by the public sector (memory clinic, healthcare centre, outpatient clinic, day care centre, etc.). In Denmark for example, the memory clinic and the municipality have a joint obligation to provide such interventions. In Denmark and Monaco, this intervention is offered to the individual at the time of diagnosis. In the UK, a referral is required to receive counselling or psychological support in the public sector. With the exception of Denmark and Latvia, in all countries where these interventions are available, people with dementia can benefit from these types of intervention in the Alzheimer's associations. In Latvia, the UK, the Netherlands, Portugal and Germany, these interventions are also organised by the private sector.

In Norway, information and counselling is provided by some clinics and voluntary groups. Nevertheless, this intervention is not systematically provided across the country and most often aims at providing information.

### 4.4.3 Social Engagement<sup>84</sup>

These interventions are available in almost all the participating countries (27)<sup>85</sup> and are typically provided by the voluntary sector (i.e. Alzheimer's associations). In addition to the interventions offered by the Alzheimer's associations, in some countries<sup>86</sup> interventions to promote social engagement are also organised by the public sector, for example in memory clinics, day care centres or by the municipality.

<sup>81</sup> Information is missing for Austria.

<sup>82</sup> Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Jersey, Latvia, Lithuania, Luxembourg, Malta, Monaco, Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, Turkey and UK.

<sup>83</sup> Cyprus, Denmark, Finland, France, Germany, Jersey, Lithuania, Malta, Monaco, Spain, Sweden, Switzerland and UK.

<sup>84</sup> This refers to interventions/services that help the person to stay socially engaged or connected with the community, e.g. peer support, Alzheimer cafes, befriending services, etc.

<sup>85</sup> This intervention is not available in Turkey and Latvia. Information is missing for Austria.

<sup>86</sup> Cyprus, Denmark, UK, Monaco, Sweden and Switzerland.

#### **BOX 11: Interventions that promote social engagement**

##### **Scotland**

These interventions are key elements of the five pillar model of post-diagnostic support:

*Support to stay connected to their community:* this involves working closely with people to maintain and build on their existing social networks, to enhance their quality of life and maximise the natural support they receive from those around them, helping to avoid isolation and reducing future reliance on care services. This will require a shift away from traditional health and social care boundaries. The named worker will need to work with the person to enable risk, plan purposeful community activity and connection, and to engage with community development partners and organisations to help people with dementia continue to use and be fully included in mainstream community activity.

*Peer support from other people with dementia and their families and carers:* this intervention is highly effective in helping people come to terms with the illness and find coping strategies, and in maintaining their wellbeing and resilience. A good example of peer support is the dementia cafés run by Alzheimer Scotland. These allow people with dementia and their families and carers to attend together, in a relaxed informal atmosphere where they can get information from professionals but, most importantly, have the opportunity to meet other people facing similar challenges.

##### **Slovenia**

In Slovenia the dementia cafés initiative has been very popular and their implementation has been very successful in the country. The first dementia café was organised in July 2012 in Ljubljana, and, in 2014, there are more than 50 cafés in the country. These are helping people with dementia and their families to live and cope better with dementia and also to raise awareness about dementia in the country.

## **4.5 Community support and care services**

Table 10 shows the type of services that are available to people with dementia living at home and the main providers of the service (public, private and voluntary sector). Information about services has to be read with caution as social care systems are complex and the socio-cultural context must also be taken into account. For example, home care services are available in Bulgaria in the private sector, nevertheless according to the national association these are quite expensive services and only a minority of people in the country can afford them. This may be quite different in other countries, as for example Luxembourg or Germany, where these services are also available privately, but where more people may be able to afford them and may also be refunded in some cases through insurance or grants.

Likewise, whilst in some countries these services are available in the public sector, it was pointed out that services are not systematically provided and that availability is often based on postcode lottery. Access may largely depend on how well the person/family can advocate locally for services (Ireland, Poland) and access for people living in rural areas can also be problematic.

## National care pathways for people with dementia living at home

Table 10: Community support and care services by country<sup>87</sup>

	Home help	How is it provided?	Home care	How is it provided?	House adaptations	How is it provided?	Assistive technology	How is it provided?	Day care	How is it provided?
Belgium	Yes	PU	Yes	PU	Yes	PU	Yes	PU	Yes	N/A
Bulgaria	Yes	PR	Yes	PR	No		No		No	
Croatia	Yes	PU	Yes	PU	No		No		Yes	N/A
Cyprus	Yes	PU, VO	Yes	PU, VO	Yes	PU	No		Yes	PU, VO
Czech Republic	Yes	PU, PR, VO	Yes	PR	No		No		Yes	PU, PR, VO
Denmark	Yes	PU	Yes	PU	Yes	PU	Yes	PU	Yes	PU
Finland	Yes	PU, PR	Yes	PU, PR	Yes	PU, PR	Yes	PU, PR	Yes	PU, PR, VO
France	Yes	PU, PR	Yes	PU, PR	N/A	N/A	N/A	N/A	Yes	PU
Germany	Yes	PR/LTCI	Yes	PR/LTCI	Yes	PR/LTCI	Yes	PR/LTCI	Yes	PU, PR,
Greece	Yes	PR	Yes	PR, PU	N/A	N/A	Yes	PR	Yes	PU, PR, VO
Ireland	Yes	PU, PR, VO	Yes	PU, PR, VO	Yes	PU, PR	Yes	PU, PR, VO	Yes	PU, VO
Italy	Yes	N/A	Yes	N/A	No		N/A	N/A	Yes	PU
Jersey	Yes	PU, PR, VO	Yes	PU, PR, VO	Yes	PU	Yes	PU, VO	Yes	PU, VO
Latvia	Yes	PU, PR	Yes	PU, PR	Yes	PU	Yes	PU, PR	Yes	PU
Lithuania	Yes	PU	Yes	PU	No		Yes	PU	Yes	PU
Luxembourg	Yes	PR	Yes	PR	Yes	PR	Yes	PR	Yes	PR
Malta	Yes	PU	Yes	PU	No		No		Yes	PU
Monaco	Yes	PU	Yes	PU, PR	Yes	PU	Yes	PU	Yes	PU
Netherlands	Yes	PU	Yes	N/A	Yes	PU, PR (insur)	Yes	PU, PR (insur)	Yes	PR (insur)
Norway	Yes	PU	Yes	PU	Yes	PU	Yes	PU	Yes	PU
Poland	Yes	PU	Yes	PU	Yes	PU	No		Yes	PU, PR
Portugal	Yes	PR, VO	Yes	PR, VO	Yes	PU	Yes	PR, VO	Yes	PR, VO
Romania	No		No		No		No		No	
Scotland	Yes	PU, VO	Yes	PU, VO	Yes	PU	Yes	PU, PR, VO	Yes	PU, PR, VO
Slovenia	Yes	PU	Yes	PU	N/A	N/A	No		Yes	PR
Spain	Yes	PU, PR	Yes	PU, PR	Yes	PU, PR	Yes	PU, PR	Yes	PU, PR
Sweden	Yes	PU, PR	Yes	PU, PR	Yes	PU	Yes	PU	Yes	PU
Switzerland	Yes	PU, PR	Yes	PU, PR	Yes	PR	Yes	PR	Yes	PU, PR
Turkey	No		Yes	PR	No		No		Yes	PU, VO
UK	Yes	PU, PR, VO	Yes	PU, PR, VO	Yes	PU, PR, VO	Yes	PU, PR, VO	Yes	PU, PR, VO

PU Public sector                      VO Voluntary sector                      LTCI Long term care Insurance  
 PR Private sector                      (insur) Insurance                      N/A No answer

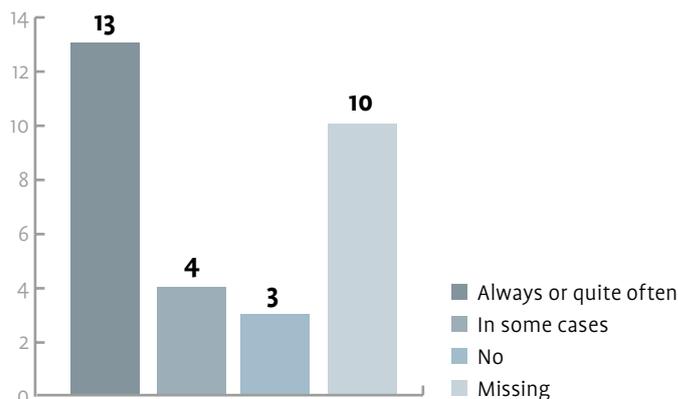
### 4.5.1 Dementia-specific services

By and large, participating countries reported that home help, home care services and home adaptation are most often not dementia specific, except in the case of the service being provided by the voluntary sector (i.e. Alzheimer's association).

Day care centres were more likely to be dementia specific, with 13 countries reporting that often people with dementia could benefit from dementia specific day care programmes and four countries reporting that this was possible but not everywhere in the country.

<sup>87</sup> Home help refers to assistance with domestic tasks, meals-on-wheels, etc. Home care involves personal or nursing care.

Figure 13: Availability of dementia-specific day care services.



**BOX 12:**

**Ireland**

In Ireland, three types of day care (also known as day respite) are available to older people with dementia depending on where the person lives. These are (i) generic day care, (ii) dementia-focused day care and (iii) dementia-specific day care (only people with dementia attend). The Alzheimer Society of Ireland (ASI) delivers dementia day care services with financial support from the Health Service Executive. The country is divided into 32 Local Health Office areas (LHO) and many of these LHOs have no dementia-specific or dementia-focused services. The generic day care centres provide care for the general population of older people and may or may not accommodate people with dementia. Referral to the dementia-specific day care provided by the ASI is made by health and social care professionals. The day care provided by ASI can also be accessed through self-referral.

*Source: Cahill, S. and Moore, V. Booklet - Coping with the Early Stages of Dementia. A Guide for people worried about Memory and Cognitive Problems or those recently diagnosed with Dementia, p. 13.*

**BOX 13:**

**Norway**

Dementia care is becoming an increasing focus of interest in the Norwegian municipal and governmental strategies. The national dementia strategy (2007-2015), stated that health and care professionals needed further training on dementia and dementia care. In addition to the national dementia strategy, 18% of municipalities have a local dementia strategy, and 65% of municipalities have embedded dementia care in their municipal strategy. In 2014, more than 18,000 health care professionals were registered in a two-year dementia-specific care training programme. Norway's authorities are satisfied by the enhanced dementia knowledge among the care staff, although informal carers would still welcome more knowledge on dementia for care staff.

**BOX 14:**

**Sweden**

The national guidelines for dementia care (2010) have had a major impact on the quality of care offered to people with dementia in Sweden. The philosophy that underpins the Swedish national guidelines is that of person-centred care. Most regions and municipalities in Sweden have developed interventions and guidelines that address the medical and social care of people with dementia. In addition, the training and education of the workforce are crucial in ensuring high quality care.

#### 4.6 Navigating the system: anticipating and signposting

Most health and social care systems in Europe are complex. The literature suggests that people with dementia and their carers often feel that navigating the care system is not straightforward and that support services to help them reach the services at the right time are needed (Irish Hospice foundation and ASI, 2012). Some of the challenges include: fragmented rather than seamless care, lack of integration between health and social systems and several agencies and providers involved and overlapping in the care of the individual. In addition, the needs of people with dementia are complex, may cross several service providers and will change over the illness trajectory.

## National care pathways for people with dementia living at home

Participating countries were asked about professionals or services in the community that could provide ongoing information and support to people with dementia, including anticipating, evaluating and signposting service options according to the changing needs of the person with dementia.

In around two thirds of the countries<sup>88</sup> the care and support needs of the individual with dementia are not systematically monitored, with most countries reporting an “on demand” approach. In these cases, the person with dementia or his/her family are expected to ask for advice or find the service/intervention when needs arise or if the person wishes to access such service. Professionals and services that people with dementia and their carers can turn to, and that can support the person if required, are the GP or specialist, the social worker, mental health or disability services, sickness funds, health insurance and counselling services. The Alzheimer’s associations play a key role in supporting the ongoing needs of people with dementia and in helping them to navigate the system.

### **BOX 15:**

#### **Croatia**

People have to manage on their own. In some cases, if there is a good relationship with the specialist, the person may arrange an appointment for advice.

#### **Switzerland**

In some parts of the country, outreach counselling services are available, but overall no organised comprehensive ongoing information and support service is available. People with dementia and their carers are expected to find a counselling service like the ones provided by the Alzheimer’s Association, Pro Senectute or some Memory Clinics. Nevertheless, unless they know the services this implies a lot of administrative work and burden to family members.

#### **Belgium**

In the Flemish region of Belgium, in some areas (e.g. Bruges) people with dementia can benefit from case management. In other areas the individual can contact the sickness funds. In the latter, the support is provided by well trained professionals. This will be greatly expanded in the coming years, once the Transition plan that has been approved by the new Flemish government is implemented.

One third of the countries<sup>89</sup> described a more preventive and proactive care planning approach. In Denmark, for example, all municipalities have a dementia nurse/coordinator. This professional is responsible for keeping in contact with people with dementia and their families and follow-up on their situation. These professionals are supposed to be proactive.

In the UK, dementia advisers provide people with dementia and their carers a named contact throughout their dementia journey. Referrals to the service may come from GPs, Community Mental Health Teams or other health and social care professionals, or self-referral. The service operates from dementia adviser centres, which can be memory clinics, GP surgeries or Society services. Currently, not all people diagnosed will have access to a Dementia Adviser; it is dependent on where a person lives.

In Scotland, during the 12 months following diagnosis the link worker will support the person with dementia to know where they can go for advice and support in the future, particularly as their condition changes. This may well be their GP or another health or social care practitioner. In addition, most areas of Scotland have an Alzheimer Scotland Dementia Advisor who can support people with dementia, their partners, families and carers.

Likewise, in countries where care plans exist, the care plan is reviewed at regular intervals and changed as appropriate. These are opportunities for identifying new needs and help the person to address them. In Monaco, the care plan is reviewed yearly by a nurse from the Gerontological Coordination Centre, or every time it is necessary, if a loss of autonomy is observed. In Finland, according to Finnish national policies, an individual treatment and rehabilitation plan is drawn up for each person with dementia and reviewed regularly as the disease progresses. If the person receives home care, the care staff can monitor the situation at home. If needs change, the home care staff or memory coordinator organise further help according to the needs of the person with dementia. In Sweden, around two-thirds of the municipalities have a dementia nurse. Care managers and dementia nurses play a key role in supporting the ongoing needs of people with dementia in Sweden. In addition, according to the national guidelines for dementia care (2010), the health and social needs of people with dementia should be monitored at least once a year.

<sup>88</sup> Austria, Belgium, Bulgaria, Croatia, Czech Republic, Germany, Greece, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Poland, Portugal, Romania, Slovenia, Spain, Switzerland and Turkey.

<sup>89</sup> Cyprus, Denmark, Finland, France, Jersey, Monaco, Netherlands, Norway, Sweden and UK.

#### 4.6.1 Transitions and crises

In the countries where there is an ongoing assessment of the support and care needs of people with dementia and people are supported to negotiate the system, it was more likely that critical events and changing needs were anticipated and that transitions between services were made smoother.

##### **BOX 16:**

###### **Finland**

Based on the Act on Supporting the Functional Capacity of the Ageing Population and on Social and Health Care Services for Older People (980/2012) all personnel in health and social care have the responsibility to refer people in need of support to suitable services. The memory coordinator, social worker and case manager are typically dealing with these types of situations.

###### **Scotland**

The Five and Eight Pillar models of support are designed to enable needs anticipation as far as possible. Each model also ensures, however, that a person with dementia and their carer(s) and family know who to contact and how, in the event of a critical event or a crisis. Local authorities and health boards provide emergency social and health care responses where needed, which are followed up with an assessment of future support needs.

In countries where such roles do not exist, when needs change either the families have to advocate for themselves to the service provider (or funder) for another or additional services, or sometimes GPs or other teams in the community can refer the person to a service or advocate for them.

##### **Box 17:**

###### **Ireland**

“Transitions” or “key events” on the dementia journey include getting the diagnosis, transitioning to community services, an admission to acute care, making the transition from home to long term residential care and the onset of a co-morbidity. In Ireland, very often these transitions are crisis driven and not planned.

In the absence of clear integrated dementia care pathways and the crisis driven nature of the care, there is very little consistency in terms of the level and nature of care and with very little opportunity for the healthcare professional to respond in a holistic, person-centred way (ASI, 2013).

In eight countries<sup>90</sup> specific arrangements exist to address emergency situations or crises. In Belgium and Finland such measures are regulated by law. For instance, in Finland, if there is a significant concern about the situation of a person with dementia, and according to the Act on supporting the functional capacity of the ageing population and on social and health care services for older people (980/2012), “the need for services should be looked into without delay”. Similarly in Sweden, in the cases of an emergency or a crisis, the necessary service can be extended on the same day that the need arises. In the UK, in the case of a crisis, a health or care professional will make an emergency referral to the local social services and an emergency plan will be put in place. Nevertheless, according to the Alzheimer’s Society, information and support will depend on the area. In Denmark, Jersey, Monaco, the Netherlands and Scotland, the case manager or the care or dementia coordinator seem to play a key role in supporting people with dementia and their families if an emergency situation develops, and most often this is done in coordination with the GP.

Seven countries<sup>91</sup> reported there are no particular procedures to address these situations in their country. Five countries<sup>92</sup> reported that the person with dementia can contact the public social and health services if a crisis or emergency develops. Six countries<sup>93</sup> referred to hospitalisation or institutionalisation (either short or long term) as a typical outcome or most common way to address these situations in their country.

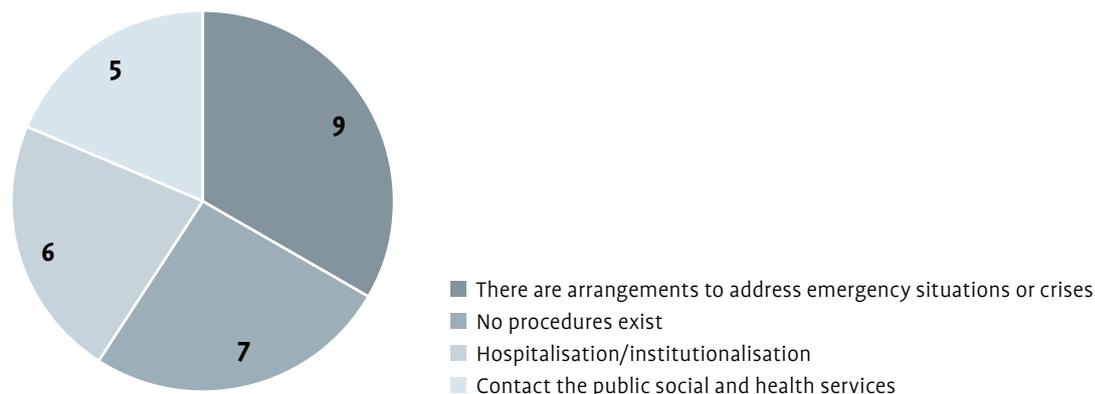
<sup>90</sup> Belgium, Denmark, Finland, Jersey, Monaco, Netherlands, Sweden and UK.

<sup>91</sup> Bulgaria, Czech Republic, Greece, Ireland, Lithuania, Luxembourg and Romania.

<sup>92</sup> Austria, Cyprus, Norway, Poland and Portugal.

<sup>93</sup> Croatia, Germany, Ireland, Latvia, Malta, Spain and Switzerland.

Figure 14: Existing procedures for emergency situations or crises



### 4.7 Main barriers and challenges to post-diagnostic support and care<sup>94</sup>

Participating countries were invited to identify the main challenges and barriers that in their opinion, people with dementia and their families face in relation to support and care after diagnosis. According to the participating countries, overall the most common barriers to post-diagnostic support and care are related to policy (18 countries)<sup>95</sup>, the model of care (11 countries)<sup>96</sup> and service provision (17 countries)<sup>97</sup>.

Among the policy barriers, the lack of or the limited provision of services and the large variation of service<sup>98</sup> provision across the country were the most frequently reported<sup>99</sup>. In addition, several countries pointed out the lack of national policies or guidelines addressing the type of post-diagnostic support that should be offered to people with dementia<sup>100</sup>.

Lack of coordination between services and the fragmentation of the care system were the most relevant barriers reported in relation to the current model of care. Finally, among the challenges related to service provision, the majority of the countries referred to poor awareness, lack of efficient information and difficulties that people with dementia and their families had to find relevant information about existing support and care.

According to the national organisations in Denmark, Monaco and Slovenia, there are few or no barriers to post-diagnostic support and care in their countries. In Denmark, most people with dementia and their families can access the appropriate information and support from the dementia nurse/coordinator in the municipality. In their country it was felt that sometimes the only barrier is the reluctance of people to involve the municipality in their care and support. Likewise, Monaco reported that there is a good coordination among services and that the Gerontological Coordination Centre provides a single point of contact for people with dementia and their families. Nevertheless, a shortcoming of the Monegasque system is the lack of measures that would allow the person to anticipate his/her future (e.g. advance directives or power of attorney).

<sup>94</sup> In this section information is missing for Italy and Luxembourg.

<sup>95</sup> Belgium (only Walloon region and Brussels), Bulgaria, Croatia, Cyprus, Czech Republic, France, Finland, Germany, Greece, Ireland, Latvia, Lithuania, Poland, Romania, Spain, Sweden, Switzerland and UK.

<sup>96</sup> Czech Republic, Finland, Germany, Ireland, Norway, Malta, Poland, Portugal, Spain, Switzerland and UK.

<sup>97</sup> Austria, Belgium, Czech Republic, Denmark, France, Ireland, Netherlands, Malta, Jersey, Norway, Greece, Poland, Portugal, Spain, Sweden, Turkey and UK.

<sup>98</sup> Croatia, Ireland, Latvia, Lithuania, Poland and Romania.

<sup>99</sup> Finland, Germany, Ireland, Spain, Sweden, Switzerland and UK.

<sup>100</sup> Belgium (Walloon region and Brussels), Bulgaria, Czech Republic, Lithuania and Romania.

Diagram 5: Interconnected barriers for post-diagnostic support and care

**Examples of policy-related barriers (N=18 countries)**

- Dementia is not a public/social priority in the country.
- There are several local initiatives but no clear national guidelines.
- Lack of national policies about post-diagnostic support and care or existing policies have not yet been implemented.
- No official pathways.
- Geographical differences: provision of care and support after diagnosis is not consistent in the country, large regional variation of service provision.
- Lack of or limited service provision – there are not enough services, long waiting lists.
- Bureaucracy.
- Eligibility criteria – e.g. diagnosis is needed to access services.

**Examples of challenges in the care model (N=11)**

- No unified, comprehensive and separated care for people with dementia.
- Fragmented provision of services; transitions among services are not seamless.
- Lack of or poor coordination between services.
- No information sharing between health and social systems.
- Lack of integrated model of care.
- Complexity of the system: several service providers, overlapping of services, complex system of eligibility criteria, etc.

**Examples of challenges in service provision (N=17)**

- Poor awareness of available support and services (people with dementia and families, but also among health professionals); lack of clear information about available support and care.
- Reluctance to use services.
- Quality of the services provided: staffing levels are insufficient or staff not sufficiently trained about dementia care; services are not person-centred; services are not flexible.
- The opinion of people with dementia is often not taken into account. No care plans are offered.
- Lack of dementia-specific services and services that can help the person to stay at home.
- Support for people at early stages and for people with young onset dementia is not always available.
- Protocols and forms to fill in by the carer, can be difficult to understand.
- Lack of professional/service for providing information, signposting and supporting people with dementia and their families.
- Cost: difference between grants and cost of services, private services are not affordable.

### 4.8 Conclusions

This section has reviewed the support and care available to people with dementia after diagnosis in 30 European countries. The comparison of this post-diagnostic support and care highlights the huge differences that exist throughout Europe. The comparison reveals that in some countries psychosocial support after diagnosis is either lacking or underdeveloped. The information provided by the national organisations suggests that, in many countries in Europe, care and support for people with dementia are not provided in a seamless manner.

In around one third of the countries, a support worker role has been developed and may facilitate the access and transitions in the care system. Nevertheless, in these countries differences are reported in terms of accessibility to this professional and also in the concrete role and approach that each country has followed.

Conversely, where this role does not exist, practices are less consistent and the information and the time at which people with dementia and their families receive information greatly varies. It is often reported that information provided by practitioners depends on their own knowledge and attitudes and may not be consistent. Similarly, whilst social workers and community nurses are also relevant providers of information and may facilitate access to relevant services, these professionals are often consulted only when care needs arise. This suggests that, too often, care and support systems are crisis driven rather than preventive and proactive.

This section has also shown the very important role of the voluntary sector – particularly the Alzheimer's associations – in the provision of information and support to people with dementia.



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# National care pathways for people with dementia living at home

The Dementia in Europe Yearbook 2014 focuses on care pathways for people with dementia living at home. It provides a comparative analysis of national policies and practices addressing different aspects of the pathways to diagnosis and to post-diagnostic support and care in the Members States of the European Union as well as in Jersey, Norway, Monaco, Switzerland and Turkey. Relevant topics addressed in this report include the timely diagnosis of dementia; referral pathways; pharmacological treatment and ongoing assessment of dementia; disclosure of diagnosis and provision of information to people with dementia; assessment of psychosocial needs and development of care plans; and access to and transitions between the existing support and care services in these countries.