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ABORDAGEM E SEGUIMENTO DA DEMÊNCIA NOS CUIDADOS DE SAÚDE PRIMÁRIOS DEMENTIA APPROACH AND FOLLOW-UP IN PRIMARY CARE ENFOQUE Y SEGUIMIENTO DE LA DEMENCIA EN LA ATENCIÓN PRIMARIA DE SALUD

Ana Jorge Lopes<sup>1</sup> Vitor Martins<sup>1</sup> João Ribeiro<sup>1</sup>

<sup>1</sup>Unidade de Saúde Familiar (USF) Viriato, Viseu, Portugal

Ana Jorge Lopes - anaj.lopes22@gmail.com | Vitor Martins - vitorbnmartins3@gmail.com | João Ribeiro - jcatarinor@gmail.com

Autor Correspondente Ana Jorge Oliveira Cardoso Lopes Rua Pedro Álvares Cabral nº124 R/C, 3500-169 Viseu, Portugal anaj.lopes22@gmail.com RECEBIDO: 21 de novembro de 2016 ACEITE: 06 de abril de 2017



# RESUMO

**Introdução:** A prevalência das demências tem vindo a aumentar nos últimos anos, em paralelo com o envelhecimento da população, sendo atualmente uma patologia frequente ao nível dos cuidados de saúde primários.

Objetivo: Rever o papel do médico de família no diagnóstico e seguimento dos doentes com demência.

**Métodos:** Revisão teórica mediante a pesquisa de normas de orientação clínica, revisões sistemáticas e artigos originais na PubMed, Clinical Key, UpToDate, Index de Revistas Portuguesas, nas línguas inglesa e portuguesa, de janeiro de 2006 a setembro de 2016 utilizando os termos MeSH: "Dementia", "Primary Health Care", "Primary Care Nursing" e "Physician Primary Care".

**Resultados:** Perante a suspeita de quadro demencial é importante efetuar uma história clínica pormenorizada ao doente com a colaboração dos familiares e/ou cuidadores com enfoque nos sintomas cognitivos, comportamentais e alterações nas atividades da vida diária. De seguida, deve proceder-se ao exame objetivo e à aplicação de testes de avaliação cognitiva, psicoafetiva e funcional reservando-se, por último, uma avaliação analítica e imagiológica. De igual relevância é o papel do médico de família no tratamento/orientação posterior do doente e apoio aos familiares e cuidadores na gestão dos cuidados.

**Conclusões:** O médico de família encontra-se numa posição privilegiada para uma deteção precoce da demência. O diagnóstico é essencialmente clínico e nem sempre é fácil numa fase inicial. O papel dos médicos e outros profissionais dos Cuidados de Saúde Primários não deve limitar-se à avaliação inicial, mas deve estender-se ao seguimento e orientação posterior do doente e respetivos familiares.

Palavras chave: Demência; médico de família; cuidador

## ABSTRACT

**Introduction:** The prevalence of dementia has been increasing in recent years in parallel with an ageing population. Today it is a common pathology in primary care level.

Objectives: To review the family physician's role in diagnosing and following up on patients with dementia.

**Methods:** Theoretical review based on researching clinical guidelines, systematic and original articles published in English and Portuguese in PubMed, Clinical Key, UpToDate, the Index of Portuguese Journals from January 2006 to September 2016 using the MeSH terms: "Dementia," "Primary Health Care," "Primary Care Nursing" and "Primary Care Physician."

**Results:** When dementia is suspected, it is important to resort to family members and/or caregivers' cooperation, to conduct a thorough medical history of the patient, focusing on behavioural and cognitive symptoms and changes in daily activities. Subsequently, an objective examination should be carried out and an array of cognitive, psycho-affective and functional assessment tests applied. Finally, an analytical and imaging evaluation should be performed. Equally important is the role of the family physician in the patient's subsequent treatment/guidance and support to families and caregivers in care management.

**Conclusions:** The family physician is in a prime position for early detection of dementia. Clinical diagnosis is essential and is not always easy at an early stage. The role of doctors and other professionals in primary health care should not be limited to the initial assessment, but should extend to following up on and guiding the sick and their respective families.

Keywords: Dementia; family physician; caregiver

## RESUMEN

**Introducción:** El predominio de las demencias ha aumentado en los últimos años, en paralelo con el envejecimiento de la población, siendo actualmente una patología muy frecuente en la atención primaria de salud.

**Objetivo:** Revisar el papel del médico de Medicina Familiar y Comunitaria en el diagnóstico y seguimiento de pacientes con demencia.

**Métodos:** Revisión teórica a través de búsqueda de normas de orientadoras clínicas, revisiones sistemáticas y artículos originales en bases de datos como PubMed, Clinical Key, UpToDate, y índices de Revistas Portuguesas, en portugués o inglés, entre Enero de 2006 y Septiembre de 2016, utilizando los términos MeSH: "Dementia", "Primary Health Care", "Primary Care Nursing" e "Physician Primary Care".

**Resultados:** Ante la sospecha de demencia es importante realizar una historia clínica completa del paciente recurriendo a la ayuda de miembros de la familia y/o cuidadores que se centre en los síntomas cognitivos y cambios de comportamiento en las actividades de la vida diaria. A continuación, debe procederse al examen objetivo y la aplicación de las pruebas cognitivas, psicoafectivas y funcionales, reservando, para el fin, una evaluación analítica y de imagen. Igual de importante es el papel del médico de Medicina Familiar y Comunitaria en el tratamiento y orientación posterior del paciente y apoyo a las familias y cuidadores en la gestión de la atención.

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**Conclusiones:** El médico de Medicina Familiar y Comunitaria se encuentra en una posición privilegiada para la detección precoz de la demencia. El diagnóstico de la demencia es básicamente clínico, pero no es siempre fácil de detectar en una fase temprana. El papel de los médicos, así como de otros profesionales de la Atención Primaria de Salud, no se debe limitar a la evaluación inicial, sino que debe extenderse al seguimiento y orientación de los enfermos y sus respectivas familias

Palabras clave: Demencia; médico de medicina familiar y comunitaria; cuidador

## INTRODUCTION

The term "dementia" derives etymologically from the Latin word *dementia* which means deprivation of the mind (Pinho, 2008). It is a complex, chronic and progressive disorder characterized by cognitive impairment which involves one or more functions (learning, memory, language, visuospatial skills and executive function), personality changes and decreased overall operation (Boustani, Schubert & Sennour, 2007; Holzer, Warner & Iliffe, 2013; Larson, 2016).

In Portugal, like other European countries, there is a growing aging population. The demographic picture in our country is characterized by a continued increase in life expectancy at birth, reduced child mortality, increased emigration, declining birth rates and consequently an aging population. Between 2011 and 2013, the aging index of the population (which reflects the number of people over 65 per 100 individuals under the age of 15 years) rose from 128 to 136 and demographic forecasts indicate that this will reach a value on the order of 287 to 464 per 100 young people in 2060. At that time, the elderly population is expected to be 36-43% of the population (Santana, Farinha, Freitas, Rodrigues & Carvalho, 2015).

The incidence and prevalence of dementia increases with age, doubling approximately every 5 years after age 65, such that a value of 0.8% in the age group from 65 to 69 years increases to 28.5% over the age of 90 years (Pinho, 2008).

The family physician is often the first physician the patient with suspected dementia turns to, although approximately 39% resort to other specialists, including neurologists or psychiatrists (Galvin & Sadowsky, 2012; Samsi & Manthorpe, 2014). Primary health care services (PHC) represent patients' first level of access to the National Health System. They allow regular contact with their respective family physician with whom they have some familiarity and establish a doctor/patient relationship of trust. They also allow hospital referral when indicated. Therefore, many authors consider PHC the first line for a timely diagnosis of dementia (Pinho, 2008; Boustani et al., 2007).

In this context, the aim of this article is to address the importance of the family physician in diagnosing and managing patients with dementia. To this end, research was conducted into clinical guidelines, systematic reviews and original articles published in English and Portuguese in PubMed, Clinical Key, UpToDate, the Index of Portuguese Journals from January 2006 to September 2016. The use of the following MeSH terms underpinned this research: "Dementia", "Primary Health Care," "Primary Care Nursing" and "Primary Care Physician," whether associated or not and sometimes supplemented by specific terms. In this selection, we gave priority to publications focusing on diagnosing dementia and care for patients with this condition, as well as their respective caregivers, within the scope of PHC.

## 1. DEVELOPMENT

#### 1.1 - Epidemiology

Studies on the epidemiology of dementia in Portugal are few in number and limited to specific geographical areas affecting the North. Between 2003 and 2008, the first population based study in Portugal was conducted. It found an overall prevalence of dementia in the population between the ages of 55 and 79 years of 2.7% (Nunes et al., 2010). In 2006, another study was carried out on the Portuguese population under observation of the Sentinel-doctors Network with the objective of estimating the prevalence of dementia diagnosed in PHC. The prevalence of this pathology in people over the age of 35 years was found to be 0.7%; and the highest rate (3.0%) was found in people aged over 75 years (Rodrigues Sousa-Uva, Galvão, Nunes & Dias, 2014).

A study was conducted recently by Santana et al. (2015) with the aim of estimating the prevalence of dementia/Alzheimer's disease in Portugal and to infer from prescriptions the number of effective diagnoses and the financial burden of the medication. A prevalence of dementia of 5.91% was estimated in individuals over the age of 60 years with an annual cost of  $\xi$ 37 million. The cost of the medication includes direct costs along with costs deriving from professional fees, clinical examinations, hospitalizations, outsourced services supporting patients' daily care, among others. Nevertheless, it is worth highlighting entitled indirect costs of dementia are significant in the economies of families and health systems. It is also worth stressing that there are costs related to patients leaving the labour force early, decreased work attendance, as well as informal caregivers abandoning their occupations, morbidity increases in caregivers, among others.

Although there is no curative treatment, early diagnosis and implementation of treatment is essential to prevent progression to more advanced stages of the disease. In addition, at an early stage, the diagnosis will allow legal and financial issues to be



planned as well as those related with patient safety so as to prolong their independence. It also enables caregiver burden to be reduced by conveying information about the disease, support groups and monitoring as provided by appropriate services in order to delay the patient's institutionalization (Dodd, Cheston & Ivanecka, 2015; Holzer et al., 2013; Pinho, 2008).

Generally speaking, the public perception of dementia is that most people are institutionalized in short-term or long-term care units. However, this is an inaccurate view since most patients with dementia reside at home with caregivers who are often the same age or older (Darrow, 2015).

Dementia is still underdiagnosed and the time from the onset of symptoms to diagnosis is prolonged. There are several obstacles that may be the basis of this pathology's late diagnosis involving the patient, the physician and the health system. With respect to the patient, it is worth emphasizing the lack of knowledge about the typical symptoms of dementia, denial before functional and cognitive changes and the stigma associated with the disease. The medical-related obstacles include the difficulty in differentiating changes inherent to memory loss brought about by the normal aging process and the early stages of dementia, pessimism about treatment and prognosis, lack of skills in recognizing dementia, as well as the belief that diagnosis of this condition should be conducted by specialists. As for the health system, it is worth mentioning the lack of time and resources in PHC to address this issue (Dodd et al., 2015; Holzer et al., 2013; Pinho, 2008).

## 1.2 - Definition and classification

There are several definitions of dementia; however, we will base ours on the American Psychiatric Association's proposal (2014) presented in the DSM-5 manual. It represents a reasonable and useful tool in clinical practice. According to the DSM-5, the criteria for dementia (currently designated major neurocognitive disorder) include identification by clinical history and evaluation of cognitive impairment in at least one of the cognitive areas (learning and memory, language, executive ability, attention, perceptual motor function and social cognition). It must be severe enough to interfere with the autonomy in DLA representing a decline from a previous level of functioning and occurring in the absence of confusional syndrome (delirium). In the case of neurodegenerative dementia, Alzheimer's disease, for example, these changes are insidious, progressive and based on clinical history and cognitive assessment studies. The changes found are not explained by other mental disorders.

Dementias can be generally classified into primary and secondary (Table 1). Primary dementias account for most cases and are associated with an irreversible degenerative brain disorder. Alzheimer's disease is the most common type and is present in approximately 60 to 80% of cases. This is followed by vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Alves & Caetano, 2010; Holzer et al., 2013; Larson, 2016; Pinho, 2008). Some studies reveal that an overlap of pathologies is more common than previously thought, particularly with an overlap of Alzheimer's disease with vascular dementia and dementia with Lewy bodies, while the frontotemporal dementia tends to be erroneously misdiagnosed as Alzheimer's disease (Holzer et al., 2013). It should be noted that in the study by Rodrigues et al. (2006) to estimate the prevalence of dementia cases diagnosed in PHC, there was a higher percentage of vascular dementias in Portugal compared to other European countries. This seems to be related to the high prevalence of hypertension in the Portuguese population.

Secondary dementias include a wide range of causes. Some may be reversible, drug intoxication, those arising in the context of depression or normal pressure hydrocephalus, among others. These represent fewer than 2% of cases (Alves & Caetano, 2010; Darrow, 2015).

Primary Dementias - degeneratives	Secondary Dementias
Alzheimer's disease	Vascular dementia
Dementia with Lewy bodies	Vitamin deficiency
Frontotemporal dementia	Endocrine
• Others	Infections of the central nervous system (CNS)
	• Toxic
	• Drug
	Head Injuries
	Expansive lesions of the CNS
	Normal pressure hydrocephalus

#### Table 1 - Causes of dementia

Source: Alves e Caetano (2010); Pinho (2008); Souza et al. (2009)



## 1.3 - Diagnostic approach

According to the American Association of Neurology and the US Preventive Services Task Force (USPSTF), there is at present no scientific evidence to recommend screening of dementia in healthy elderly people (Larson, 2016). However, these entities, together with others which are significant in this area, emphasize the importance for physicians to be alert and carry out timely assessments of patients with suspected cognitive decline (Pinho, 2008). According to Poggesi and Pantoni (2009), screening for cognitive decline should be performed in three groups of patients: those with cardiovascular risk factors; those with cognitive or minimal, subjective behaviour changes reported by family members; those returning home after cerebral vascular accidents.

## 1.4 - Clinical history

Most patients with dementia do not turn to their family physician with complaints of memory loss. It is often family members, friends or caregivers who address the issue (Larson, 2016). However, it is common for individuals to complain of occasional "memory loss" with advancing age. Studies conducted in the community suggest that 35 to 40% of the elderly aged over 75 years, who are healthy and without dementia, reported memory problems (Poggesi & Pantoni, 2009). Indeed, the aging process can condition cognitive decline which is considered normal and should be distinguished from dementia. This only affects the memory and does not affect the functional capacity of the individual (Darrow, 2015; Larson, 2016; Poggesi & Pantoni, 2009).

Given a suspicion of dementia, it is essential to carry out a detailed, thorough and complete medical history. The clinical interview should be directed not only to the patient but also to the caregiver and/or family members who live with the patient (Alves & Caetano, 2010; Holzer et al., 2013; Larson, 2016; Pinho, 2008). It is recommended that evaluating the patient occurs in at least two distinct periods, given the restrictions on PHC, including limited consultation time (Darrow, 2015; Pinho, 2008).

At first, research should fall on cognitive, psycho-behavioural and functional changes, such as difficulty learning and retaining new information (difficulty in remembering events, repeating questions, not placing objects in their proper places); difficulties in performing complex activities (managing financial issues, preparing meals); problems in terms of orientation and visuospatial ability (disorientation in familiar locations); changes in language (trouble finding the right word); impairment in reasoning and ability to make decisions (difficulties in solving problems at home or at work) and behavioural changes (apathy, irritability, mistrust). If found, they point towards diagnosis (Alves & Caetano, 2010; Larson, 2016; Pinho, 2008). It should be noted that at an early stage symptoms differ from patient to patient and can therefore be difficult to recognize. It is therefore important to first ask the caregiver/family about the patient's previous personality, education and intellectual capacity (Holzer et al., 2013).

Then, information must be collected concerning the personal and family history of dementia that will aid in the differential diagnosis. For personal history, it is necessary to obtain relevant data, including cardiovascular risk factors (hypertension, diabetes mellitus, atrial fibrillation, etc.); neurological disorders (cerebral vascular accident, Parkinson's disease, Huntington's disease, etc.), psychiatric disorders (depression), infectious diseases (syphilis, HIV infection, etc.), endocrine-metabolic diseases (hypothyroidism); history of head injury; medication; alcohol, smoking and toxicological habits as well as previous surgeries (Alves & Caetano, 2010; Galvin et al., 2012; Pinho, 2008).

Age is the main risk factor for dementia. Greater susceptibility to develop this condition based on the cumulative effect of risk factors that include genetic, biological and environmental factors. Risk factors include alcohol abuse, obesity, hypertension and dyslipidaemia, while the practice of mental and social activities appear to be protective (Holzer et al., 2013).

The general physical examination is required and must include a brief neurological examination with special attention to focal neurologic signs, gait disturbance and signs of Parkinsonism ((Alves & Caetano, 2010; Larson 2016; Pinho, 2008). Causes that may affect cognitive decline such as urinary tract infection, heart failure, decreased visual or auditory acuity should be ruled out (Pond, 2012). Alterations in cardiac auscultation may suggest a vascular cause (Alves and Caetano, 2010). On suspicion of vascular aetiology of dementia, the physical examination should focus especially on the cardiovascular system. Peripheral pulses, blood pressure, body mass index (BMI) and waist circumference must be evaluated (Poggesi & Pantoni, 2009). Thyroid enlargement can mean a secondary endocrine dementia. Signs of liver disease, alcoholism and renal failure should also be looked for (Alves & Caetano, 2010).

## 1.5 - Cognitive, psychoaffective and functional evaluation

Following the clinical history it is crucial to undertake a cognitive, psycho-affective and functional assessment. The cognitive assessment helps to detect and characterize cognitive deficit. According to the standard of the General Health Directorate (DGS), No. 053 of 27/12/2011 on the therapeutic approach of cognitive changes translated tests which are adapted to the language and cultural context of the country should be used.

The brief mental status examination (Mini-Mental State Examination, MMSE) is a test that is quickly run and assesses orientation, attention, retention, language and ability to follow instructions. With a possible score ranging from zero to thirty, a score less than equal to 15 for illiterate people, less than or equal to 22 for individuals with 1 to 11 years of schooling and less than or equal to 27 for individuals with higher education, is considered cognitive impairment. This test is limited in that it is not



generally altered in the early stages of cognitive decline. Given that it does not assess executive function, it is considered to be complemented with the Clock Test (Alves & Caetano, 2010; Norma da DGS nº 053/2011; Pinho, 2008).

The Montreal Cognitive Assessment test (MOCA) is more sensitive in detecting the early stages of cognitive decline and encompasses several cognitive domains including executive function. The maximum score is 30 and a score below 26 is considered abnormal. In some instances a more extensive cognitive assessment may be necessary, with a more detailed characterization of the affected cognitive domains which should be performed by professionals, including psychologists and other professionals with proper training (Larson, 2016; Norma da DGS nº 053/2011).

Of equal importance is evaluating depressive symptoms. This can be carried out by applying the Geriatric Depression Scale. The answers compatible with depression receive one point and a 3-5 point score confirms the diagnosis. If, on the one hand, depression can interfere with cognition and be wrongly diagnosed as dementia, on the other hand, it can also be present in dementia, occurring with some frequency (Norma da DGS nº 053/2011).

The functional patient evaluation will assess the individual's performance in DLA. The questions are directed to the caregiver/family who accompanies the patient daily. The questionnaire functional activities, for example, can be used. This tool assigns a score from 0 to 3 according to whether activities are performed normally, with difficulty or help, or the individual is unable to perform the activity. A score less than or equal to 9 suggests there is functional dependency (Alves & Caetano, 2010; Pinho, 2008).

## 1.6 - Laboratory tests and other tests

To identify or rule out secondary causes of dementia or other diseases it is necessary to use an analytical assessment (Souza, Sarazin, Goetz & Dubois, 2009). The American Academy of Neurology recommends only studying thyroid function and determining vitamin B12 levels in an initial assessment of individuals with dementia. They add that to date there is no clear data supporting the routine request of other laboratory tests (Larson, 2016). Serology of HIV and Syphilis is not recommended unless there is clinical suspicion (Larson, 2016; Souza et al., 2009).

Alternatively, and according to the recommendation by DGS standard No. 053/2011, laboratory blood tests including complete blood count, blood sugar, calcemia, ionogram serum, liver function, kidney, thyroid, vitamin B12, folic acid and serologic test for syphilis should be ordered in an initial assessment. Some authors consider assessment of lipid form, homocysteine level and performing chest radiography and electrocardiography may be indicated in specific situations (Pond, 2012). Lumbar puncture should be performed in patients with atypical manifestations of dementia, as in, for example, young patients (<60 years) and rapidly progressive dementia (Larson, 2016; Souza et al., 2009). In these cases an electroencephalogram (EEG) and more specific serological tests may also be indicated (Larson, 2016).

Conducting a neuroradiological examination is indicated to rule out treatable causes of cognitive decline and to provide information to determine the specific causes of dementia (vascular changes, abscesses, subdural hematoma and normal pressure hydrocephalus) (Darrow, 2015; Norma da DGS nº 053/2011; Poggesi & Pantoni, 2009). However, the use of neuroimaging studies in patients with dementia is controversial. While some authorities advise conducting an imaging study in all patients, others limit it to patients with atypical clinical presentations (Larson, 2016; Pinho, 2008). The imaging exam chosen must be computed tomography (CT) of the skull and brain due to the lower cost and greater availability of this exam (Darrow, 2015; Norma da DGS nº 053/2011; Pinho, 2008). Magnetic resonance imaging (MRI) is superior in demonstrating brain lesions, including ischemic changes, which may be important in diagnosing vascular dementia (Norma da DGS nº 053/2011). Some authors consider that this may be useful in evaluating patients who have at least one of the following characteristics: dementia at an age under 65 years; sudden onset and rapid progression of symptoms; presence of focal neurological deficits; clinical assessment compatible with normal pressure hydrocephalus (ataxia, urinary incontinence, cognitive decline); history of recent head injury (Darrow, 2015; Pinho, 2008).

## 1.7 - Patient follow-up

After confirmation of the clinical suspicion of dementia it is essential to refer the patient in a timely manner to secondary health care in order to institute appropriate pharmacological therapy. However, in parallel, or prior to beginning drug treatment, a non-pharmacological approach should be implemented in order to stabilize or improve cognitive function and reduce psychological and behavioural symptoms which are characteristic of dementia (Alves & Caetano, 2010; Darrow, 2015; Holzer et al., 2013). This approach should be multidisciplinary and include not only the family physician but also the caregiver/family, psychologists, occupational therapists, nurses and social workers (Figure 1).

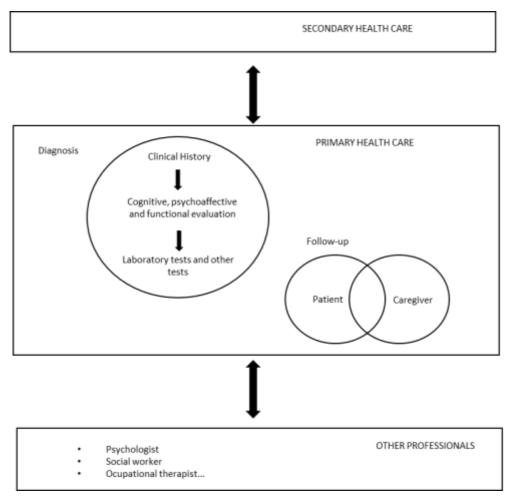


Figure 1 – Approach to dementia in primary health care

Family doctors should inform patients and caregivers on existing resources in the community that may be useful to improve the patient's quality of life, such as day centres, long-term care at home and inpatient institutions. They should also provide information about support groups and manage patients' needs as well as their families' so as to accompany patients in the course of the disease. It is also important to schedule appointments at the health unit at intervals of 4 to 6 months, and to evaluate disease progression, complications, nutritional status and health and safety at home as well as medication adherence. Conducting at least one home visit is extremely important to determine the safety conditions at home and recommend necessary adjustments where possible (Alves & Caetano, 2010).

It is important to familiarize patients with their environment (pictures, curios, etc.) and introduce a routine in their daily activities as far as possible, for example, establish a schedule for meals, medication and bedtime. Simple physical exercise and recreational activities, such as dancing, singing or playing games seem to be effective in reducing anxiety and some behavioural symptoms and are thus recommended (Darrow, 2015). It is also important to be alert to the possibility of caregiver change or the addition of new caregivers as this situation may generate agitation and confusion (Alves & Caetano, 2010).

It further worth noting the crucial role of caregiver in following up on the patient with dementia. Creating a partnership between the family physician and caregiver introduces an improvement in the approach and treatment of patients with dementia. Many caregivers are the same age or even older and consideration should be given to caregivers themselves as patients also. They are at increased risk of depression and physical illness, such as, cardiovascular and respiratory diseases and blood pressure (Galvin et al., 2012; Norma da DGS nº 053/2011). In addition to research into distress signals (complaints of stress, sleep disturbance and others), overload, or psychiatric symptoms, caregiver assessment should also focus on their knowledge about the disease, expectations of treatment and services, quality of the patient-caregiver relationship and family conflicts (Boustani et al., 2007; Norma da DGS nº 053/2011). Evaluating the caregiver's health status can lead to the implementing measures to minimize patient/caregiver conflict and allow delaying patient institutionalization (Galvin et al., 2012).



## CONCLUSION

The increase in the elderly population in Portugal has been accompanied by an increase in the number of cases of dementia. According to population projections, it is estimated that in the coming decades, this figure will continue to grow.

This is a complex and progressive condition characterized by changes in memory, behaviour, personality and overall functioning, whose diagnosis is essentially clinical but is not always easy in the early stages. Family physician, with their close relationship with patients and in following them over the years, are thus in a prime position for the early detection of dementia.

Given the suspicion of dementia, it is advisable to evaluate the patient in at least two consultations and the medical history should be extended to a caregiver/close relative of the patient. This should be based on personal history, family history, previous personality and the patient's level of education. Additionally, there should be to a cognitive, psychoaffective and functional assessment and laboratory and imaging tests should be requested to clarify the diagnosis and rule out a secondary cause.

The role of the family and other PCH professionals should not be limited to the initial assessment, but should also be extended to follow-up and guidance of the patient and their respective family members/caregiver in close coordination with the various stakeholders that make up the network of patient support.

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