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Evaluation of special care facilities for people with neurodegenerative diseases

Report

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2021-104R
July 2022

SUMMARY

[1] This report, written at the request of the Minister of Solidarity and Health as part of the preparation of the new neurodegenerative diseases roadmap, concerns the special care facilities in the city and in institutions for people suffering from Alzheimer's disease or a related disease (Lewy body disease, Parkinson's dementia, vascular dementia and frontotemporal lobar degeneration).

[2] Alzheimer's disease and the sometimes severe cognitive, psychological and behavioural disorders associated with it (apathy and depression, but also aggressiveness, anxiety and sleep disorders) represent a major public health issue because of the number of people concerned (1.2 million people directly affected in France today, including more than one in three people aged 90 and over, and almost twice as many in France in 2050; one new case every three seconds in the world) and the costs of all kinds that it imposes on them, on their relatives and their families and on society, being in particular the first cause of dependence and disability among the elderly according to the WHO. The majority of residents in long-term care facilities now suffer from Alzheimer's disease or a related illness, and this proportion will increase in the years to come.

[3] Progress in research into the nature of Alzheimer's disease and related disorders, in understanding the risk factors that can be acted upon to delay or even prevent the onset of the disease, in non-medicinal interventions, which are increasingly used because of their recognised impact on quality of life, and in drug treatments, should lead to increased efforts at prevention and early treatment in the future.

[4] The special care facilities that exist today have been gradually developed in towns and institutions, particularly after the 2008-2012 Alzheimer's plan. At the beginning of 2022, there were 1,921 « Pôles d'activité et de soins adaptés » (PASA), 333 « Unités d'hébergement renforcé » (UHR), 145 « Unités cognitivo-comportementales » (UCC) and 505 « Equipes spécialisées Alzheimer » (ESA). There were also Alzheimer's living units (UVA) in just over 40% of the EHPADs.

[5] The development of such a range of special care and legally defined facilities is quite original at the international level. It is probably due to the very French desire for uniform and equal deployment throughout the country and to the requirements of the EHPAD funding system, which is based on complex co-financing between health insurance, departmental councils and residents. Although there are similar services abroad, which were identified during interviews and field visits, they mainly resemble Alzheimer's living units or reinforced accommodation units. PASAs, UCCs and ESAs do not seem to have many equivalents.

[6] In general, the special care facilities have responded well, on the whole, to the needs of people with Alzheimer's disease and related disorders and have been a vehicle for change in their care.

[7] The contribution of special care facilities is recognised by the vast majority of stakeholders: health professionals, social and medico-social professionals, families, representatives of people with Alzheimer's disease or a related disorder, administrations, etc. In the case of moderate or severe disorders, special care facilities open the way to solutions for the people concerned and, consequently, to prospects for the staff who support them. According to the available surveys, the special care facilities are well targeted overall. They have made it possible to professionalise and protocolise the care of people, while allowing the gradual integration of architectural and interior design elements, as well as non-medicinal interventions, into the reality of many institutions.

[8] The fact remains that the special care facilities have limitations and drawbacks that are becoming increasingly apparent in the field.

[9] On the one hand, in addition to the general shortage of health professionals (doctors, paramedics, etc.) in towns and cities to meet the needs of elderly people at home, there is still a very significant shortage of special care facilities, particularly when psychological and behavioural disorders appear in people with Alzheimer's disease or a related illness. Thus, only 50,000 people can benefit from ESA services each year, i.e. less than 5% of the total number of people with Alzheimer's disease or a related illness. In addition, a large part of the country is not covered, resulting in long waiting lists. Finally, the services offered by the ESAs are not sufficient to meet the needs of patients whose situation is too deteriorated.

[10] Secondly, a similar deficit exists in the establishments, despite the investment efforts made. Thus, the number of PASAs, UHRs, UCCs and UVAs remains modest in relation to the total number of EHPADs and the characteristics of their populations. Nearly half of the EHPADs have no facilities at all in their establishments and nearly one EHPAD in three has only an isolated Alzheimer's unit. Only 26% of EHPADs have a PASA, which means that only 10% of people living in EHPADs can benefit from a PASA, while it is estimated that the number of residents with Alzheimer's disease or a related illness now exceeds 50% of the total number of residents. Less than 3% of EHPADs have a UHR and only about 1% of residents with Alzheimer's or a related disease have one. The number of places in Alzheimer's living units represents less than 10% of the total number of places in EHPADs.

[11] There are also many difficulties in the operation and organisation of special care facilities, due in particular to the limits of their specifications (e.g. the overly rigid operation of PASAs) and serious recruitment problems, which certainly go beyond the specific case of special care facilities, but concern, for example, the lack of psychiatrists in the UHRs and UCCs.

[12] The sequential approach adopted in France, which provides for a to-and-fro between a special care facility and the person's usual place of residence (or the ordinary EHPAD), does not work well in practice: the length of stay in UHRs, in particular, is very long and there are few discharges from this facility. And it has inherent flaws for increasingly elderly and vulnerable residents, half of whom reside in EHPAD for only a year and two months before they die, and above all need stability in their environment. Bringing together people with severe disorders in the same unit can also sometimes even aggravate their disorders and result in too rapid a burnout of staff.

[13] Basically, the investment in special care facilities since 2008 has been made, in a way, at the cost of a global transformation of the EHPADs sufficient to adapt them to the rapid change in the profile of their residents, who now mostly suffer from Alzheimer's disease or a related illness, and who have cognitive, but also psychological and behavioural disorders that are sometimes severe.

[14] Under these conditions, it is now desirable to improve prevention efforts and to prioritise investments in increased and improved care for people with Alzheimer's disease or a related illness in the city, as well as in ordinary places in establishments better adapted to the needs of their new residents.

[15] With regard to prevention, the mission recommends that health education campaigns should be targeted at the risk factors for Alzheimer's disease, many of which are now well identified, with particular emphasis on hearing and depression.

[16] In terms of care in towns and cities, the mission recommends, as a priority, setting the objective of doubling the number of ESA beneficiaries within the framework of the new neurodegenerative diseases roadmap, or in any case for the years 2023-2025. The priority will be to cover departments with a shortage of services and to expand the range of ESA services for people with Alzheimer's

disease or a related illness with moderate to severe psychological and behavioural disorders. This is likely to prevent these disorders from worsening and to delay entry into institutions.

[17] With regard specifically to institutions, the mission makes several key recommendations. The first is to undertake an overall transformation of all EHPADs, and not just certain facilities within them, to adapt them to the significant influx of people with Alzheimer's disease or a related illness with moderate to severe psychological and behavioural disorders. In order to have adequate staff resources and the means to adapt the premises, it is essential to reform their funding: it is therefore essential to reform the AGGIR grid and the PATHOS reference system so that the severity of cognitive disorders and psychological and behavioural disorders is better taken into account in the funding of all establishments.

[18] Five other recommendations are also priorities for EHPADs. Firstly, the effective presence of gerontological care assistants (ASG) at night in EHPADs should be increased, by adapting this presence according to the size of the establishments and the profile of the residents. It is also necessary to implement, with appropriate support for EHPAD directors, architectural recommendations that are suitable for residents with Alzheimer's disease or a related illness with psychological and behavioural disorders for the EHPAD renovation and construction programme, and to establish and implement equally appropriate interior design recommendations, which are well identified internationally. Thirdly, it is recommended that specifications for Alzheimer's living units be drawn up, adapted to the severity of the cognitive, psychological and behavioural disorders of residents with Alzheimer's or related diseases.

[19] Similarly, it seems essential to encourage the development of EHPADs without closed living units and, because of the need to respect people's dignity, to draw up and disseminate legal and organisational guidelines applicable to all establishments on physical and chemical restraints and restrictions on movement. The mission's recommendations are rounded out by doubling the number of PASAs over the next three years and making their operating procedures more flexible.

[20] In conclusion, the mission recommends opening a UCC in the ten or so departments that lack one and halting the deployment of UHRs, while developing their links with the geriatric sector.

RECOMMENDATIONS OF THE MISSION

n°	Recommendation	Priority	Responsible authority	Deadline
Better prevention of exposure to risks and improved early identification and treatment				
1	Conduct national health education campaigns on risk factors for Alzheimer's disease, especially those related to hearing and depression	1	DGS/SPF/ CNAM	2022-2025
2	Experiment with the creation of a regional register of psychological and behavioural disorders	2	DGS/SPF/ARS	2024
3	Launch calls for projects in a few departments for studies analysing the health and social pathways of people with Alzheimer's disease or a related illness with cognitive, psychological and behavioural disorders	3	DGS/SPF/ARS	2023
4	Launch in each region a programme of support by the ARS and the health insurance, in conjunction with the URPS, for the 10% of accommodation establishments with the highest rate of psychotropic drug prescriptions	2	DGCS/DGOS/ ARS/Sickness Insurance	2023
5	Create a national multidisciplinary centre of expertise dedicated to the evaluation of non-medicinal interventions, starting with those adapted to psychological and behavioural disorders, and to the dissemination of good practice in their use in institutions, in special care services and among professionals in the community	2	DGOS	2024
Better support for people and their caregivers at home				
6	Better coordination of ESAs with attending physicians, medical auxiliaries and other existing services (day care centres, day hospitals, respite care platforms, etc.)	3	DGCS/DGOS/ ARS	2023
7	Create a mechanism to coordinate a national network of ESAs, possibly also including other forms of day care in the city	2	CNSA	2023
8	Double the number of ESA beneficiaries within the framework of the MND roadmap by covering, as a priority, the departments with a shortage of services and by expanding their offer of services for people with Alzheimer's disease or a related disorder with moderate to severe psychological and behavioural disorders	1	DGCS/CNSA	2023-2025
9	Fund local innovations to support people with Alzheimer's disease or a related disorder with moderate to severe psychological and behavioural problems	3	DGOS/DGCS/ CNSA/ARS	2023-2025
10	Develop training for carers and various distance support services for carers and relatives	2	DGCS/CNSA	2023-2025
Transforming nursing homes to accommodate new residents				
11	Undertake a comprehensive transformation of all EHPADs to adapt them to the significant influx of people suffering from Alzheimer's disease or a related illness with moderate to severe psychological and behavioural disorders	1	DGCS/CNSA/ Departments	2023-2025
12	Reform the AGGIR grid and the PATHOS reference system to better take into account the severity of cognitive disorders and psychological and behavioural disorders in the financing of all establishments	1	DGCS/CNSA/ Health insurance	2023
13	Experiment with a specific package for the financing of non-medical interventions in institutions	2	DGCS/CNSA/ Health insurance	2023

n°	Recommendation	Priority	Responsible authority	Deadline
14	Strengthen the presence of ASGs at night in EHPADs, adapting it according to the size of the establishments and the profile of the residents	1	DGCS/CNSA	2023-2025
15	Develop awareness-raising and training programmes, particularly at a distance, for all staff working in EHPADs in contact with residents with psychological and behavioural disorders	3	DGCS/CNSA	2023-2025
16	Implement, with appropriate support for EHPAD directors, architectural recommendations adapted to residents with Alzheimer's disease or a related illness with psychological and behavioural problems for the EHPAD renovation and construction plan for the period 2021-2025 and establish and implement recommendations for adapted interior design	1	DGCS/CNSA	2023-2025
17	Draw up specifications for Alzheimer's living units adapted to the severity of cognitive, psychological and behavioral disorders of residents with Alzheimer's disease or a related disorder	1	DGCS/CNSA	2023
18	Encourage the development of EHPAD without closed living units	2	DGCS/CNSA	2023-2025
19	Evaluate the impact of existing Alzheimer EHPADs and Alzheimer villages in France and abroad before extending them	3	DGCS/CNSA	2023
20	Develop and disseminate legal and organizational guidelines for all facilities on physical and chemical restraints and restrictions on movement	1	DGCS/DGOS/ HAS	2023
21	Double the number of PASAs under the new MND roadmap and make their operation more flexible	1	DGCS/CNSA	2023-2025
22	Strengthen the social life of residents and the structuring of their days in all establishments by offering more activities	2	DGCS/CNSA/ Departments	2023-2025
Optimizing crisis management				
23	Strengthen the national steering of CCUs and RHUs	3	DGCS/DGOS	2023
24	Open a CCU in departments that do not have one	2	DGOS	2023
25	Ensure the territorial outreach of CCUs by pooling their resources through the use of tele-expertise and tele-consultation	2	DGOS	2023-2025
26	Develop, in the absence of available human resources, the use of tele-expertise, and if necessary tele-consultation, of psychiatrists in CCUs	3	DGOS	2023-2025
27	Provide mobile geronto-psychiatric or psycho-geriatric units, possibly attached to the CCUs, to provide emergency assistance at home or in institutions in crisis situations	3	DGOS	2023-2025
28	Stop the deployment of RHUs on the national territory	2	DGCS/DGOS/ CNSA	2023

n°	Recommendation	Priority	Responsible authority	Deadline
29	Develop the articulation of the UHR with the geriatric network and in support of the EHPAD	3	DGCS/DGOS/ CNSA	2023-2025

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REPORT

Introduction

[21] The 2008-2012 Alzheimer's plan, the 2014-2019 neurodegenerative disease plan and the 2020-2021 neurodegenerative disease roadmap, which have followed one another over the past fifteen years, have led to the creation of a national network of various special care facilities for people with Alzheimer's disease and related disorders, particularly those with moderate to severe psychological and behavioural disorders, both in the city and in institutions. These people are among the most vulnerable and difficult to care for in the health and social care system.

[22] While Professors Jeandel and Guérin made recommendations concerning these facilities in their report on USLDs and EHPADs submitted in June 2021[1] , the evaluation report on the 2014-2019 neurodegenerative disease plan written in 2020 by Professors Grand and Joanette[2] suggested that impact studies be carried out to better determine their adequacy to current and future needs.

[23] In the context of the elaboration of a new roadmap for neurodegenerative diseases and the next social security financing bill, the question posed to the Inspectorate General of Social Affairs by the letter of assignment from the Minister of Solidarity and Health, Olivier Véran, dated 3 November 2021, is precisely to know to what extent these special care facilities meet current and future needs and whether their development should be pursued or changed.

[24] The societal and public health issues related to people with Alzheimer's disease or a related disorder[3] are considerable. The prevalence of Alzheimer's disease and related disorders is already very high: approximately 1.2 million people are directly affected, and more than one person in three aged 90 and over is affected. This prevalence will increase significantly in the coming years: between 2.2 and 2.3 million people will be affected in our country by 2050. The costs of Alzheimer's disease and related disorders are very high for society, for the individuals concerned and for their families and friends.

[25] The analysis of the mission letter carried out by the mission, in conjunction with the sponsors, led to the definition and distinction of two very distinct evaluation fields:

- On the one hand, the evaluation of specialized home-based (ESA) and institutional (PASA, UHR, UCC and also Alzheimer's living units, which are not mentioned in the mission statement) care for people with Alzheimer's disease or a related disorder and, in particular, those with moderate to severe psychological and behavioral disorders[4] . It is the subject of this summary report. The situation of people suffering from multiple sclerosis, amyotrophic lateral syndrome (ALS) and Parkinson's disease, who do not have psychological and behavioural disorders, was excluded from the scope of the evaluation, as was the financial aspect;

[1] Claude Jeandel and Olivier Guérin, *Pour une prise en soin adaptée des patients et des résidents d'EHPAD et d'USLD*. July 2021.
[2] Alain Grand and Yves Joanette, *Evaluation report of the national neurodegenerative diseases plan 2014-2019*. October 2020.
[3] The terminology used in France differs from the international terminology. The term "Alzheimer's disease or related disorders" is specific to France. Internationally, the term "dementia" is used and covers more or less the same group: Alzheimer's disease, Lewy body disease, vascular dementias, frontotemporal dementias and dementias linked to Parkinson's disease. In the remainder of the report, the mission will use the term "Alzheimer's disease or a related disorder" because of the pejorative connotation associated with the term dementia in our country.
[4] Other terms include "major neurocognitive disorder", "neuropsychiatric disorder" and "psychological and behavioural symptoms of dementia" (PBSD).

- On the other hand, the evaluation of the Parkinson's expert centres, which are hospital-based research and treatment units for people with Parkinson's disease at all stages of the disease[5] .

[26] Arrangements for relatives and carers of people with Alzheimer's disease and related disorders (respite care platforms, etc.) have not been evaluated, but another mission by the General Inspectorate for Social Affairs, currently under way, will shed light on this subject.

[27] The mission, composed of Dr Nicole Bohic, Inspector General, Delphine Corlay, Inspector General, and Louis-Charles Viossat, Inspector General, conducted its work between the beginning of January 2022 and the end of May 2022. It met with nearly 200 stakeholders in Paris and in the territories, in the course of several dozen face-to-face or video-conference meetings. The mission also visited health and medico-social establishments in five regions (Brittany, Grand-Est, Hauts-de-France, Ile-de-France, Centre-Val-de-Loire). It met by videoconference with the vast majority of regional health agencies, which responded to a detailed questionnaire. It also carried out and used national surveys with EHPADs and USLDs, ESAs, patient associations and carers themselves, as well as with Parkinson's expert centres.

Investigations carried out by the IGAS mission

In the absence of sufficient up-to-date data on many aspects of its scope of investigation, the mission decided to carry out a series of online questionnaire surveys with patient associations, family carers living in EHPADs and USLDs or at home, EHPADs, USLDs as well as ESAs and Parkinson's expert centres.

Thanks to the support of France Alzheimer, the main federations and organisations in the sector (FHF, FEHAP, Synerpa and UNCCAS for EHPADs and USLDs, as well as ANARESSIAD and ADEDOM for ESAs), more than 1,200 responses, containing quantitative and qualitative data, were received, which constitutes a very large sample. Thus, 780 EHPADs responded to the survey, from all French departments and Martinique. 120 USLDs also responded to the mission, present in 60 departments in France and Martinique. 260 ESAs throughout France, with the exception of 12 French departments, participated in the survey. 37 departmental associations that are members of France Alzheimer also responded, as well as 96 family carers of people with psychological and behavioural disorders living in ordinary homes and 50 family carers of people with psychological and behavioural disorders living in EHPAD or USLD.

The results of these original surveys were analysed by the mission in seven separate annexes. They provide input for the findings and proposals in the appendices devoted to the various special care facilities and in the summary report.

[28] The mission's work had to take into account the lack of available data and studies on the special care facilities themselves, on current and future care needs, due to the lack of sufficiently detailed and precise knowledge of certain characteristics (particularly psychological and behavioural disorders) of people with Alzheimer's and related diseases, and on the impact of the special care facilities on the people themselves, in terms of their state of health and quality of life, and on their families and loved ones or their staff.

[29] This summary report, which contains twenty-nine recommendations, is supplemented by fifteen annexes.

[30] In its first part, the report stresses that the significant changes in the prevalence of Alzheimer's disease and related disorders require changes in prevention and care for people suffering from them (I). It then shows that the various special care facilities have met the needs of people with Alzheimer's disease and related disorders, but that they now offer a graduated response that is insufficient in

[5] It is the subject of a separate annex and is not included in the summary report.

volume and whose limitations are increasingly evident (II). Lastly, it recommends that priority be given to investments in increased care in the city and in the ordinary places in institutions that have been reformed to meet the needs of their new residents (III).

1 The significant and rapid changes in the prevalence of Alzheimer's disease and related disorders require changes in the prevention and care of people with the disease

[31] Faced with a rapid increase in the prevalence of Alzheimer's disease and related disorders, the progress made in prevention, research on drug treatments and non-drug interventions is numerous and far-reaching. They are bound to have significant consequences for the special care facilities which are the subject of this evaluation: in quantitative terms, on the one hand, but also by placing greater emphasis than at present on early diagnosis, prevention and care of people, including at home.

1.1 Neurodegenerative diseases, including Alzheimer's disease, are accompanied by psychological and behavioural disorders that are sometimes very severe

1.1.1 Neurodegenerative diseases, with Alzheimer's disease and related disorders at the forefront

[32] Neurodegenerative diseases, or neuro-evolutionary diseases, are chronic progressive diseases affecting the central nervous system which, according to the 2014-2019 neurodegenerative disease plan, have several characteristics in common: they are often very disabling conditions and, for the most part, have no curative treatment; they have common mechanisms but the nervous system is affected in a diverse and localised manner, which explains the diversity of symptoms; finally, when the onset of the disease occurs late, the effects of ageing are added to the consequences of the disease.

[33] Alzheimer's disease and related disorders are the main forms of neurodegenerative diseases. Parkinson's disease and multiple sclerosis are also examples, but are actually quite different. On the other hand, Alzheimer's disease is the most common form of dementia in the sense recognized by WHO. It is the subject of this report and is characterised by the presence of marked impairment in two or more cognitive domains relative to what is expected, taking into account the person's age and general level of previous cognitive functioning.

[34] Alzheimer's disease is named after a German psychiatrist and neurologist (Alois Alzheimer, 1864-1915) who, in 1906, first associated the symptoms of dementia with specific brain lesions, now identified as extracellular deposits of beta-amyloid protein and intracellular deposits of tau protein. It accounts for at least two-thirds of dementia cases and is characterized by the slow evolution, over many years, of neuronal damage (asymptomatic stage) and then by the secondary and progressive appearance of symptoms (prodromal stage and then dementia stage, which is reached when cognitive and behavioral disorders affect activities of daily living). There are usually three stages of dementia: mild, moderate and severe.

[35] Other diseases are said to be "related" to Alzheimer's disease and constitute other origins or forms of dementia. Mixed forms of dementia are nevertheless very common in the elderly. In particular, there are:

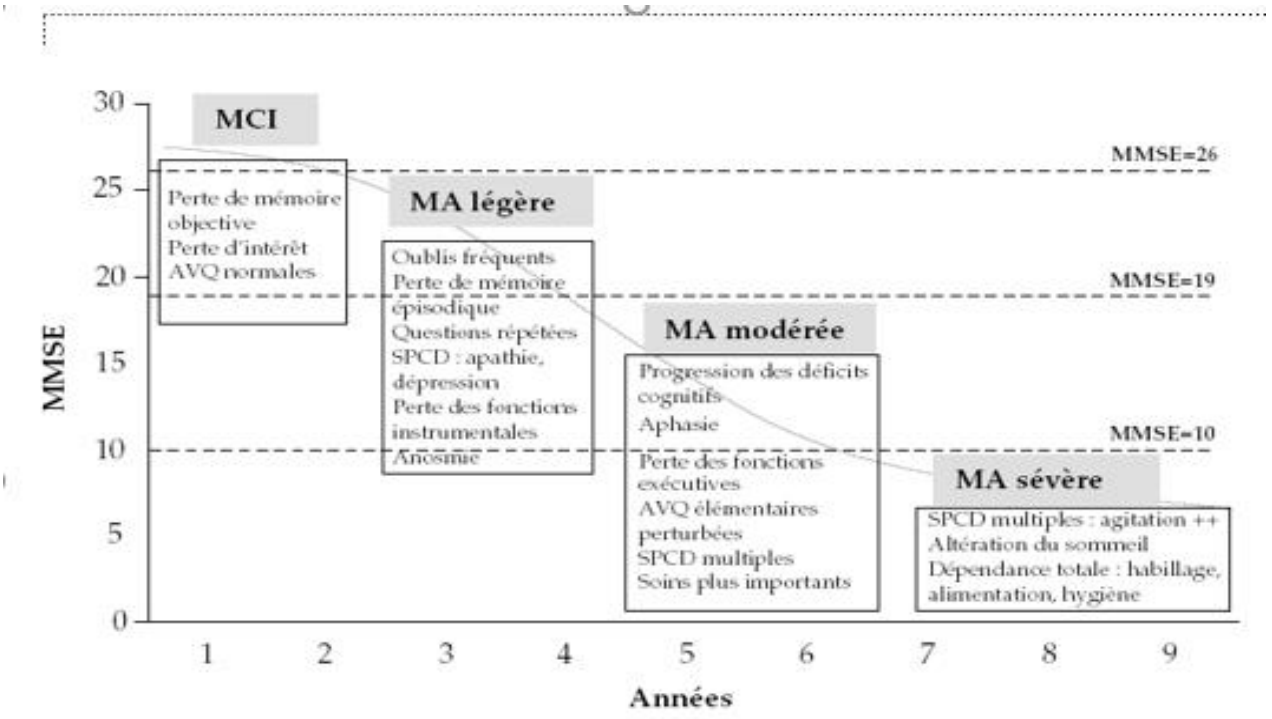
- Lewy body disease, which is characterized in particular by the presence of early hallucinations, mainly visual, fluctuating cognitive disorders, nocturnal agitation, anxiety, hyper-sensitivity and aggressiveness ;

- Parkinsonian dementia, which is reportedly observed in 20% to 30% of patients followed for several years for Parkinson's disease;
- Vascular dementia, related to ischemic or hemorrhagic vascular injury, and often mistaken for post-stroke depression or fatigue, which is characterized by, among other things, decreased cognitive functioning and emotional irritability, impulsivity, and lability ;
- Frontotemporal lobar degeneration, which is the least common except in young people and is often familial.

1.1.2 Neurocognitive disorders and psychological and behavioural symptoms that are sometimes very severe and often hidden

[36] Alzheimer's disease and related disorders have progressive and significant consequences on cognition: memory disorders (episodic memory, etc.), language disorders (lack of words, etc.), praxis disorders (difficulty positioning objects in space, performing gestures, etc.), executive function disorders and recognition disorders.

Schéma 1 : Progression of stages and symptoms of Alzheimer's disease



Source : From Feldman & Woodward, 2005

[37] They also have consequences, sometimes very severe, on the behaviour of people with dementia. Psychological and behavioural disorders, otherwise known as psychological and behavioural symptoms of dementia (PBSD) or neuropsychiatric disorders, were recognized by the International Psychogeriatric Association in the 1990s, but are still sometimes denied by the people themselves, their families and loved ones, as well as by health professionals.

[38] The French National Authority for Health (HAS) defines them as "attitudes or expressions judged by those around them (carers, relatives, professionals working with the patient, other patients, etc.) to be disturbing, disruptive or dangerous for the person or for others, which may be

observed during Alzheimer's disease and most related diseases". These symptoms are different from one another, but they share common characteristics: they vary greatly from one person to another, are very complex, fluctuate greatly in intensity and frequency, are interdependent and often associated.

[39] It is estimated that the vast majority, at least 60%, of people with dementia suffer or will suffer from at least one psychological and behavioural disorder, with a very significant proportion suffering from several symptoms at once. The expression of the different symptoms of dementia varies according to the disease; some, such as Lewy body disease, are particularly accompanied by significant anxiety and hallucinations, while cognitive impairment may be less. A good understanding of the disease and its associated disorders is important to better support each person.

[40] A significant portion of the time and stress of family members and caregivers, who are neither prepared nor trained to identify and manage them, is directly related to them, more than to cognitive and somatic disorders.

[41] The main psychological disorders observed in people are delusions, hallucinations, illusions, depression, apathy and anxiety. The main behavioural disorders are wandering, agitation and aggression, resistance to care, but also inappropriate sexual behaviour, and sleep and eating disorders.

[42] The most difficult to manage by families, relatives and staff in institutions are hallucinations, violence and disinhibition, as shown by the survey carried out by the mission. In contrast, apathy, which is the most frequent symptom, as well as other deficit or withdrawal disorders are less complicated to manage. They seem, moreover, to be associated with more severe forms of cognitive deterioration.

Alzheimer's Disease Rating Scales

The purpose of the NPI-ES (Psychiatric Inventory - Caregiver Version) is to collect information on the presence of one of the twelve most common symptoms of dementia and the impact on the caregiver or professional. The NPI-ES was developed to assess patients living in institutions. There is also a shorter version that can be completed more quickly at home by the caregiver or professional. The NPI-ES can be used by an external assessor or directly by a member of the care team. Ten behavioural domains (delusions, hallucinations, agitation and aggression, depression and dysphoria, anxiety, mood elevation and euphoria, apathy and indifference, disinhibition, irritability and mood instability, and aberrant motor behaviour) and two neuro-vegetative variables (sleep, appetite/appetite disturbance) are included in the NPI-ES. The total NPI-ES score is calculated by adding up all the scores of the different domains.

Nom: Age: Date de l'évaluation:

Fonction de la personne interviewée: **Type de relation avec le patient :**
Très proche/ prodigue des soins quotidiens;
proche/ s'occupe souvent du patient;
pas très proche/ donne seulement le traitement ou n'a que peu d'interactions avec le patient
NA = question inadaptée (non applicable) F x G = Fréquence x Gravité

Items	NA	Absent	Fréquence	Gravité	F x G	Retentissement
Idées délirantes	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Hallucinations	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Agitation/Agressivité	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Dépression/Dysphorie	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Anxiété	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Exaltation de l'humeur/ Euphorie	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Apathie/Indifférence	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Désinhibition	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Irritabilité/Instabilité de l'humeur	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Comportement moteur aberrant	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Score total 10					[ ]	
Changements neurovégétatifs						
Sommeil	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Appétit/Troubles de l'appétit	X	0	1 2 3 4	1 2 3	[___]	1 2 3 4 5
Score total 12					[ ]	

The MMSE (Mini-Mental State Examination) test consists of a series of thirty questions (for example: *Show me a pencil. What is the name of this object?* or *Would you like to count from 100 and take out 7 each time?*) divided into six categories (orientation, learning, attention and calculation, language, constructive praxis), and scored out of 30 points. They allow a global cognitive evaluation to be carried out, to orientate towards a diagnostic approach or to follow the evolution of the disease already diagnosed. The degree of severity of the dementia is considered as mild with a score above 20, moderate between 10 and 20 and severe below 10.

Several ESA teams that responded to the mission's survey stated that assessment by the MMSE is not always possible, for various reasons: patient refusal, major anxiety, phasic disorders, deafness, speaking a foreign language, etc.

The MMSE was originally a diagnostic test. It is now also used to monitor the evolution of the disease. During mild to moderate forms, this test can be experienced as a trial for the person. This may explain why ESAs, which are carried out after diagnosis, are often opposed or even refused by patients who fear that they are being set up to fail.

1.2 A major public health and social issue

[43] In 2019, according to the WHO, there were 55.2 million people worldwide, including 21.4 million in high-income countries, with dementia, about half of them with mild dementia and just over 13 million with a severe form. And there is a new case of the disease every three seconds worldwide.

[44] In France, the number of people with Alzheimer's disease or a related illness was around 1.2 million. In the same year, the prevalence of dementia was 1.5% of the population on average in the OECD, with France at around 2%, on a par with Italy and Germany, behind countries such as Poland and Ireland at around 1%.

Young patients

The number of young people affected by Alzheimer's disease or a related illness is not well known. According to the DREES in 2017, there were approximately 35,000 people aged 40 to 64 with Alzheimer's disease or a related disorder, including nearly 20,000 men and 15,000 women. According to France Alzheimer, there are 5,000 new young Alzheimer's patients diagnosed each year.

The rare cases of hereditary forms of Alzheimer's disease usually develop early, in relatively young patients. However, not all young patients have an inherited form of dementia.

Often misunderstood by family and friends, the disorders of young Alzheimer's patients are frequently attributed to depression or other mental illnesses. This is detrimental to younger patients: the delay in diagnosis after the first symptoms of Alzheimer's disease is estimated at five years, compared to three years for patients over 65.

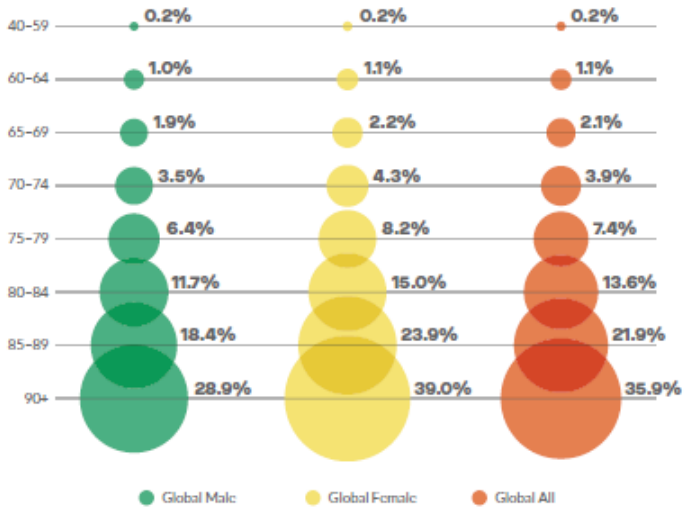
Young patients have a very different profile from that of older people with Alzheimer's disease. They most often live at home, and nursing homes, which are not accessible to them unless they are exempted under the age of 60, are not really suitable for them. Their care is even more difficult than for older people. The survey of ESAs carried out by the mission shows how important these structures are for the care of young patients.

As part of the 2008-2012 Alzheimer's plan, a National Reference Centre for Young Alzheimer's Disease was created in 2009. Three memory centres in France have been selected because of their experience to form this CNR-MAJ: Lille-Bailleul; Rouen and Paris-Salpetrière, each with specific missions.

Source : DREES, France Alzheimer

[45] The prevalence of dementia also varies greatly with age. It is higher in women, for reasons that are not yet fully understood. Early forms of the disease appear between the ages of 30 and 60, but fortunately they are rare. The prevalence doubles approximately every five years from the age of 60 and exceeds 35% over the age of 90 worldwide.

Schéma 2 : Prevalence of Alzheimer's disease in the population by age and gender worldwide



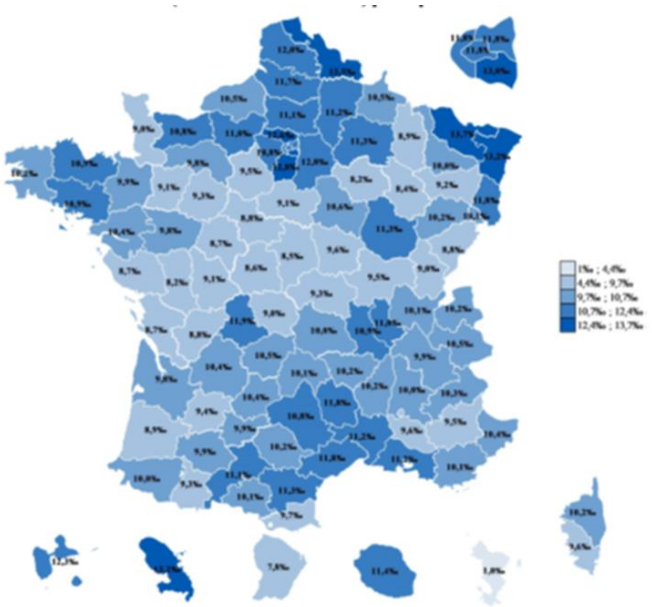
Source : WHO, 2022

Imperfect knowledge of the epidemiology of Alzheimer's disease and related disorders and their under-diagnosis

The exact number of people affected by neurodegenerative diseases in France, both in the general population and among residents of nursing homes, is not well known. Estimates are neither sufficiently reliable nor sufficiently complete and up-to-date. The creation of the National Alzheimer's Data Bank (BNA) within the framework of the 2008-2012 Alzheimer's plan should, in principle, constitute an epidemiological surveillance tool but, in practice, due to the quality of the data and the representativeness of the patients, it does not, for the moment, make it possible to provide reliable or robust epidemiological data.

Santé Publique France's surveillance of neurodegenerative diseases is mainly focused on Alzheimer's disease, since 2014 only, and on Parkinson's disease, a little earlier, in a context of limited resources. All data are based on cohort data, some of which are old and have been closed (PAQUID cohort for example, formed in 1988, and the 3 cities cohort, Bordeaux-Dijon-Montpellier, formed in 1999). SPF therefore uses the prevalence rates of these cohorts by applying them to the current population. The possible decline in incidence is not taken into account in the projections, which are made on the assumption of a stable incidence.

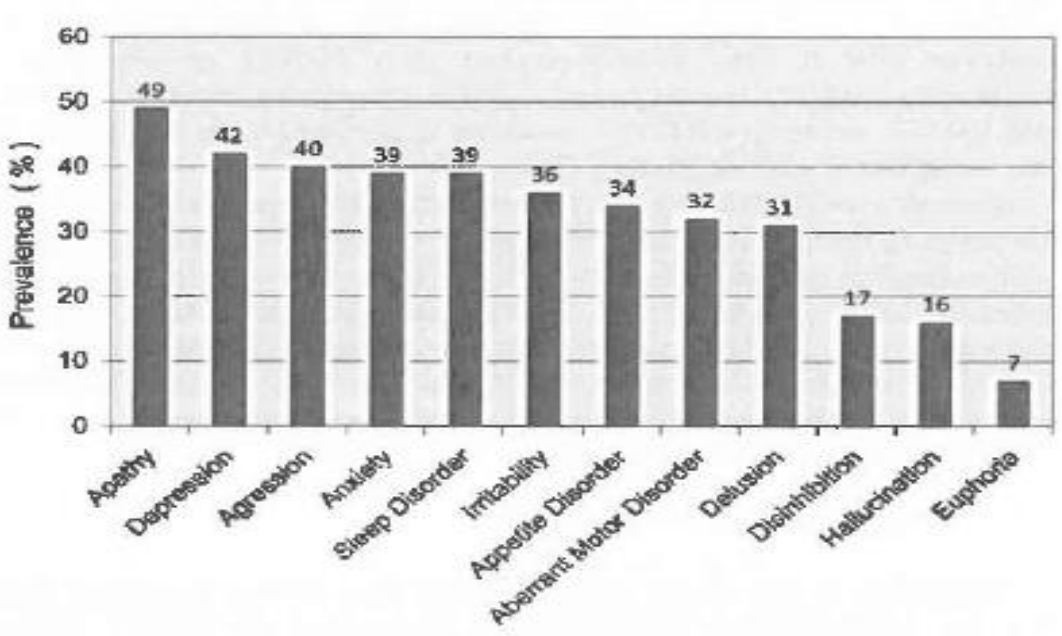
The SNDS data underestimate the number of people affected, as they are far from being all treated, particularly among the elderly. Nevertheless, we can obtain interesting information on the variation in prevalence by department.



Alzheimer's disease and related disorders are under-diagnosed, even at a relatively advanced stage. The WHO and OECD estimate that only half of all cases are diagnosed. And when a diagnosis is made, most often by the treating physician, it is usually made late. It is, in fact, difficult today to detect the disease in its early stages, just like what is called "mild cognitive impairment".

[46] Psychological and behavioural disorders, which are characteristic of Alzheimer's disease and related disorders, significantly complicate their management in both urban and institutional settings. According to international studies, apathy is the most prevalent psychological and behavioural disorder, followed by depression, aggression, anxiety and sleep disorders.

Graphique 1 : Frequency of psychological and behavioural disorders



Source : Zhao, 2015

[47] The recent report written by Professors Jeandel and Guérin on long-term care facilities (USLDs) and long-term care homes (EHPADs) estimates that depressive states, anxiety states and psychoses, delusions and hallucinations are the most frequent disorders among residents of long-term care facilities (USLDs) and long-term care homes (EHPADs).

[48] In Australia, according to Professor Henry Brodaty[6], 30% of people suffering from dementia have mild psychological and behavioural disorders (insomnia, wandering, mild depression, apathy...), 20% have moderate psychological and behavioural disorders (severe depression, verbal aggression, psychosis, sexual disinhibition, wandering...), 10% have severe psychological and behavioural disorders (severe depression, psychosis, shouting, severe agitation...) and finally, less than 1% have very severe psychological and behavioural disorders.), 10% would have severe psychological and behavioural disorders (severe depression, psychosis, shouting, strong agitation...) and, finally, less than 1% would have very severe psychological and behavioural disorders (physical aggression, severe depression, suicidal tendencies...). Only a few people would have extreme psychological and behavioural disorders (physical violence).

[49] The mission's survey of EHPADs and USLDs generally confirms these hypotheses in the French case. Thus, in the 746 EHPADs that responded to the question in the survey conducted by the Mission, 66% of residents have cognitive problems with or without behavioural problems, and 82% of establishments state that at least 50% of their residents have cognitive problems with or without behavioural problems. Among the 739 EHPADs that answered the question on behavioural problems, the results are even more demonstrative of the difficulties encountered by EHPADs. 65% of residents have behavioural problems, which are distributed as follows, according to NPIES scores

- 22% have mild disorders (median 18%);
- 22% have moderate disorders (median 20%);
- 16% have severe disorders (median 14%);
- 5% have acute disorders (median 2%).

[50] Dementia was the seventh leading cause of death worldwide in 2019, the year before the Covid epidemic, according to the WHO, and the fourth leading cause of death for people aged 70 and over, and even the leading cause in high-income countries in the Asia-Pacific region, according to the Institute of Health and Metrics Evaluation (IHME) in Seattle. It is the fastest growing cause of death since 2000[7] .

[51] An estimated 1.64 million people worldwide will die from dementia in 2019, accounting for about 3 per cent of all deaths, including just over 800,000 in high-income countries. Women would have accounted for two thirds of the deaths.

[52] In France, according to the health insurance, the average age at death is 88 years, for an age of onset (diagnosis) of the disease of about 75 years.

[6] Henry Brodaty, *Behavioural and psychological symptoms of dementia: A seven-tiered model of service delivery*, The Medical Journal of Australia, April 2003.
[7] The mission did not find reliable French mortality data for 2019 or for other years.

[53] Although the WHO estimates that dementia is the leading cause of dependency and disability among older people, the international institution ranks dementia only 25th in the world in terms of disability-adjusted years of life lost[8] .

Tableau 1 : Alzheimer's disease among top 10 causes of years lived with disability in 2019

	1	2	3	4	5	6	7	8	9	10
Global	Age related hearing loss 1.09	Diabetes 0.94	Low back pain 0.96	Blindness and vision loss 1.30	COPD 1.74	Stroke 1.19	Alzheimer's disease 1.05	Falls 1.19	Osteoarthritis 1.04	Oral disorders 0.90
Central Europe, Eastern Europe, and Central Asia	Low back pain 1.19	Age related hearing loss 1.18	Diabetes 0.92	Alzheimer's disease 1.13	Blindness and vision loss 1.49	Stroke 1.18	Falls 1.07	Oral disorders 1.17	Osteoarthritis 0.98	Depressive disorders 1.14
Central Asia	Age related hearing loss 1.00	Low back pain 1.04	Diabetes 0.90	Blindness and vision loss 1.25	Oral disorders 1.30	Alzheimer's disease 1.14	Stroke 0.90	Depressive disorders 1.29	Osteoarthritis 0.99	COPD 1.01
Central Europe	Diabetes 1.32	Age related hearing loss 1.16	Low back pain 1.06	Falls 1.35	Alzheimer's disease 1.17	Stroke 1.33	Oral disorders 1.09	Blindness and vision loss 1.16	Osteoarthritis 0.75	COPD 0.89
Eastern Europe	Low back pain 1.29	Age related hearing loss 1.22	Blindness and vision loss 1.76	Alzheimer's disease 1.10	Osteoarthritis 1.13	Oral disorders 1.20	Stroke 1.12	Diabetes 0.65	Falls 0.90	Depressive disorders 1.25
High income	Low back pain 1.06	Age related hearing loss 1.13	Diabetes 1.20	Falls 0.97	COPD 1.26	Alzheimer's disease 1.09	Osteoarthritis 1.15	Stroke 1.07	Oral disorders 0.96	Other musculoskeletal 2.84
Australasia	Age related hearing loss 1.24	Falls 1.45	Low back pain 0.85	Diabetes 1.00	COPD 1.30	Osteoarthritis 1.17	Alzheimer's disease 1.02	Oral disorders 1.20	Other musculoskeletal 3.19	Atrial fibrillation 1.53
High Income Asia Pacific	Age related hearing loss 1.26	Low back pain 1.03	Alzheimer's disease 1.20	Osteoarthritis 1.18	Stroke 1.54	Diabetes 0.87	Falls 0.60	Other musculoskeletal 3.41	COPD 0.70	Oral disorders 0.93
High Income North America	Low back pain 1.23	Age related hearing loss 1.39	COPD 1.99	Diabetes 1.56	Falls 1.05	Osteoarthritis 1.29	Alzheimer's disease 1.13	Stroke 1.40	Other musculoskeletal 3.91	Atrial fibrillation 1.74
Southern Latin America	Age related hearing loss 1.05	Diabetes 0.95	Low back pain 0.81	Other musculoskeletal 5.49	Osteoarthritis 1.39	Alzheimer's disease 1.06	Oral disorders 0.95	Falls 0.94	COPD 1.00	Blindness and vision loss 0.68
Western Europe	Low back pain 0.99	Diabetes 1.18	Falls 1.12	Age related hearing loss 0.92	Alzheimer's disease 1.00	COPD 1.12	Osteoarthritis 1.03	Oral disorders 1.05	Depressive disorders 1.21	Blindness and vision loss 1.03
Latin America and Caribbean	Diabetes 1.20	Age related hearing loss 0.97	Blindness and vision loss 1.13	Low back pain 0.80	Oral disorders 1.20	Alzheimer's disease 0.98	Osteoarthritis 1.15	Other musculoskeletal 3.44	Falls 1.40	Depressive disorders 1.05
Andean Latin America	Age related hearing loss 1.05	Blindness and vision loss 1.27	Diabetes 0.88	Chronic kidney disease 1.42	Low back pain 0.77	Osteoarthritis 1.16	Alzheimer's disease 0.86	Other musculoskeletal 3.13	Depressive disorders 0.88	Falls 0.88
Caribbean	Diabetes 1.48	Age related hearing loss 1.10	Low back pain 0.80	Blindness and vision loss 1.00	Oral disorders 1.01	Falls 1.32	Osteoarthritis 1.01	Alzheimer's disease 0.81	Depressive disorders 1.26	Ischaemic heart disease 0.98
Central Latin America	Diabetes 1.44	Age related hearing loss 1.03	Blindness and vision loss 1.10	Low back pain 0.75	Other musculoskeletal 3.84	Osteoarthritis 1.22	Oral disorders 0.95	Alzheimer's disease 0.83	Depressive disorders 1.04	Chronic kidney disease 1.78
Tropical Latin America	Diabetes 0.98	Age related hearing loss 0.86	Blindness and vision loss 1.17	Oral disorders 1.43	Low back pain 0.85	Alzheimer's disease 1.13	Other musculoskeletal 3.52	Osteoarthritis 1.10	Falls 1.70	Depressive disorders 1.05
North Africa and Middle East	Diabetes 1.22	Age related hearing loss 1.05	Blindness and vision loss 1.49	Low back pain 0.99	Stroke 1.25	Alzheimer's disease 1.24	Oral disorders 1.09	COPD 1.50	Osteoarthritis 0.91	Chronic kidney disease 1.89
North Africa and Middle East	Diabetes 1.22	Age related hearing loss 1.05	Blindness and vision loss 1.49	Low back pain 0.99	Stroke 1.25	Alzheimer's disease 1.24	Oral disorders 1.09	COPD 1.50	Osteoarthritis 0.91	Chronic kidney disease 1.89
South Asia	Blindness and vision loss 1.57	COPD 3.62	Age related hearing loss 0.99	Diabetes 0.96	Low back pain 0.86	Falls 3.29	Dietary iron deficiency 3.85	Road injuries 2.95	Depressive disorders 1.31	Other musculoskeletal 2.41
South Asia	Blindness and vision loss 1.57	COPD 3.62	Age related hearing loss 0.99	Diabetes 0.96	Low back pain 0.86	Falls 3.29	Dietary iron deficiency 3.85	Road injuries 2.95	Depressive disorders 1.31	Other musculoskeletal 2.41
South East Asia, East Asia, and Oceania	Age related hearing loss 1.14	Stroke 1.86	Blindness and vision loss 1.34	COPD 2.40	Low back pain 0.85	Diabetes 0.64	Alzheimer's disease 1.13	Osteoarthritis 0.92	Oral disorders 0.82	Falls 1.20
East Asia	Age related hearing loss 1.19	Stroke 1.96	COPD 2.47	Blindness and vision loss 1.19	Low back pain 0.78	Alzheimer's disease 1.20	Diabetes 0.54	Osteoarthritis 0.98	Oral disorders 0.82	Falls 1.22
Oceania	Diabetes 1.70	Low back pain 1.26	Age related hearing loss 0.99	Blindness and vision loss 0.76	Stroke 1.52	COPD 1.79	Oral disorders 1.28	Alzheimer's disease 0.97	Osteoarthritis 0.82	Ischaemic heart disease 1.39
South East Asia	Blindness and vision loss 1.83	Diabetes 1.04	Age related hearing loss 0.99	Low back pain 1.14	Stroke 1.49	COPD 2.09	Alzheimer's disease 0.87	Oral disorders 0.83	Other musculoskeletal 2.25	Neck pain 2.09
Sub-Saharan Africa	Blindness and vision loss 1.09	Age related hearing loss 0.96	Diabetes 0.99	Low back pain 1.00	Depressive disorders 1.51	Stroke 0.96	Osteoarthritis 1.11	COPD 1.14	Alzheimer's disease 0.94	Road injuries 1.67
Central Sub-Saharan Africa	Age related hearing loss 0.96	Diabetes 1.16	Low back pain 1.02	Depressive disorders 1.47	Blindness and vision loss 0.61	COPD 1.41	Alzheimer's disease 1.25	Onchocerciasis 30.15	Stroke 0.92	Osteoarthritis 1.07
Eastern Sub-Saharan Africa	Blindness and vision loss 1.03	Age related hearing loss 0.96	Low back pain 1.00	Diabetes 0.85	Depressive disorders 1.52	Stroke 0.97	Osteoarthritis 1.10	Alzheimer's disease 1.03	COPD 0.90	Road injuries 1.55
Southern Sub-Saharan Africa	Diabetes 1.24	Age related hearing loss 1.09	Blindness and vision loss 1.36	Low back pain 0.87	COPD 2.11	Stroke 1.10	Depressive disorders 1.53	Osteoarthritis 1.11	Alzheimer's disease 0.92	Oral disorders 0.75
Western Sub-Saharan Africa	Blindness and vision loss 1.21	Age related hearing loss 0.93	Low back pain 1.04	Diabetes 0.95	Depressive disorders 1.51	Osteoarthritis 1.15	Stroke 0.90	Road injuries 1.96	COPD 1.01	Alzheimer's disease 0.81

Values shown in brackets represent ratio of observed YLDs to estimated YLDs based on sociodemographic index rounded to two decimal places. Colour ranges calculated to place a roughly equal number of cells in each column

Colour key:	(0.00 to 0.86)	(0.86 to 0.95)	(0.95 to 1.00)	(1.00 to 1.05)	(1.05 to 1.13)	(1.13 to 1.19)	(1.19 to 1.26)	(1.26 to 1.40)	(1.40 to 1.90)	(1.90 to ...)

Source : BMJ, 2022

[54] In 2019, the WHO estimated the cost of Alzheimer's disease and other forms of dementia at US$1.3 trillion, or 0.76% of global GDP, with most of it in high-income countries, and one-third in Europe (at a cost of US$31,000 per person per year).

[55] Globally, only 16% of costs are attributed to direct medical costs, 34% to direct social costs, particularly institutional care, and half of the costs are attributable to informal care, with WHO estimating that caregivers (families, relatives and neighbours) spend 133 billion hours a year caring for patients, an average of about eight hours a day. The global cost of dementia, according to the WHO, will be US$2.8 trillion in 2030, more than twice as much as in 2019.

[56] In France, the Fondation Méderic Alzheimer estimated the cost of neurodegenerative diseases for society and individuals at €32 billion in 2015, or 1.4% of GDP. Medical and paramedical costs were in the order of €5bn per year, medico-social costs at €13bn and informal help of the same order (€14bn per year)[9] .

[57] The repercussions of the disease for families and their loved ones (carers, etc.) go far beyond the financial aspect. Studies have shown that their own health deteriorates as a result of caring for people with Alzheimer's or a related disease. The burden is particularly heavy when the diagnosis is

[8] It is also the fastest growing cause of disability-adjusted life years (DALYs) lost between 2000 and 2019, far ahead of diabetes or high blood pressure. According to the IHME, dementia is among the top five causes of disability-adjusted life years lost in 51 countries worldwide.

[9] Alain Bérard et al. *How much does Alzheimer's disease cost?* Study report, Fondation Médéric Alzheimer, September 2015.

announced, for the organization of assistance when the person's situation is stabilized, and in the management of crises when the health and condition of the person with Alzheimer's or a related disease deteriorate.

[58] The presence of a person with Alzheimer's or a related disease has repercussions on the psychological state of their family members or caregivers. Even before the disease is announced, when they notice the cognitive deterioration and its consequences in terms of behaviour, the people close to the person experience difficulties and a deteriorated quality of life at an age when, for some, there is a desire for a calmer or more self-centred life. The difficulties encountered by relatives include the lack of availability on a daily basis due to the care burden, the need to have the person moved to make the home accessible and/or to be close to care and carers, the fear that the ill person will become demotivated and thus unable to take charge of his or her own life, and the fear for the future of the ill person and of the person's own future, with financial and health consequences.

[59] Furthermore, the carer must manage the illness of their loved one and, sometimes at the same time, the relationship with their spouse, if not the ill person, the relationship with their family and friends and the relationship with their professional environment. This simultaneous management is complex and costly financially and psychologically.

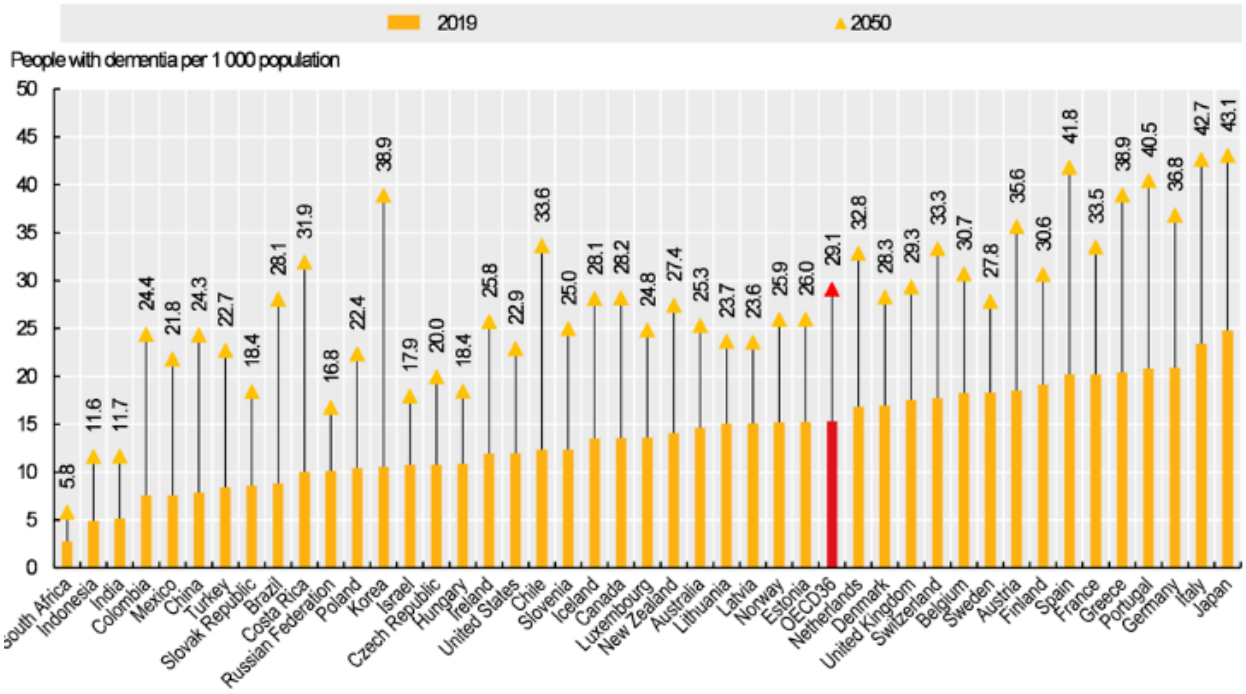
[60] Under these conditions, it is not very surprising that the perception of Alzheimer's and related diseases is very negative in the French population. In 2017, according to the Ipsos Institute, it was the second most feared disease by the French after cancer. And two-thirds of French people were afraid of being affected by this disease one day. According to Odoxa (2019), Alzheimer's disease is feared in particular because it is a pathology with which the French are familiar: 26% of the French and 31% of seniors would count among their entourage a person affected by Alzheimer's disease.

1.3 Increasing needs are due to the growing prevalence of Alzheimer's and related diseases and the severity of their disorders

[61] The WHO estimates that 78 million people will suffer from dementia in 2030 and 139 million in 2050, or even 153 million if we rely on the projections of the Institute for Health Metrics and Evaluation (IHME) and Alzheimer Europe. The growth in prevalence in the various countries will be significant overall, as shown in the graph below, with sometimes particularly significant increases, as in South Korea and Brazil for example.

[62] In France, we must prepare for a near doubling in the number of people suffering from Alzheimer's disease or a related illness by 2050, which will be between 2.2 and 2.3 million according to available estimates.

Graphique 2 : Prevalence of dementia in the general population (per 1000 population), 2019 and 2050



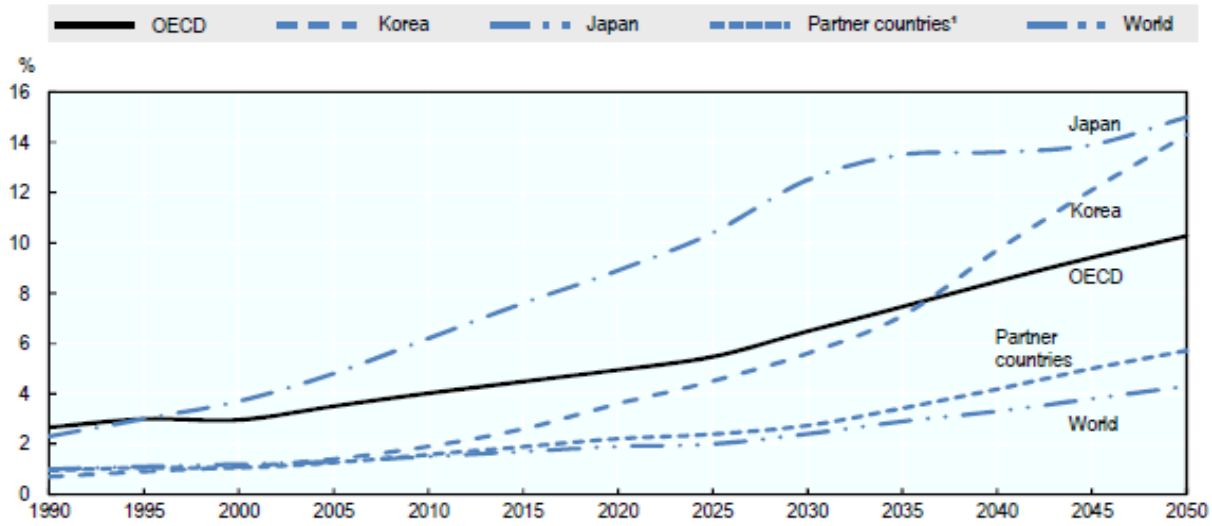
Source : OECD, 2022

[63] The predicted sharp increase in the number of people with Alzheimer's disease or a related disorder, in France as in the rest of the world, is linked to population growth and the deformation of the age pyramid.

[64] It is globally unstoppable even if it could be tempered by a decrease in incidence due to the decrease in diabetes, hypertension and the improvement in education and nutrition[10] . The discovery of disease-modifying therapies could be a second temperament to this increase, but only in the medium term.

[10] Nevertheless, there is considerable debate among experts as to whether the incidence of dementia is actually declining. Several studies highlight this: cf. Wolter et al. *Twenty-seven-year time trends in dementia incidence in Europe and the United States*. Neurology, 2020. But some researchers argue that this drop in incidence could be a methodological bias due to the repetition over time of the same tests in the same cohorts.

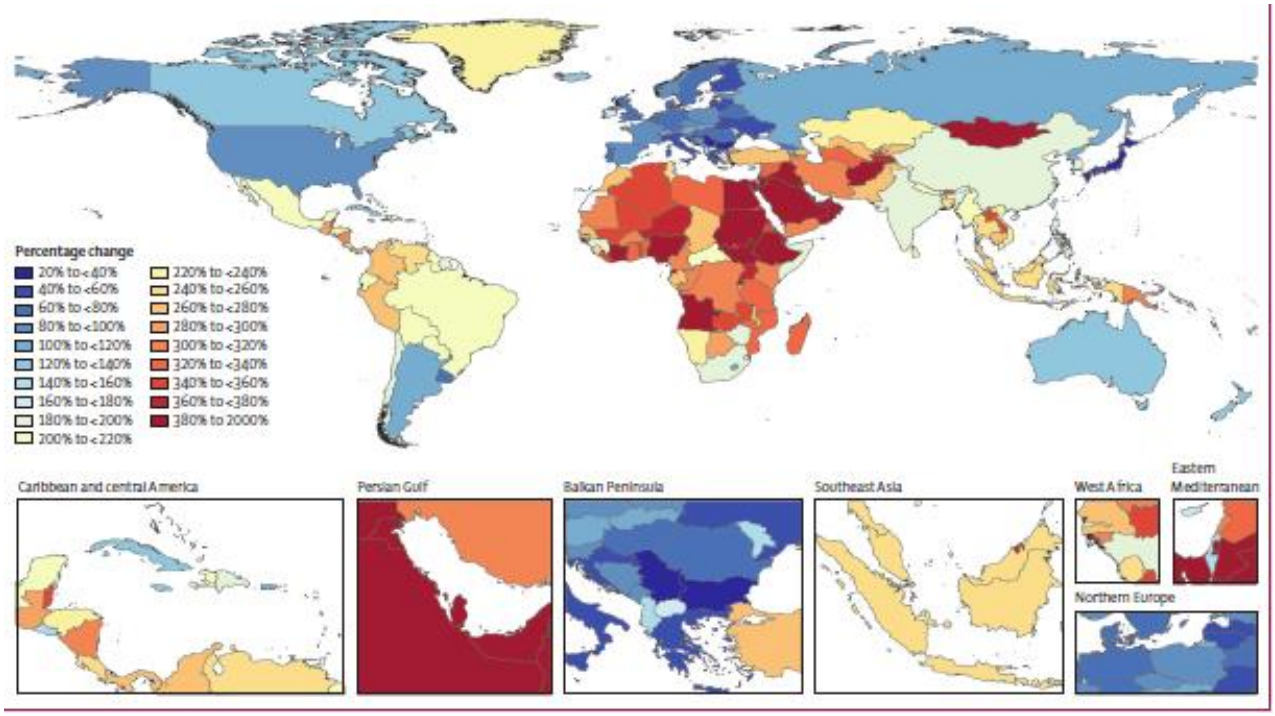
Graphique 3 : Proportion of the population aged over 80 years between 1990 and 2050



Source : OECD, 2019

[65] The smallest percentage increase in the number of people with dementia by 2050 is expected to be in the Asia-Pacific (+53%) and Western Europe (+74%) regions, according to the IHME, and the largest increase is expected in the Eastern Africa (+357%) and Middle East-North Africa (+367%) regions, which are starting from a lower level.

Graphique 4 : Growth in the number of people with dementia between 2019 and 2050



Source : Lancet, 2022

[66] Finally, it should be noted that both the IHME and the WHO predict that there will still be more women with dementia than men in 2050, both in proportion and in absolute numbers.

[67] While the proportion of Alzheimer's or related diseases currently represents more than half of the residents of EHPADs in France (and even more than two-thirds if we exclude EHPADs that refuse to take in these people), this proportion is likely to increase over the coming years. Indeed, the ageing of residents, which has already been observed for a long time and should logically continue in the years to come, will also probably increase the severity of the cognitive, psychological and behavioural disorders they will suffer.

[68] Thus, while the average age of entry into an institution for the elderly was 83 years and 5 months according to the 2007 EHPA survey, it was 85 years and 2 months according to the 2015 EHPA survey[11] . And many of the mission's interlocutors cited average entry ages of between 85 and 90 years in their establishments. It is true that the epidemic crisis has led families to think less about their loved ones entering an institution for two years, which is now contributing to an increase in the average age of entry. As a result, while residents of EHPADs aged over 90 represented 28.3% of all residents in 2007, this was already the case for 38.2% in 2015, a proportion that has certainly increased and will continue to do so[12] .

1.4 Prospects are opened up by increasingly early prevention and treatment

[69] However, advances in research, understanding of risk factors and non-medicinal interventions should lead to increased efforts in prevention and early management of people with Alzheimer's disease and related disorders. The discovery of disease-modifying drugs could also lead to changes in care in the years to come.

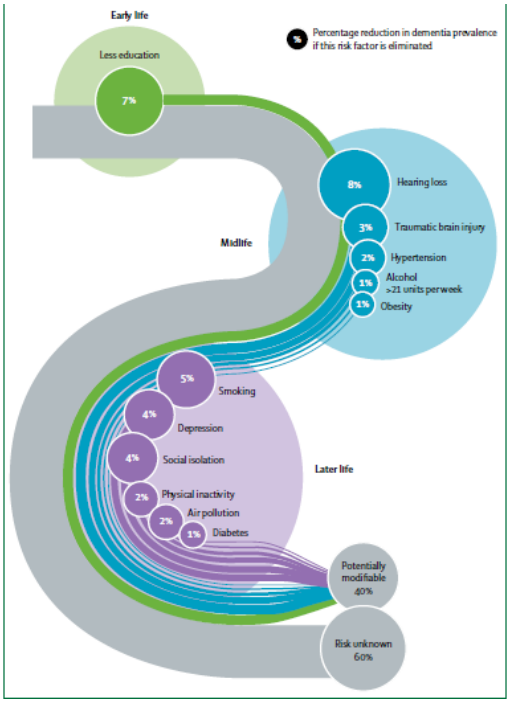
1.4.1 Risk factors on which it is more desirable than ever to act upstream

[70] It is obviously not possible to act on the main risk factor for Alzheimer's disease, which is age. Nor is it currently possible to influence the genetic factors of the disease for the people concerned themselves. On the other hand, it is now estimated that 40% of cases of Alzheimer's disease or a related disorder are linked to risk factors that can be acted upon either to postpone their onset or even to prevent it. Postponing the onset of the disease by just a few years would significantly reduce the number of people affected by Alzheimer's disease or a related disorder.

[71] The priority retained by the WHO in its latest report is therefore the adoption of public health programmes linked to the dozen or so risk factors identified, such as the fight against hypertension, diabetes, overweight or alcohol and tobacco consumption, but also hearing loss and depression, which are more recently identified factors, as shown in the following graph which traces the relative importance of the various risk factors[13] .

[11] The results of the 2019 EHPA survey were not yet available at the time of writing.
[12] It should be noted that the average length of stay for residents is short overall: according to the 2015 EHPA survey, residents spend an average of two years and five months in their EHPAD, with a median of only one year and two months. The leading cause of discharge, by far, is death.
[13] Organized screening exists in some countries but is not currently recommended due to the lack of curative treatments.

Graphique 5 : Key risk factors for Alzheimer's disease and dementia



Source : Lancet, 2020

[72] The HCSP also pointed out in a recent report that it is possible to prevent Alzheimer's disease at an earlier stage than dementia, whether it is the decline in cognitive functions or the decline in other more specific functions such as memory, attention or executive functions[14] .

[73] Nevertheless, information that the risk of dementia and psychological and behavioural disorders can be prevented is still lacking in the population. Thus, in 2019, the global report on Alzheimer's published by Alzheimer's Disease International showed that a quarter of people surveyed worldwide thought that nothing could be done[15] . And the data available in France confirms this relative lack of awareness: 75% of French people surveyed by Ipsos, for example, wrongly believe that there are no preventive behaviours that can limit the risk of developing Alzheimer's disease; and 76% of French people believe, also wrongly, that Alzheimer's disease is often hereditary[16] .

[74] From this point of view, increased efforts in health education for families, carers and health and social care staff are absolutely essential in the future.

1.4.2 Non-medicinal interventions are increasingly used because of their recognized impact on quality of life and their lack of risk

[75] In the absence of curative treatments for Alzheimer's disease and related disorders, numerous non-medicinal interventions have been developed over the years. Even in the absence of unquestionable scientific proof of their effectiveness in improving health, professionals consider that

[14] See HCSP report, *Prevention of Alzheimer's disease and related disorders*, December 2017.
[15] Alzheimer's Disease International, *World Alzheimer Report 2019. Attitudes to Dementia*. September 2019.
[16] IPSOS. 2017

they can at least partially prevent the onset or worsening of psychological and behavioural disorders and improve the quality of care provided to people.

[76] Non-medication interventions are based on several ideas. One of these is that much of the behavioural problems could be prevented or at least delayed or tempered by the architectural and social environment. Several theoretical models exist to explain this, including the "unmet needs" model. It postulates that the process of dementia results from a decrease in the ability to satisfy oneself and to respond to these needs due to an increasing difficulty in expressing them. Another approach, that of person-centred care for people with dementia, based on the needs of the person and linked to the interpersonal relationship, is in line with this approach.

[77] Four elements are important from this point of view: valuing and respecting people with dementia and their carers; treating people with dementia as individuals with specific needs; understanding the world from the point of view of the person with dementia, in order to understand the behaviour of the person and what is being communicated, and validating the subjective experience that is perceived as the reality of the individual; and creating a positive social environment in which the person with dementia can find a sense of wellbeing through the building of interpersonal relationships.

[78] Dementia syndromes should be understood as phenomena experienced by the person and with which he or she must live, and not as an illness that inevitably produces problems to be managed. According to this approach, the psychosocial environment plays a major role in self-confidence, self-esteem and self-respect.

[79] Another idea is to adopt specific care practices that can be divided into two groups: communication attitudes such as avoiding sources of distraction when communicating with the patient, using short sentences, not raising one's voice, etc.; care attitudes such as setting up a routine adapted to the patient's habits, dividing the various tasks into several stages, etc.

[80] The HAS distinguishes between non-medicinal interventions relating to quality of life (physical and psychological comfort and adapted environment), psychological and psychiatric care (individual or group psychotherapy, brief psychotherapy, psychotherapeutic support, cognitive-behavioural therapy, reminiscence and validation therapies, etc.), speech therapy, which is particularly recommended for diseases with primary language impairment (semantic dementia, primary progressive aphasia, etc.), and interventions relating to cognition, which must be differentiated from other interventions.), speech therapy, which is particularly recommended in diseases with primary language impairment (semantic dementia, primary progressive aphasia), cognitive interventions, which must be differentiated from animation sessions, memory workshops or other occupational sessions, motor activity interventions and, finally, behavioural interventions (music therapy, aromatherapy, multisensory stimulation, reality orientation, reminiscence therapy, animal-assisted therapy, massages, simulated presence therapy and light therapy)

[81] The goals of non-medication interventions include preventing, managing, reducing or eliminating the severity and frequency of psychobehavioural disorders, as well as reducing caregiver stress, and preventing the adverse consequences of these disorders.

[82] A great deal of work has been done around the world to assess the effectiveness of various non-medication interventions on people's health. In general, studies tend to show that certain non-medicinal interventions are promising for the treatment of Alzheimer's disease and psychological

and behavioural disorders. However, as the HAS pointed out in 2011: "due to methodological difficulties, none of them have provided [scientific] proof of their effectiveness"[17] .

[83] Several systematic reviews of the literature published over the years seem to confirm this judgement, while nevertheless qualifying it. For example, in 2006, a study concluded that there was "no robust evidence to recommend the use of non-drug interventions to reduce or prevent ambulation in people with dementia"[18] . In 2011, a meta-analysis concluded broadly along the same lines, while noting the beneficial effects of massage as well as music therapy on agitation, and to some extent multisensory stimulation (Snoezelen)[19] . In 2016, a new meta-analysis concluded that the indisputable evidence was weak and the results did not differ between the patient groups studied[20] .

[84] However, recently, in 2017, a Norwegian study, the first truly double-blind study in 33 EHPADs in the country, showed the effectiveness of the TIME (cognitive behavioural therapy and person-centred care) approach on agitation in residents with dementia[21] . And in 2021 a meta-analysis published in the BMJ highlighted, albeit often with a low degree of confidence, the effectiveness of cognitive stimulation, massage, occupational therapy or reminiscence therapy on depression[22] .

[85] In practice, we are witnessing a rapid and widespread development of non-medicinal interventions in France as in all countries of the world. They have been promoted for many years by real schools or commercial approaches (Carpe Diem, Montessori, Humanitude...). They are recommended by doctors and health authorities, despite the still fragile scientific evidence, to deal with psychological and behavioural disorders in people with dementia and have become an important element of therapeutic care, both in outpatient and institutional settings. In particular, they have the advantage of being risk-free for the persons concerned and of clearly improving their quality of life.

[86] Thus, the HAS recommends the first-line use of appropriate care techniques to prevent the onset or worsening of disorders and to avoid the use of drug treatments[23] . The guidelines published by NICE in 2018 for the assessment, management and support of people living with dementia and their carers also include the use of "interventions to promote cognition, independence and wellbeing" as well as the use, initially and routinely, of psychosocial and environmental interventions, but these guidelines nevertheless remain underdeveloped on this subject.

1.4.3 Slow but potentially significant progress in drug treatments

[87] The treatments currently available on the market for Alzheimer's disease and other forms of dementia are essentially symptomatic: they are cholinesterase inhibitors (donepezil, galantamine, rivastigmine...) and an antiglutamate (memantine). Since August 2018, and on the basis of an opinion of the HAS which was similar to the one issued a decade earlier by NICE but which the British

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[17] HAS. *Alzheimer's disease and related disorders: diagnosis and management. Recommendations for good practice*. December 2011.

[18] Robinson et al. *A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use*. Health Technology Assessment. August 2006. Vol. 10. No. 26. See also Lai et al. *Special care units for dementia individuals with behavioural problems. Review.* Cochrane Library. 2009.

[19] Department of Veterans Affairs. *A systematic evidence review of non-pharmacological interventions for behavioral symptoms of dementia*. March 2011.

[20] M. Brasure et al. *AHRQ Comparative effectiveness reviews*. Agency for healthcare research and quality. 2016.

[21] Bjorn Lichtwarck et al. *Targeted interdisciplinary model for evaluation and treatment of neuropsychiatric symptoms: a cluster randomized controlled trial.* American Journal of Geriatric Psychiatry. 2017.

[22] Jennifer Watt et al. *Comparative efficacy of interventions for reducing symptoms of depression in people with dementia: systematic review and network meta-analysis*. BMJ 2021. 372 : n532

[23] HAS. 2011.

authorities had not followed at the time, the French health authorities decided to delist the four drugs then marketed (Aricept, Ebixa, Exelon and Reminyl)[24] .

[88] Significant research efforts over the past two decades or more have not yet been rewarded with success in innovative treatments, particularly disease-modifying drugs.

[89] The June 2021 FDA approval of Aducanumab in the U.S. was to be a milestone. However, this authorization to market this drug, which clearly reduced plaque accumulation but demonstrated only limited effects on patients' health in one clinical trial and none in another and generated undesirable, sometimes serious, side effects in 40% of the patients concerned has, in practice, generated enormous scientific, political and media controversy in the United States (resignation of scientists at the EMA, Congressional investigation...) and worldwide. In Europe, the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA), for its part, refused to recommend marketing authorization for the drug, and the laboratory threw in the towel in April 2022 before a new identical recommendation was made on appeal.

[90] The number of new drug submissions to the FDA and EMA has also increased in the recent period. In 2021, at least 126 different agents were in 152 different clinical trials worldwide (including 28 phase III trials, 74 phase II trials and 24 phase I trials). However, while eight out of ten trials address biological factors, only 7% are aimed at reducing the neuropsychiatric symptoms of the disease.

[91] Ultimately, there is considerable uncertainty about the timing and effectiveness of treatments that will delay the progression of dementia and/or limit the associated psychological and behavioural problems.

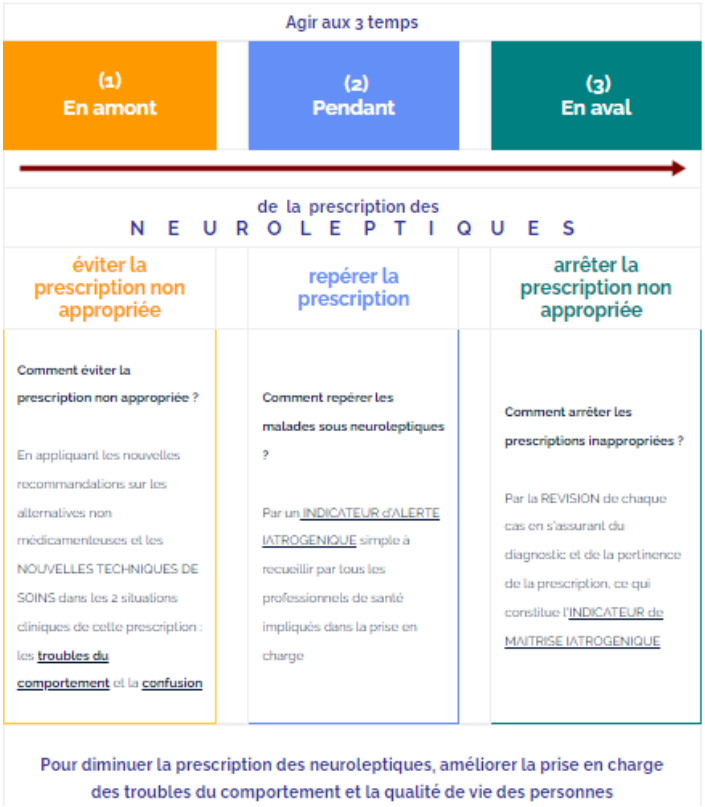
[92] While research will hopefully reduce the age of onset of cognitive, psychological and behavioural symptoms of dementia, it will not prevent an increase in the prevalence of the disease in the next five to ten years, which is fundamentally linked to the ageing of the population and increased life expectancy, and therefore to the need for increased care in the home and in institutions.

[93] However, the introduction of disease-modifying drugs in the near future should have a major impact on the diagnosis and management of patients, for which early detection will be essential and for which we must be prepared. The new treatments will require early identification of patients, and therefore an incentive for patients and their families to consult as soon as the first memory complaints appear, the development of identification tools (software solutions and dedicated applications, etc.) and the development of clear information for the general public. It will also be necessary to increase awareness among primary care physicians to identify the patients concerned, to improve the link between primary care medicine and specialized memory consultations, and to reduce the time required to access specialized consultations (one to three months maximum compared to three to nine months today).

The proper use of psychotropic drugs in patients with Alzheimer's disease and related disorders

The use of psychotropic drugs is another sensitive issue. In a 2009 recommendation, the HAS recommended not prescribing a treatment with a specific indication for the treatment of Alzheimer's disease as a first-line treatment, nor a psychotropic drug in case of opposition, shouting or wandering. The HAS then specified that "psychotropic drugs do not have a preventive effect on the occurrence of behavioural disorders". Then in 2012, the HAS developed a pilot program for the control of iatrogeny.

[24] According to Alzheimer Europe, France is now the only country in the European Union, along with Latvia, that does not reimburse existing anti-Alzheimer drugs.



Psychotropic drugs may be used when appropriate care techniques are insufficiently effective, particularly when the severity of the disorder endangers the patient, impairs his or her functioning, or is a threat or a significant source of suffering for those around him or her. Thus, antidepressants are indicated for certain depressive episodes that may be characterized by emotional instability, anxiety, impulsivity, agitation or delusions. Antipsychotics have been advised against by the EMA since 2004 for atypical antipsychotics and since 2008 for conventional antipsychotics because, as shown by a large number of scientific publications, they are associated with a higher risk of death and stroke. They are strongly discouraged in Lewy body disease.

In any case, an antipsychotic should only be prescribed for a very limited period of time and at a low dosage in cases of severe psychotic disorders that cannot be controlled otherwise, after other non-medicinal measures have failed, or in an emergency. The prescription of anxiolytics should also be limited to crisis situations or should be of short duration after correction of the various causes. The same applies to hypnotics.

Apathy is sometimes confused with depressive episodes and antidepressants are particularly inappropriate in this case.

Despite this, prescription rates for antipsychotics vary by as much as two-fold across OECD countries. On average, one in 20 people aged 65 and over is prescribed an antipsychotic, and this includes people with Alzheimer's disease and related disorders. France is rather among the OECD's good performers in this respect. However, the OECD pointed to a 2015 US government report that 39.4% of people with psychological and behavioural symptoms residing in EHPAD in the US were prescribed antipsychotics without a diagnosis of psychosis. Similarly, the prescription of tranquillisers and sedatives is not uncommon in the home or in institutions for patients with Alzheimer's disease, particularly those with psychological and behavioural disorders. The associated risks include increased confusion and disorientation in moments of consciousness and an increased risk of falls. However, the use of different forms of "chemical restraint" is difficult to identify and quantify in detail.

2 Special care units have met the needs of people with Alzheimer's disease and related disorders, but they now offer a graduated response that is insufficient in volume and whose limitations are becoming increasingly apparent

2.1 Original special care facilities have been gradually being deployed in towns and institutions

2.1.1 A range of special care facilities based on a sequential approach to care

[94] The creation of the Cantous at the end of the 1970s was the first French example of a structure adapted to the needs of people with Alzheimer's disease or a related illness, in imitation of the "Special Care Units" (SCUs) that had appeared in the United States a few years earlier, and which then spread to almost all countries.

[95] The "Cantou" (natural activity centre based on useful occupations) is a concept created at the end of the 1970s by Gérard Caussanel and Louis Gallard, director and psychologist of the Emilie de Rodat home in Rueil-Malmaison, and inspired by a word which means "fire corner" in Occitan. Each Cantou had, in principle, twelve individual rooms, each with a bathroom with sink, toilet and shower. The rooms were distributed around a common room where meals could be prepared, shared, rested and spent the day. The families were free to decorate and furnish the rooms as they wished. The resident was free to choose his or her own doctor. The resident had to provide his own personal trousseau. The residents of the same Cantou lived with the housekeepers (four per Cantou in principle) and the multi-skilled staff who accompanied them and were at their disposal while avoiding substituting for them for the acts that they could still perform alone.

[96] In order to avoid loss of autonomy, the elderly were invited, according to their possibilities and wishes, to participate in all the acts of daily life (peeling vegetables, setting the table, washing up, folding the laundry). A monthly meeting was organised in which all the families of the Cantou, the housekeepers and the management participated.

[97] The Cantou model became a reference when the problem of receiving and housing elderly people with cognitive disorders began to be more acute and developed in "classic" establishments in the 1980s.

[98] In a groundbreaking report published in 2000, Professor Jean-François Girard proposed to promote the creation of specific care units for people with Alzheimer's disease or a related illness[25] . According to him, these units would have 10 to 15 places for non-temporary stays. However, it is the 2008-2012 Alzheimer's plan that is responsible for the creation and development of a wide range of special care facilities in France.

[99] In fact, this plan proposed, in an innovative and original way, a graduated medico-social and health response to people with Alzheimer's disease or a related illness who have psychological and behavioural disorders by creating three categories of special care facilities in establishments intended for different stages of the disease and severity of behavioural disorders:

[25] Jean-François Girard and Anna Canestri, *Alzheimer's Disease*, 2000.

- The Pôles d'activité et de soins adaptés (PASA) which consist of a day care centre for residents of EHPADs with moderate behavioural problems;
- Reinforced housing units (UHR), which are units established either in EHPAD or in a health establishment (USLD) and which are intended for people suffering from Alzheimer's disease or a related illness and with severe or acute behavioural problems;
- Cognitive-behavioural units (CBUs), which are units set up in follow-up and rehabilitation care services (SSR), mainly geriatric, where care is provided for a few weeks to people with Alzheimer's disease or a related illness at times of crisis in their behavioural disorders.

[100] The 2008-2012 Alzheimer's plan curiously did not include in this range the Alzheimer's living units, or specific or protected living units, which are the successors of the Cantous, and accommodate in EHPADs patients with Alzheimer's disease or a related illness, mainly with moderate behavioural problems.

[101] These special care facilities are based on similar or similar principles:

- From an architectural point of view, they include walking areas, a common area, access to a garden;
- From the point of view of the activities proposed to the residents, they call upon different types of non-medicinal interventions and therapeutic and recreational animations;
- In terms of human resources, they have more and better-trained staff whose skills are adapted to the management of behavioural disorders (in particular gerontological care assistants, psychologists, occupational therapists and, in the health sector, psychiatrists).

[102] In France, the care offered in case of psychological and behavioural disorders is sequential: each level (moderate to severe) of disorder and dependence has its own type of care. The PASAs are mostly located in a single unit and correspond to a form of day care within the EHPAD[26] ; the UHRs and UCCs involve moving people from their original home to the institution or hospital service and vice versa when the disorders are considered to have subsided. In all three situations, the physical dependency situation is initially decisive, since the ability to come and go is still considered a condition of access in a large number of cases. The French special care facilities involve strong regulation of access to support, and their gradation, and an internal division into different units whose interactions are supervised, and whose access and discharge conditions are specified.

[103] The specifications for PASAs, UHRs and UCCs were implemented very quickly after the adoption of the 2008-2012 Alzheimer's plan[27] :

- In 2008, the specifications for the UCCs, published as an appendix to the circular[28] on the implementation of the health component of the Alzheimer's plan;

[26] A day care centre welcomes non-residents, whereas a PASA gives priority to residents (cf. article D312-155-0-1 of the CASF).
[27] The UVAs do not have any specifications for their part.
[28] Circular DHOS/O2/O1/DGS/MC3/2008/291 of 15 September 2008 on the implementation of the health section of the Alzheimer's plan 2008-2012.

- In 2009, the specifications for the UHR and PASA, published in Annex VIII of the circular on the implementation of the medico-social component of the Alzheimer's plan[29] .

[104] The 2008-2012 Alzheimer's plan was not limited to the institutionalization phase for people with Alzheimer's disease or a related illness. It also provided for the creation of specialised Alzheimer's teams (ESA) for people suffering from the disease and their families, in addition to all the common law measures created in towns and cities (day care, respite platforms, temporary accommodation, CLIC and MAIA, etc.).

[105] The ESAs are attached to the SSIADs (in the vast majority of cases) or SPASADs and are made up of occupational therapists, gerontological care assistants and psychologists. They usually intervene for three months for 12 to 15 sessions, after the diagnosis or shortly afterwards. Their aim is to provide support for the person with cognitive problems and their carer, and they carry out personalised assessment and activities on medical prescription. Interventions can be renewed after one year.

2.1.2 A strong dynamic initiated by the 2008-2012 plan

[106] In application of the orientations of successive plans and in response to the growth in needs, the number of special care facilities and the places they offer to people with Alzheimer's disease or a related illness has increased significantly since the end of the 2000s.

[107] A summary of this progress is given in the table below. Whereas in 2008, there were essentially Alzheimer's living units, there were 767 PASAs in 2012 and 1,921 in 2022, 310 UHRs in 2012 compared with 333 in 2022, 120 UCCs in 2012 compared with 145 in 2022, and nearly 500 ESAs since 2012, i.e. more than 2,900 special care facilities (excluding Alzheimer's living units) at the beginning of 2022 compared with nearly 1,320 in 2012, i.e. a multiplication by about 2.2, which has made it possible to slightly surpass the objectives of the Alzheimer's plan 2008-2012[30].

[29] DGAS/DSS/DHOS Circular No. 2009-195 of July 6, 2009 on the implementation of the medico-social component of the Alzheimer's and related diseases plan 2008-2012

[30] Since 2012, however, the growth in the number of facilities and places has been slower than after the initial 2008-2012 plan period.

Tableau 2 : Number of special care facilities between 2008 and 2022

	OBJECTIVES Alzheimer's PLAN 2008-2012	Achieved as of 31/12/2012 (Evaluation of the 2008-2012 plan)	PMND OBJECTIVES 2014-2019	Realized in April 2022
PASA	1784	767	No additional PASA	1921
RHU	310	146 (91 medical and social and 55 health (USLD))	no additional RHUs	333
ESA	500	273	plus 74 teams	505
UCC	120	78	plus 20 to 30 teams	145
UVA		2600 (in 2015)		

Source : Evaluation report on the implementation of the 2008-2012 Alzheimer's plan, Fondation Médéric Alzheimer and ARS.

2.1.3 Special care facilities that have few international equivalents

[108] The development of such a range of special care facilities, with a legal/regulatory definition, in a sequential logic, is original at the international level. The French choice is probably due to several factors specific to our country:

- The desire, which can be found in many other areas, for a uniform and equal deployment throughout the country of the policy of care for people with Alzheimer's disease or a related illness, with the use of a priori quality control of facilities by the State and specifications (supplemented by numerous recommendations from ANESM and HAS);
- The method of financing EHPADs, which is based on complex co-financing between health insurance, the departmental councils and the residents, and which required the creation of special care facilities for the provision of additional financing, and for this reason, regulated by law[31] .

[109] The issue of care for people with Alzheimer's disease or a related disorder with behavioural problems is not, in fact, a subject that has yet been fully explored internationally[32] . Most, if not all, developed countries seem to have some form of special *care unit*. The Alzheimer's plans or equivalents of Australia, the Netherlands, Norway, South Korea, England and the United States recommend the establishment of such units.

[110] While the mission's discussions with representatives of Australia, the Netherlands, Luxembourg and Norway and of Alzheimer's International, and a field visit to California, shed further light on the scope of their special care facilities[33] , the range of services available in France, with its sequential approach to people with Alzheimer's disease and psychological and behavioral disorders, seems to have no real equivalent.

[31] The 2008-2012 Alzheimer's plan has largely departed from the previous rules by extending, by circular, the financing by the health insurance of expenses that are in principle the responsibility of the departments.
[32] See Annex 2.
[33] In Australia, there is the equivalent of the AVU, and the Australian government is developing the equivalent of our RHU. There are no CCUs. In Luxembourg, there are only AVUs. In Norway too, it seems.

[111] The facilities identified abroad during these interviews or by reading the published literature mainly resemble either our Alzheimer's living units (UVA) or our reinforced housing units (UHR). The equivalent of PASA and UCC facilities do not seem to exist as such, with some exceptions. The mission did not identify an exact equivalent of ESAs in the city either, but it is clear that a whole series of mobile teams can be identified in the various countries, which are poorly documented in detail, and which could be similar to them[34] .

[112] It is also possible that a larger number of people with Alzheimer's disease, with moderate to severe psychological and behavioural disorders, are hospitalized abroad in geriatric or psychiatric services than in France.

[113] Finally, there is little theoretical reflection on the graduated and sequential management of patients with psychological and behavioural disorders. The main relevant reference seems to be an old article (2003) by three Australian authors, Henry Brodaty, Brian M. Draper and Lee-Fay Low, who emphasized the ad hoc and fragmented nature of services in their country. They propose a seven-level model that is interesting, depending on the level of severity of the symptoms and inversely depending on the prevalence, from people without dementia (level 1) to patients with the most severe psycho-behavioural disorders (level 7). And it seems that the Australian authorities, who were inspired by this model, are, along with France, the ones who have done the most thinking in this area.

[114] In the equivalent of EHPADs and USLDs abroad, the structures deploy similar architectural projects and recruit staff with specific skills (occupational therapists, speech therapists, animators and specially trained care assistants, etc.), but for all their residents, according to their individual needs.

Reports on site visits in California

The mission was able to visit assisted living facilities combined with the equivalent of memory care units in California. The establishments visited by the mission were relatively recent and may not be representative of all Californian establishments in terms of the quality of the services offered, with, moreover, an extremely different method of financing. In the three visits carried out by the mission, people were likely to move from the "assisted living" part to "memory care" if their cognitive problems worsened and were accompanied by behavioural problems. On the other hand, there was no offer outside the institution if the problems became acute. Several aspects converged with the French special care facilities:

- In terms of architecture, the memory care units had the same specifications as the French recommendations: small unit, outdoor walking area on the same level and easy to access, indoor kitchen allowing moments of conviviality, various convivial areas, walking area, adapted lighting (orientation and intensity);
- In terms of interior design, the principles were the same but much more advanced in their implementation, giving priority to the appearance of the living space over the place of care: search for a friendly environment, presentation of the floors (some had chosen carpeting), individualization of the doors to facilitate orientation, decoration and personalized furnishings;
- In terms of staffing, the professions involved were similar: occupational therapists, psychomotor therapists, speech therapists, nurses and care assistants, as well as a coordinating doctor and a facilitator. A night presence (care assistant or nurse) was systematically present with a lighted and welcoming care station for people who were awake;

[34] On the other hand, the special care facilities that exist in Scotland, which are the subject of significant criticism in a report by Alzheimer Europe, are hospital units, the equivalent of which cannot really be found in France.

- In terms of activities, there were many similarities: occupational or social activities (reading the newspaper, singing, etc.), cognitive stimulation (memory games, analysis of charts, weekly themes), physical approaches (walking, gentle exercise, occupational therapy), and sensory approaches (even though few snoezelen areas were developed).

Memory care" relied heavily on a very strong structuring of the day around a variety of activities by an activity leader. The training courses followed by the staff aim, like the ASG training, to enable them to manage psychological and behavioural problems and to calm down situations.

2.2 Special care facilities have represented an advance in care

[115] Specialized facilities have been a vehicle for change in the care of people with Alzheimer's disease or a related disorder.

2.2.1 Stakeholders are quite positive about the proposed care

[116] The overall positive contribution of special care facilities is recognised by the vast majority of stakeholders, whether health professionals, medico-social professionals, families or representatives of people with Alzheimer's disease or a related disorder, and administrations.

[117] The surveys carried out by the mission show this, as do the interviews it conducted with a large number of interlocutors. For both staff and management teams, the elements of satisfaction revolve around several aspects: the existence of solutions, the professionalism of the teams and the safety of residents in relation to their disorders in particular.

[118] In the case of moderate or severe disorders, the very existence of the facilities opens the way to solutions for the people, and consequently, prospects for the staff who support them: either because a relay is organised internally in the EHPAD (the PASA team takes over the toilet, for example), or because the person is directed towards a facility that seems more suitable. The ARS also tend to want to develop special care facilities, in particular UHRs, to deal with patient profiles that can put EHPADs and their staff at risk.

[119] The reinforcement of human resources is a reinforcement of skills and allows, when well organized, a transmission of knowledge and a modernization of the approaches towards the persons and the expressed disorders. Finally, carers' associations are less concerned about possible abuse of their relatives in units with more staff than in units that are neither regulated nor reinforced to deal with patients with severe disorders.

2.2.2 Special care facilities are generally well-targeted

[120] The targeting of special care facilities is generally well respected. Thus, the specific facilities effectively take care of people with psychological and behavioural disorders as provided for in the plan and the specifications, as shown by the CREAI-ORS survey in 2018 and the survey on UCCs conducted by the General Secretariat of the Ministry of Social Affairs:

- In the city, the ESAs receive patients with an MMSE score of 18.8 (± 2.1) at the time of admission (the NPI-ES scale is not used because the patients in care are not considered to have psychological and behavioural disorders);
- The majority of PASA patients (70.6%) have a NPI-ES score ranging from 10 to 29%;

- The majority of people in the UHRs (70.1%) have an NPI-ES score ranging from 30 to 59%;
- CCUs admit patients with an average NPI-ES score of 36 (in 2011, the survey conducted with the SFGG showed that the average score was 32.42 at admission and 18.98 at discharge)[35] .

[121] There is a certain similarity in the severity of disorders in terms of the NPI-ES score between PASA and UHR (12.4% of people in PASA have an NPI-ES score between 30 and 39%, and 20.6% of people in UHR; in UHR, 15.5% of people have an NPI-ES score between 10 and 29%). It would certainly be advisable to identify the reasons why these people are admitted to one structure rather than the other: this could be the nature of the disorders presented.

[122] The main behavioural disorders observed in the available surveys differ according to the facilities. Thus, for PASAs, the CREAI-ORS survey mainly notes anxiety (21.4%), apathy (14.2%) and depression (14.8%); agitation and aggression, aberrant motor behaviour, and delusions follow. For RHUs, aggression and agitation (33.8%) appear to be, along with disinhibition (20.5%), the main disorders before delusions (10.5%), anxiety (8.5%) and aberrant motor behaviours (7.6%).

[123] As regards CCUs, the characteristics of the disorders are not recorded in the surveys; but in 2011[36] , they were used in 65% of cases for crisis situations, as provided for in the 2008-2012 Alzheimer's plan. Overall, the CCUs meet clear needs, particularly as an interface between acute hospitalisation and admission to an EHPAD, especially after a crisis at home. They also play a useful role in the care process as a preparation for admission to an institution and as a source of respite for carers.

2.2.3 A useful professionalization and protocolization of the care of people

[124] Special care facilities have made a major contribution to the professionalization of care for patients with Alzheimer's disease or a related illness, with the creation of the gerontological care assistant diploma at the same time[37] .

[125] In all the establishments visited by the mission, as well as in the survey it conducted, the psychological and behavioural disorders affecting people are known, identified in their diversity, and measured using the NPI-ES, which is widely used by the teams. The survey conducted among EHPADs and USLDs also shows a capacity to measure the severity of disorders as well as their characteristics.

[126] The operation of these services with admission criteria set out in the specifications, such as the obligation to regularly re-evaluate the situation of individuals and to define a personalised project, has also allowed for a protocolisation and the inclusion of a therapeutic vision in the support projects.

[127] The teams met by the mission recall the contribution of this protocolisation of support in the functioning of teams and establishments, at the service of patients, in particular of homogeneous groups in terms of needs and disorders. The recent report by Professors Jeandel and Guerin also underlines this contribution, emphasising the continuous adaptation of skills made possible by such an organisation.

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[35] No equivalent data are available for the Alzheimer's Living Units.
[36] *State of the art of cognitive-behavioral units (CBU): results of a national survey*. Geriatr Psychol Neuropsychiatr Vieil 2013; 11 (2): 151-6.
[37] Caregiver or medical-psychological assistant who has been trained to work with elderly people who have lost their independence due to Alzheimer's disease or a related illness.

2.2.4 A factor in the integration of architectural elements and non-medical interventions into the reality of the institutions

[128] The architectural elements introduced by the specifications for UHR, PASA and UCC are now widely accepted, sought after and implemented, even beyond the requirements of these specifications in some cases.

[129] Thus, in the context of current renovations, the ARS provide for rooms adapted for PASAs even without funding in terms of human resources, and the renovation projects include the operation of small living units identified within the EHPAD. The specifications for UCCs are much less demanding than those for PASAs and UHRs, yet the teams met by the mission have integrated the same requirements as for UHRs. The CNSA confirms these observations and notes that EHPADs now need more technical support in terms of project management for their renovation. The mission confirms that there is still considerable room for improvement between the integration of the main principles and the implementation methods, particularly with regard to interior design.

[130] The special care facilities have also provided an opportunity to develop non-medicinal interventions in PASAs, UCCs and UHRs, but also in Alzheimer's living units and, in the city, through ESAs. Thus, a variety of activities are now offered to maintain cognitive abilities, encourage social interaction, support physical activity and maintain life reference points. The mission was able to observe activity programmes aimed at integrating all this diversity. Some EHPADs have expressed regret that they are unable to offer similar programmes for their residents in ordinary units.

2.3 Special care facilities have increasingly visible limitations and drawbacks

[131] Despite the contribution they represent, the special care facilities existing in France have limitations on the one hand, and disadvantages on the other, which are becoming increasingly apparent in the field.

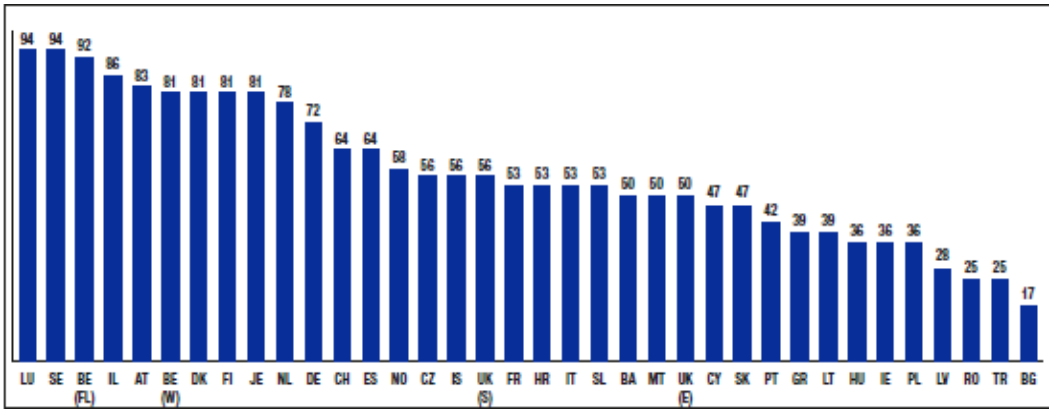
2.3.1 A still very important deficit of supply in the city, especially in the case of psychological and behavioural disorders

[132] The ESAs created by the 2008-2012 Alzheimer's plan were designed to allow a real choice between home and an institution and to ensure that people enter an institution as late as possible. They are part of a more general landscape of care in the city, in particular with day care centres, some of which are specialized for people with Alzheimer's disease or a related illness. The gradual increase in the average age of entry into long-term care facilities is evidence of a gradual postponement of the decision to live in an institution, but it is not, however, a measure of the success of the various plans.

[133] Many problems, which have been well described in many recent official reports, arise in the care of people with Alzheimer's disease or a related illness, with or without psychological and behavioural disorders, in towns and cities: too few formal diagnoses and too late from the identification of the first symptoms, lack of knowledge of the first psychological and behavioural disorders, overly complex patient pathways, insufficient coordination and management of care, non-reimbursement by the health insurance of non-medical interventions by professionals such as psychologists, occupational therapists and psychomotor therapists (excluding ESAs), constant changes in the field and coordination arrangements (CLIC, MAIA, DAC, EHPAD resources, etc.).

[134] In general, it was noted that France is not in an excellent position in Europe in terms of the quantity and quality of services it provides in the home for people with Alzheimer's disease.

Graphique 6 : Ranking of European countries in terms of availability of services at home for people with dementia



Source : European Dementia Monitor Report 2020, Alzheimer Europe

[135] Known problems that are difficult to solve in the short term include the lack of trained GPs, geriatricians, psychiatrists and neurologists and other health and social care professionals (nurses, care assistants, occupational therapists, etc.) in all or part of the country, as well as the lack of sufficient help, support and training for informal carers, who bear a considerable burden.

[136] Thus, in January 2021, there were only less than 2,000 geriatricians in France, including nearly 650 in the Ile-de-France region, a little over 2,800 neurologists and a little over 15,000 psychiatrists. There are still few specialists and geronto-psychiatry and psycho-geriatric units among them, and cooperation between neurologists, geriatricians and psychiatrists is generally perfectible, at least as far as Alzheimer's disease is concerned.

[137] The survey of patients' associations conducted by the mission shows that they have little knowledge of existing services, particularly day care centres and day hospitals.

[138] As regards ESAs specifically, the persistent shortage of supply is quite obvious in cities, given their number and the number of places they offer in relation to the population of people with Alzheimer's disease or a related disorder, with or without behavioural problems, who still live at home.

[139] The growth in the number of ESAs has certainly been very rapid, most of them having been created during the 2008-2012 plan. While at the end of 2013, 415 teams were authorised, there has been no massive increase since: at the beginning of 2022, only 497 ESAs were counted in metropolitan France. According to the surveys carried out by the mission, the increase in the number of places is not mainly due to an increase in the number of ESAs but to an increase in the number of places per ESA and consequently in their active file, by exceeding the threshold set by the specifications (ten places).

[140] In total, only 50,000 people per year, or less than 5% of all people with Alzheimer's disease or a related disorder, would benefit from the intervention of ESAs, if the average active file is related to the number of places installed. And among these 50,000 people, some may already have benefited from these interventions the previous year.

The mission's survey of ESAs

A survey was conducted during the months of April and May 2022 among ESAs. An online questionnaire developed by the mission was sent to them by the associations or federations of the sector: Anaressiad, Adedom, UNCCAS and FEHAP. A complementary message was sent by the mission to the services and groups listed as having an ESA. 260 ESAs in France and 3 ESAs in Martinique responded to the survey, i.e. a representativeness rate of about 52%. Among the main findings, we can highlight the following:

- It is mainly the SSIADs that carry the ESAs (88.5%), with a name that varies;

- The team includes, on average, 1.67 FTE gerontological care assistants, 0.77 FTE occupational therapists, 0.34 FTE psychomotricians and 0.27 FTE nurse coordinators;

- The average active file is not known, but the average number of people on the waiting list is estimated at 37.6;

- The average time spent in the home (16.4 weeks) slightly exceeds the three months stipulated in the specifications;

- The ESAs are part of a rich network of partners, in which day centres, memory consultations and general practitioners are at the forefront;

- The average age of the persons accompanied is 81 years and the average MMSE is 19.7 out of 30, on the borderline between mild and moderate cognitive disorders;

- The most frequent objectives are cognitive rehabilitation, support for caregivers, maintenance of social life and rehabilitation for activities of daily living;

- The main actions carried out allow the maintenance of remaining capacities, the learning of compensation strategies and the reduction of behavioural problems;

- The three main non-medication interventions are cognitive, physical and occupational approaches;

- The main intermediaries are day care centres and home help and care services;

- The first impacts of ESA intervention are, according to them, a reduction in isolation, the strengthening of social ties, an improvement in daily life and an improvement in the quality of life of the caregiver.

[141] The reports of the ARS also show that it is very difficult to ensure complete territorial coverage in a significant number of rural and urban areas, given the mobility of the teams.

[142] The limited number of specialised Alzheimer's teams and places results in long waiting lists. According to the CREAI-ORS survey, 85% of the ESAs had such lists and, according to the mission's survey, an average of 32 people are on these lists, with a minimum of 22 people. As a result, the ESAs report that they intervene too late in relation to the appearance of the first symptoms and are sometimes unable to act because the person's condition has deteriorated too much. Lastly, the ESAs have too few human resources to really support people with psychological and behavioural problems, even though they should be taking care of them.

[143] Among the symptoms of this inadequate care in the city, with diagnoses that are too late and not very precise, as well as rare and insufficient care by ESAs, the EHPADs emphasise the difficulties in assessing the needs and the psychological and behavioural situation of future residents before they are admitted. In some cases, they note that the situation is worse than expected, with disorders that cannot be explained solely by the change in environment. One EHPAD met by the mission also indicated that more and more residents were being admitted directly into an Alzheimer's unit rather than into a so-called "ordinary" EHPAD.

2.3.2 The operation of institutional facilities is not adapted to some of the residents' needs

[144] Forty years after the creation of the first Cantous and almost fifteen years after the Alzheimer's plan which created the special care facilities, the latter, like the sequential approach which underpins them, have increasingly visible limits and drawbacks.

2.3.2.1 Difficulties in recruiting and organizing services to meet the needs of residents

[145] The creation of the different special care facilities was accompanied by restrictive specifications to ensure a response to the needs of the residents from an architectural, human resources and therapy organization point of view.

[146] The specifications, produced from 2008 to 2011, were split in 2016 into a regulatory part and a part of recommendations established by ANESM. These recommendations are both more precise because they are more developed and detailed, and more flexible in that there is no longer a requirement for a unit of location for PASAs.

[147] However, there are a number of difficulties that demonstrate the limitations of the specifications and their implementation:

- Some EHPADs and ARSs have continued to impose strict PASA operations, even though the ANESM recommendations are now more flexible, so that the existing PASAs do not always respect people's rhythm over the course of a day: for example, a large proportion of residents often prefer to have a nap in their room rather than with PASA staff, and do not wish to come back for activities in the second half of the afternoon, for example. This rigidity limits the possible number of residents who can benefit from an ASAP intervention;
- The decrees, specifications and recommendations are not very explicit on the use of psychiatric resources, even though CCUs and RHUs in particular were built with the objective of combining neurology, psychiatry and geriatric skills. For example, the 2016 decree on UHRs states that "the opinion of a psychiatrist is systematically sought", whereas the initial specifications for UCCs do not include psychiatrist time.

[148] In terms of human resources, the terms of reference vary in terms of the obligations provided for.

Tableau 3 : Human resources provided for in the specifications

ESA Circular 2011	PASA Decree 2016	RHU Decree 2016	UCC Specifications 2009
Nurse coordinator (IDEC) in charge of partnerships, basic evaluation and coordination of interventions and their follow-up (**0.25 FTE**) **Occupational therapist and/or psychomotor therapist** in charge of evaluating the patient's abilities, rehabilitation and support care sessions and the assessment sent to the attending physician (**1 FTE**) **Gerontological care assistants (ASG)** who carry out part of the rehabilitation and support care based on the assessment and objectives assigned by the occupational therapist and/or psychomotrician (**1.5 FTE**).	The team of the pole of activities and adapted care is composed : " 1° A psychomotrician or occupational therapist ; " 2° A gerontology care assistant ; "3° A psychologist for residents and caregivers.	The reinforced accommodation unit has : 1° A doctor, if necessary, the coordinating doctor may carry out this mission; (2) a nurse; 3° A psychomotrician or occupational therapist; 4° A nursing assistant or a medical-psychological assistant or an educational and social support assistant; 5° A gerontology care assistant; 6° A nursing staff at night; 7° A psychologist for residents and caregivers.	Attachment to the technical platform of the SSR, with **dedicated human resources** with care and support skills: - physician with experience or training in cognitive-behavioural rehabilitation; -psychologist ; - rehabilitation professionals (psychomotor therapist, occupational therapist, etc.); -paramedical staff of medical-psychological assistant or care assistant having benefited from or engaging in an appropriate training. The use of a psychologist must be provided for the care teams.

Source : Terms of reference

[149] The heterogeneous size of the teams can be explained in part by the fact that they are attached to different structures which may provide a technical platform (e.g. the UCC is attached to a care and rehabilitation department) or allow for the sharing of skills and working time (inclusion of the UHR in the EHPAD). However, it poses difficulties in measuring the actual working time devoted to the unit in question, and the methods of associating certain external skills (physiotherapist, professional for adapted physical activity, speech therapist), and counting the time available remains difficult. The current revision of the specifications for CCUs has attempted to achieve greater precision, without however managing to completely clarify the modalities of recourse to the various skills.

[150] The surveys also show persistent recruitment difficulties, in a general context of very tense human resources, which prevents full compliance with the specifications. During the period 2020-2021, in order to cope with the difficulties related to the pandemic, a large number of units were closed and the staff distributed among the various departments, not so much to comply with health regulations as to cope with the general shortage of staff in the establishments. Some PASAs and UCCs were still closed at the time of the mission's visit, and the prospects for reopening were uncertain.

The mission's survey of EHPADs

A survey was conducted by the mission during the months of April and May 2022 among EHPADs. The internet questionnaire was sent to them by four federations (FHF, FEHAP, UNCCAS and SYNERPA), with a supplementary message sent to establishments listed as having a PASA or a UHR.

The title of the survey specified the scope of the mission but opened the questionnaire to establishments that do not have PASA or UHR facilities in order to obtain their feedback on "other solutions developed", and in particular UvA.

780 EHPADs, spread across all French departments and Martinique, and accommodating an average of 102 elderly people, responded to the survey. The results show that 60% of the EHPADs that responded have an Alzheimer's unit, 50% have a PASA and 13% have a UHR. 17% have no such facilities.

The main findings are as follows:

-Cognitive disorders are present in two-thirds of residents, and severe or acute behavioural disorders in one resident out of five; acts of violence are frequent on the part of certain residents towards other residents and professionals (45% frequently; 27% daily); the rate of residents treated with neuroleptics does not differ significantly according to whether or not the respondent EHPADs have special care facilities in place;

The resources that can be mobilized in the region are numerous: the most frequently cited are, in order, memory consultations (65%), psychiatric services (64%), geriatric care units (62%), geriatric short-stay units (60%), mobile geriatric teams (49%), geriatric consultations and day hospitals (41%), geriatric day units within another EHPAD (32%) and a mobile geronto-psychiatric team (29%);

-The two main reasons for not setting up special care facilities are architectural constraints and lack of funding;

-The presence of severe psychological and behavioural disorders is the primary criterion for admitting residents to an RHU; the main obstacles to accessing RHUs are the lack of places (58%), the unavailability of places due to the lack of downstream solutions (51%), the reluctance of families to change their place of residence (45%) or lack of knowledge of what is available in the region (37%);

-There is an average of 2.36 FTE per PASA, including 1.62 FTE of ASG, for structures that open on average 21 days in the month (March 2022) for the benefit of 21.8 residents on average; 78% of PASAs operate in a "classic" manner;

The Alzheimer's living units have an average of 22 places, i.e., one-fifth of the facilities where they are installed; their architectural features are similar to those of the UHRs for about 75% of them (90% of the UVAs have an opening onto an enclosed, secure terrace or garden); the profile of the population cared for in the UVAs does not differ from the average of the respondents.

[151] In addition, the location of the EHPADs (whether in a medical desert zone or not) and the UCCs (in a general hospital centre or a university hospital centre) has an impact on recruitment capacities. These recruitment difficulties and the limited number of staff have resulted in a relative compliance with the specifications and/or initial objectives:

- While the PASAs were initially supposed to be open every day, including weekends, they are finally only open on average 5.1 days a week, with the result that disorders worsen during weekends;
- The UHRs were supposed to have night staff, but the mission's survey shows that the use of a night nurse is lower than expected, even though the disorders may be more marked at night for these patient profiles;

- CCUs were expected to combine geriatric and psychiatric expertise, and the latest survey conducted by SG-MAS in 2018 shows that a large majority (79%) of CCUs do not have psychiatrist time;
- The ESAs were intended to accompany the onset of the first behavioural problems, but they cease their interventions because of a lack of staff to reinforce these situations.

[152] In general, EHPADs are concerned about the growth in the number of residents with a psychiatric history, but without the medical resources and training to support them.

[153] Lastly, it should be noted that the participation of families and relatives in the various special care facilities, particularly in the day-to-day running of the institutions, is generally limited. This is, however, in principle one of their distinctive features.

2.3.3 A sequential approach in institutions that is no longer perfectly adapted to the characteristics of the residents

[154] The sequential approach which is the basis of special care facilities now raises a series of questions: the possible selection bias at entry, successive moves which do not actually work, or the gathering of all people with severe disorders in the same place. Its international originality also raises questions.

[155] The special care facilities created in 2008 are part of a care pathway involving a change in place of residence depending on the person's psychological and behavioural situation. The sequential approach therefore provides for return trips between a special care unit in charge of calming the situation and the person's usual place of residence. However, with nearly fifteen years of hindsight, it appears that the pathways are not really sequential and that it would not even be desirable for them to become so.

[156] Thus, the length of stay in the UHRs is very long, and there are few people who leave the system (the UHRs are sometimes the last residence of the person before their death), in particular because of the difficulties in calming people down, the risks of a resurgence of disorders in the event of a move and a new change in their environment, or because of the refusal of families who are aware of the need for a greater human resources presence around their relative. Finally, given the length of stay, it is often impossible to return to the initial residence and a discharge from the UHR implies the search for a new place in an EHPAD.

[157] There are thus significant selection biases on entry into UHRs: applications for admission to UHRs are abandoned because of waiting times, or families are opposed to transferring to a UHR because of the geographical distance or the need for stability in their relative's environment. UHR teams also report difficulties in identifying suitable beneficiaries due to a lack of available psychiatric expertise.

[158] In practice, the residents of the EHPADs to which the UHRs are attached represent a large proportion of the beneficiaries and these units are an additional reception component of a sequential pathway within the EHPAD itself. The majority of UHRs quickly reach saturation as soon as they are created, with the result that the entire system becomes clogged.

[159] Another major weakness of the RHUs is their difficult linkage, like the CCUs, with psychiatry, particularly because of the lack of psychiatrists, and more particularly geronto-psychiatrists.

[160] In short, in a context where people live in an EHPAD for an average of two years and five months, and one year and two months for half of them, after entering it, a system based on the principle of successive moves between EHPADs does not meet the need for environmental stability specific to people suffering from Alzheimer's disease or a related illness. In the course of its survey of family carers, the mission even identified extreme cases, such as one person who had undergone seven changes of location from the time she entered the EHPAD until her death thirteen months later (traditional Ehpad, then psychiatric unit, then back to EHPAD, then UCC, then USLD, then Alzheimer's living unit, etc.).

[161] Finally, the specialisation of units and residents according to the severity of the disorders is contested insofar as bringing together people with acute disorders in the same unit can aggravate the latter, resulting in rapid exhaustion of staff and less effective drug treatment and non-drug interventions. In this sense, UHRs have important limitations in their operating principle. Specialisation by pathology may also be difficult if the aim is to maintain proximity to families, as the prevalence of certain pathologies is too low to justify the creation of units in all EHPADs. Some EHPADs nevertheless choose to group together in small units patient profiles that are similar in terms of their medical history (old age and Alzheimer's disease or a related disease, on the one hand, and psychiatric disorders on the other, for example), or their disorders (anxiety, for example).

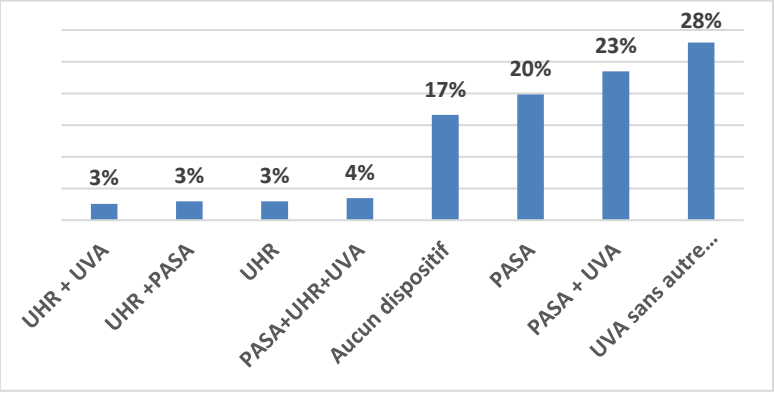
2.3.4 Insufficient priority given to the care of people with Alzheimer's disease or a related illness with behavioural problems in all EHPADs

2.3.4.1 Insufficient growth and territorial coverage to meet the scale of needs.

[162] Despite the financial efforts made, the number of PASAs, UHRs and UCCs remains modest in relation to the total number of EHPADs, and to the characteristics of their populations (age, proportion of people with cognitive, psychological and behavioural disorders).

[163] According to an analysis of the 2018 ANAP dashboard and a sample of approximately 5,500 EHPADs, nearly half of EHPADs have no facilities in the establishment. Nearly one out of three EHPADs would only have an isolated Alzheimer's unit, with no other special care facilities (PASA, UHR or UCC). These data are broadly consistent with the mission's survey of EHPADs: of the 780 EHPADs that responded, 28% had only an Alzheimer's unit (and 17% had no facility at all, but there was clearly a bias in the sample of respondents).

Graphique 7 : Distribution of the EHPADs responding to the survey according to the combination of measures



Source : Mission survey

[164] Moreover, of the 7,434 EHPADs in metropolitan France[38] , we note that :

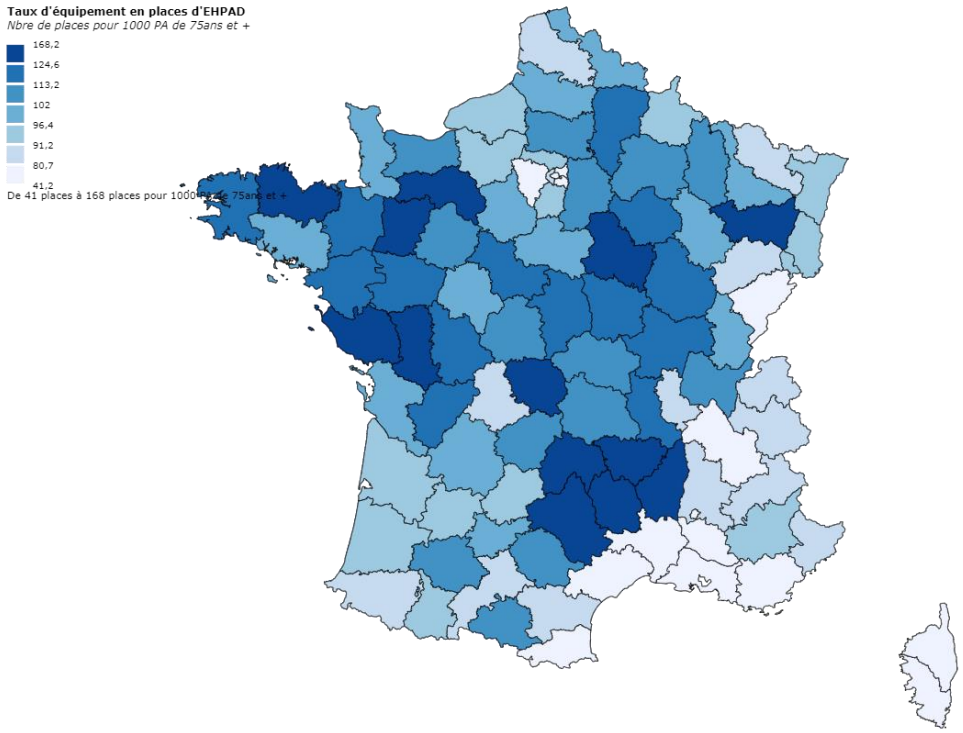
- Only 26% of EHPADs have a PASA and less than 10% of people with a place in an EHPAD have access to a PASA, even though the number of residents with Alzheimer's disease or a related illness exceeds 50% of the total;
- Less than 3% of EHPADs have an UHR and approximately 1% of residents with Alzheimer's disease or a related illness benefit from it. It should be noted, however, that the proportion of USLDs with an UHR is higher: 21% of the 583 USLDs have an UHR, and these units represent between 1% and 10% of USLD places depending on the region;
- There would be 1,584 CCU places (based on an average of eleven CCU places) for 144 CCUs. It is difficult to estimate the adequacy of this supply to a demand that is not precisely known.

[165] As regards Alzheimer's units, which are not special care facilities in the administrative sense of the term, only less than one in two EHPADs (between 43.3% in 2019 according to the ANAP and 46.7% in 2015 according to the EHPA survey) would have one. And the number of places available in Alzheimer's living units compared to the total number of places in EHPADs would be less than 10%.

[166] In addition, there are major territorial disparities in the supply, with many white areas or areas poorly covered by special care facilities. This disparity is in line with the more global inequalities in the supply of EHPAD itself, as shown on the map below.

[38] ARS data concerning special care facilities, DREES data concerning places in EHPAD and USLD

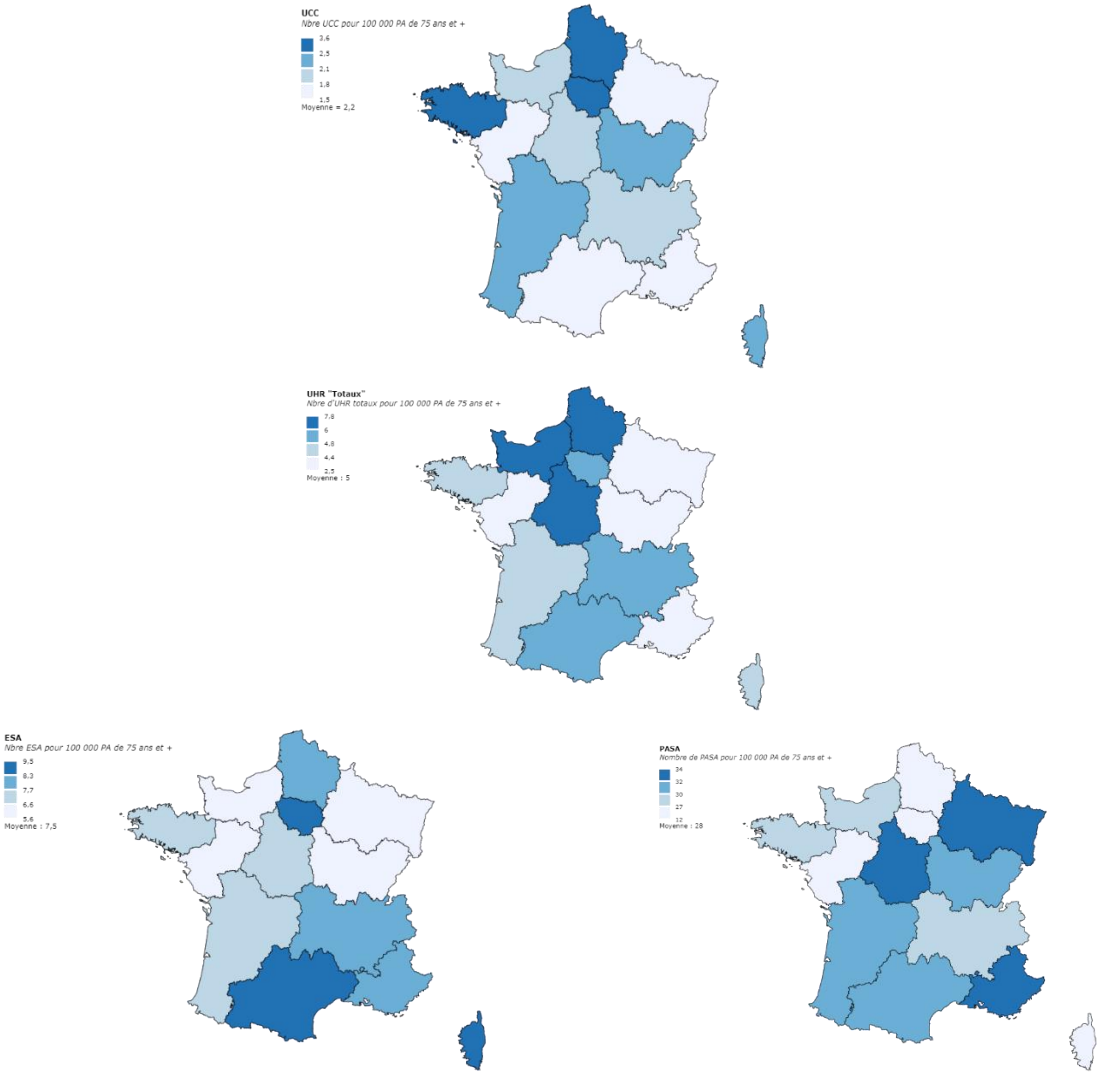
Carte 1 : (Map) Equipment rate on 31.12.2020 in terms of number of EHPAD places per 1,000 inhabitants aged 75 and over



Source : DREES, Finess, ISD; Insee, population estimate 2021 (Panorama statistique de la cohésion sociale, du travail et de l'emploi, 2021)

[167] Thus, in practice, the departments where there are the most elderly people do not generally have a supply of EHPAD places that meets the needs.

Graphique 8 : Distribution of facilities per 100,000 persons aged 75 and over



Source : ARS, INSEE

[168] And as far as PASAs are concerned, there are also significant variations in supply between regions, which can be as much as double.

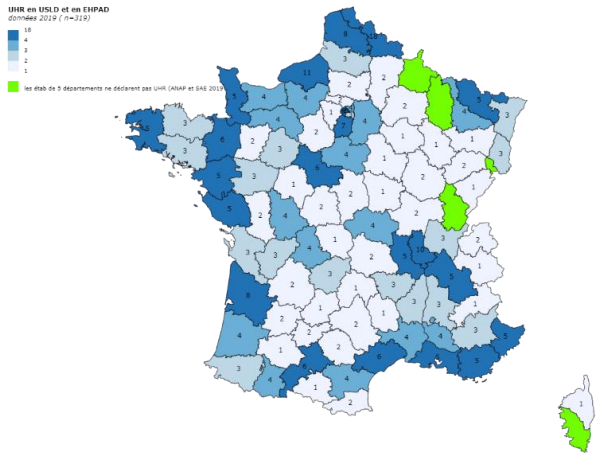
Tableau 4 : FSEP supply vs. need

	PASA installed in 2022	Estimated number of residents attending PASA (average of 32.2 people per PASA)	Total number of installed places (number of residents present at a given time)	Percentage of EHPAD residents who have access to a PASA
AUVERGNE-RHÔNE-ALPES	239	7 696	77 622	10 %
BURGUNDY-FRANCHE-COMTE	101	3 252	33 540	10 %
BRITAIN	111	3 574	41 403	9 %
CENTRE-VAL DE LOIRE	92	2 962	29 500	10 %
CORSICA	5	161	1 935	8 %
GRAND EST	172	5 538	52 071	11 %
HAUTS-DE-FRANCE	136	4 379	47 465	9 %
ILE-DE-FRANCE	206	6 633	65 454	10 %
NORMANDY	100	3 220	34 193	9 %
NEW-AFRICA	225	7 245	71 590	10 %
OCCITANIA	210	6 762	60 416	11 %
COUNTRY OF THE LOIRE	105	3 381	47 191	7 %
PACA	206	6 633	46 462	14 %
TOTAL	1 908	61 438	608 842	10 %

Source : ARS

[169] The following maps also show the existence of geographical areas with little or no coverage by an UHR and, even more so, by a UCC. The map of UHRs includes UHRs in EHPAD and USLD and relates to 2019, with 319 UHRs declared in the annual statistics of establishments. Since then, both Corsica and the Grand Est are deploying additional UHRs, but those in the Grand Est have not yet opened.

Carte 2 : Territorial coverage of the UHR

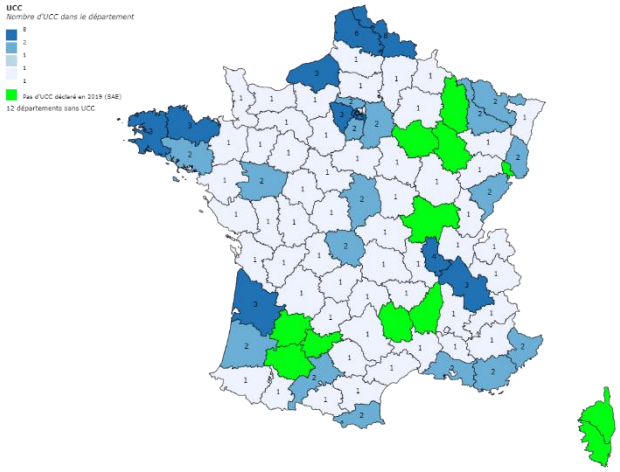


Source : Annual statistics on establishments and ANAP

[170] The 144 existing CCUs, with approximately 1,600 places, are distributed heterogeneously throughout the country. This disparity is largely due to the existence, or not, of SSR teams to which the CCUs can be attached and the possibility, or not, of creating them in hospitals, mainly in general hospitals and to a lesser extent in university hospitals, which are sometimes already very dense. The existing white zones are a cause for concern insofar as the UCCs are clearly identified by the EHPADs as resources in the territory in the event of a crisis and the UCCs meet clear needs.

[171] The map below illustrates this disparity, based on the 137 CCUs identified as authorized by the 2019 health facility statistics. There were twelve metropolitan departments for which no establishment had declared a CCU. Since then, a few CCUs have been created, notably in Corsica, and some departments could be considered as covered by CCUs from neighbouring departments, but the white areas remain worrying.

Carte 3 : Territorial distribution of CCUs



Source : Annual establishment statistics, 2019

2.3.4.2 A global transformation of the offer that is still pending

[172] The emphasis placed on special care facilities over the last fifteen years, mainly in institutions, has in some ways been to the detriment of a global transformation of efforts in all EHPADs to adapt them to the rapidly changing profile of their residents, who are now mostly suffering from Alzheimer's disease or a related illness with cognitive, psychological and behavioural disorders.

[173] In view of the general increase in the population aged 75 and over, the choice of proceeding solely through special care facilities is no longer appropriate, as the rate of creation would be insufficient.

Tableau 5 : Increase in special care facilities in relation to the increase in the population aged 75 and over

	OBJECTIFS PLAN Alzheimer 2008-2012	Réalisé au 31/12/2012 (Evaluation du plan 2008-2012	population 75 ans et + en 2012 (France entière)	objectifs 2012 pour 100 000 personnes de 75 ans et +	offre 2012 en nombre de PASA pour 100 000 personnes de 75 ans et +	OBJECTIFS PMND 2014-2019	Réalisé en Avril 2022	Population 75 ans et + en 2022 (France entière)	Offre 2022 en nombre de dispositifs pour 100 000 personnes de 75 ans et +
PASA	1784	767	5 850 800	30	13,1	Pas de PASA supplémentaires	1921	6 650 289 (+13,6% en 10 ans)	28,9
UHR	310	146 (91 Médico-sociaux et 55 sanitaires (USLD))	5 850 800	5,3	2,5	pas d'UHR supplémentaires	333	6 650 289	5,0
ESA	500	273	5 850 800	8,5	4,7	plus 74 équipes	505	6 650 289	7,6
UCC	120	78	5 850 800	2,1	1,3	plus 20 à 30 équipes	145	6 650 289	2,2

Source : Data from INSEE, ARS, and the 2008-2012 Alzheimer's plan evaluation report

[174] As we have seen, the number of places in Alzheimer's units is still relatively small. EHPAD teams sometimes develop real interior design projects and seek to make the premises more user-friendly, even changing the designation of patients, who are considered as "inhabitants" rather than "residents". However, most of the EHPADs visited by the mission are clearly not adapted to receiving people suffering from Alzheimer's disease or a related illness with cognitive, psychological and behavioural disorders in the best possible conditions. Thus, during the visits, the architecture of the EHPADs installed in old buildings, which are the most numerous, was insufficiently adapted to the residents' ability to wander and interact with each other and their families. The architecture of the recently built buildings visited seemed to meet the recognised principles (spaces for walking, gardens, openings, etc.) but was sad and impersonal. Even in the recently built buildings, the interior layout observed by the mission was, with some exceptions, most often very bare, like in a hospital ward, far from the desired personalised and human atmosphere; catering was collective, and sometimes in rooms with several dozen residents; the rooms were rarely decorated with personal objects; the lighting was harsh and the signage cold.

[175] In addition to the shortcomings of renovation and fitting out, the data collected by Professors Jeandel and Guerin, as well as the mission's survey, largely show the difficulties encountered by EHPADs, whether or not they have special facilities (cf. part 1 concerning the number of residents with behavioural disorders), in dealing with behavioural disorders in their residents, with 21% of residents presenting severe or even acute disorders, and a high frequency of disorders. The disorders may be spread over a large number of residents, without those who present these disorders on an occasional basis being considered for referral to a UCC, UHR, or other facilities. Thus, the survey

conducted by the mission among EHPADs shows that for 20% of EHPADs, acts of violence are regular, i.e. every month or two to three months, for 45%, they are frequent, and 27% daily[39].

[176] All of the EHPADs rely in one way or another on the organisation of a closed space. Most of the EHPADs visited have a secure access and residents cannot easily leave this space. Within the EHPADs with special care facilities, access to the corridors or wings of the building housing the device(s) is said to be "secure". This security consists mainly of locking the doors. This can be done by means of digicodes, keys available to staff but not to residents, or doors that are heavy enough to be impossible for residents to open. The closing of spaces can be more or less restrictive and confining for residents depending on the overall size of the unit and the amount of walking space available, both indoors and outdoors. While UHRs are subject to a precise architectural framework, this is not the case for UVAs or even UCCs.

[177] However, it can happen that a wing of a building is closed without the architecture of the building corresponding to the needs of the people cared for. The EHPADs that responded to the mission's survey indicated that the adaptation of the architecture and layout play a very important role in reducing disorders. The staff we met in some UCCs spontaneously emphasised the gap between the architecture of their building and what they considered desirable for the people in it. The survey of EHPADs is particularly alarming for the UVAs: the EHPADs emphasise that confinement increases the disorders, and that many residents spend their days trying to get out. In addition to these observations, there are difficulties specific to the locking methods (type of door, visibility of the door) and the alternative offered within the unit. The survey carried out among the EHPADs shows that confinement is not accompanied by a systematic structuring of the days adapted to the needs, and some emphasise the need to develop occupational activities with the support of an activity leader.

[178] In addition to these constraints imposed on the freedom to come and go, EHPADs are largely looking for special care facilities to secure residents' rooms so that people can wander around without the risk of entering (voluntarily or involuntarily) neighbouring rooms and possibly endangering the person who lives there. Without specific solutions for personalised door opening by badge, EHPADs are faced with violence between residents, and it is often to secure the other residents that closed units are organised. The EHPADs therefore clearly indicate that another way of managing disturbances, with modular spaces, better distributed staff support, and more appropriate technological means could be alternatives to closed units. One of the EHPADs visited by the mission had decided to reopen the Alzheimer's unit during the day, allowing people to wander freely throughout the EHPAD, and noted a reduction in the residents' problems and a reduction in the suffering expressed by the staff.

[39] The data collected by the mission must be interpreted in the light of several factors: the EHPADs responding were certainly interested in the survey and possibly more concerned than others by psychological and behavioural disorders; the majority of them were members of the health sector and 83% had a system for dealing with behavioural disorders, even if 28% of them were in the form of unregulated UVAs. For these reasons, the number, severity and frequency of disorders could be overestimated. However, they are very much in line with those of Professors Jeandel and Guérin.

3 It is now desirable to prioritise investments in favour of increased care in the city and in ordinary places in establishments adapted to the needs of their new residents

[179] Twenty years after the first Alzheimer's plan, and given the significant changes in prevalence, a better understanding of prevention, particularly of behavioural disorders, and the progress in drug treatments and non-drug interventions, it is time for the policy of prevention and care for people with Alzheimer's disease or a related disorder to evolve quite substantially.

[180] In general, the aim is to improve prevention as much as possible. It is also a matter of increasing the number and duration of home care for people with Alzheimer's or related diseases, including those with moderate to severe psychological and behavioural disorders. It is also a question of increasing the quantity and quality of care for these people in all EHPADs, by integrating, as it were, the Alzheimer's living units and PASAs into common law. Lastly, it is a question of modernising the operation of crisis special care facilities.

[181] These structural and complex changes will require significant additional funding, particularly in terms of personnel. They will also require a change of culture and management in the establishments, and therefore time for their implementation. This is a real transition from one paradigm, that of special care facilities, to another, that of full inclusion of people with Alzheimer's or related diseases in all institutions.

3.1 Desirable improvement in prevention efforts and drug and non-drug intervention modalities

[182] The mission had neither the resources nor the time to investigate all the issues related to the prevention of Alzheimer's disease, diagnosis, epidemiology or care paths. However, it would like to make a few recommendations in this area that it considers particularly important.

[183] First of all, given the proven identification of risk exposure factors, and the interest for both the people concerned and the care system themselves in delaying the onset of the disease and its symptoms, or even avoiding them, it seems particularly appropriate to conduct health education campaigns on the main risk factors for the disease. Some of the mission's interlocutors argued in particular for campaigns on lesser-known factors such as hearing and depression.

Recommandation n°1 Conduct national health education campaigns on risk factors for Alzheimer's disease, particularly those related to hearing and depression

[184] The still imperfect knowledge in our country of the epidemiology of Alzheimer's disease and related disorders contrasts with the importance of this issue for public health and for society as a whole. The even more imperfect knowledge of the precise prevalence of psychological and behavioural disorders among people in cities and institutions calls for the implementation of appropriate solutions. It would be interesting to experiment in one or two regions with the creation of a register of these disorders, as has existed in Sweden, for example, since 2007[40] , which has led to a reduction in the misuse of neuroleptics and has facilitated the training of professionals, as the OECD

[40] Cf. SveDem: www.ucr.uu.se/svedem

points out in its reports on Alzheimer's disease[41] . Each registry would be managed, for example, by a CM2R or a health institution. If successful, such registries could be extended nationally.

Recommandation n°2 Experiment with the creation of a regional register of psychological and behavioural disorders

[185] The different types of health and medico-social pathways for people with Alzheimer's disease or a related disorder are still not well known. This hinders the implementation of the most appropriate solutions for their care. It would therefore be appropriate, in addition to the research work carried out on the basis of SNDS data, to launch calls for projects in some departments to finance studies on the health and medico-social pathways of people with Alzheimer's disease.

Recommandation n°3 Launch calls for projects in a few departments for studies analysing the health and social pathways of people with Alzheimer's disease or a related illness with cognitive, psychological and behavioural disorders

[186] Excessive use of chemical restraint, or its misuse, is a medical and ethical problem. It would therefore be advisable to launch a support programme (support, training, etc.) in each region, led by the ARS and the health insurance medical officers, in conjunction with independent professionals working in EHPADs, and targeting one tenth of residential establishments, and where appropriate USLDs, which have the highest rate of psychotropic drug prescriptions, according to health insurance data. The ARSs would have to prioritise establishments according to a range of indicators (presence of a coordinating doctor, size, patient base, etc.), given the very wide diversity of EHPADs and USLDs.

Recommandation n°4 Launch in each region a programme of support by the ARS and the health insurance, in conjunction with the URPS, for the 10% of residential establishments with the highest rate of psychotropic drug prescriptions

[187] Non-drug interventions, which are at the heart of care for people with Alzheimer's disease or a related disorder, are increasingly used, although little is known about their precise impact on people, their families and carers, and professionals, nor about their cost/efficiency. In this context, it would be useful to create a national multidisciplinary centre of expertise, based on an existing structure (e.g. CM2R or Alzheimer's centre of excellence, or the national centre for resources and evidence on the prevention of loss of autonomy created at the CNSA as part of the 2022-2026 COG), bringing together experts in gerontology, mental health and neurology, dedicated to evaluating and, above all, disseminating good practice in the use of these interventions in the territories.

Recommandation n°5 Create a national multidisciplinary centre of expertise (gerontology, mental health, neurology) dedicated to the evaluation of non-medicinal interventions, starting with those adapted to psychological and behavioural disorders, and to the dissemination of good practice in their use in establishments, in special care facilities and among professionals in the community

3.2 A home-based ESA offer that must evolve qualitatively and quantitatively

[188] As the OECD, Alzheimer's International and many others have repeatedly stressed, more and longer care at home for people with Alzheimer's or a related disease is a desirable direction, including for people with moderate psychological and behavioural problems. This corresponds to the

[41] An epidemiological register is "a continuous and exhaustive collection of nominative data concerning one or more health events in a geographically defined population, for research and public health purposes, by a team with the appropriate skills" (cf. decree of 6 November 1995). In France, for example, cancer registers already exist. Registers make it possible to accurately estimate the incidence and prevalence of diseases as well as the mortality that may result from them, in a given territory.

preference of the people themselves, helps to slow the progression of the various stages of the disease, provides a better quality of life than in institutions, and is often less costly.

[189] To this end, it is first necessary to better coordinate the ESAs with other existing and future offers, in particular the treating physicians, who often seem to be unfamiliar with them, but also the medical auxiliaries in town, psychologists, day care centres, day hospitals, respite care platforms, etc...

Recommandation n°6 Better coordination of ESAs with attending physicians, medical auxiliaries, psychologists and other existing services (day care centres, day hospitals, respite care platforms, etc.)

[190] The ESAs would also benefit from more structured national coordination by the CNSA and regional coordination by the ARSs, in order to develop synergies between them, to have additional common resources, to disseminate know-how, etc.

Recommandation n°7 Create a mechanism to coordinate a national network of ESAs, possibly also including other forms of day care in the city.

[191] Longer home care for more people suffering from Alzheimer's disease or a related disorder with psychological and behavioural problems requires, first of all, better access to the services provided by ESAs. To achieve this, the mission recommends doubling the number of ESA beneficiaries, at least during the period of the future neurodegenerative diseases roadmap. Priority should be given to covering departments with a shortage of services and ARSs should be left to determine the best method for ensuring the most complete coverage of the territory (see the ESA appendix for examples of methods).

[192] It is also necessary to expand the range of services offered by ESAs beyond cognitive disorders in order to enable more people with mild or even moderate behavioural disorders to remain at home and to delay institutionalisation as much as possible.

[193] The cost of this measure can be estimated at around €100 million per year, based on €150,000 per ESA per year at constant scope of supply and an additional 30% of the cost due to the increase in services provided.

Recommandation n°8 Double the number of ESA beneficiaries within the framework of the MND roadmap by covering, as a priority, the departments with a shortage of services and by expanding their offer of services for people with Alzheimer's disease or a related disorder with moderate to severe psychological and behavioural disorders

[194] As the mission was able to observe, many initiatives exist at local level to support people with Alzheimer's disease or a related illness. However, as the mission's survey of ESAs shows, the supply is still too limited when behavioural problems are on the increase, and increased funding, particularly from the FIR but also from the CNSA where appropriate, would be useful. Similarly, it would be particularly useful, as shown by international experience (OECD) and the mission's survey of ARS, if the CNSA were to provide more funding for prevention training for carers, in line with measure 4 of the 2020-2022 mobilisation and support strategy "Acting for carers", The CNSA should, in particular, provide more funding, in line with measure 4 of the 2020-2022 mobilisation and support strategy "Acting for carers", for training carers in the prevention, detection and management of these disorders, as well as for remote assistance services (by telephone or video conference, 24 hours a day, 7 days a week), in order to know how to deal with a crisis while avoiding unnecessary and sometimes harmful hospitalisations, particularly in emergencies.

Recommandation n°9 Fund local innovations to support people with Alzheimer's disease or a related disorder with moderate to severe psychological and behavioural problems

Recommandation n°10 Massive development of training for carers and various distance support services for carers and relatives

3.3 Priority should be given to transforming the supply of common law establishments

[195] The quantity and quality of ordinary care provided by nursing homes must be adapted to the new population of people suffering from Alzheimer's disease or a related illness. This population already accounts for a large proportion of residents and is likely to represent a growing proportion in the years to come.

[196] This is a long-term project that goes beyond the modernization of Alzheimer's units and the development of PASAs and must involve a global transformation of the organization, management and financing of all EHPADs.

3.3.1 A necessary global transformation of the EHPAD

[197] On the whole, the current stock of long-term care facilities does not meet the requirements of quality care for their residents, who will increasingly be affected by Alzheimer's disease or a related illness, with cognitive disorders but also psychological and behavioural problems, in terms of staffing, architectural configuration and interior design, but also in terms of practices. The mission's field visits to various regions, including establishments presented as models, confirmed this observation.

[198] Generally speaking, it is a global transformation project that must be undertaken to prepare for the future. The prospect of investment focused on special care facilities, which refers to the period when only a minority of residents were concerned, is now outdated and will be increasingly so. The additional funding needed must be within the budgetary framework outlined by the report of the Grand Age and Autonomy consultation which was delivered in 2019.

Recommandation n°11 Undertake a comprehensive transformation of all EHPADs to adapt them to the significant influx of people suffering from Alzheimer's disease or a related illness with moderate to severe psychological and behavioural disorders

[199] This transformation project concerns, of course, staffing levels, which are insufficient in long-term care facilities, as highlighted by the report of the Grand Age Autonomie consultation and, more recently, the Jeandel-Guérin report. The shortage of staff is even more significant in establishments with a high proportion of residents suffering from Alzheimer's disease or a related illness with moderate to severe psychological and behavioural disorders, due to the lack of a link between the severity of cognitive disorders and psychological and behavioural disorders, on the one hand, and the amount of funding on the other.

[200] To cope with the increase in the number of people suffering from Alzheimer's disease or a related illness, it is therefore necessary to review the methods of financing establishments in order to take into account not only the somatic disorders of residents but also their cognitive disorders and psychological and behavioural problems. Technical work has been carried out on the PATHOS reference system, but the task now is to rapidly complete the revision of the orders.

Recommandation n°12 Reform the AGGIR grid and the PATHOS reference system to better take into account the severity of cognitive disorders and psychological and behavioural disorders in the financing of all establishments

[201] If this ambitious project, which is very costly for public finances (estimates range from €0.5 billion to €1.7 billion), which was launched ten years ago and goes beyond the issue of people with Alzheimer's disease and related disorders, cannot be completed quickly, a specific package for the financing of non-medical interventions in establishments should be tested in a few départements and extended later. This would make it possible to finance the recruitment or temporary employment of care personnel such as dieticians, speech therapists, occupational therapists and psychomotor therapists, teachers of adapted physical activity (APA) or psychologists in institutions.

Recommandation n°13 Experiment with a specific package for the financing of non-medical interventions in institutions

[202] With regard to personnel, the effective presence of gerontological care assistants (ASGs) on site at night in EHPADs with a significant proportion of residents with Alzheimer's disease would be particularly desirable. This recommendation complements the one made in the report by Professors Jeandel and Guérin concerning the presence of nurses, which is most often in the form of on-call duty. The experiment carried out in the PACA region shows that it provides better support for residents with an altered nycthemeral rhythm and ensures quality sleep for all the other residents, thus reducing psychological and behavioural disorders. It would therefore be advisable to reinforce this presence while adapting it according to the size of the establishments and the profile of the residents.

Recommandation n°14 Strengthen the presence of ASGs at night in EHPADs, adapting it according to the size of the establishments and the profile of the residents

[203] Another important issue is the information and training of staff working in EHPADs on the specificities of caring for people with Alzheimer's disease or a related illness with psychological and behavioural disorders. According to the survey carried out by the mission among the EHPADs, this training seems to be insufficient at present and should be significantly developed, either through face-to-face programmes, such as those organised by the Fondation Médéric Alzheimer, or remotely using the new tools available today.

Recommandation n°15 Develop awareness-raising and training programmes, particularly at a distance, for all staff working in EHPADs in contact with residents with psychological and behavioural disorders

[204] As indicated by the mission, although the general architectural principles are becoming better known by all, the architecture and interior design of facilities are still not sufficiently adapted. These are key elements in the prevention of psychological and behavioural disorders and in the quality of care for residents with Alzheimer's disease or a related disorder. Good practice in this area is increasingly recognised internationally. In particular, the Alzheimer's Disease International 2020 report stresses the importance of the following principles Reducing risk without creating barriers; allowing people to see and be seen; reducing unnecessary stimulation and maximising useful stimulation which should be personalised; encouraging movement and engagement in activities, particularly outdoor activities; creating a familiar and personalised place; providing opportunities

for seclusion and socialising depending on the time of day; being connected to the surrounding community; having an architecture that is aligned with the facility's philosophy of living[42] .

[205] Given the feedback from EHPADs on the frequency and intensity of behavioural problems, beyond the statistics known at the international level, the link between current architecture and facilities and these problems can legitimately be questioned.

[206] It is essential to take advantage of the vast national programme to renovate, and to a lesser extent build, EHPADs, worth €1.5 billion over the years 2021-2025, which is already underway, so as not to repeat the mistakes of the past and to have establishments for the decades to come that meet best practices, particularly around small living units. As emphasized by the CNSA, which has set up a "Laboratory for Tomorrow's Solutions" for this purpose, personalized support for EHPAD directors with projects is particularly necessary in this respect.

[207] Recommendations on interior design should also be drawn up and disseminated, and support for EHPAD directors is, once again, highly desirable. It is, in fact, possible to make a great deal of progress in terms of interior design without significant costs, both in the ordinary places in EHPADs and in Alzheimer's units (see below).

Recommandation n°16 Implement, with appropriate support for EHPAD directors, architectural recommendations adapted to residents with Alzheimer's disease or a disease with psychological and behavioural disorders for the implementation of the EHPAD renovation and construction plan over the period 2021-2025 and establish and implement recommendations for adapted interior design

3.3.2 Alzheimer's units that should be fully integrated into the common law of EHPADs

[208] In the context of the overall transformation of EHPADs, the question of the future of Alzheimer's living units has been raised. More than twenty years, or even thirty or forty years after their creation, it seems appropriate to move towards their harmonisation and to draw up specifications that would set out the main principles to be followed, in terms of the number of places (small units with between five and ten places, or even fifteen places at the most), the staffing (reinforced), the architecture and interior design in particular, but also in terms of the type of non-medicinal interventions, depending on the severity of the cognitive, psychological and behavioural disorders.

Recommandation n°17 Draw up specifications for Alzheimer's living units adapted to the severity of cognitive, psychological and behavioral disorders of residents with Alzheimer's disease or a related disorder

[209] The issue of confinement and segregation of people with Alzheimer's disease or a related disorder with psychological and behavioural problems is an important and sensitive issue.

[210] There are many criticisms in the international literature. In practice, confinement is also the subject of numerous criticisms in the responses to the IGAS survey of EHPADs, with mention of the suffering of certain residents who wish to leave the Alzheimer's unit, the helplessness of the staff in the face of their distress, and the risk of worsening behavioural problems.

[42] Alzheimer's Disease International. *World Alzheimer Report 2020. Design, dignity, dementia: Dementia-related design and the built environment.* 2020

[211] Under these conditions, the development of open EHPADs without closed living units should be encouraged, when there is sufficient staffing in the establishment.

Recommandation n°18 Encourage the development of EHPAD without closed living units

[212] Similarly, in the absence of a full evaluation, it is premature to comment on the experiments with Alzheimer's villages, the first of which in France opened in Dax, in the Landes region, based on the Dutch Weesp model. The risks of segregation and stigmatisation are significant, as are the costs, which are sometimes high because of the high level of supervision. It would therefore be advisable to take the time to assess their impact before investing in new schemes of this type. The same applies to EHPADs reserved exclusively for people with Alzheimer's disease or a related illness.

Recommandation n°19 Evaluate the impact of existing Alzheimer EHPADs and Alzheimer villages in France and abroad before extending them

[213] The mission recommends, as has been done in Australia[43] , that legal and organisational guidelines on physical and chemical restraints and restrictions on movement be drawn up and distributed to all establishments. This should be complemented by a labelling process that would mobilise EHPAD teams in a dynamic and inclusive approach.

Recommandation n°20 Develop and disseminate legal and organizational guidelines for all facilities on physical and chemical restraints and restrictions on movement

3.3.3 PASAs, a formula to be expanded and made more flexible in order to irrigate EHPADs

[214] The PASAs, which are intended to accommodate during the day residents of EHPADs suffering from Alzheimer's disease or a related illness and presenting moderate disorders, are a useful formula and a response deemed effective overall to the cognitive needs of residents by trained professionals (ASGs, occupational therapists, psychomotor therapists, psychologists) within the framework of an individualized program.

[215] Doubling their number within the framework of the future roadmap on neurodegenerative diseases or over the period 2023-2025, i.e. creating around 2,000 PASAs, seems an ambitious but realistic objective. It would allow better coverage of small and medium-sized establishments in particular and would make it possible to accommodate approximately 120,000 people each year, i.e. one third of the current number of residents suffering from Alzheimer's disease. The estimated cost would be around €140 million per year in total, based on a cost of €70,000 per PASA.

[216] Furthermore, although the requirements for PASAs were relaxed in 2016 and then confirmed in 2018, their operating methods and the rules applied are still too often inappropriately restrictive. Thus, the "split PASA" mode of operation, which may involve PASA professionals intervening in the different wings of an EHPAD, or the distribution of PASA activities between different places or units of an EHPAD, or the support of PASA professionals to the teams of an EHPAD, is not sufficiently widespread. Nevertheless, the organisational methods should be specified so as not to lose the therapeutic and protocolised aspects of the support: the operation of a fragmented PASA should make it possible to better adapt to the rhythm of the residents, to benefit a greater number of them, and to disseminate the culture of prevention of disorders. However, it is important not to transform the whole PASA into purely recreational activities.

[43] Australian Royal Commission into Aged Care Quality and Safety, *Final Report: Care, Dignity and Respect*, 2021.

[217] Finally, given the ambition to keep people at home for longer and to ensure that they and their families can really make this choice, it is necessary to support the first appearances of behavioural disorders by providing for PASAs to be opened to the outside world in the form of day care.

[218] Many EHPADs are calling for the deployment of night PASAs. However, this concept is not yet clearly defined in terms of its objectives and implementation methods. In this respect, a distinction should be made between the presence of an ASG at night and the creation of a PASA at night, as was done by the ARS in the PACA region.

Recommandation n°21 Double the number of PASAs in the framework of the new neurodegenerative diseases roadmap and make their operation more flexible

[219] In a similar vein, the mission observed that there was little apparent involvement of relatives and families, as well as volunteers, in organising and leading the day of residents with Alzheimer's or related diseases and psychological and behavioural disorders. However, according to international experience, this is a factor in the quality of care.

[220] It would therefore be advisable to reinforce the animation of residents' days by offering more activities in which families and relatives themselves would be invited to participate.

Recommandation n°22 Strengthen the social life of residents and the structuring of their days in all establishments by offering more activities with the participation of their families and friends

3.4 Crisis mechanisms that need to be reformed

[221] The supply of CCUs and RHUs in France does not appear to be sufficient to meet the needs of people suffering from Alzheimer's disease or a related disorder. Moreover, while the need for UCCs appears to be real, the UHR system is encountering more difficulties.

[222] Generally speaking, the few dozen CCUs and RHUs that exist in the country are not sufficiently coordinated at national and regional level to enable them to pool resources, disseminate information and skills across the board, optimise available resources and measure results. This must be remedied by setting up an operational national steering system.

Recommandation n°23 Strengthen the national steering of CCUs and RHUs

3.4.1 The useful role of CCUs that needs to be developed

[223] In practice, it would be appropriate to open at least one UCC in each department that does not have one over the period of the next neurodegenerative disease roadmap. This corresponds to the creation of around ten new UCCs nationwide (including three UCCs in Nouvelle-Aquitaine and three in the Grand-Est).

Recommandation n°24 Open a CCU in departments that do not have one

[224] Similarly, as the UCCs are already well identified by the EHPADs as resources that can be mobilized in their territories, unlike the UHRs, it would be appropriate to strengthen their outreach and projection capacities, particularly by pooling their resources through the use of tele-expertise and tele-consultation. As indicated in the appendix, exchanges between UCCs and EHPADs make it possible to alleviate certain crises without the need for physical reception in a UCC.

Recommandation n°25 Ensure the territorial outreach of CCUs by pooling their resources through the use of tele-expertise and tele-consultation

[225] As pointed out by Professors Ankri and Van Broeckhoven in their evaluation report[44] , the dual geriatric and psychiatric expertise of CCU teams and doctors is important for the proper functioning of these facilities. However, in almost eight out of ten cases, CCUs do not have the time of a psychiatrist. It is important to compensate for this by developing, in the absence of available human resources, the use of tele-expertise and, if necessary, tele-consultation.

Recommandation n°26 Develop, in the absence of available human resources, the use of tele-expertise, and if necessary tele-consultation, of psychiatrists in CCUs

[226] Finally, the existence of mobile geronto-psychiatric or psycho-geriatric units is a useful complement to the UCCs in order to provide emergency assistance at home or in institutions in crisis situations. This offer is fairly well identified by the EHPADs that responded to the mission's survey, and it would therefore seem appropriate to provide these units in their territories and to ensure that they are properly networked, by linking them to the UCCs where appropriate.

Recommandation n°27 Provide mobile geronto-psychiatric or psycho-geriatric units, possibly attached to the CCUs, to provide emergency assistance at home or in institutions in crisis situations

3.4.2 A desirable evolution of RHUs that is more profound because of the very limits of the model

[227] It is preferable to strengthen reception arrangements in ordinary EHPADs, particularly through better supervision of the UVAs, by improving the architecture and facilities and by increasing human resources. The aim is to prevent disorders and keep people with severe behavioural problems in their environment, rather than forcing them to move. In addition, it is necessary to reposition existing UHRs as far as possible for the benefit of all people suffering from Alzheimer's disease or a related illness with severe psychological and behavioural disorders and living within their jurisdiction, by ensuring the recruitment of people from outside the EHPADs to which they are attached. It is also necessary to develop the links between the UHRs and the geriatric care system and to support the EHPADs.

Recommandation n°28 Stop the deployment of RHUs on the national territory

Recommandation n°29 Develop the articulation of the UHR with the geriatric network and in support of the EHPAD

[44] Joel Ankri and Christine Van Broeckhoven. *Evaluation of the 2008-2012 Alzheimer's plan*. With the assistance of Catherine Hesse (IGAS) and Armand Renucci (IGAER). June 2013.

CONCLUSION

[228] The findings of this IGAS mission show how important it is, in France as in the other countries of the European Union, to be more prepared than we have been up to now for the challenges posed by the rapid increase in the number of people suffering from Alzheimer's disease and related disorders, with their attendant cognitive, psychological and behavioural problems.

[229] If we are powerless against the inertia of demographic projections, it is possible and desirable to act as a priority on four key levers:

- prevention of exposure to risks in the first place, as well as early detection, which have significant room for improvement;
- better support for people and their family carers at home. This is a direction that should concern more and more people with Alzheimer's disease or a related illness, including those with behavioural problems, thanks in particular to the resizing of the ESAs and the extension of their skills;
- an architectural, managerial and cultural transformation of EHPADs to bring them into line with their new residents, who are increasingly older and mostly suffer from Alzheimer's disease, with increasingly severe cognitive and behavioural disorders, and to generalise the capacity to deal with these disorders in all establishments;
- UCC reform.

[230] Important issues concerning respect for the rights of the individual, in particular the right to come and go, and the dignity of the person are also before us and deserve to be taken more seriously, in all lucidity. The same applies to the effective involvement of families and friends in the lives of residents of nursing homes with Alzheimer's disease.

[231] The twenty-nine recommendations made by the mission, which cannot be detached from the more general proposals for reforming nursing homes and their financing put forward in several reports, form, by their very ambition, a project for the entire decade, and could usefully feed into the next neurodegenerative diseases roadmap.

LETTER OF ENGAGEMENT

MINISTÈRE
DES SOLIDARITÉS
ET DE LA SANTÉ
Liberté
Égalité
Fraternité

Le Ministre

Paris, le 0 3 NOV. 2021

Nos Réf. : CAB/NN/D-21-026674

Objet : Mission d'évaluation des dispositifs spécialisés destinés aux personnes atteintes de maladies neuro-dégénératives

Madame la Cheffe de l'Inspection Générale des Affaires Sociales,

Les trois plans Alzheimer qui se sont succédé en France depuis 2000, suivis du plan Maladies neurodégénératives (PMND) à compter de 2014, ont construit en France un maillage de dispositifs spécialisés destinés aux malades atteints de ces pathologies, dont l'évaluation n'a encore pas vraiment été réalisée. Les rapports d'évaluation du troisième plan Alzheimer par le Professeur Ankri et du plan national maladies neurodégénératives par les Professeurs Grand et Joanette n'ont pas conduit cette évaluation.

Alors qu'une feuille de route maladies neurodégénératives a été engagée afin de poursuivre le travail sur certaines priorités, les questions du maillage en dispositifs spécialisés, de l'adéquation de leur cahier des charges et des moyens qui leur sont délégués aux besoins actuels et à venir se posent.

En effet, le nombre de malades a évolué depuis la création de ces dispositifs, que leurs missions doivent s'articuler avec d'autres acteurs créés depuis lors : dispositifs d'appui à la coordination, équipes mobiles gériatriques… ; et que certains de ces dispositifs ont été ouverts à d'autres pathologies, notamment les plates-formes de répit, un point d'étape est nécessaire pour permettre d'identifier les besoins restant à couvrir.

Aussi, je souhaite que vous procédiez dans cet esprit à l'évaluation des dispositifs suivants et à la définition de la place qu'ils peuvent occuper dans les années à venir :

- les centres experts Parkinson ;
- les Unités cognitivo-comportementales (UCC) ;
- les unités d'hébergement renforcé (UHR) ;
- pôles d'activité et de soins adaptés (PASA) ;
- les équipes spécialisées Alzheimer (ESA).

Madame Nathalie DESTAIS
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Le traitement de vos données est nécessaire à la gestion de votre demande et entre dans le cadre des missions confiées aux ministères sociaux.
Conformément au règlement général sur la protection des données (RGPD), vous pouvez exercer vos droits à l'adresse ddc-rgpd-cab@social.gouv.fr ou par voie postale.
Pour en savoir plus : https://solidarites-sante.gouv.fr/ministere/article/donnees-personnelles-et-cookies

Pour mener à bien la mission qui vous est confiée, vous disposerez de l'appui de la mission maladies neuro-dégénératives rattachée au secrétariat général, qui pourra notamment vous appuyer dans la collecte des données et les échanges avec les acteurs du territoire, en particulier les ARS.

Vous remettrez votre évaluation et vos propositions pour le 15 décembre 2021.

Je vous prie d'agréer, Madame la Cheffe de l'Inspection Générale des Affaires Sociales, l'expression de ma considération distinguée.

Olivier VÉRAN

LIST OF ANNEXES

LIST OF PEOPLE WE MET

Office of the Minister of Solidarity and Health

Nabet	Norbert	Public Health Advisor

General Secretariat of the Ministries in charge of Social Affairs (SG-MAS)

Pasquay	Corinne	Head of the Neurodegenerative Disease (ND) Mission

Directorate-General for Social Cohesion (DGCS)

Cadin	Louise	Head of office; Prevention of loss of autonomy and pathways for the elderly
Cons	Hélène	Inspector of the ARS Centre-Val de Loire in training at the DGCS
Dutheil	Nathalie	Assistant to the Head of the Office for the Prevention of Loss of Autonomy
Genet	Diane	Project manager for the pathways
Morin	Catherine	Assistant to the deputy director of the autonomy of the PH and the PA
Puiseux	Anatole	Assistant Director; Autonomy of disabled and elderly people

Directorate General for Health Care (DGOS)

Escalon	Sylvie	Sub-Director for the regulation of health care supply
Boillet	Pauline	Assistant to the Head of Office R4
Coone	Thomas	Head of Mission SRH
Machu	Anne-Noëlle	Project Manager
Pichereau	Alice	Apprentice, R4 Office
Terrenoir	Vincent	Commissioner General of Police, Delegate for General Security, ONVS
Barat	Claude	National Observatory on Violence in the Health Sector, ONVS
Schill	Hugo	trainee at the NSO

Health Branch (HB)

Ambroise	Patrick	Assistant to the Deputy Director of Population Health and Chronic Disease Prevention
Gales	Amélie	Patient Autonomy and Disability Officer
Moreux	Flora	Assistant to the Head of the Chronic Non-Communicable Diseases Office
Dr. Vanecke	Eliane	Office of Chronic Non-Communicable Diseases

Directorate for Research, Studies, Evaluation and Statistics (DREES)

Everyone	Fabien	Head of the Health Facilities Bureau
Martial	Elodie	Head of the dependency unit
Ricroch	Layla	Head of the Disability and Dependency Office

Directorate General for Research and Innovation, Ministry of Research (DRI)

Lavallard	Benoit	Project Manager

Ministerial Delegation for Mental Health and Psychiatry

Bellivier	Franck	Ministerial Delegate
Risselin	Patrick	Secretary General

National Health Insurance Fund (CNAM)

Leblanc	Garménick	Coordinator of the medico-social unit, DDGOS/DOS/Department of Hospitalization (DHOSPI)
Dr. Van Oost	Beatrice	Medical expert in public health
Ulian	Capucine	Head of Medication Reconciliation and Antibio-resistance Studies

National Solidarity Fund for Autonomy (CNSA)

Hilleret	Gael	Director; management of medico-social establishments and services
Magnant	Virginie	Executive Director
Paul	Olivier	Deputy Director; Medical and Social Services Department
Thiron	Fanny	Head of the Supply Programming Unit; Directorate of medico-social establishments and services

High Authority for Health (HAS)

Ghadi	Véronique	Director of the quality of social and medico-social support
Grimaldi	Sandra	Head of the ESMS evaluation department
Ayata	Aylin	Project Manager - Recommendations Department

Santé Publique France (SPF)

Carcaillon-Bentata	Laure	Referent "Healthy aging and neurodegenerative diseases
Beltzer	Nathalie	Unit Manager; Non-Communicable Diseases and Injuries Directorate

ARS Auvergne-Rhône-Alpes

Glabi	Raphaël	Director; Autonomy Directorate
Fayolle	Serge	
Lesbros-Alquier	Astrid	Deputy Director of the medical and social services, DA
Dr. Masblanc	Jocelyne	Directorate of Health Care Supply
Sanitas	Christelle	Directorate of Autonomy
Dr. Rusterholtz	Thierry	Directorate of Autonomy
Vidalenc	Muriel	Deputy Director General

ARS Bourgogne Franche Comté

Dr. Bollotte	Dominique	Physician, neuro-evolutionary diseases
Casagrande	Christine	ARS PMND Bourgogne Franche-Comté referent
Dr. Meillier	Agnès	Physician, Elderly Pathway, Directorate of Autonomy
Patriat	Damiens	Director of Autonomy

ARS Bretagne

Lahoucine	Malik	Deputy Director General; Director of Hospitalization, Autonomy and Performance
Penhouet	Dominique	Deputy Director; Directorate of Hospitalization, Autonomy and Performance, Deputy Directorate of Autonomy and Mental Health

ARS Centre Val de Loire

Dr. Annaheim-Jamet	Isabelle	Director, Medical and Social Services Department
Buchet	Sophie	Project Manager
Gauthier	Fabienne	Project Manager
Masi	Angelique	Head of the department in charge of the elderly population
Dr. Steinbach	Daniele	Pathways for people with disabilities, Medical and Social Services Department
Sally-Scanzi	Myriam	Departmental Director of Indre et Loire

ARS Corsica

Lecenne	Marie-Hélène	Executive Director
Magnavacca	Joseph	Director of Medical and Social Services, Health Surveillance and Health
Colonna	Audrey	Deputy Director in charge of medico-social affairs
Dr. Suard	Catherine	Medical advisor to the regional medico-social centre

ARS Grand Est

Bread	Laure	Territorial Medical Advisor
Muller	Anne	Director of Health Services
Remay	Frédéric	Deputy Director General
Seein	Peggy	Chief of Staff, Executive Office
Gerbeaud	Anne	Director of Autonomy

ARS Hauts de France

Dremaux	Fanny	Head of the medico-social steering department for ageing; sub-directorate for planning and authorisation programming; Directorate for medico-social services;
Dr. Defebvre	Marguerite-Marie	public health doctor; in charge of the ageing mission; PRS department; Strategy and Territories Directorate
Douay	Christophe	in charge of missions ARS des Hauts de France

Duplanc-Divandary	Marie-Alexandra	Head of Planning-Authorization-Contracting Department
Fallara	Cecilia	Public Health Intern

ARS Ile de France

Boreux	Céline	Health pathway, autonomy department
Dr. Crassard	Isabelle	Neurology referent, Department of Health Care Services
Durand	Annaïck	Care pathways, Health Care Supply Department
Ghulam	Sadia	Project Manager, SRH and Neurological Pathway
Dr. Le Noc-SOUDANI	Martine	Geriatrician, medical advisor
Moitsinga	Flora	Referent PMND, Directorate of Autonomy

ARS Normandy

Deroche	Thomas	Director General
Noguera	Elise	Deputy Director General
Dupont	Jérôme	Assistant to the Director of Autonomy
Lullien	Kevin	Director of Health Care Supply
Cap	Eva	Deputy Director, Health Care Supply Department
Rouquet	Ronan	Executive Assistant, Office of the DG
Garces	Carole	Doctor in charge of the elderly project

ARS New Aquitaine

Baudry	Delphine	Head of the Territorial Animation and Pathways Unit
Pratmarty	Samuel	Director of Health Care Supply

ARS Occitania

MorfoisseJean-JacquesDirector General

PrudhommeauxBertrandDirector DOSA

MichaudEmmanuelleDeputy Director , DOSA, Head of the Hospital Care Unit

MartinetRégine Deputy Director, DOSA, in charge of the medico-social division

Fabre-KramarzLaura DOSA, Head of the Care Supply Unit

Blazy CendrineDOSA , Head of the Ageing Policy Unit

Pascal Jean Medical Advisor, DOSA

Coast SandrineDOSA , Project Manager

Habba Najat DOSA, respite care referent

Medou Marie-DominiqueDOSA , chronic diseases and transplants referent

ARS Pays de la Loire

Dr. Collineau	Christine	Medical Advisor and MND Roadmap Pilot
Peribois	Elodie	Deputy Director, DOSA
Paddling pool	Thierry	Project Manager, Mental Health
Guillaumin	Charlotte	Elderly pathway, DOSA
Dr. Bargman	Philippe	Medical inspector, MND referent

ARS Provence Alpes Côte d'Azur

de Mester	Philippe	Director General
Dr. Ferrand	Nadine	Regional referral physician for neurodegenerative diseases
Catillon	David	Deputy Director, Medical and Social Services Department
Marcangeli	Fabien	Head of the Elderly Department, Medical and Social Services Directorate
Pasquini	Aurélie	in charge of the implementation of medico-social services
Dr. Munoz	Manuel	Medical Advisor, Community Care Directorate

Fondation Médéric Alzheimer

Dr. Bérard	Alain	Public Health Physician, Assistant Director
Jacquemont	Hélène	President
Tabuenca	Christine	Executive Director

France Alzheimer

Gilly	Lorène	Responsible for monitoring public policies
Durand	Benoit	Deputy Director
Jaouen	Joël	President

France Parkinson

Lagarde	Amandine	Executive Director
Robiliard	Didier	President

Association of caregivers and Lewy body patients

of Linares	Philippe	President

France DFT Association

From Blanchard	Dominique	President
Foulon	Bertille	regional delegate, Haut de France

National Association of SSIAD and SPASAD Managers (ANARESSIAD)

Martin	Hervé	Treasurer
Lequien Drecq	Virginie	Secretary

Federation of Hospitals and Personal Assistance Institutions (FEHAP)

Djedjero	Raphaël	Doctor of Economics
Lecoq	Anne	Medical Advisor
Sovrano	Jean-Christian	Director; Department of Autonomy and Life-Course Coordination

French Hospital Federation (FHF)

Courtois	Sandrine	Co-manager of the autonomy division
Thevenot	Marc-Antoine	Deputy Head of the Autonomy and Pathways Unit

FFAMCO-EHPAD

Dr. Gervais	Xavier	Vice-Chairman
Dr Maubourguet	Nathalie	President

French Society of Geriatrics and Gerontology

Dr. Aquino	Jean-Pierre	General Delegate
Pr Bonin Guillaume	Sylvie	President of the Scientific Council
Prof. Salles	Nathalie	President

National union of private establishments, residences and home help services for the elderly (Synerpa)

Dr Malfuson-Clot-Faybesse	Priscilla	South-East medical referent at Korian, Care Commission
Dr. Arabian	Emilie	Medical and Social Director at OMERIS Network, Care Commission
Dr. Guenniche	Esther	medical director of the DomusVi Group, care commission
Savatier	Valerie	Director of CareDirector of Care, Domidep, Care Commission
Dr. Haÿ	Paul-Emile	Medical and quality director at Colisée France, care commission

Assistance publique-hôpitaux de Paris (AP-HP)

Davy	Claire	Strategy and Transformation Directorate

Lariboisière-Fernand Vidal Hospital Group (AP-HP Nord)

Dr. Cognat	Emmanuel	Center for Cognitive Neurology
Prof. Paquet	Claire	Head of Department Cognitive Neurology Centre

Bretonneau Hospital (AP-HP)

Dr. Drunat	Olivier	Head of Geriatrics

Corentin Celton Hospital (AP-HP)

Professor Limosin	Frédéric	Head of Department - Department of Psychiatry and Addictology for adults and the elderly

University Hospitals of Paris Ouest

Prof. Saint Jean	Olivier	Geriatric Service

Salpétrière Hospital (AP-HP)

Prof. Dubois	Bruno	Director of the Institute of Memory and Alzheimer's Disease (IM2A)

Les Magnolias Geriatric Hospital

Agostino	Isabelle	Director of Care
Grazzini	Stéphane	Director
Dr. Luquel	Laurence	Medical Director

University Hospital Centre (CHU) of Lille

Dr. Roche	Jean	Psychiatrist - Geriatrician; Referent for the Psychogeriatric Sector
Prof. Defebvre	Luc	Head of the Parkinson's expert centre

University Hospital Centre (CHU) of Montpellier

Prof. Jeandel	Claude	President of the National Professional Council of Geriatrics

Ethical space occitania

Prof. Clanet	Michel	President PMND 2014-2019

University of Montreal

Prof. Joanette	Yves	Deputy Vice-Rector; Digital Health Consortium Director; Laboratory Director

University of Versailles, Saint-Quentin Paris

Prof. Ankri	Joel	Emeritus; Inserm U1018

University of Toulouse

Prof. Grand	Alain	Professor of Public Health

Nancy University Hospital

Professor Debouverie	Marc	Head of Neurology

Dr. Frismand	Solene	Head of the Parkinson's Expert Centre
Thomas	Sabrina	Parkinson's nurse referral

University Hospital of Toulouse

Prof. Vellas	Bruno	head of the geriatrics department of the Toulouse University Hospital and coordinator of the gerontopole
Prof. Soto	Maria-Eugénia	Geriatrician and public health researcher at the Toulouse University Hospital.
Dr. Voisin	Thierry	Neurologist and geriatrician at the Gerontopole of the Toulouse University Hospital.

University Hospital of Rennes

Pr Somme	Dominique	Head of Department
Dr. Delarue	Nolwenn	Hospital practitioner

University Hospital of Tours

Dr. Balageas	Anna-Chloe	Neurologist, Head of Department CM2R
Prof. Camus	Vincent	Gerontopsychiatrist
Dr. Desmidt	Thomas	Gerontopsychiatrist

University Hospital Centre (CHU) of Nice

Dr. Giordana	Caroline	Neurologist, Parkinson's Expert Centre
Dr. Alecu	Cosmin	Neurologist, Parkinson's Expert Centre
Faustini	Amélie	Nurse, Parkinson's Expert Centre

Residence Debrou Joué-les-Tours

Dr. Boissaye	Daniel	Qualified member of the SVC and family representative
Beal	Georges	Referent PASA, ASG
Deiber	Alexandrine	Finance Manager
Desmares	Lea	Executive Assistant
Dulong	Marie-Claire	Vice President of the CVS and representative of the families
Essalhi	Abdelkabire	Director
Girault	Louise	Senior health executive
Piro-Mahé	Mathilde	Deputy Director
Roy	Marie-Gaëlle	Reception, communication
Dr. Schmitt	Frédéric	Chief Medical Officer

EHPAD les Parentèles Paris 9

Boulemia	Mustapha	Director
Dr. Saillon	Alfred	Psychiatrist, co-founder of ALMAGE
Saillon	Anne	Neuropsychologist, co-founder of ALMAGE

Asad Agoat Guingamp (22)

Fesselier	Alain	Director General

Bouvier	Katia	Nurse coordinator, Specialized Team for Memory and Autonomy at Home (ESMAD)
Léauté	Elena	Caregiver, ASG, Specialized Team for Memory and Autonomy at Home (ESMAD)
The Bear	Marine	Occupational Therapist, Specialized Team for Memory and Autonomy at Home (ESMAD)

Tréguier Hospital (22)

Hervé	Laetitia	Deputy Director, Geriatrics and User Relations Sector
Le Merrer	Martine	Executive Assistant, Medical and General Affairs
The Morvan	Sophie	Senior health executive
Mayor	Adrianne	Director of Finance, Management Control, IMG
Remy	Patrick	director, head of school
Dr. Simaga	Aliou	geriatrician, president of the medical commission of establishment

EHPAD CIAS Mordelles (35)

Brumant	Nadine	Referent PASA (ASG)
Capon	Beatrice	IDE Day care UVP UHR
El Hamzaoui	Soumaya	Protected living unit framework
Lesec	Agnès	Psychologist
Patis	Jocelyne	Nurse coordinator
Piton	Alain	President
Regnier	Catherine	Director

EHPAD-COS family hospitality

Gilhet	Eve	Director
Lelo Soki	Julie	nurse coordinator
Dr. Koenig		coordinating doctor

EHPAD-Kersalic

Antoine-GuillaumeCorinne		Director
Guy	Geneième	Psychologist
Menguy	Mélanie	AS/AMP
Mellin	Marina	AS/AMP
Lecuyer	GeorgetteAS/AMP	
Bludgeon	MarylineAS/AMP	
Quelen	Mickael	Responsible for social life

La Maison du Thil, alternative housing

Binet	Blandine	Animator of social and shared life project

EHPAD La Brunetterie

Robuchon	Pauline	Deputy Director
Peruchon	Catherine	IDEC
Rech	Laure	Hospital Administration Assistant

Association Les Ages

Lambert	Rémi	Deputy Director
Lafleur	Anne	Psychologist
Lavalette	Ingrid	AMP referent, ASG autonomy - UVP
Maquignon	Catherine	Care assistant - EHPAD - autonomy referent
Lemaire	Sylvie	Health Executive Director - PARC SEP

GHLH (Loos-Haubourdin Hospital Group)

Hochert	Ian	Coordinator EAPA Esprève
Scappe	Camille	Territorial and regional coordinator of Esprève Hauts de France
Durand	Amélie	Occupational Therapist
Bialecki	Stephanie	Dietitian
Heurteaux	Nathalie	Senior Health Executive
Casaert	Clementine	Health executive
Medjkoune	Jennifer	Nurse coordinator
Laboue	Séverine	Director
Robert	Clelia	Coordinator

Korian Group

Dr. Kabirian	Fariba	Medical Director France
Mathias	Aymeric	Director of Operations Korian France Seniors
Merigot	Nicolas	Managing Director France

SOS Group

Lerousseau	Stephanie	Director of the Ile-de-France SSIAD - SSIAD Paris
Maghous	Sara	Psychomotrician coordinator of the ESA d'Ile-de-France - SSIAD Paris

World Health Organization

Dua Tarun

Seeher Kathrin, focal point

Jang Hyobung

Alzheimer's Disease International

Barbarino Paola, CEO

Lynch Chris, Deputy CEO

Weidner Wendy, Scientific Director

Suharya Dy

Germany - Ministry of Health

Berranger Christian

Dahl Niels

Australia - Federal Department of Health

Maden Marianne

Alfort Marie

Luxembourg - Ministry of Health and Family

Weydert Murielle

Sibenaler Claude

Norway - Norwegian National Centre on Ageing and Health

Kirkevold Øyvind, Professor

Switzerland - Faculty of Medicine, Geneva

Prof. Michel	Jean-Pierre	Professor Emeritus of the Faculty of Medicine of Geneva, member of the Academy of Medicine

United States - California, memory care visits

Augsburger	Michel	Chairman and CEO, Chancellor Health Care, LLC
Casey	Simon	Director of community Relations, Revere Court, Memory Care
Chappel	Brenda	Executive Director, Revere Court, Memory Care
Shier Anzelmo	Nancy	Principal, Alzheimer's Care Associates LLC
Olivas	Luis	Executive Director, Oakmont of East Sacramento
Ramirez	Luna	Traditions Activity Director, Oakmont of East Sacramento
Troxel	David	MPH, bestfriendsapproach

ACRONYMS USED

AGGIR	Autonomy gerontological iso-resource groups
ANAP	National agency for health and medico-social performance
ANARESSIAD	National Association of SSIAD and SPASAD Managers
ANESM	National agency for the evaluation and quality of social and medico-social establishments and services
APA	Adapted physical activities
ABS (2)	Personalized autonomy allowance
ARS	Regional Health Agency
ASG	Gerontological Care Assistant
ASH	Hospital Service Officer
ASMR	Improvement in the medical service rendered
STROKE	Stroke
BNA	National databank for Alzheimer's and related diseases
CASF	Code of social action and families
CHMP	EMA Committee for Medicinal Products for Human Use
ICD-11	International Classification of Diseases
CLIC	local information and coordination centres
CMAI	The Cohen-Manfield agitation inventory
CNAM	National Health Insurance Fund
CNSA	National Solidarity Fund for Autonomy
CREAI	Regional Centres for Studies, Actions and Information, in favour of people in vulnerable situations
DGCS	Directorate General of Social Cohesion
DGOS	Directorate General for Health Care
DGS	Health Branch
DLFT	Fronto-temporal lobar degeneration
DMS	Average length of stay
DREES	Directorate for Research, Studies, Evaluation and Statistics
EHPA	Residential facility for the elderly
EHPAD	Residential establishments for dependent elderly people
EMA	European medicines Agency
ESA	Specialized Alzheimer team
ESSMS	Social and medico-social establishments and services
FDA	US Food and Drug Administration
FEHAP	Federation of private non-profit hospital and personal assistance establishments
FINESS	National file of health and social establishments
GCSMS	Grouping of Social or Medical-Social Cooperation
HAD	Hospitalization at home
HAS	High Health Authority
HCSP	High Council on Public Health
IGAS	General Inspectorate of Social Affairs
IHME	Institute of Health and Metrics Evaluation

INSEE	National Institute of Statistics and Economic Studies
MAIA	House for the autonomy and integration of the sick
MCO	Medicine-Surgery-Obstetrics
MMSE	Mini-Mental State Examination
MND	Neurodegenerative disease
MPR	Physical and Rehabilitation Medicine
NICE	National institute for Health and Care Excellence
NPI-ES	Neuropsychiatry Inventory Care Team
OECD	Organization for Economic Cooperation and Development
WHO	World Health Organization
OPEPS	Parliamentary Office for the Evaluation of Health Policies
PACA	Provence-Alpes-Côte d'Azur
PASA	Pole of activities and adapted care
S.A.A.D	Service d'Aide et d'Accompagnement à Domicile
SAVS	Social life support service
SCPD	Psychological and behavioural symptoms of dementia
SCU	Special care units
SFGG	French Society of Geriatrics and Geronotology
SG-MAS	General Secretariat of the Ministries in charge of Social Affairs
NSDS	National Health Data System
SPASAD	Multipurpose home care services
SPF	Public Health France
SSIAD	Home nursing service
SRH	Follow-up and rehabilitation care
PET SCAN	Positron emission tomography
UCC	Cognitive-behavioural unit
RHU	Reinforced housing unit
UNCCAS	National Union of Communal Social Action Centres
USLD	Long-term care unit
UVA	Alzheimer's Unit