

Dementia

Final Report of the Steering Committee
for the establishment of a national action plan "dementias"
as approved by the Council of Government
dated March 13, 2013

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Members of the steering committee

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Introduction

Introduction

Apart from AIDS and cancer, Alzheimer's disease, a term often used by the general public as a generic term for all forms of dementia diseases, is among those that people fear most. This is a neuro-degenerating disease operative where the person gradually loses his cognitive functions and autonomy. For this reason, the disease is often wrongly associated with a loss of identity of the individual and social isolation.

The dementias are diseases whose prevalence is increasing rapidly from the age of 65. The rates go from about 1.6% for the age group of 65-69 years to 32.4% for men and 48.8% for women in the age group 95 years and more.¹

As European countries are aging societies where the proportion of older people compared to other age groups continues to increase, we could see significantly increase the number of people with dementing disease in the coming years. Research² Some estimate that by 2020, the number of sick people may double.

In 2050, according to estimates from STATEC, the percentage of people aged over 65 in the population reaches approximately 28.6% from the current rate of 13.9%³. A fortiori the number of those who will be affected by a dementing disease could increase also.

In recent years, many European countries have implemented specific action programs and to name the "Alzheimer Plan 2008-2012" in France, the "National Dementia Strategy for England" in the UK or the "Dementia Plan 2015" Norwegian.

At European level, following a Communication to the European Parliament and the European Council on a European initiative on Alzheimer's disease and other dementias 2009, the Commission launched in 2010/2011 the project "ALCOVE- Valuation Alzheimer cooperative in Europe "joint action on neurodegenerative diseases, particularly Alzheimer's sick die.

The action aims to improve knowledge on supported Dementia and make proposals on how best to preserve the quality of life, autonomy and rights of patients and their caregivers. The project is coordinated by France and has a budget of over one million euros of which the EU provides 50%.

After a brief introduction on the approach set up to prepare a Luxembourg Action Plan (Chapter 1), a short introduction on dementias (Chapter 2), this report seeks to establish an inventory of Luxembourg's situation on the basis of statistical data available (chapter 3).

Chapter 4 articulates the strong elements of the analysis carried out in groups working.

The final chapter identifies the key concepts of a future action plan and as the framework of the priority measures in the coming years.

Faced with an aging population and the relative growth of dementia diseases with age, they are thinking now about the means that the company is and will bring in the coming years - available to the persons concerned and their families to enable them to live dignified life to its end.

If on one hand it is necessary to guarantee supported by both medical and nursing quality, on the other side there is also the issue of integration and active participation of our seniors in society.

Maintaining the home in a context of normal life of people with dementing disease is largely dependent on the commitment and availability of family caregivers to support the sick in managing daily activities. It is therefore also to pay attention to their health and well-being.

As dementia gradually affect the cognitive functions of the sick, the company must adapt the means of existing rights in order to enable them to participate as long as possible in decisions about including situations involving the end of life.

1. Approach

1. Approach

The Luxembourg government program for the period 2009-2014 introduced two measures on the part of two separate departments:

The Ministry of Family and Integration is assigned the establishment of an action plan "dementia" in consultation with the Ministry of Health.

The development of a prevention program and the management of dementia is selected for the Ministry of Health.

As part of the mission delegated to him, the Ministry of Family and Integration takes from fall 2010 initiatives to prepare an action plan for dementia diseases.

Of specifications is developed that holds two priority themes.
Relative to each selected axis, two working groups were set up:

Axis I:

Improving the quality of life of patients and informal caregivers:

1.1. The continuity of the medical chain / care / social with particular attention to the prevention respectively
early diagnosis

1.2. Support for the family circle

Axis II:

Mobilize for a social issue:

2.1. The rights and protection of people with the disease

2.2. The social denial of illness

The four working groups under the coordination of a pilotage⁴ committee. They incorporate stakeholders, members of families sick people, field professionals, government officials and institutional delegates from many associations and political actors and civil society.

Each working group consists of 15-19 people. Groups meet on the period from December 2010 to January 2012 in plenary 6-8, plus intermittent preparation meetings.

Upon completion, each group submits a comprehensive report containing proposals for priority actions to the steering committee responsible for drafting this final report.

2. Definition

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Dementia is a decline of intellectual faculties and functions, including the progression is usually slow. The dementias affect memory, thinking and judgment of the individual. Generally they are accompanied by important consequences for the overall functioning of the person and for his welfare. They take influence on daily life and personal autonomy. However if a majority of intellectual faculties experiencing deterioration, it is also established that emotions remain.

Dementia is currently defined as a syndrome⁵ whose criteria are described in the "Diagnostic and Statistical Manual" (4th ed, APA Press, Washington DC, 1994) published by the American Psychiatric Association under Chapter IV⁶:

Criteria for dementia diseases (DSM-IV)

1. Memory impairment, amnesic syndrome
2. At least one of the following cognitive disturbances:
 - Aphasia
 - Apraxia
 - Agnosia
 - Disorders instrumental executive functions
3. The cognitive deficits described under 1 and 2 result in disruption of social and occupational functioning and represent a significant decline from the previous operating levels.
4. The disturbances do not occur exclusively during a period of confusion.

Additional criteria for the type of dementias:

1. Alzheimer
progressive and continuous cognitive decline can not be associated with other medical conditions, psychiatric or neurological identifiable logical
2. Vascular Dementia
focal neurological signs or clinical examinations confirming cerebrovascular diseases
3. dementia due to other diseases
Some diseases of the central nervous system leading to progressive memory deficit and cognitive function (AIDS, stroke, Parkinson's disease, Huntington's disease, Pick's disease, Creutzfeld-Jacob disease)

The disease develops due to various diseases: primary degenerative diseases (Alzheimer's disease, Parkinson's disease, Huntington's disease, Pick's disease, Lewy body dementia, ...), vascular disease (vascular dementia), metabolic disorders and endocrine (thyroid, kidney, ...), infections (CJD, AIDS, syphilis, ...), neoplasms (tumors of the brain, subdural hematoma,) toxic (alcohol, drugs, drugs), lack of oxygen, trauma and disorders of nutrition.

Alzheimer's disease is with some 50-70% of cases, the most common cause and it was followed by vascular dementia (+/- 30%) related to multiple infarcts. A third group includes all other conditions (including Pick's disease, Binswanger's disease, dementia with Lewy bodies, Parkinson's dementia). This represents only a very small number of cases.⁷

We talk about dementia from the time when cognitive decline is not temporary and lasts more than 6 months. In addition, the symptoms must have reached a level where the management of daily life is really affected.

We must distinguish between dementia and stage pre-dementia and / or situations "Mild Cognitive Impairment" (MCI) where finds no significant unrest level of personal autonomy. MCI is distinguished from normal aging by capacity deficits intellectual, higher than the norm. The MCI situations can include either a brain function as including memory either involve several. Neuropsychological tests, as namely the MMSE (mini-mental state examination) identifies the severity of deficits. Once the results of the are between about 20 and 26 on a scale 30, we enter the field of shapes slight dementia, below 10 points, we speak of a stringent assignment. In these cases, patients require ongoing assistance even the simplest acts of everyday life. We must distinguish between dementia and pre-dementia stage and / or situations. "Mild Cognitive Impairment" (MCI) where there is no evidence of significant problems in terms of individual autonomy. MCI is distinguished from normal aging deficits in intellectual abilities, higher than the norm. MCI situations can include either a function of the brain as memory including either involve several.

According to recent research about 30% of people affected by mild cognitive impairment develop in the following years with dementia, mainly Alzheimer's disease. As against this risk is 50% for people with MCI with disorders mémoire.⁸

Malnutrition and dementia

Undernutrition in the elderly is common. At present, there are no figures for Luxembourg.

In a 2006 article in the "Journal of Nutrition, Health & Age" Y Guigoz⁹, established based on a literature search, malnutrition risk for different groups of seniors. It is this risk within a range of 8 to 76% for the elderly living at home, from 8 to 63% for those who are supported in the hospital, 27 to 70% for people living in institutional settings and ranging from 19 to 87% for people with cognitive deficits.

If these data are certainly not directly transferable on the Luxembourg situation, established rates are nevertheless point to a particularly high risk of malnutrition for the group of people with a neurodegenerative disease. Indeed, because of their growing cognitive impairments, people with dementing illness experiencing

more and more difficult to prepare a meal or to go shopping, experience changes in taste and smell, forget to feed and are often subject to a hypermotricité which generates an expense greater than normal calorie.

Malnutrition contributes to a general weakening of the body and / or osteoporosis, and may thus give rise to frequent falls even hip fractures. For the healing of these fractures, it happens regularly that the patient is fixed for safety but with an increased risk of bedridden and for the development of contractures and bedsores.

Proper and adequate diet can help prevent such problems.

3. The situation in Luxembourg

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National epidemiological data:

In Luxembourg, the Project MémoVie (prospective assessment of neuropsychological and biological characteristics of mild cognitive and impairment of associated sub-clinical health problems) is coordinated by the Public-Health Research Centre with financial support from the National Research Fund (FNR).

The project involves the prospective evaluation of clinical and subclinical associated conditions for the emergence and evolution of mild cognitive impairment (Mild Cognitive Impairment, MCI) to Alzheimer's disease. The project was conducted on a cohort of people 65 and older, residing in Luxembourg. Note that 1377 people were contacted with a view to participation in the study of which 173 were been included in the project and are the subject of examinations and a thorough follow up.

The field phase is now complete and the exploitation of the data collected is currently ongoing.

The study protocol was published July 12 2012.10

Statistics

Under the EuroCoDe11 project, coordinated by Alzheimer Europe, prevalence rates have been established for European populations:

Table 1

Extrapolation of prevalence established in the EuroCode project on the Luxembourg population affiliated to the regime of the Luxembourg social security for 2010 (data igss12 13)

	Groupe âge	Population féminine	Taux de prévalence (F) (%)	Extrapolation sur groupe (F)	Population masculine	Taux de prévalence (M) (%)	Extrapolation sur groupe (M)	Population globale	Taux de prévalence global	Extrapolation sur groupe d'âge
PERIODE 2010	65-69	9.496	1,4	133	9.135	1,8	164	18.631	1,6	298
	70-74	9.100	3,8	346	7.655	3,2	245	16.755	3,5	586
	75-79	7.949	7,6	604	5.979	7,0	419	13.928	7,4	1.031
	80-84	6.677	16,4	1.095	4.211	14,5	611	10.888	15,7	1.709
	85-89	3.884	28,5	1.107	1.531	20,9	320	5.415	26,2	1.419
	90-94	1.330	44,4	591	382	29,2	112	1.702	41,0	702
	95-99	376	48,8	183	76	32,4	25	452	46,3	209
	100+	46	48,8	22	12	32,4	4	58	46,3	27
Total 2010	38.858		4.081	28.981		1.899	67.839		5.981	

Table 2

Extrapolation of prevalence established under the project EuroCode on the Luxembourg population for the year 2025 on the only demographic assumption (stAtEC14 projections)

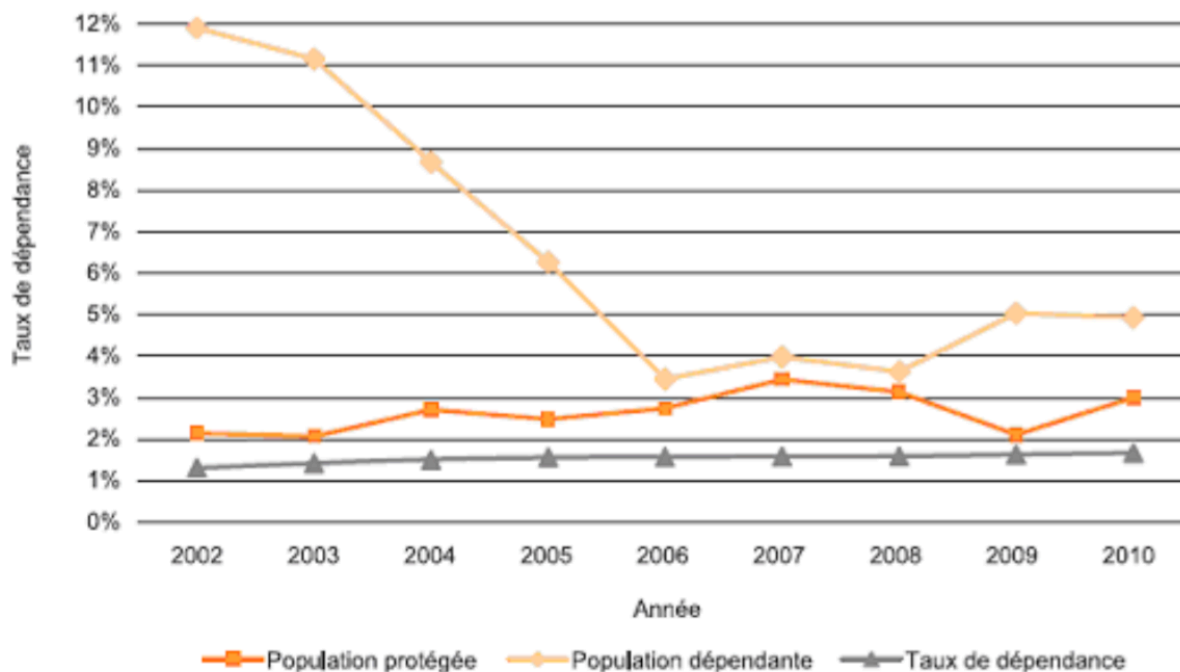
	Groupe âge	Population féminine	Taux de prévalence (F) (%)	Extrapolation sur groupe (F)	Population masculine	Taux de prévalence (M) (%)	Extrapolation sur groupe (M)	Population globale	Taux de prévalence global	Extrapolation sur groupe d'âge
PERIODE 2010	65-69	9.496	1,4	133	15.735	1,8	283	31.481	1,6	504
	70-74	12.740	3,8	484	12.238	3,2	392	24.978	3,5	874
	75-79	10.017	7,6	761	9.047	7,0	633	19.065	7,4	1.411
	80-84	7.258	16,4	1.190	5.491	14,5	796	12.749	15,7	2.002
	85-89	5.123	28,5	1.460	3.020	20,9	631	8.143	26,2	2.133
	90-94	2.547	44,4	1.131	1.080	29,2	315	3.627	41,0	1.487
	95	303	48,8	148	67	32,4	22	370	46,3	171
	Total 2025	47.485		5.308	46.679		3.073	100.413		8.582

The general report on social security annually by the General Inspectorate of Social Security (IGSS) provides information on the Grand Duchy of Luxembourg established care insurance data.

Table 3: General data on the dependent population. Evolution of the number of insurance recipients from dependence 200015

Année	Nombre	Variation en %	Dont résidents	En % du total
2000	5.810		5.735	98,7%
2001	6.632	14,1%	6.533	98,5%
2002	7.422	11,9%	7.292	98,2%
2003	8.250	11,2%	8.078	97,9%
2004	8.966	8,7%	8.776	97,9%
2005	9.528	6,3%	9.303	97,6%
2006	9.857	3,5%	9.612	97,5%
2007	10.249	4,0%	9.985	97,4%
2008	10.621	3,6%	10.328	97,2%
2009	11.156	5,0%	10.855	97,3%
2010	11.706	4,9%	11.376	97,2%

Table 4: Dependency ratio of the population protected 16



The line "dependent population (Light orange) shows the growth of the dependent population, most important in the years of implementation of care insurance. Since 2006, this rate has stabilized and is growing by about 4% per year.

In 2010 the care insurance beneficiaries represent some 1.7% of the resident population covered (dependency rate). Of 11706 beneficiaries, 7674 people are women and 4032 of sex masculin.¹⁷

Considering the only age group of people 65 and older, the dependency rate rises in late 2010 to 13.2% .¹⁸

Admission to the care insurance benefit is related to a need of at least 3.5 hours per week on care and assistance.

The causes of addiction are established during the medical assessment demandeurs.19

This report refers to the classification developed by the doctors of the Unit for Evaluation and Orientation (CEO).20 This puts very prominently relevant diagnostics for the field of addiction. In this classification the dementing diseases are group 1 - "Dementia and cognitive impairment."

The data are organized by main cause of addiction used for the beneficiary at the time of diagnosis.

The number of people belonging to the group 1 "dementias and cognitive impairment" grew by 2296 (in 2005) to 2774 people in 2010, representing an increase of 478 cases in 5 years. In parallel the total number of recipients of LTC Password 9258 people in 2005 to 11,706 persons in 2010 (2,448 people).

Comparing the data for the "Group 1" on the years 2005 and 2010, there was a relatively stable rate of people concerned.

Tables 5 and 6: Distribution of recipients of insurance because of dependence
Main dependency and age for the years 2005 and 2010 (% total).

Données 2005²¹

Cause de la dépendance	Groupes d'âge							Total	
	0-19 En % (N=548)	20-39 En % (N=359)	40-59 En % (N=767)	60-69 En % (N=710)	70-79 En % (N=1892)	80-89 En % (N=2916)	90-100 En % (N=1162)	Nombre	En %
Groupe 1 Démences et troubles des fonctions cognitives	0,0	0,8	2,0	8,6	20,3	29,5	33,0	1708	20,4
Groupe 2 Troubles psychiatriques	0,4	2,2	6,1	10,4	7,1	3,5	1,6	385	4,6
Groupe 3 Maladies du système cardio-vasculaire	0,2	0,0	1,2	2,4	4,0	5,0	3,6	290	3,5
Groupe 4 Maladies du système nerveux	28,5	27,3	30,8	28,2	22,4	12,0	6,1	1533	18,4
Groupe 5 Malformations congénitales - Troubles mentaux et/ou moteurs chez l'enfant et l'adolescent	46,7	22,6	16,7	5,6	1,8	0,7	0,1	561	6,7
Groupe 6 Maladies du système ostéo-articulaire	1,3	2,2	9,6	17,3	23,9	31,7	35,0	1995	23,9
Groupe 7 Troubles sensoriels	2,4	13,6	6,8	5,1	4,1	4,4	5,9	423	5,1
Groupe 8 Tumeurs malignes	0,7	0,8	3,0	2,4	1,9	0,9	0,7	117	1,4
Groupe 9 Autres	2,9	3,3	8,1	11,4	8,4	6,8	8,5	627	7,5
Groupe 10 Absence de codification	17,0	27,0	15,8	8,6	6,2	5,6	5,4	715	8,6
TOTAL	100,0	100,0	100,0	100,0	100,0	100,0	100,0	8354	100,0

Données 2010²²

Cause de la dépendance	Groupes d'âge							Total	
	0-19 En %	20-39 En %	40-59 En %	60-69 En %	70-79 En %	80-89 En %	90+ En %	Nombre	En %
Groupe 1 Démences et troubles des fonctions cognitives	0,0	0,2	2,0	6,2	19,6	29,7	32,2	203	20,3
Groupe 2 Troubles psychiatriques	0,4	1,4	6,0	12,2	6,8	3,6	1,8	47	4,7
Groupe 3 Maladies du système cardio-vasculaire	0,4	0,4	2,0	8,4	7,7	6,9	6,4	60	6,0
Groupe 4 Maladies du système nerveux	22,5	24,6	31,4	25,3	19,3	11,2	5,6	165	16,5
Groupe 5 Malformations congénitales - Troubles mentaux et/ou moteurs chez l'enfant et l'adolescent	57,7	32,8	15,4	6,7	2,0	0,4	0,1	75	7,5
Groupe 6 Maladies du système ostéo-articulaire	1,4	1,8	13,3	17,7	26,3	34,4	38,8	265	26,5
Groupe 7 Troubles sensoriels	3,0	14,1	7,0	3,4	3,1	3,0	4,4	40	4,0
Groupe 8 Tumeurs malignes	1,0	1,2	3,3	3,0	3,6	1,8	1,2	22	2,2
Groupe 9 Autres	4,1	4,7	7,2	8,2	7,0	5,6	7,0	63	6,3
Cause non codée	9,7	18,7	12,4	9,1	4,6	3,5	2,6	59	5,9
Nombre de bénéficiaires	735	488	1063	1004	2389	4578	1449	11706	

Table 7
Distribution of profit by main cause of addiction, gender and place of residence in 2010 (% total)
.23

Classification CEO	Femmes			Hommes		
	Etablissement En %	Domicile En %	Total En %	Etablissement En %	Domicile En %	Total En %
Groupe 1 Démences et troubles des fonctions cognitives	39,8	12,7	23,3	30,5	10,4	14,8
Groupe 2 Troubles psychiatriques	5,6	3,7	4,4	9,2	4,1	5,2
Groupe 3 Maladies du système cardio-vasculaire	4,2	6,7	5,7	6,0	6,6	6,5
Groupe 4 Maladies du système nerveux	10,9	13,9	12,7	20,0	24,6	23,6
Groupe 5 Malformations congénitales - Troubles mentaux et/ou moteurs chez l'enfant et l'adolescent	0,6	7,8	5,0	2,4	15,1	12,3
Groupe 6 Maladies du système ostéo-articulaire	27,5	34,5	31,8	18,6	16,0	16,5
Groupe 7 Troubles sensoriels	1,8	5,0	3,8	2,3	5,1	4,5
Groupe 8 Tumeurs malignes	1,1	2,6	2,0	1,9	2,9	2,7
Groupe 9 Autres	5,6	6,5	6,2	5,9	6,8	6,6
Cause non codée	2,9	6,6	5,2	3,3	8,5	7,3
Nombre de bénéficiaires	2988	4686	7674	882	3150	4032

For all care insurance beneficiaries, the number of people treated at home (7836 cases or 66.95%) is more than double of the institutional population (3870 or 34.44%). Men are mostly cared for at home (4/5), women represent 77% of beneficiaries in institutions.

Persons belonging to group 1 "Dementia and other cognitive impairment" some 1458 people are supported in institutions (1189 women and 269 men), 61% (against 34% for all beneficiaries "dependence insurance").

Subgroup 1 "Dementia and other cognitive impairment" are the largest group of beneficiaries of the insurance arm in institutions.

A possible hypothesis could be the relative intensity of support life situations of people with dementia compared to other situations of dependency that lead families to place more frequently the person in an institution.

In a second step a query on the data available at the level of health insurance has been made to the IGSS and this especially to approach the persons who are in the early stages of the disease and which are not yet recipients care insurance.

Currently the prescription of certain drugs (inhibitors of acetyl-cho- linesterase and hydrochloride memantine) in non-hospital settings requires prior authorization of the medical examination of health insurance. It is in this way that it has been tried to approach the group of people mentioned above.

However, as these drugs are not indicated for all life situations and / or dementias, data obtained remains patchy.

Table 8

Comparison of actual data for the female population suffers from a dementing disease (LTC insurance statistics and maladie24) prevalence rates established by the EuroCode25 project:

Groupe âge	Bénéficiaires de l'assurance dépendance (col. 1)			Non- bénéficiaires ass.dep. (col. 2)	Total des personnes recensées (col. 3)	Extrapolation des taux "EuroCoDe" sur groupes d'âge (col. 4)	Rapport personnes ccnées et extrapolations "EuroCoDe" (%) (col. 5)
	Pers. maladie Alzheimer (col. 1a)	Pers. démence type non spécifié (col. 1b)	Pers. non groupe 1 avec médication (col. 1c)				
65-69	4	14	2	1	21	133	15,79
70-74	16	62	4	6	88	346	25,43
75-79	56	167	3	13	239	604	39,57
80-84	94	411	12	23	540	1.095	49,32
85-89	82	477	8	14	581	1.107	52,48
90-94	22	262	1	1	286	591	48,39
95+	5	124	0	2	131	183	71,58
Total 2010	279	1.517	30	60	1.886	4.059	302,57

Table 9

Comparison of actual data for the male population suffers from a dementing disease (care insurance and health insurance statistics) to the igss26 prevalence rates established by the EuroCode27 project:

HOMME PERIODE 2010	Groupe âge	Bénéficiaires de l'assurance dépendance (col. 1)			Non- bénéficiaires ass.dep. (col. 2)	Total des personnes recensées (col. 3)	Extrapolation des taux "EuroCoDe" sur groupes d'âge (col. 4)	Rapport personnes ccnées et extrapolations "EuroCoDe" (%) (col. 5)
		Pers. maladie Alzheimer (col. 1a)	Pers. démence type non spécifié (col. 1b)	Pers. non groupe 1 avec médication (col. 1c)				
	65-69	8	10	0	6	24	164	14,63
	70-74	17	44	2	10	73	245	29,80
	75-79	20	97	5	24	146	419	34,84
	80-84	36	165	6	11	218	611	35,68
	85-89	23	110	2	7	142	320	44,38
	90-94	5	38	1	1	45	112	40,18
	95+	0	15	0	0	15	25	60,00
	Total 2010	109	479	16	59	663	1.896	259,51

Comments

As the data are derived from the main cause of addiction at diagnosis, the column 1c includes people with a cause separate spring cipal of dementia diseases.

The statistics of 1c and 2 columns are necessarily incomplete because they identify that the only people whose drug therapy incorporates a drug belonging to the two groups of molecules mentioned above.

The last three columns of the table are a glimpse of a large enough margin between the number of identified persons and extrapolations rates established in the framework of the "EuroCoDe".

In conclusion

Data available for the care insurance beneficiaries possible to have a very good appreciation in the number of people affected by advanced stages of dementia diseases and correlated to a need for assistance and care of another person.

For this group of people, necessary to note that there are proportionately more dependent people with dementing disease that are supported in institutional settings for all other causes of addiction groups.

Comparisons between 2005 and 2010 support a finding of relative stability in the proportion of people in group 1 compared to the whole of care insurance beneficiaries.

Much remains unknown about the number of people with dementing disease in early stages of the disease.

To the extent that these people are not beneficiaries of the dependency insurance, few data are available.

And a realistic assessment of the situation in Luxembourg is difficult.

Based on international data disponibles²⁸ is estimated that the ratio of people with dementing disease supported the home and those framed in institutions is about 2/3 to 1/3. According to figures in care insurance (see Table 7 above) the number of people belonging to the group 1 "Dementia and cognitive function disorders" living in institutions is about 1,460 people in 2010.

As estimated and established, the 1460 persons would constitute a third of all people with dementing disease in Luxembourg. The total number of sick people, all stages and be close to 4380 people (3x1460).

For the record, the total number of persons receiving care insurance and in group 1 "Dementia and cognitive impairment" is from about 2380 (see Table 6). Accordingly, some 2,000 other people would be affected by a dementing disease.

If the estimate thus established (4380) falls short of the numbers obtained on the basis of established prevalences in the project "EuroCoDe" (5981 people), do not forget that the number of institutional beds is particularly important in the Grand Duchy of Luxembourg.

In 2012 the country has +/- 5,500 beds for a population of some 71084 personnes²⁹ in the age group 65+ that which constitutes a rate some 7.7 beds / 100 citizens over 65 years.

4. State of play

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4. State of play

The description of the current national situation and in particular the analysis of resources and services available or the enumeration of missing effects was the first mission - common - the four working groups.

This chapter contains the findings of the working groups in a condensed form. Note that some statements made had been discussed by several groups, others had been discussed by one or other of the four groups.

In each of the four panels the same element returned and was appointed keystone of the success or otherwise of any future project, namely an overall strategic plan: the fight against the very negative image of dementia diseases.

The very diverse compositions of the working groups brought an unexpected richness to the discussions and appropriate to once again thank all participants for their active and persevering commitment. Combining these discussions in a single premium application first report to identify any differences in the thematic approaches in order to balance the conclusions of the working groups from each other.

Thus the working group 1.2. "The support to the family circle" integrated family caregivers or family members of people suffering from the following three neurodegenerative diseases: dementia disease, Parkinson's disease and multiple sclerosis. Soon the discussions revealed not only similarities but also significant differences in life situation and needs related to supported these diseases.

A second element is to meet the very different situations of appreciation made of professionals and people concerned. In their contributions, they had adopted an approach of "Developer needs" based on their experiences personal or that of others in their particular environment (voluntary or not). Professionals in turn were based more on structural analysis of existing resources.

To organize as far as possible the conclusions of the working groups, both the starting lines of thought, namely the quality of life of those affected and dementia as a social issue remains the common thread.

As mentioned earlier in the report, four working groups were organized as follows around two axes:

1. The quality of life of those affected

GT 1.1. The continuity of the medical chain / care / social / with particular attention to preventing early diagnosis respectively

GT 1.2. Support for the family circle

2. Dementia as a social issue

GT 2.1. The rights and protection of persons with the disease

GT 2.2. The social denial of illness

4.1. The quality of life of those affected

The conclusions of the working groups are gathered on the basis of several sequences. The listing also notes the work of groups who have made a contribution there.

- Primary prevention (GT 1.1. And 1.2 GT.)
- The mild cognitive impairment (GT 1.1.)
- Diagnosis and 1st coaching needs families (GT 1.1., 1.2 GT. GT and 2.2.)
- Monitoring the disease over time (GT 1.1. And 1.2 GT.)
 - a) home
 - b) Institutions
 - c) hospital

4.1.1. Primary prevention (gt 1.1. And 1.2 gt.)

According to the analysis by the Working Group 1.1. Primary prevention campaigns are usually campaigns a healthy lifestyle incorporating exercise physical and cognitive and active participation in social life. They address an audience of a certain age (50+).

Luxembourg does not have a particular awareness materials for the primary prevention of dementia diseases. Furthermore existing prevention materials on lifestyles (brochures, campaigns, etc.) are not necessarily refer.

As scientific research do not recognize (yet) link (s) of causality (s) charge (s) between behavior and dementia diseases, necessary to think about a general emphasis of prevention campaigns promoting a style healthy life. A successful example is the multi-year campaign "Eat & Gesund, méi bewegen" of the Ministry of Health, the ministry of Sport, which is realized in close partnership with the Ministry of Family and Integration and the Department of National Education. In 2012 it focused on the 50+ group.

Besides the primary prevention campaigns themselves, it is also to emphasize the preventive work done by the some 17 Seniors Clubs across the country.

Seniors Clubs are open structures to the 50 + generation. They work for the healthy maintenance of their target population by initiating sports activities, life-long-learning in the most diverse fields and social gatherings.

4.1.2. Mild cognitive impairment (MCI) (gt 1.1.)

There is a pilot project with the Centre Hospitalier du Nord (CHDN) entitled "neurokognitives Training für Patienten MCI."

1.1 group. considers important to await the outcome of the current project before deciding on a subsequent initiative or extending the project to other hospitals.

The shares for secondary prevention for patients MCI resp. for people with prodromal stage of a dementing disease, conducted by geriatric services or teams involved in specific management

these people in hospital will also be analyzed in this context.

4.1.3. 1st diagnosis and supervision needs of families (Gt 1.1., Gt 1.2. And 2.2 gt.)

At first, the working group WG 1.1. has already dwelt on the diagnosis to implement in older adults experiencing changes in their behavior. As these modifications can also have other causes, some of which are curable (pseudo- dementia, depression, etc.), it is particularly important to develop a differential diagnosis from the first signs of changes in the person concerned.

The working group also discussed the issue of systematic detection of people with a predisposition for the further development of a dementing disease and pronounced, due to ethical considerations and scientific against systematic genetic detection.

Regularly observed that people do for physicians only when are confirmed in disease states. However, detecting the earliest possible disease can accompany the best people involved and their social environment in sickness and in understanding the disease. Such an approach presupposes an awareness at several levels: professionals, physicians and others as well as the existence of adequate management means.

Participating physicians working groups agree that the continuing education of physicians should lead to more consistent manner the issues of diagnosis and therapy of dementia diseases.

Furthermore, they draw attention to the limits of their professional scope in relation to the supported psychologically and socially.

In the analysis of existing information, the group reports 1.1 information materials on Alzheimer's disease itself, with the Association Luxembourg Alzheimer association (ALA). Departmental materials (brochures, website, ...) usually refer to definitions even very general information. They also refer to the ALA, respectively disposable equipment from ALA.

Note that ALA has an annual convention with the Ministry of Family and Integration for information missions, advocacy and support for people (management Help-line SOS Alzheimer held a library / resource center, ...).

Families on their side (GT 1.2.) Regret the difficult conditions of the diagnosis. Given the traumatic shock experienced, they often say overwhelmed by the situation at the time. A fortiori, they do not feel able to request information or discuss suites to predict.

The positions of the two working groups meet at a need of medical diagnostic work itself as well as improvement in the subsequent management (information and advice).

Professionals wishing to concretely:

- Having a validated diagnostic tool
- Have national guidelines for the care therapeutic (medical diagnosis, medication, ...)
- Having an actor identified to guide that person (the patient and caregiver informal person) for psychological treatment and / or social adequate
- Cooperate with all actors involved in particular cases
- Have ongoing training.

For their part, families fall under the following needs:

- The availability of an empathic connection or an optimization of the conditions of the diagnosis
- The availability of a "precise" information on medical care and that greater access to information about the disease, existing resources and services on the part of persons sick and informal caregivers (greater presence in the media, on the internet portals and other information technology and communication, multilingualism) 30
- Be available in the direct result and throughout the disease course a "counseling31" an emphatic listening, support and information / explanation / precise orientation, structuring and customized to the patient and the caregiver informel.30

4.1.4. The monitoring of the disease in time, the treatment time (Gt 1.1. And 1.2 gt.)

- a. The home and the particular situation of informal carers
- b. Institutions
- c. hospitalization

a. The home and the particular situation of informal carers

With resources provided by insurance and dependency by existing services and organizations, a quality care can be arranged for any person with a dementing disease framed home with his family from entitlement to the care insurance benefit.

In the context of their supported, families cite several live situations they say "hardly":

- The care of people know- ing disorientation in time and are very active at night
- Changes in caregivers that can cause feelings of insecurity and anxiety among sick
- Fear of not being able to have the appropriate support at particular times liers (exit "spontaneous" crisis, respite, sickness, hospitalization, etc.).

Caregivers also describe the peculiarity of their own situation. They say live a triple status, that the "expert" and "caring" more present with the same time as the patient

a person seeking support and personal assistance. As a parent of the patient, family caregivers are also obliged, upon reaching a certain dependence of the sick person to make decisions for him. They require the recognition of this particular from professionals on one side does not necessarily reflect the expertise of the caregiver and the other does not realize his particular needs in its function 'helping.

If the definition of triple-status of informal carers is shared by all involved in one of three neurodegenerative diseases, it also proved that differences exist in direct connection with the peculiarities of each of these three disease groups.

Since dementias are diseases that appear with age and that, let alone a majority of informal caregivers are family members or even spouse, it should not underestimate their need for respite seen especially advanced age also often.

Informal carers confirm their continuing need for information, training and consultancy to understand the disease and its implications • on family and social life, to know about existing services and benefits and how to choose the most adequate benefits in relation to their particular situation in life and

Finally, to help them ensure their own state health (physical and mental). Guilty feelings about an optionally "abandonment" of the ill spouse its own respite or holidays are also discussed.

The following requirements are formulated:

- The concern for many professionals trained (including doctors, health professionals and care, Personal frames) which ensure the organization and execution of Supported quality 30
- Continuity possible nursing staff person at home or semi-stationary medium
- Need help with nocturnal wandering situations or other pro- care problems of sick people treated at domicile³⁰
- Be available throughout the course of the disease a "counseling³²" of information and clear direction, structuring and customized to the patient and the caregiver informel³⁰, 33
- Supervision of lone or isolated people including in situations where the latter refuse any help
- The worry of not finding a / occasional and spontaneous frames by insiders to management problems and / or disease at nécessaire³⁰
- The worry of not having available a holiday respite bed for times or other emergencies
- The desire to diversify respite means always with the double objective needs of the informal caregiver and the person with the disease
- Demand for greater support from professional services in waiting situations of a final placement

- Monitoring the health of informal carers with a burnout prevention work (fight against stress, ...) based necessarily on a déculpabilisante³⁰ approach.

b. The Institutions

Representatives of the families fear of long waits in connection with an investment in definitive CIPA (Integrated Centre for the Elderly) or home care including not being able to have access to appropriate care needs individuals of a dementing disease.

The institutionalization is a stressful situation from a psychological point of view for both families and for those involved. According to members of the working group 1.2., It would be necessary to create a standardized procedure based on examples of "best practice" to existing buffer the break whenever possible.

Families also show their desire for greater involvement in the institutional life. On the one hand they want to have a special representative appointed by the institution, to allow exchange on the life situation of the closest living in the institution concerned. On the other side, the establishment of a possibility of exchange with other families close to their heart. Finally they emphasize the appreciation manifest the continuity of staff for the welfare of the close.

The formulated needs:

- The desire to find an institutional setting in place to ensure special care
- The request for the establishment of a procedure for liaison between the home and the institution with promotion of "best practice" among existing managers
- The desire to have an institutional partner (professional reference) informing about the state of health and supported their proposed to close
- Demand the institutions to make the effort to ensure as far as possible the continuity of staff and thus promote the most stable human environment possible.

c. Hospitalization

Both professionals and families are dissatisfied with respect to supported specific behaviors associated with dementia diseases when such persons are hospitalized. 1.1 Members of the working groups. and 1.2. are aware of the efforts already made in the various institutions. However, due to two potential specific risks namely one side the aggravation of the spatio-temporal disorientation status of the person due to the hospital organization and across a slower healing process / difficult due to inadequate taken care of dementia-related behaviors individuals with possibly a "anticipated" return home (private or institutional), members of the two working groups consider that improvements can and should still be achieved .

The formulated needs:

- Adaptation of the caregiver support in relation to particular needs due to dementia diseases during hospital stays

- Implementation of specific training for caregivers and professionals en- cadrement working in an institution under the hospital plan.

4.2. Dementia as a social issue

The Luxembourg policies LTC always favored main- taining the home institutional care.

Demographic trends of the coming years and the limitations of resources in this instance by reference staff we already partly know today force us to think about coaching people so as to ensure them a long time over the life independent outside professional support needs in the home and in institutions.

2.1 Working Group. (The rights and protection of people with the disease) mission was to discuss the status of the patient within the company and specifically the protection of the person, including protection of his fundamental rights.

The fourth working group (WG 2.2. The social denial of illness) focused on dementia diseases as social and societal phenomenon. To the extent that current medical responses have limitations and do not allow healing or even a definitive stabilization of the disease at some stage, individuals and their families are forced to live with their illness.

4.2.1. The rights and protection of the persons concerned

2.1 Working Group. sought to identify the rights and protection of the elderly needs by addressing issues in different aspects.

In a first time an inventory of national legislation was produced and discussed in the groupe.³⁴

A critical discussion of the provisions of the Civil relating to the protection of incapable adults Code lieu.³⁵ also had some developments in international law in the United Nations Convention on the Rights of occurrence handicapées³⁶ people of different Foreign laws (German, Austrian and English) as well as recent charters of rights of the elderly (European project under the Daphne III program and the German charter) were treated. In the following, a concrete case based on reflection has helped identify key issues and the group was able to identify priority action areas.

The group concluded that all discussions revolve around a single dialectic: to find the right balance between individual protection measures and measures guaranteeing individual freedoms to the individual. Analysis of individual cases has shown that this balance remains singular, dependent on the specific situation and priorities or concerns of all stakeholders; the person himself, his family, professionals and other supervisors.

Based on the principles defined by the "European Charter of the rights and responsibilities of older people requiring care and long-term assistance" ³⁷, the Working Group issued several findings. A series of principles established by the European Charter is well established either at

national legislation or practices in professional personal.

Despite current laws and established rules of ethical conduct, the group identifies a need of more systematic incentives compared to the prevention of child abuse and particularly at the information and training of professionals and members of the family circle. It is a fact that the abusive behavior is mainly caused by a sense of powerlessness and even more lack the necessary skills to meet the needs of the patient. The census of these situations by a non-coercive authority would allow the implementation of supportive measures and / or capacitation adapted to specific situations.

The same is true for critical life situations especially in institutional settings (Ethische Fallbesprechungen).

4.2.2. The Social Denial

The importance assumed by dementia diseases in our aging societies and their increasing prevalence with age are that sooner or later every citizen is concerned.

According to Prof. Dr GRONEMEYER, German sociologist, met during the visit of the German organization "Aktion Demenz" Western societies are in the process to remove any social role to the elderly in general and even more so to the person with dementing disease. The teacher. Dr GRONEMEYER speak from experience (existential) made by the person to lack of meaning "Erfahrung der Sinnlosigkeit".

Taking inventory of existing resources, the Working Party notes as information and various services / institutions exist for the people concerned, people with a disease and their tial démen- familles.³⁸

In view of the discussed experiments, the group notes that the information and awareness campaigns often occur in individuals already affected by dementias (member of the immediate family or sick away, behavioral changes and / or 1st symptoms found with d a member of his entourage, etc.).

The information disseminated by the media are often limited to give a partial picture these life situations, to show the human being in the final stage of the disease with a high dependence on others.

It is therefore necessary to put more emphasis on the fact that between the time of diagnosis and severe situation of dependence lie years of life when the person can still participate in social life through the assistance and / or small media.

Group members are positively surprised by the interest met Germany and Belgium by calls to be co-financed projects by "Aktion Demenz / Robert Bosch Foundation" and the "King Baudouin Foundation" for better integration people with a dementing disease in the local social fabric.

In its conclusions the group highlights the more social and societal nature of dementia diseases and considers it appropriate to promote better integration and participation of people involved in the local social life. This presupposes a general and concerted action to lift the taboo and to achieve a change in attitudes to individuals and groups.

Such action requires strong political commitment at national level and action at two levels:

- Dissemination of information nuanced going against the purely negative image
- Awareness raising involving the most diverse social groups in an immediate and direct live together with the people concerned.

5. Towards a national plan

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5. Towards a national plan

The dementias are currently still incurable and a medical solution not seem so soon. However, drug measures and taken specific load can slow down the development of the disease.

Furthermore, they help to improve, at least temporarily the situation of the person concerned and his entourage. This should prompt us to review the various existing support levels and optimize them wherever possible. In doing so we will offer quality services to those affected in particular in the diagnosis and we will have efficient services when a medical solution will be available.

The dementing diseases are the leading cause of dependence care insurance beneficiaries residing in the Integrated Centres for the Elderly and Care Homes. The supervision 24/24 hours that require sick people knowing spatiotemporal UIDELINES désobéissant or defiant behavior could be a possible cause.

Demographic changes to come, by the relative increase in the elderly group and the average age require us to ensure the quality of supported at home and that enough means to provide decision institutionalized as burden for living situations where maintaining the home is no longer possible.

Without having national data, it should also be recalled that the French Alzheimer Plan indicates:

- The development of depression in the head of more than half of spouses of patients
- Increased mortality of more than 60% of caregivers in the three years following the onset of the disease.

Help maintain the home and the inclusion of people ill in society, so also requires special attention to the health of people from the family environment and needs in relation to the care of the person sick.

At present, it is therefore to approach dementia diseases with priority given to the "promotion of good living his life with the disease."

To get there the steps to set up must meet the following principles:

Healthy aging

Today we still do not have specific knowledge of the elements trigger researchers of dementia diseases, with the exception of vascular dementia where it is assumed that patients with cardiovascular disease have a factor of risk equal to 10.

It is therefore appropriate to continue a policy of promoting active aging integrating both the physical health component as mental health and promoting active social life.

Autonomy and self-determination

"Autonomy is the process by which a man ..., acquires or determines for itself its own rules of conduct. (...) The battery life is correlative to the construction of the identity of the person ".39

The UN Convention on the Rights of Persons with Disabilities says that all people with any disability are entitled to all the rights and freedoms fondamentaux.40

The agreement also defines the person as a subject of rights, able to take decisions itself. The objective to pursue is therefore to provide the person with the necessary assistance to enable him to exercise his rights.

In doing so, the Convention implicitly links the right to self-determination of duty "empowerment" that is to say to the empowerment of the individual (patients and family circle) in particular through objective information, guidance and adequate support and adapted to be able effectively make informed choices in relation to a concrete situation of life and personal priorities.

In this context a study include SPIJKER by A. et al., Which consisted of a meta-analysis of 13 support programs and demonstrating that to combine dinner the active involvement of informal carers to decision for treatment is the determinant of the effectiveness of the support program set oeuvre.41

Quality services in a holistic approach

With the evolution of the disease, the patient and his needs change. This requires the family environment and professional continuous adaptation of their care. A major challenge in the head professional is to ensure continuity of care. These are the result of a set of policies and well-defined strategies to improve care for dominant cult and health services throughout the disease cycle. continuity of care draw on existing health programs and envelopes. It is therefore also well take advantage of existing infrastructure and services in a broader context, such as the services of "meals on wheels" and "remote alarm".

For its part, saw the family circle "Mutations" in roles within the family, should be at the Chan giant attitudes of the social environment and is facing changes in mood or behavior of the patient.

The persons concerned are aware of the many services and taken into existing load Luxembourg. However, in their experiments they nevertheless make businesses see one side a need unfulfilled emotional support and other support they require a decision because of their knowledge and imperfect knowledge about the content and quality of services and existing benefits.

For an inclusive society and accessible promoting inclusion of persons concerned in ordinary life

This is Ervin Goffman, who in 1960 coined the term "stigma" to refer to "an attribute deeply discredited as a social interaction." The stigma diminishes the status of the normal person to that of a "corrupt and cheap and it can lead to labeling, stereotyping and loss of the person's status."

Thomas Kitwood, dementia subjects people at risk of being regarded as external to the human community along the lines of "us and them". He also sees the greatest threat to living well with dementia in having to live with the con- depersonalizing and dehumanizing consequences of stigma and sociale distance. 42

Often the nearest informal carers of the person with dementia also experience stigmatization or even increased isolation.

In their conclusions, the working groups have issued a number of policy priorities for the future.

Three themes were common to four groups:

- The need to mobilize the whole society to break the taboo around dementing diseases conditio sine qua non for a change of mentality and attitudes
- The duty to support and train more family circle

The continuous training of workers (professionals and volunteers) framing people with dementing disease.

The proposals for action adopted by the steering committee to be sent to the Government have been classified taking into account the route of the person with a dementing illness and his entourage. They fall into seven categories which are:

1. "Active Ageing", the "Healthy Ageing"
2. At the first signs of the disease: diagnosis and care medical
3. The support of the individual and his entourage
4. Home care
5. The institutional care
6. Ethics and Law
7. "Dementia Friendly Society"

5.1. The measures in the plan

5.1.1. "Active Ageing", the "healthy aging"

Since 1999, the Ministry of Family and Integration promotes the creation of Clubs Seniors who are structures addressing the age group of 50+. Clubs offer the most diverse activities whose goal is to promote aging in good physical and mental health and social participation of seniors. Seniors 17 regional clubs were created throughout the national territory.

2012 was declared "European Year for Active Ageing and intergenerational solidarity". Of the 3 main objectives of the European Year two go hand in hand with the work of the Senior Clubs, namely "age in good health" and the social participation of seniors. Added to the European Year, the maintenance of good health in the use of the persons concerned and intergenerational dialogue. Under the coordination of the Ministry of Family and Integration entire program was developed. This includes activities related to each of the above objectives. In this context also recall that, as part of the 2020 strategy, the EU set itself the goal of giving every person on average two years of healthy life more by 2020.

Goal: Active aging and healthy (physical and mental) with maintaining social contacts

Actor institutional coordinator: Ministry of Health

5.1.2. at the first signs of the disease: diagnosis and medical management

There is currently no molecule that can permanently stop the progression of the disease or stop it, energy must be paid to ensure the best care possible. Identify as early as possible these disorders can accompany the persons concerned and their social environment in sickness and in understanding the disease. So it set up the means to necessary diagnostics and to train physicians, generalists and specialists.

Level 1: Demtec + "Uhrentest" especially in generalist physicians

Level 2: In-depth diagnosis (eg neutral ropsychologique, radiological and biological) if there is suspicion of a documented illness (pathological findings at Level 1 or obvious symptoms of subjective or objective). with:

- Validation of the cited tests and translation into the three official languages,
- Definition of national guidelines for the diagnosis,
- Establishment of a continuing education on the subject "two levels Diagnosis" for doctors.

Goal: Promote diagnosis and medical quality care

Actor institutional coordinator: Ministry of Health

Note: The question of the time of diagnosis was discussed. In the framework of international publications, if on one hand the attention is drawn to the advantages of the earliest possible diagnosis, the other side experts and doctors speak about it also with a sword double-edged : Once diagnosed, the patient will not only live with the disease but also face the stigma is bound if the concrete risk of exclusion and social isolation. Thus the international scientific community tends to speak more of a "Timely" diagnosis or diagnosis at "appropriate time." Committing to a diagnosis at the right time (Timely) necessarily goes hand in hand with the work on the image of the disease. Currently the diagnosis of the disease is often too late, with all the harmful consequences that entails.

Goal: To ensure the quality of medical care according to international standards

Actor institutional coordinator: Ministry of Health / Social security

5.1.3. The accompaniment of the person concerned and his entourage

For 25 years, the Luxembourg Alzheimer Association (ALA) association is involved in helping patients and members of their social circle. With conventional ment with the Ministry of Family and Integration, ALA offers listening and support groups for persons concerned, an emergency helpline that operates 24/24 for situations distress and a library.

With the introduction of dependence insurance, aid and care networks have been set up covering the territory Luxembourgish. As the Foundation "Hellef Doheem" the Network "Help" also offer listening groups to the persons concerned to support families in the care of their patients.

In a broader context, the "Seniorentelefon", the Ministry of Family and Integration and the "Helpline" of the Red Cross offer active listening to people, inform and direct them to the most appropriate services and supports. In this context there is also worth noting the social management work proposed by the social offices and Healthcare League.

The "practical guide for seniors," the website "Luxsenior" and a list containing all the managers authorized for seniors are available to the public by the Ministry of Family and Integration. The practical guide is published in four languages: French, German, Italian and Portuguese.

Despite the commitment of these actors, particularly at diagnosis, individuals (patients and family members of the entourage) were difficult to identify the appropriate actor for support in understanding the disease and to direct them towards the most adapted Tees aid. In this context, the issue of continuity of services arises.

Action: Assess information needs, guidance and counseling of the persons concerned and their family environment with definition players needed to respond while considering ways / existing structures

Goal: Having a structural actor / a neutral system responsible for the direction and guidance whose mission is to support (on a psychological and organizational) the sick and their family environment in the organization a coordinated management over time including informed advice on how to provision to articular ler life choices and make early arrangements.

Actor institutional coordinator:

- Ministry of Family and Integration
- Ministry of Health
- Ministry of Social Security

Note: The discussion on the creation of a responsible actor guidance and information was carried out in three working groups (1.1, 1.2 and 2.4.). It was considered essential to have a player not involved directly and / or immediately in the implementation of services for the benefit of the sick person. Its role should be limited to information, guidance and counseling or mediation in the only head of the person and / or his family face field workers prestant concrete services. Insofar care insurance establishes the freedom to choose the service provider, it therefore seems even more important to have a formal guarantee of neutrality of such a structure.

Goal: To have information and documentation available to the general public providing information on all forms of dementia diseases and existing supported. Take maximum advantage of new technologies and means of communication.

Actor institutional coordinator:

- Ministry of Family and Integration • Ministry of Health
- Ministry of Social Security

In a first approach, it is evalu- luer how existing resources are sufficient to such conditions and an umpteenth deu-, necessary to define possible means to expand or extend the existing offer.

Action: Awareness of informal carers with respite from existing resources and reflect on new ways of primary and secondary prevention to implement

Goal: Better preventive health status of informal carers

Actor institutional coordinator:

- Ministry of Family and Integration (psycho-social aspect)
- Ministry of Health (medical component)

Note: The status of informal carers:

In Articles 354 and 355 the Social Security Code provides that the dependent person may use "one or more persons associated with him in a position to aid and necessary treatment" (art. 354).

Art 355 (1) states "to support the action of third parties under Art. 354, ...

Under the same Article (2), the law says "supports the contributions for pension insurance of one person not receiving a personal pension that ensures"

If the law recognizes the intervention and aid to dependent persons by non-professional third parties, beyond the links at the pension insurance, it nevertheless creates no formal connection with that person who would identify in taking concrete load.

Consequently, if we want to think about a special care on the part of such persons, it should be set in parallel the group of persons falling within the category of potential beneficiaries.

5.1.4. Home support

The last thirty years, government policy for the elderly and / or dependent is geared towards keeping people as long as possible in their usual environment.

As has been said at the beginning of the report malnutrition in older people and particularly among people with dementing disease is common.

The meals on wheels services, together with the remote alarm service are very important links measures ensuring maintaining in people's homes.

Indeed, in the context of life situations of people at the beginning of a dementing disease, these services are reassuring aid. The wheels on meals service guarantees a balanced meal to any guest and the daily passage of a service agent ensures social contact with the person concerned.

The service "Remote Alarm" has undergone important technological developments in recent years. New tools allow the implementation of solutions based on the evolution of the disease of each individual person.

To support the members of the family environment in the frame of their sick members, a large network of psycho-geriatric day center was also set up during the last decade.

In the same logic to support family carers, managers of institutions for the elderly offer holiday beds for the sick to also allow the framing to be able to relax.

More recently an experimental action project care insurance, was enjoying a particular group of its recipients of a predefined number of night shifts in a person's home or for emergencies related with informal carers is due to the needs of the dependent person himself.

Action: Setting up an offer of secondary prevention for MCI patients and / or those with mild dementia if ongoing experiments are conclusive.

Goal: promote the maintenance of the activities of daily living

Actor institutional coordinator: Ministry of Health

Goal: Support for the family circle

Actor institutional coordinator: Ministry of Social Security

The experimental action project

"NUETSWAACH" led by Steftung "Hellef Doheem" from March 2009 to February 2011 and funded by the LTC had touched some beneficiaries during his unwinding. A number of findings had nevertheless been drawn. Thus, the evaluators noted that to assign this type of service should be taken into account:

- diseases and disabilities which the plaintiffs suffer and requiring constant presence of another person because of the risks they incur for themselves or others, such as dementia and behavior disorders ...
- the situation of informal carers, particularly their health, their age in order to help them fulfill their role with applicants over the long term and in conditions that do not affect their health and allow them to maintain an acceptable quality of life.

At a reform of dependence insurance that is likely to impose medium-term view of the evolution of the dependent population, it will be necessary to consider these aspects.

Measurement Evaluation of the accommodation needs of holiday / Emergency

Goal: have an adequate number of holiday beds for affected persons of a dementing disease

Actor institutional coordinator: Ministry of Family and Integration

Note: Members of the family circle who participated in the working group 1.2. clarified their mission within the working group by limiting the evocation from the needs within the supported provided to sick people. Current information does not draw enough concrete conclusions on the real needs in holiday accommodation / emergency.

5.1.5. Institutional support

Since the late 90s until today, the Ministry of Family and Integration, leading a broad political investment aid in connection with the renovation and adaptation of old structures or construction new institutions for the elderly; care homes and centers for the aged.

The State aid for the years 2001 to 2011 correspond to investments of some EUR 466 448 745. Adapting supported the changing needs of people with a dementia disease also requires an ongoing commitment of professionals long stay to train and adopt new skills. RBS - Center fir Altersfroen, under agreement with the Ministry of Family and Integration, has for more than twenty years to this task.

At plugs in hospital expenses, the Ministry of Health focused on the care of older people in hospital with the introduction conceptually acute geriatric services and specialized mobile teams in geriatrics. In two institutions, including services of medical specialists in geriatrics, have already been created; intrahospita--border mobile teams have also been. These efforts will be continued.

Measure: information / awareness on specific supported that exist for people with dementing disease in different structures for the elderly

Goal: empowerment of families to make informed choices

Actor institutional coordinator: Ministry of Family and Integration

Note: In the discussions it emerged that the group does not necessarily know all the support concepts implemented in structures in favor of people with dementing disease.

Measure: Introduction of quality standards for benefits and services in the legislation on the elderly

Goal: better information and control over the quality of services

Actor institutional coordinator: Ministry of Family and Integration

Action: Evaluation and adaptation of offers of existing charges taken in institutions under the plan hospitalier with implementation of a concept and special training for staff involved

Goal: better care for people with a fragmentary démen- disease in hospitals and / or institutions under the hospital plan

Actor institutional coordinator: Ministry of Health

Action: Proposal to Ministries of Education and Vocational Training, Higher Education and Research for cooperative work in the revision of the core curriculum in the field of health- about geriatrics.

Goal: Revision of curricula of initial training for professionals in the field of health and, if necessary, update / adaptation to international standards.

Institutional coordinators Actors:

- Ministry of Health
- Ministry of Education and professional training
- Ministry of Higher Education and Research
- Ministry of Family and the integration

Action: Needs Assessment form special continuous for personal infor- based on two intervention areas

1. The institutions and services of long stay
2. Institutions under the hospital plan

Goal: ensure quality care

Actor institutional coordinator: For 1:

- Ministry of Family and

Integration For 2:

- Ministry of Health

Note ad (1): Continuing training existed for years in psycho-geriatrics and the specific approaches of dementia diseases at the Institute training of the long stay area seniors. A number of managers have opted for a management model and generally perform these internal training. An interesting idea is to widen the training modules "online".

5.1.6. Ethics and law

The dementias affect memory, thinking and judgment of the individual. In that they affect the human being in what he considers to be the preeminent element granting him the status of a person.

With the gradual loss of these faculties, the person with a dementing disease is losing more and more control of her life situation and becomes increasingly dependent on help from others.

A society is measured by the consideration and respect it pays to its weakest members. Recognizing that human dignity is inherent in the human person, regardless of his condition of existence, necessarily requires the establishment of means to ensure the protection and respect of persons who are no longer able to make their own defense.

Action: Fight against abuse

The abuse of older people is a set of behaviors or attitudes, single or repeated, concerning the elderly in the context of a relationship of trust or dependency and can cause distress or injury to these people. Abuse can be physical kind, moral, financial, sexual or constitute negligence.

Of abusive treatment intentioned professionals or persons of the family circle exist and they are to report to the competent authorities. Apart from these rather exceptional situations, we frequently find that attitudes and abusive acts may result from a feeling of helplessness or lack of training of a person, a professional or a member of family circle respectively imperfect organization of care in the face of provocative behavior not

intentioned people with dementing disease.

Faced with this second group of people, awareness of the disease and pipes that can lead to the patient or training in managing these situations are key tools to prevent incorrect treatments. It is also to develop other forms of support and appeals to the concerned; at first to people abused but also maltreating people when evil could happen or just arrived.

In 2010 and 2011, Luxembourg participated in MILCEA project (Monitoring in Long- Term Care Elder Abuse) funded by the European Commission. The project was conducted by the Evaluation Unit and orientation and the Public Research Centre Henri Tudor. The project goal is to contribute to the prevention of abuse of older people with a need for long term care, identifying tools to identify the indicators of abuse and risk factors. This should lead to propose an appropriate response to the specific nature of each situation.

Goals to be achieved:

1. Better information for seniors and their families the means available to them under the existing laws of said law and ASFT care insurance (Seniorentelefon, complaint management MIFA Helpline dependence, CEO complaint management).
2. Based on the conclusions of MILCEA project which closely involved the Department of Family and definition of additional resources integration to prevent maltreatment of people with dementing illnesses.

Actor institutional coordinator:

For 1 :

- Ministry of Family and Integration • Ministry of Social Security

For 2 :

- Ministry of Social Security
- Ministry of Family and Integration

Measure: Promotion of Human Rights

Goal: Raising awareness of the elderly, their family entourage and professionals on the fundamental rights of the elderly

Actor institutional coordinator: Ministry of Family and Integration

Action: Revision of Civil Code provisions on major protected by law

Goal: Current forms of protection of incapable adults will be replaced by a new form of assistance (Beistandschaft) for adults to protect. This assistance (Beistandschaft) may be established based on the individual needs of the person. It will enable the creation of customized solutions. The arrangements will be limited to the strictly necessary. Their necessity and proportionality will be regularly reassessed. The person concerned will be assisted while retaining its autonomy and independence to the extent that his physical and mental state the permettra.⁴³

appropriate institutional actor: Ministry of Justice

Action: Definition of a formal framework organizing and limiting the implementation of restraints in institutions of long-stay elderly

Goal: setting up a working group with the mission to make a proposal on the structuring rules useful and necessary and proper formal framework

appropriate institutional actor: Ministry of Family and Integration

Measure: Introduction of the concept of trusted person in the bill concerning the rights and obligations of the patients

Goal: help the patient can no longer speak with a trusted person previously designated as part of a decision making in the field of health (Article 14 and 15 of PL 6469)

appropriate institutional actor: Ministry of Health

Measure: Introduction of a new model of "house counsel" in the legislation on the elderly

Goal: greater involvement of families and / or representatives of sick persons in the organization of long stay institutions to defend the rights of those concerned and more particularly people with dementing disease

Actor institutional coordinator: Ministry of Family and Integration

5.1.7. "Dementia Friendly Society"

Today, too often the announcement in person from a dementing disease to members of their social environment, leads to isolation. It is the same for relatives who help in everyday life. The stability of the living environment is a reassuring element for the patient and supports her independence. It is therefore to preserve this living environment as far as possible, or even implement structural aid for sick people.

Furthermore successful social contacts help to prevent depression in both the head of the patient that his caregivers.

Unfortunately, the anxiety about the disease and the fear of not knowing how to manage contacts with the person with a dementing illness are still very present.

Action: Promoting the inclusion of persons involved in society

Goal: promoting social inclusion of patients and members of the family circle

Actor institutional coordinator: Ministry of Family and Integration

Awareness component

Any awareness campaign / solidarity must benefit from a strong political commitment and should, in the background, linking all the other actions.

Designing such a campaign request to reflect on the reference, the image and status is meant to give démentielles⁴⁴ diseases. Therefore it comes to ger interviewed on the core values and existing social representations and the changes are to be introduced. A first priority will be to work on the disease picture to arrive at a realistic and nuanced presentation.

In this context it should seek active collaboration and time with the media and especially with the journalists.

In view of what is done in other European countries, the commitment of notable actors, directly or indirectly affected by dementias can positively influence on the results sought. It remains to decide the priority supports (or other media such as eg a "Demenzkoffer").

Component Inclusion

Promote greater participation and inclusion of patients and their families at the level of social life: initiate activities for active inclusion in the society like "Dementia Friendly Soceity" German project or the project of the King Baudouin Foundation " common Alzheimer admitted".

As the number of people living alone or isolated considerably increase due to family breakdown (divorce, departure of children in remote areas, widowhood, ...) in the coming years, special attention should be paid to this group of people.

An important element is education / training actors of daily life (police, first aid, local authorities, banks, ...) on what the dementia diseases and attitudes to adopt vis-à vis these persons to their independence and their participation in social life.

References

(Note- In the original document, references are posted on the page in which they appear)

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2 First Results from the Survey of Health, Ageing and Retirement in Europe (2004-2007) http://www.share-projet.org/t3/share/uploads/tx_sharepublications/BuchShareganz250808.pdf

3 STATEC statnews No. 49/2007 recent statistical information, 28.09.2007, <http://www.statistiques.public.lu/en/news/population/population/2007/09/20070928/20070928.pdf>

4 For the composition of the Steering Committee see Appendix 1

5 "a set of clinical signs and symptoms in syndrome means that a patient is likely to present in certain diseases, or in the clinical circumstances of deviation from the norm not necessarily pathological. "

6 CF. NIHDI Chronicles Advisory Committee Specific Diseases and Disorders, Dementia Working Group Report, July 2008, p.2

7 cf. Note 6, *ibid*, p.2

8 cf. Final report of Working Group 1.1, Chapter II "Begriffsbestimmung"

9 cf Y Guigoz "The Mini nutritional Assessment (MNA®) Review of the Literature- What does it tell us? ", in The Journal of Nutrition, Health & Aging, Volume 10, Number 6, 2006, pp 461-487

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12 IGSS statistics include all affiliated persons resident in the National Fund of Health while data "population" Statec are based on the entire population resident and therefore cover also those affiliated to other social security schemes.

13 cf. IGSS calculation, administrative data from the CNS

14 cf. STATEC, [2010], Bulletin No. 5/2010 socio-economic projections 2010-2060, last updated Nov. 4, 2010, <http://www.statistiques.public.lu/fr/publications/series/bulletin-statec/2010/05-10-Projpop/index.html>, consulted the April 19, 2012.

15 Department of Social Security, General Report on Social Security in the Grand Duchy of Luxembourg 2010 Luxembourg, November 2011, p.143 Table 4 Data refer to the situation at 31 December 2010. These provisional data for 2010.

16 Ibid, p.144 Chart 1 The data refer to the situation on 31 December 2010. These provisional data for 2010. N.B. The population increase strongly in the first few years because care insurance did not exist before 1999. The growth rate of the dependent population in the early years has not the same meaning as it takes from 2005/2006.

17 Department of Social Security, General Report on Social Security in the Grand Duchy of Luxembourg 2010, Luxembourg, November 2011, p.145

18 Ibid, p.144

19 The Evaluation Protocol provides five diagnoses retain the basis of addiction. The responsible medical officer of the folder can hold five other diagnoses.

20 cf. Schedule February

21 cf. Department of Social Security, General Report on Social Security in the Grand Duchy of Luxembourg 2005 Luxembourg, November 2006 65 Table 22 p.223 cf. Ministry of Social Security, General Report on the Social Security in the Grand Duchy of Luxembourg 2010 Luxembourg, November 2011, Table 15, p.151 (lack reference to the year 2010) Note that this is preliminary data resulting from the situation December 31, 2010.

23 Department of Social Security, General Report on Social Security in the Grand Duchy of Luxembourg 2010 Luxembourg, November 2011, Table 16 p.151 Note that this is preliminary data resulting from the situation on 31 December 2010.

24 cf. Administrative Data of CNS IGSS calculations;

25 cf. Alzheimer Europe Prevalence of dementia in Europe, EuroCoDe prevalence group, [2009], last updated Oct. 8, 2009, <http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia/Prevalence-of-dementia-in-Europe>, accessed April 19, 2012

26 ibidem, note 24

27 ibidem, note 25

28 cf, Alzhiemer's Association, 2011 Alzheimer's Disease – Facts and Figures, p. 39 et suivantes, www.alz.org. Le rapport établit que 70% des personnes atteintes de la maladie d'Alzheimer et ou d'autres types de maladies démentielles vivent à domicile cf. Dossier de Presse publié lors du 4e anniversaire du Plan Alzheimer, Contribution de M. Alain Paraponaris, maître de conférence, Faculté d'Economie et de Gestion, Aix-Marseille-Université, Paris, 2012.02.01, M. Paraponaris précise dans sa contribution que 60% des personnes atteintes de la maladie d'Alzheimer ou d'une maladie apparentée de 75 ans et plus vivent en domicile ordinaire.

29 cf. Statec, Etat de la population, Année 2011, <http://www.statistiques.public.lu/stat/TableViewer/tableView.aspx>, consulté le 19/07/2012

30 Items marked with (*) under 4.1.3 and sub chapters are common needs expressed by members of the working group involved in neurodegenerative diseases 3 (Dementias, Parkinson's disease and sclerosis Sclerosis), while the other points are the needs identified by the only members of the group in connection with people with disease insane.

31 'counseling is defined as a relationship in which a person tries to help another to understand and solve the problems it faces. Fields of application Counseling often refer producing social realities in themselves, only in individuals with a set of problems or difficulties. "Definitions times Site www.counselingvih.org

32 cf footnote on page 24 of this before

33 see Section 4.1.3)

34 cf. Construction Labour Force 2.1.

35 cf. cf. ibid

36 ibid

37 Note that the charter gives each principle a particular interpretation. In its conclusions, the group referred exclusively to those labels. cf. EUSTaCEA project, European Charter of Rights and responsibilities of older people requiring care and long-term assistance in November 2010 http://www.unccas.org/unccas/europe/22495_guide_accompagnement_FR_low.pdf

38 cf. group work 2.2.

39 Roland Doron and Françoise Parot, psychology dictionary, definition of "autonomy" editions PUF, Quadrige 2nd edition, March 2007, page 75

40 cf. United Nations Full text of the Convention on the Rights of Disability - Convention on the Rights of Persons with Disabilities and Optional Protocol, [S.D.]
<http://www.un.org/french/disabilities/default.asp?id=1413> see also Article 2 of the European Charter rights? and responsibilities of older people requiring care and long-term assistance.

41 Spijker A. et al, Effectiveness of non-pharmacological interventions in Delaying the institutionalization of patients with dementia: a meta-analysis. J. Am Geriatric Soc 2008 Jun; 56 (6) III6-28 Review, op cit. Raeymaekers in Peter, Michael D. Rogers supported by Magda Aelvoet, Improving the quality of life of people with dementia: a challenge for European society, preparatory report for the high level conference organized in the framework of the Belgian Presidency of the EU in 2010. June 2010 op.cit. p. 23

42 Peter Raeymaekers, Michael D. Rogers supported by Magda Aelvoet, Improving the quality of life of people with dementia: a challenge for European society, preparatory report the high level conference organized in the framework of the Belgian Presidency of the EU in 2010. June 2010 op.cit., p.17

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44 To raise the excellent document produced by the Belgian researcher Baldwin Van Gorp of k.ú. Leuven on "Framing and reframing - otherwise communicate about Alzheimer's disease" for the Foundation King Baudouin.