



EVALUATION OF THE NATIONAL DEMENTIA POLICY PLAN IN THE GRAND DUCHY OF LUXEMBOURG

December 2024

Expertisecentrum Dementie Vlaanderen



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1. Introduction: our mission and methodology



(Photo: Leo de Bock)

1.1. Our mission

In November 2023, the new Luxembourg government published its coalition agreement. This document includes attention for the ageing population and increase of persons with dementia. In that context, it foresaw an evaluation of, among other national plans, the dementia policy plan of 2013: « L'augmentation substantielle du nombre de personnes atteintes de différentes formes de démence dans les années à venir aura un impact significatif sur les générations futures. En conséquence, le Gouvernement évaluera le Plan d'action national « maladies démentielles » datant de 2013, en vue de l'adapter aux besoins actuels. » (*Accord de coalition 2023-2028 « Lëtzebuerg fir d'Zukunft stäerken »* 2023, p. 72).

Early summer 2024, the Luxembourg government asked the Flemish Centre of Expertise on Dementia (CED, see annex 2) to work on an evaluation of its dementia policy plan (2013) and, especially, to make suggestions for updates and improvements taking into account international developments.

The objective of the consultancy was formulated as follows:

- To carry out an evaluation by taking stock of the results achieved and not achieved, following the actions carried out within the framework of the dementia plan according to the 2 axes initially retained in the 2013 plan. See chapter 3.

- Identify the actions carried out under other plans that have an influence on the risk factors for dementia. See chapter 3.
- Draw up recommendations (see chapter 5) that take into account the current state of scientific knowledge, public health priorities and the framework of the global public health action plan against dementia 2017-2025, in order to identify critical points and guide national priorities. See chapter 4.

This is and was never meant to be a substantial in-depth evaluation, given the restricted time available. Our aim was to write an assessment of what has been achieved and what the ingredients could be for a way forward over the next couple of years, taking into account the challenges an ageing society poses regarding dementia and dementia care.

1.2. Methodology

The Flemish Centre of Expertise on Dementia (CED) is partner organisation of the Flemish government on topics and activities related to dementia, dementia care and dementia prevention (see annex 2). This report will be heavily influenced by the work we do in Flanders, which is naturally one of our points-of-reference.

In order to enhance our work, we are internationally active within Interdem¹ (the pan-European network of researchers collaborating in research on and dissemination of early, timely and quality psychosocial interventions in dementia), in Alzheimer Europe working groups (e.g. the meetings of the European Group of Governmental Experts on Dementia and as member of their Expert Advisory Panel), and actively participate yearly in the Alzheimer Europe conferences, as well as the meeting of the North Sea Dementia Group². Their 2024 conference took place in Luxembourg, which gave us, through a series of presentations and field visits, a preliminary insight in your dementia policy and practice.

This is the context from which we reflected on the Luxembourg dementia policy plan, taking into account the period of end of August to December 2024 as restrictive timeframe for this consultancy. This work started with an analysis of documents (see annex 5), such as the 2013 plan. In the course of our consultancy, the ministry of family (MIFA, now ministry of family affairs, solidarity, living together and reception of refugees) and the ministry of health (MISA, now ministry of health and social security) developed an overview of the measures implemented.³ These internal working documents include concrete references to developments and legislation and constitute an important starting-point for our analysis. They offer a collection of information important to assist further development of policy-making.

As external observers, we cannot always properly judge the importance of certain activities or 'partenaires'. Our aim is to offer an overall view of actions taken in the context of the 2013 dementia plan (chapter 3). We do appreciate all efforts made by the actors in the field as well as in policy-making to work towards good dementia care. We do apologise if we have not given adequate attention to certain initiatives.

¹ see www.interdem.org

² see www.northseadementiagroup.eu

³ We are aware that the names of the ministries have changed: since we are looking at the 2013 plan, we use the abbreviations MIFA and MISA throughout the report.

The core of our work consisted of a series of semi-structured interviews (see annex 3) that we conducted in the period of September to November 2024, both in Luxembourg and online. A list of the persons we interviewed can be found in annex 4. We thank all our respondents for the time they took and the openness of the conversations we had. Unless otherwise mentioned, the views and opinions of our respondents were only taken into account in this report if they were expressed and confirmed by other respondents. Both ministries have been supportive by providing material and getting in touch with most of the respondents.

In several interviews, we further asked our respondents whom they thought we should have an interview with to guarantee we received good-quality information. Once we talked with these persons/organisations, we again asked whom they thought we should talk to. In that way, we established what is known as 'a snowball sample' and ultimately had conversations with about \pm 50 different persons.

Although we have spoken with several persons who worked with and in the Luxembourg hospitals, we regret it was not possible to have a meeting with somebody who could speak on behalf of these hospitals.

We subscribed to the daily newsletters of Luxembourg news media such as Le Quotidien, Virgule or RTL, and searched their websites for older articles on dementia and dementia care. Following the news media that publish or broadcast in Luxembourgish language was unfortunately beyond our capabilities. We also checked the websites of the organisations of our respondents and organised several google-searches with 'demence' and 'site:.lu' as keywords, and installed a daily google alert on the same keywords.

2. Luxembourg & demography



(Photo: Leo de Bock)

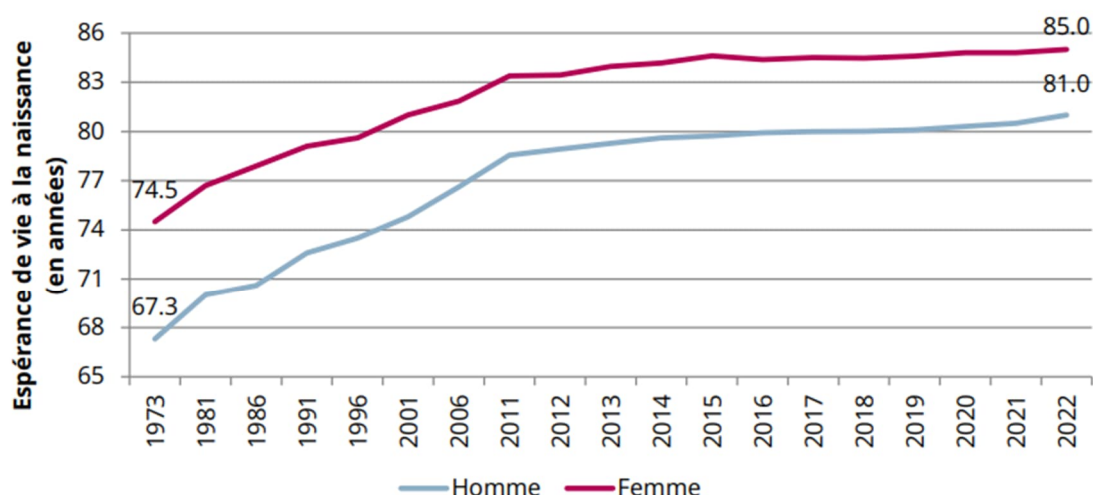
2.1. Setting the scene

Luxembourg is, apart from Malta, the smallest country of the European Union. The country has about 672.050 inhabitants with an average life expectancy of 81 years for men and 85 for women.⁴ Life expectancy at birth is still increasing⁵, and the difference between women and men is decreasing. Luxembourg has, apart from four countries, the highest life expectancy in Europe. Those four are Sweden (83.1 year), Spain (83.2 year), Switzerland (83.7 year) and the small Liechtenstein (83.9 year) (Eurostat, 2024).

⁴ <https://statistiques.public.lu/fr/actualites/2024/stn16-population-2024.html>

⁵ <https://statistiques.public.lu/dam-assets/actualite/2024/stn16-pop-2024/stn16-2024-population-2024-v20.pdf>

GRAPHIQUE 2 : UNE ESPÉRANCE DE VIE EN HAUSSE SURTOUT POUR LES HOMMES



Source : STATEC

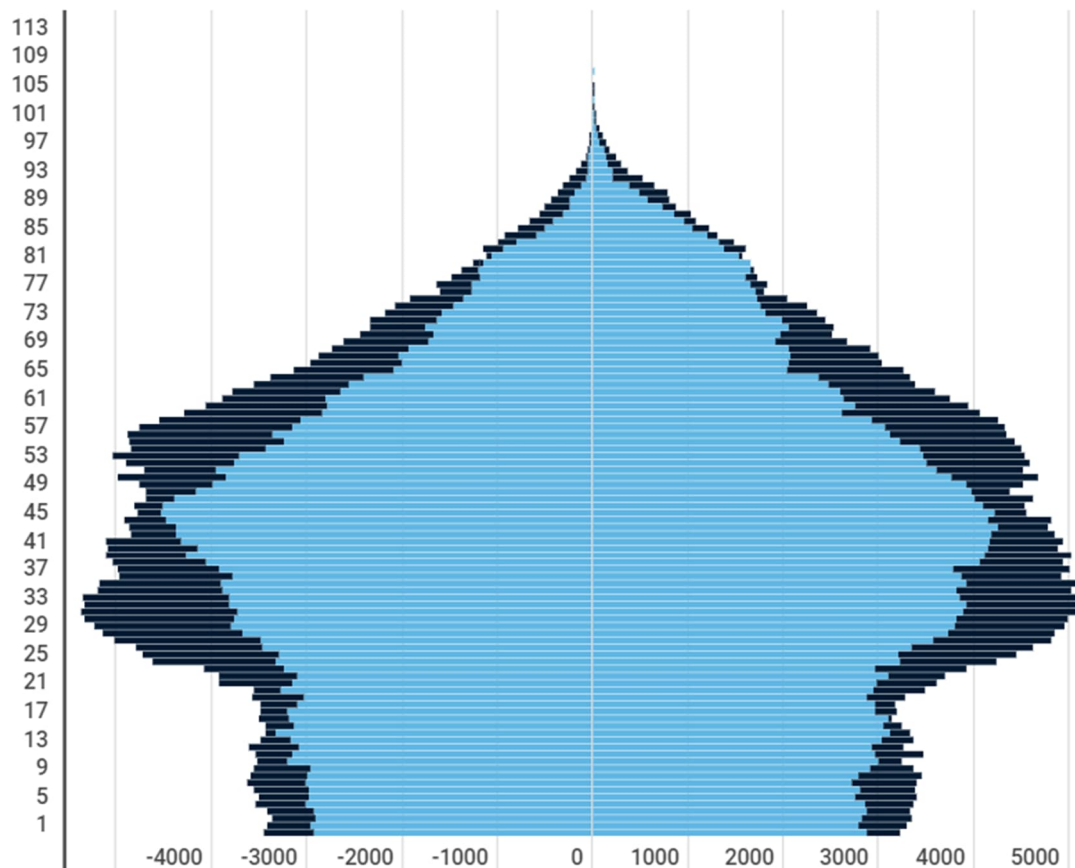
L'écart entre les femmes et les hommes se réduit et passe de 7.2 ans en 1973 à 4.0 ans en 2022.

Source: (Statec, 2024)

The average age of the population in 2021 was 39.7 years⁶⁶, which is an increase from a decade earlier, but still relatively young compared to other West-European countries. This can also be seen in the population pyramid, where the group above pension age is increasing, but again, not too heavy at the top of the pyramid compared with e.g. Flandres, The Netherlands or France. It is mostly the years of working age that see an increase in population, partly because of immigration.

⁶⁶ <https://statistiques.public.lu/fr/recensement/evolution-de-la-population.html>

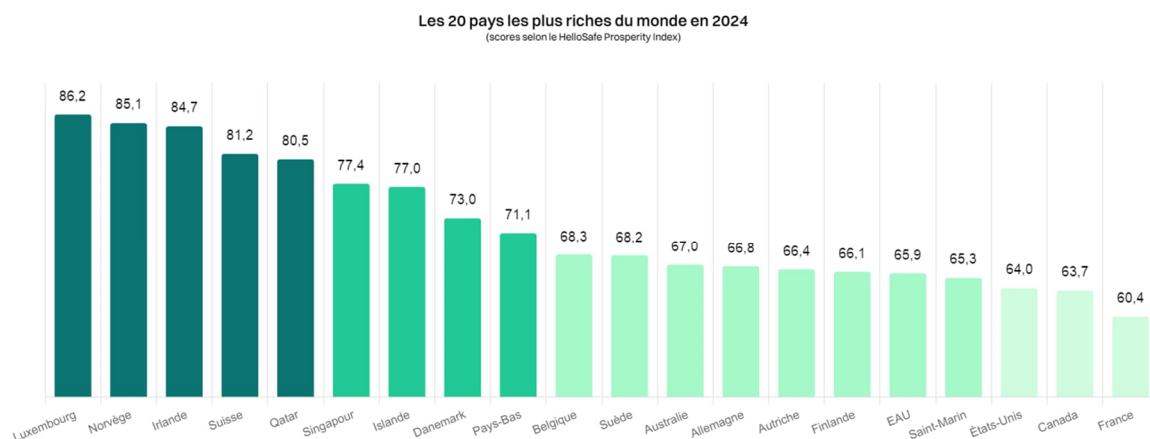
Hommes 2021 Hommes 2011 Femmes 2011 Femmes 2021



Source: statistiques.public.lu

The country is just short of 2.600 km², it borders France, Germany and the French and German-speaking parts of Belgium. Despite its small size, it has a high GDP per capita, more than double than its neighbouring countries. In a recent international comparison, Luxembourg came out as the richest country in the world.⁷

⁷ <https://www.virgule.lu/luxembourg/le-luxembourg-est-le-pays-le-plus-riche-du-monde-selon-cette-etude/27257732.html>



Source : HelloSafe Prosperity Index, sur la base de données de la Banque Mondiale et du PNUD

Of course, as was pointed out to us during one of our interviews, this GDP per capita is highly inflated as the contribution of the about 200.000 daily ‘frontaliers’ and their household members are not taking into account in the ‘per capita’. But when considering this fact and estimating that every ‘frontalier’ has 2.5 household members, the GDP would still be around 75.000 \$, still 1.5 times higher than the neighbouring countries.

This high GDP allows Luxembourg to attract ‘frontaliers’ which make substantial concerns about labour market developments in other EU-countries maybe less urgent, and certainly different (see § 4.12).

GDP per capita, 2023, in US \$

Luxembourg	128.259 \$
Belgium	53.475 \$
Germany	52.745 \$
France	44.460 \$

Source: <https://data.worldbank.org/>

With 650.000 inhabitants and 2.600 km², it is a country with rather low population density, about 255 persons per square kilometre. The EU27 average is 109 persons per square kilometre, but that is influenced by countries like Finland (18) and Northern Sweden (6). Antwerp, with a population just a bit smaller than Luxembourg, has 2.666 persons per square kilometre.

Only a few local authorities have a substantial population. Luxembourg city has 130.000+ inhabitants, and only 12 local authorities have between 10.000 and 40.000 inhabitants, most of them situated in the Esch-sur-Alzette canton in the south. In the regions with low population density, this creates a challenge to ensure equity in dementia care. On the other hand, having free public transport helps.

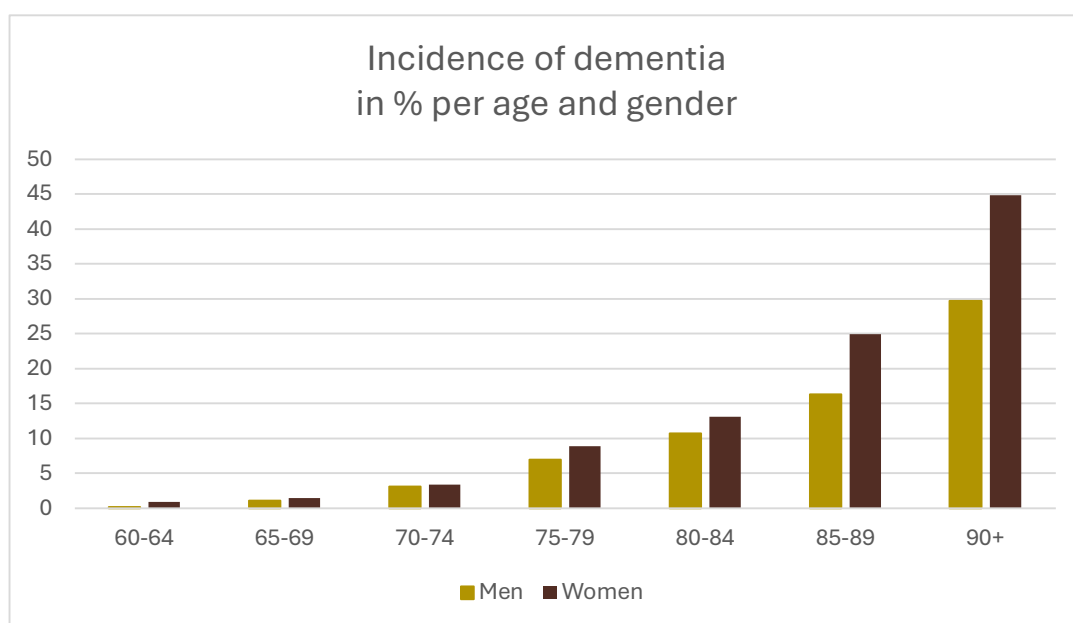
2.2. Prevalence of dementia in Luxembourg

Anyone with policy or management responsibilities should have a broad timeline. You obviously want to ‘survive’ until and beyond the next elections or board meeting, but many processes take longer than that. Demography is considered by many to be a boring and often too mathematical

subject, but it is a science about slow and robust developments. If you look at demographic graphics that cover a long timeline, it's about only the first and second world war that caused a temporary dent in the graphics. Even corona and its many unfortunate deaths are hardly visible. Given that increasing life expectancy, in itself a more than good development, is the major cause of current and future dementia, demographic data do matter.

The data we most frequently mentioned during our interviews and the numerous emails between interviews, is the 2019 yearbook of Alzheimer Europe on prevalence of dementia (Alzheimer Europe, 2019). It updated the previously often-used EuroCode risk model, taking into account more recent research that indicated prevalence of dementia was slightly decreasing. The new model differentiated between risk percentages per 5-year age group and gender. Given availability of these data for the current population and/or population prediction for the next decades, a likely number of persons with dementia can be estimated.

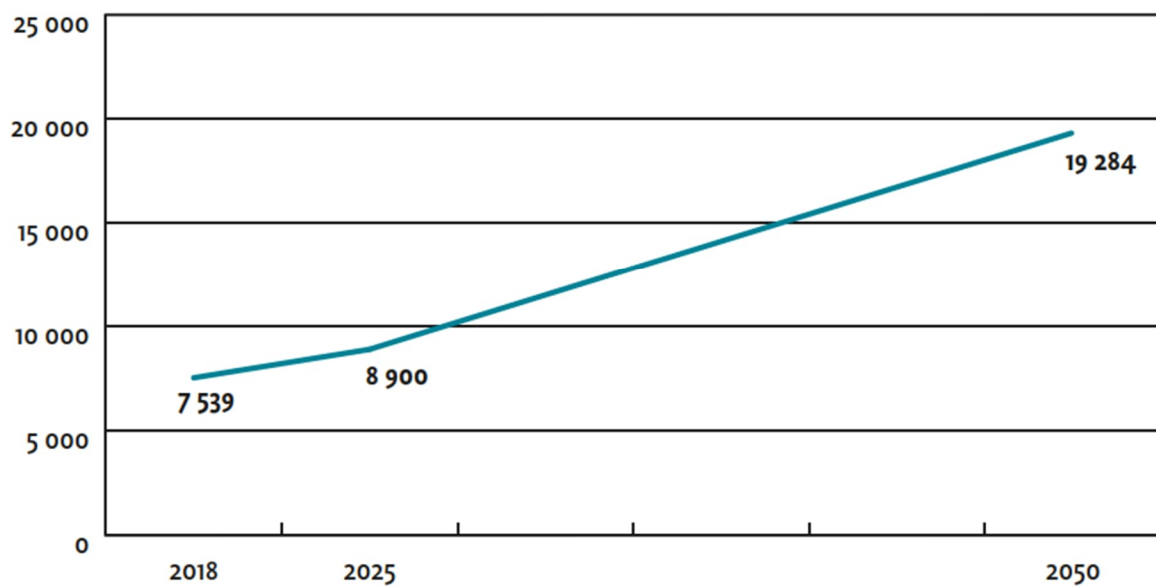
The risk model of Alzheimer Europe per age group and gender is:



Source: (Alzheimer Europe, 2020)

Using this risk model and the at that time available population data for Luxembourg, estimations are there were 7.539 persons with dementia in 2018 and 8.900 persons with dementia in 2025. For 2050, Alzheimer Europe estimates there will be 19.284 persons with dementia in Luxembourg.

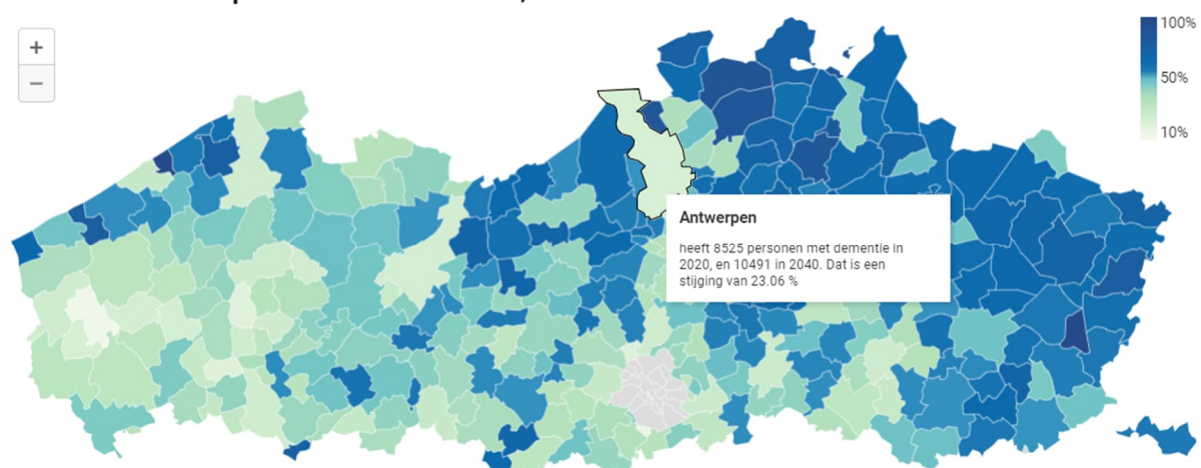
The number of people with dementia in Luxembourg from 2018 to 2050



Source: (Alzheimer Europe, 2020, p. 61)

For Belgium, using the risk model of Alzheimer Europe (2020), we can estimate the number of persons with dementia per local authority up to 2040. This allows us to predict that e.g. the city of Antwerp will see an increase of persons with dementia by about 2.000 between 2020 and 2040, from 8.525 to 10.491. Given that about 30% of these persons will need residential care, and the average Flemish nursing home has about 100 residents, this implies 6 new nursing homes will have to be opened the coming years to guarantee the next generation receiving the care we are able to currently organise.

% toename aantal personen met dementie, 2040 t.o.v. 2020



Map: Jan Steyaert • [Get the data](#) • Created with [Datawrapper](#)

Zooming out to the level of provinces or regions, we have estimations up to 2070. Of course, the longer timeframe we take, reliability becomes an issue, and currently unknown developments can greatly make estimations obsolete.

Although we did look for similar data and asked our respondents for estimations of future population developments or prevalence of dementia in Luxembourg, we did not find these data, beyond what is available in the Alzheimer Europe report. If they would not exist, this makes planning of e.g. the capacity for home care or long term care the next decades difficult. And if e.g. extra nursing homes are currently not in the planning, they will not be available the next decade as they take time to plan/develop/build/staffed.

In a European report on long term care, we found the following quote: “Luxembourg will experience one of the sharpest increases in the share of people aged 65 and over among EU-27 Member States. Indeed, the share of people aged 65 and over is projected to increase from 14.4 % in 2019 to 25.5 % in 2050; the number of people aged over 65 will double” (Social Protection Committee (SPC) et al., 2021, p. 242).

2.3. Some observations about prevalence data

Some observations need to be made about this methodology and these data. Firstly, new research emerged after the publication of the Alzheimer Europe risk model in 2019, suggesting that incidence rates of dementia in high income countries have slightly declined further (Wolters et al., 2020). Additionally, for young-onset dementia, a more refined risk model has been developed by Dutch researchers (Hendriks et al., 2023). Alzheimer Europe is planning to update their risk model and prevalence data in 2025, taking into account this new research.

Secondly, there is increasing consensus that the future number of persons with dementia will be influenced by the brain-healthy lifestyle that is currently being adopted. Dementia is a process in slow motion, hence current lifestyle influences the future prevalence (see § 4.7.).

Thirdly, we know that in Europe persons with non-Western migration background have a 3 to 4 fold increased risk on dementia (Parlevliet et al., 2016). However, few population data provide information on ethnicity in combination with gender and age. So this higher risk is an unquantifiable factor. See § 4.11. for more information on this topic.

These developments are relevant for all European countries. There is however another development very specific for Luxembourg. It is clear that cognitive activity at any age lowers the risk on dementia. Maintaining cognitive activity at middle age, even for persons with low education, reduces the incidence of dementia. During our meetings, we were more than often surprised by how swiftly our respondents switched between Luxembourgish, French, German and English, often even having another mother tongue. The multilingualism of Luxembourg citizens might well have an important impact on cognitive reserve and consequently lower the prevalence of current and future persons with dementia (Anderson et al., 2020; Perquin et al., 2015), slightly lower than the risk model of Alzheimer Europe foresees.

Having said that, a recent report on senior citizens in Luxembourg (Pacht et al., 2024) notes that multilingualism is at the moment stronger in the working population, and less so amongst the elderly. Multilingualism might still be a slight advantage (in the future?) compared to other Western countries, but this will not imply the number of persons with dementia would not increase the next

decades. That development has important consequences, not only for those involved, but also for policy.

Across Europe, the often quoted estimation is that 70% of persons with dementia are community-dwelling and 30% are residents of nursing homes. Given that building and planning additional nursing homes is a long term process, policy makers need to look forward at least 10 to 15 years. Home care needs less infrastructure and might consequently allow for more gradually planning, but with 70% persons with dementia living at home, it will have a more significant impact on budget and staff.

In many West-European countries, no serious planning is being made to expand the capacity of nursing homes. This results in long waiting lists for vulnerable elderly citizens in need of residential care. The lack of capacity adds to the reluctance of this same group to move to residential care, given they feel most comfortable in their own house and community, especially considering the budgets involved. Another important factor contributing to this reluctance is the news media often focusing on what goes wrong and creating a bad reputation for nursing homes, which is recently reinforced by strong (French) testimonials (Castanet, 2022; Eribon, 2023).

3. Reflections on the 2013 national dementia plan



(Photo: Leo de Bock)

3.1. The 2013 Luxembourg dementia policy plan

The governmental programme (2009-2014) for Luxembourg had foreseen 2 measures in the field of dementia (care): (1) the ministry of family and integration (MIFA) will enable the implementation of a dementia action plan, in cooperation with the ministry of health (MISA); and (2) the ministry of health will elaborate a prevention programme with regard to dementia.

Within this framework, MIFA then set up working groups to cover the following topics:

- the improvement of the quality of life of patients and informal caregivers, with two subtopics:
 - the continuity of the medical/care/social chain, with a particular focus on prevention and early diagnosis,
 - and support for the family,
- taking action on the social challenge of dementia with the focus on:
 - the rights and protection of people with the disease,
 - social denial of illness.

Professionals, people with dementia, caregivers, civil servants and others were involved in the four working groups that met several times in the period December 2010-January 2012. Their work was integrated in a final report with the view of establishing an action plan. The report was approved by

the 'Conseil du Gouvernement' on March 13, 2013. The initial period of implementation for this policy plan was 2013-2018 and two 'axes of improvement' were foreseen, consistent with the topics of the working groups. These axes were grouped in 6 domains and 21 measures, for any which a responsible ministry was designated. In 2018, a 'reconduite' (extension) of the plan was decided upon, we understood this to be a prolongation, without evaluation as such.



In the following paragraphs, we offer a summary of the main results and challenges with regard to the implementation of the dementia plan, as we have discerned them. We differentiate between the main results that have been achieved (see § 3.2.) and measures for which some action has been taken, but for which further work needs to be done (see § 3.3.).

We will not dive into specific details, since (1) this would take us too far, (2) it would enhance the chance of us making mistakes, not knowing the concrete nuances and Luxembourg specificities and (3) it is most important for local actors to have the detailed overview, so they can build on those for a future plan.

We did find that our mission, as well as the extensive number of interviews, not only enhanced the actors' view on how things have proceeded in practice, but also improved communication and cooperation between various partners. This will surely improve the decision-making and coherence of actions for the future.

3.2. Results of the 2013 Luxembourg dementia policy plan

During our interviews and visits, we were provided with information on four main results of the 2013 policy plan on dementia. These are the Info-Zenter Demenz, the training manual on psycho-geriatrics, the PDP initiative on prevention and the 2023 law on quality of care for the elderly. Other initiatives were taken but results are either broad (installation of the assurance-dépendance) or remain rather fragmented, such as the law on patient rights (importance of the 'tutelle').

3.2.1. Info-Zenter Demenz (IZD)

Throughout our interviews, there was a broad consensus on the importance of the work of Info-Zenter Demenz. The Centre was set up in order for the broader public to have a first independent contact point. It was thus established to address the aspirations as voiced by the working groups that the general public, people with dementia and caregivers would receive 'neutral' information on what the disease entails as well as what services are available.

The Info-Zenter Demenz has different missions. (1) Sensibilisation: this mission aims at enabling people to talk about dementia, making it more present in society and making Info-Zenter Demenz more visible. This mission is put into practice through the website⁸, 'classic' media, networking and being present in the field, e.g. at local markets. (2) Information: IZD offers information to the general public and professionals by organising conferences, providing movies in the cinema, giving talks to e.g. Club séniors, having a library, participating in the 'formation continue psycho-gériatrique', rolling out the pilot-project 'Demenz mat Häerz' and consulting the project 'Demenzfrëndlich Gemeng'. And (3) orientation: IZD has as primary task to inform, orient and support people with dementia and their caregivers. Receiving the public, either in person or by phone/email is therefore a core-business. In 2023, IZD had 728 contacts, which is an increase by 17% compared to 2022 (Info-Zenter Demenz, 2023). The main reasons for taking contact were to receive information on available services and to get information on the disease. This accords with the aim of setting up IZD. About 6% of the contacts were taken by professionals, in that sense, IZD clearly has a different target group than our Centre of Expertise on Dementia (CED).

Reflections

Some remarks are to be made when it comes to IZD's activities and set-up. First of all, despite their small staff, our respondents noted that IZD achieve good results in awareness raising about dementia. The actors that we interviewed cooperate well with IZD, for example during info-sessions, conference or training sessions. A comment was made by some respondents about various videos that were made in the direct aftermath of the 2013 dementia plan, in which people with dementia and their caregivers spoke about their experiences. Some of these videos have been taken over on the IZD's website, others not. Some respondents found this nuanced portraying still needed, since the taboo remains within the Luxembourg society and the witnesses filmed offered a very nuanced view.

Secondly, the embedment within l'Association Luxembourg Alzheimer (ALA) leads to confusion: IZD is positioned within ALA structures, and yet it was created with the intention of having an independent entering point for people with dementia and their caregivers. ALA is one of the service providers and therefore the concern was raised during the debates that a more neutral information centre would be needed. In comparison: in Flanders, the CED are, in the first place, oriented toward professionals,

⁸ <https://demenz.lu/>

offering training, consultancy and support for policymakers. The Alzheimer Liga, as a Flemish patient organisation, supports people with dementia and their caregivers. Both organisations work together in overlapping themes but are separate ngo's with different tasks and missions. In recent years, so-called 'walk-in centres' have been developed, in cooperation between CED and the Alzheimer Liga, in which people can just pop in and ask questions. Although we understood that cooperation between ALA and IZD runs well, we think considering the establishment of IZD as a separate organisation seems favourable to clearly distinguish between sensibilisation/advocacy and care provision. In any case, clarifying the role of both organisations and their respective tasks is crucial.

Thirdly, people with dementia seem not to be involved in debates around the topic, nor in research or policymaking. In Flanders, the Alzheimer Liga coordinates a Working group of people with dementia as well as a Working group of caregivers. This enables their input on various levels and to a certain extent ensures that measures taken actually improve their situation. When clarifying the roles of IZD and ALA, a place for cooperation with people with dementia is crucial when one is serious about improving the (quality of) lives of people.

And finally, the International Day on Alzheimer (21 September) offers ample opportunities to put dementia in the picture, also to pro-actively contact journalists and provide a more nuanced image of the disease. ALA does seize the opportunity⁹ as does IZD.¹⁰ The ministry of health also participates, according to the MISA interview. All-in-all, these seem to be one-shot activities: a more coordinated, national approach could be considered (see § 4.4.).

3.2.2. Training on psycho-geriatrics

Qualitative training of those involved in caring, be it professional carers or family carers, is necessary to achieve good dementia care. Ideally such training would be initiated in basic training, e.g. as a nurse, an occupational therapist or other caring profession. Luxembourg is specific in this, as most of these caring professionals receive their training in the neighbouring countries and not in Luxembourg itself. This results in a lot of variety in the knowledge and attitudes of dementia care among professionals at the beginning of their career. Guaranteeing quality of care then becomes difficult, as well as ensuring equality of care across regions and institutions. And it makes continuous education essential to check on and improve the quality and equality.

In the context of the 2013 dementia policy plan and explicitly mentioned in the quality law of 2023 (see § 3.2.4.), a standardised education on psycho-geriatrics was established. The manual for the participants as well as the trainer is becoming available around autumn 2024, in the German language. A French language version is in the planning/making. The manual was developed by MIFA, Gero and IZD, in consultation with a working-group of the training centres of the 'gestionnaires'.

⁹ <https://ala.lu/de/2022/09/21/21-september-welt-alzheimertag/>

¹⁰ <https://demenz.lu/fr/actualites/info-zenter-demenz-au-memory-walk-2024/>

The manual exists of 5 modules:

- 'I am part of society': basic knowledge on elderly and positive framing
- Basic knowledge on dementia
- Communication: interpretation of the person's behaviour as well as communication within a team
- Misunderstood behaviour
- An elective module

Module 5 can be filled in by service providers as they see fit. In that way, they can e.g. use it to explain and elaborate on the care concept they adopted, which can enhance a diversified offer of services. MIFA checks the proposed contents of this module.

Reflections

Respondents generally welcome the publication of the manual. We note some challenges to still be addressed:

- How will the quality of the trainings be ensured? We understood that freedom of choice is important in Luxembourg, and therefore the various providers can freely decide how to develop Module 5. Service providers with their own training centre can provide attestations about the training. How can one then guarantee that people were indeed trained and that the training covered all topics as foreseen?
- A train-the-trainer is provided for, but the question was risen whether the manual as such would be enough of a base to ensure qualitative training? For sure, offering a manual in itself is insufficient to be able to train colleagues. Trainers have to be recognised by the MIFA in order to be able to give the training, which is a good start. A follow-up of the actual implementation is nevertheless crucial. Also, intervision and networking offer good tools to ensure a standardised approach. Reference was made to palliative care trainers as a good practice in that regard.
- Only the German version is available so far, while the quality law has already come into practice. MIFA should look into the process of implementing trainings and follow-up formations regarding palliative care and discern what improvements can be made to roll out the psycho-geriatric training. Also, a regular update of the manual as well as the formats of training should be foreseen in order for both the content and format to be and remain relevant for practice and changing populations. With an ageing target-group, articulateness of people and diversity will for example come to the foreground more often.
- The training is oriented towards care institutions and 40% of the personnel needs to follow it. For hospitals and GPs, such training is not foreseen in a standardised manner, although a good cooperation and coordination between the various actors is crucial to prevent deterioration of the person's health. Multiple respondents voiced their concern about the need for continuous formation of medical personnel. A translation of the manual towards nurses and doctors could offer a major step forward.
- Besides for care personnel, trainings are also offered for family caregivers to be informed about what dementia is and how to deal with it. These trainings are not that often attended, research is needed to understand the reasons beyond the non-use as well as the needs of caregivers, especially since international research shows the importance of psycho-education of caregivers and its effect on ageing in place (see § 4.2.).

3.2.3. Programme Dementia Prevention (PDP)

We congratulate Luxembourg for including primary prevention already in their 2013 policy plan, years before the 2017 report from The Lancet committee created an urgency to work on this subject: “be ambitious about prevention!” (Livingston et al., 2017). The 2020 and 2024 update of their report only strengthened and enforced that message (Livingston et al., 2024; Livingston et al., 2020). In all three reports from this commission of The Lancet, focus was on primary prevention.

Following the 2013 dementia plan, Luxembourg established the PDP-programme (Programme Démence Prévention) in 2015. The programme focuses on patients who have mild cognitive impairment (MCI) or subjective cognitive decline (SCD) (Schröder et al., 2024). This makes PDP an initiative focusing on secondary prevention, at the stage where there is already (a strong suspicion of) memory loss. Participants are identified and referred to the programme by their treating general practitioner or neurologist. Following a neuropsychological assessment and risk factor profiling, participants receive vouchers that provide them with access to relevant interventions or activities (e.g. yoga, Nordic walking, consultation with a dietician, ...). Since the start, about 450 participants have been included in PDP, with a mean age of 69.5 years (Schröder et al., 2024). During our meeting with PDP-staff, that figure was updated to 744 referrals, the mean age becoming 68.7 years, about equally distributed among men and women, 84.2% of the participants already having MCI. A great majority (83.1%) of these referrals/participants came through the Centre Hospitalier de Luxembourg (CHL), raising the question why there are so few referrals from other regions of Luxembourg. Noteworthy is also that only 63% of the vouchers were redeemed, implying that about 1/3 of them were never used.

The very recent expansion with an app¹¹, inspired by the Dutch app Breincoach, and the associated media campaign, is an excellent way to enlarge the initiative to a broader audience and shifts the focus of PDP from secondary to primary prevention.



¹¹ <https://www.pdp-app.lu/>

Reflections

The PDP-initiative is, according to our respondents, a good initiative but some observations need to be made. One is that several of our respondents found the coupling with Parkinson disease confusing and obsolete. The historical origin of this coupling is understandable, and there are initiatives to broaden the scope, but PDP could avoid it in their communication to the general audience.

We also wonder if and who is working on getting information on brain healthy lifestyle in mainstream and social media. As mentioned, we e.g. did not see news about the launch of the app in Luxembourg media beyond an interview with RTL, nor did we see news about the third report of The Lancet commission on dementia in summer 2024. An article in L'essentiel in September 2024¹² did refer to the link between physical activity and the risk on dementia referred to a Chinese study, but looks like 'a lucky shot' of having this subject in the media. Of course, as outsiders, we probably missed elements, but the impression is that in this area more can be achieved by building liaisons between the dementia sector and media (see § 4.4.).

3.2.4. Law on quality of services (2023)

The 2013 policy plan on dementia had as first focal point the improvement of quality of life of patients and informal carers. There are a great number of variables that can influence this quality of life, such as the stage of dementia, the financial resilience of the household, the number of family caregivers being involved or the degree to which the residence (the house, the locality) makes ageing-in-place easy or difficult (to name but a few of the variables). Many of these variables are shaped throughout the life course. It is important to note that the policy ambition to improve the quality of life of patients and information carers gives government few instruments to actually make that happen: a lot is beyond control.

One of the key instruments the government does have though to improve quality of life once there is dementia, is guaranteeing good dementia care, both quantitative (no waiting lines) and qualitative (up to standards of good dementia care). Given this is one of the few instruments for a government to contribute to the quality of life of patients with dementia and their informal caregivers, it is remarkable that it took 10 years before the law 'sur la qualité des services pour personnes âgées' was established (23rd of August 2023).¹³

The law of 2023 puts into place some new elements that are important when it comes to dementia. Firstly, 40% of the personnel in both home care and nursing homes needs to be trained into the specificities of dementia (care). Secondly, there will be a 3-yearly evaluation of the quality in care institutions, which will use criteria that go beyond the five criteria as checked by the 'assurance-dépendance'.¹⁴ Thirdly, the installation of ethical committees within care providers enables reflections on e.g. fixation and mistreatment. The latter element will also come more to the fore through the concept of 'bientraitance', which has been installed through the quality law.

¹² <https://www.lesessentiel.lu/fr/story/sante-un-peu-de-sport-suffit-a-prevenir-la-demence-103179570>

¹³ <https://legilux.public.lu/eli/etat/leg/loi/2023/08/23/a562/jo> (Loi du 23 août 2023 portant sur la qualité des services pour personnes âgées)

¹⁴ <https://legilux.public.lu/eli/etat/leg/rgd/2017/12/13/a1094/jo> (Règlement grand-ducal du 13 décembre 2017 déterminant le contenu de la documentation de la prise en charge et les indicateurs de qualité de la prise en charge)

Reflections and ways forward

Although it is not our intention to evaluate the law, this was not a task in our mission and its implementation is only recent, it proves to be an important instrument to ensure the translation of some of the concerns that were raised in the 2013 plan. Therefore, we reflect upon the provisions and offer some ways forward, which will be translated in recommendations in chapter 5.

We came to understand through the interviews that freedom of choice is important in Luxembourg, both for citizens as for care providers. Specific care providers are encouraged to select and adopt their own care concept (e.g. the concept of Erwin Böhm or the validation concept of Naomi Feil) and take care of implementation within their organisation (e.g. through training of staff). This, at least in theory, allows for 'a free market' of care environments from which citizens can make an informed choice, according to their needs and preferences. In the framework of the law of August 2023, a register has been launched in Luxembourg.¹⁵

However, key elements of a free market are not available. Citizens are looking for care within the immediate proximity of their residence, taking into account waiting lists, which greatly limits what can be chosen from. Consequently, that choice is too often made in the context of an urgency: where what is readily available takes priority over critical choice.

The consequence for us is that the implementation of the quality law will be essential to establishing good quality of dementia care in Luxembourg. In Flanders, we work hard to guarantee that this quality monitoring should not be limited to check-list items such as hygiene of food, availability of nurses at night, number of square meters per room in nursing homes, ... but it should go to the hearth of good dementia care, of person-centred care. Such approach doesn't need to be in contrast with the freedom of choice of each care provider in choosing a specific care concept. On the contrary: it offers a general availability and provision of good person-centred care, with certain specificities of care providers on top of the general standard. In Flanders, for example, our reference framework (see annex 2) is used as a standard, but various models are implemented that further focus on specific elements such as creating a homely environment, dealing with challenging behaviour or developing meaningful activities.

Throughout our interviews, we understood that the evaluation system in Luxembourg will consist of two main components: a quantitative and a qualitative assessment. The quantitative evaluation works with binary criteria: something is either present or not. The qualitative evaluation gathers feedback through interviews with among others care recipients themselves, focusing on their experiences and opinions about the care received, with particular attention to aspects such as respectful treatment.

Written procedures and concepts around specific themes form a crucial component. The individual living and care plan is central: how are medical needs integrated with the client's personal wishes? There is explicit consideration of both cognitive capabilities and personal preferences. An essential requirement concerns staff qualifications: staff members must receive appropriate training, with a specific requirement that 40% of the personnel must have specialised training in psychogeriatrics (one of our respondents wondered why not all personnel would receive this training, this could be a suggestion for the future). This training ensures a high standard of professional care, particularly for elderly residents with specific psychological needs.

¹⁵ <https://infosenior.public.lu/>

After this initial binary evaluation phase, a second phase follows in which the practical implementation is verified. This will be done through a sample of approximately ten cases that are then thoroughly examined. The review checks whether the documentation and procedures established by the care provider are actually being applied in individual cases. A specific point of attention is the organisation of activities for people with dementia, separate from regular group activities.

This system ensures a thorough evaluation that checks both the presence of procedures and their actual implementation, with special attention to the personal experience of the care recipient.

The establishment of this 'cellule de qualité' is an improvement, since it offers possibilities to check whether the criteria as mentioned in the law of 2023 are indeed fulfilled. Making the reports public will offer citizens a chance to look into the evaluations and make an informed decision on what institution fits their needs best.

It will be important to evaluate in March 2027 not only if all institutions were indeed visited, but also whether other, more qualitative elements need to be considered in the future. To give a concrete example: with regard to the 'formation psycho-gériatrique', it will only be checked whether the training was given and maybe asked during the interview whether personnel remember and practice the content. More in-depth information could be gathered or questionnaires could be administered to get a more overall view on the adherence to the principles of the training.

One challenge will be to ensure that people with dementia are involved in the evaluations. In Flanders, we are currently running a project to evaluate the quality of life for people with dementia in a further-developed stage, not being able to use their words anymore. Personnel observes people with dementia, using a well-researched tool (Qualidem) (Dichter et al., 2016). This can be of inspiration for Luxembourg.

3.2.5. Law on patient rights (2014)

The 2013 dementia plan mentions the introduction of the 'personne de confiance'. The law on patient rights¹⁶ has offered a partial response to the questions raised with regard to the rights of the person with dementia. This person, often a member of the family, can support the person in executing their rights, having known the person and preferences over a longer period of time. One can give the mandate to whomever they see fit, at any time.¹⁷

Nevertheless, this concept remains to be further developed, especially when it comes to its relation to the 'tutelle' and really enabling persons to exercise their rights in practice. There are currently no guidelines for doctors to assess the person's ability to make decisions. A reform is underway to adapt the Code civil to the United Nations Convention on the rights of people with disabilities (CRPD)¹⁸, in which these discussions also come to the fore. This can be of inspiration for addressing people with dementia.

¹⁶ [A - N° 140 / 31 juillet 2014](#)

¹⁷ [Personne de confiance - Vos droits et obligations - Médiateur Santé - Luxembourg](#)

¹⁸ [Plan d'action national - Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil - Le gouvernement luxembourgeois](#)

When the person with dementia cannot (fully) exercise their rights, they can be placed under guardianship ('tutelle').¹⁹ This is a judicial procedure and a 'juge tutelle' can decide for the following measures to be taken:

- 'Au sauvegarde de justice' (for 6 months)
- 'Curatelle' : the 'curateur' can support the person in exercising their rights
- 'Tutelle' : when the person cannot exercise their rights, the 'tuteur' will do so on their behalf.

Reflections

We understood that in practice, there is no overview nor evaluation of the tasks of the 'tuteur', which can lead to problems and uncertainties. This, as well as the possibility of inheritance by the 'tuteur' from the person under 'tutelle', will be changed under the new law, which has the aim of protecting the person as much as possible while simultaneously not taking away their rights. It is interesting to note that the rights of the person were already a focal point in 2013 and that setting up a legal framework to enhance this situation takes such a long time. The consultation of 11 December 2024 collects recommendations and ideas of the various partners with regard to the law of 2014. Hopefully, this will also help to clarify the relation between the 'tutelle' and the 'personne de confiance', in view of having the interests of the person with dementia best served. We would recommend to include 'advanced care planning' into the debate as well (see § 4.5.).

3.3. Measures from the 2013-plan to be (further) developed

Besides the initiatives taken and the measures that have been implemented, as described in the previous paragraphs, four elements that were foreseen in the 2013 plan have been (under)developed. Concerns were raised by respondents on the topic of diagnostics, hospitals, fixation and the still-existing taboo in Luxembourg society when it comes to dementia.

3.3.1. Diagnostics

Already in the 2013 plan, the development of diagnostics at two levels was foreseen: Demtec at the level of general practitioners (GPs) and a more profound diagnostic with validated tests, national guidelines and continuous trainings for specialists.

People in Luxembourg can choose what GP they go to. We understood through our interviews that the free choice of people to go to a doctor of their liking, be it a GP or specialists, is very important. Nevertheless, it could also impede citizens building a relation of trust with their GP, as well as an advanced implementation of the 'dossier de soins partagé' (DSP). Le 'médecin référent' uses the DSP to centralise all medical information of the patient, at least in theory.²⁰ There is however only a small financial incentive to be reference doctor, and no obligation to use the DSP, so it remains to be seen what the effects of these evolutions will be in practice.

Generally, the GP would be the central doctor to follow the person with dementia, in casu their family. Dementia is a long-term condition that permits billing such tasks of coordination. In our interviews it was mentioned that the DSP is not used because it is a 'cemetery of data', since no overview is foreseen and it is not user-friendly (although reforms also seem to be underway). We understood that the freedom of choice also entails the freedom of the doctor to decide as he sees fit,

¹⁹ [Tutelle - curatelle - Famille - La Justice - Luxembourg](#)

²⁰ [Médecins et spécialistes - CNS - Luxembourg](#)

and thus for diagnostics other instruments than Demtec are used in practice. There seems to be no guideline on when to use what instrument.

Reflections

European and international evolutions should be monitored and followed up. The EU wants to move towards a more patient-based registration of health data, in the framework of the creation of a European Health Data Space.²¹ In Flanders, InterRAI instruments are translated into Belgian environments in order for data to be more easily available between various care professionals.²²

In Flanders, GPs are sometimes reluctant to go for a diagnosis since, for the time being, there is no medication that can cure the condition (see § 4.6.). This was already the case in the 90s (De Lepeleire et al., 1999) and stills seems to be the case, also in Luxembourg, as we understood from our respondents. Nevertheless, timely diagnosis is important for people to get rid of uncertainty, to be guided in how to best cope with the condition and also to start talking about advanced care planning. Furthermore, it is crucial for the direct environment of the patient to better understand the changing behaviour and to be able to maintain their supportive role (see § 4.2. and 4.3.). Generally, the GP can look into the daily functioning of the person, where dementia may only gradually come to the fore, and together assess and work on the quality of life. This is not self-evident in a setting where the GP is paid by visit and thus may not have the time to thoroughly talk things through.

Geriatric services do exist in hospitals in Luxembourg and they can provide for dementia diagnostics. Some respondents did voice the concern that neurologists are generally more focused on strokes. Furthermore, there is no structured or multidisciplinary method to work towards diagnostics, nor a general adherence to international standards. Although there are only four 'centres hospitaliers' in Luxembourg, there is no coordinated approach towards diagnosing and treating patients with dementia, nor a network in place. The recent 'réseau de compétence' for Parkinson can offer a first step towards a more coordinated approach and lessons could also be learned from the oncology field, where cooperation seems to be developing. These networks were already foreseen in 2018²³ and apparently know a slow start.

An update on who can diagnose and what medication can be described should be foreseen, since this is a very rapidly evolving field. We understood in our interviews that insurance does pay for the psychosocial diagnosis when it is carried out by a geriatrician, but waiting lists may lead people to other settings. It can then come as a surprise when the patient needs to pay the bill of about 300EUR themselves.

The syndrome-based diagnosis process can be started by the GP with referral to a memory clinic and a multidisciplinary team if appropriate. Guidelines on each step should be available for each profession involved and for the team. The development of a memory clinic could enhance this. We understood that, for now, Alzheimer and Parkinson are mostly focused upon in Luxembourg. Attention should be given to differential diagnosis, as there may be other causes than dementia. Also, aspects of the follow-up of Alzheimer disease differ from e.g. frontotemporal dementia of Lewy body dementia, which could lead to different behavioural problems. Diagnosis should be up to professional standards and guarantees are to be in place to ensure equity across the country. The

²¹ [EU Health Data Space: more efficient treatments and life-saving research | News | European Parliament](#)

²² [interRAI | Improving Health Care Across The Globe](#)

²³ <https://legilux.public.lu/eli/etat/leg/loi/2018/03/08/a222/jo> (loi du 8 mars 2018 relative aux établissements hospitaliers et à la planification hospitalière (article 28))

‘Conseil scientifique du domaine de la santé’ should certainly be involved in the challenge of developing recommendations on diagnostic tools.

Moreover, with the rapid developments of biomarkers and disease modifying treatments (see § 4.6.), the need for additional ‘waves’ of biomarker-based diagnoses becomes necessary for a selection of patients. Both European and American experts have recently published guidelines on these supplementary ‘waves’ of assessment (Frisoni et al., 2024; Jack Jr et al., 2024). It should be noted that in this area, the equally rapid development and implementation of artificial intelligence is also having an impact.

We understood that doctors can be rather reluctant to diagnose dementia when no medication is available. The developments in that field may yield interest and could offer a gateway into a more coordinated approach on diagnosis. Therefore, doctors may on the one hand now be more open for a more general and standardised approach, compared to 2013. On the other hand, medication is not the only element to focus on: diagnosis of care needs should not be forgotten (De Lepeleire et al., 1999).

3.3.2. Hospitals

Care institutions have an obligation to provide information on their residents (with dementia) when they are transferred to the hospitals for e.g. diagnoses, a kidney failure, a broken leg after a fall-incident.²⁴ Most often, information will indeed accompany the patient when they are brought to the hospital, but this information may be lost upon arrival. More importantly though, although information is usually provided, there is no standardised reporting tool for the stay in the hospital, which impedes the continuation of care upon return to the home/care situation. A prescription regarding medication may be included in the dossier when the patient leaves the hospital, but according to our respondents, that is often about the most information that is transferred in a timely manner. Other information may follow, or not. Further developing the ‘dossier de soins partagé’ and guaranteeing a clear transfer between care organisations seems to be an essential way forward here.

Another challenge identified by our respondents was bringing the diagnosis process up to international standards (see previous paragraph). There seems to be no uniformity in how this is done in the different hospitals in Luxembourg.

We were also informed that for staff working in hospitals, no continuous medical education similar to the standardised training on psycho-geriatrics for staff working in social care (see § 3.2.4.) is required for doctors or nurses. MISA did provide us with information of the number of hours of training for nursing staff in the hospitals.²⁵ This shows that training was given on dementia, sometimes in cooperation with ALA. Respondents also mentioned that doctors would follow training or conferences on their own initiative or from a deontological point of view²⁶, linked to the institutions and networks of their basic education. DeWidong also provides trainings on dementia.²⁷ There are thus certain initiatives, but no general requirement for training. It was questioned whether this would cost too much or be rather hard to evaluate (is attendance as such enough guarantee?). Some

²⁴ Règlement grand-ducal du 13 décembre 2017 déterminant le contenu de la documentation de la prise en charge et les indicateurs de qualité de la prise en charge.

²⁵ Document d’information DiSa, par Dr. Romano et Dr. Bourgeois, provided to us in preparation for the meeting with the Ministries in September 2024.

²⁶ Code de déontologie des professions de médecin, art.13,
<https://legilux.public.lu/eli/etat/leg/code/sante/20240929>

²⁷ [COMPRENDRE LA DÉMENCE - DeWidong - Santé + Développement + Compétence](#)

respondents described this lack of training requirement as unethical and unprofessional, given that medicine and more broadly care is a continuously developing field. If staff do not keep up with developments and update their initial training, where is the improvement?

MISA has published a brochure with regard to people with dementia in hospitals (Ministère de la Santé, 2018). Our respondents assumed that the hospitals are aware of this brochure, but no standardised approach has been developed to guarantee dissemination and implementation of its recommendations. Maybe the 'reference nurses' in the emergency ward are aware?

Reflections

Although quality of care in hospitals in general seems to be rather good, with high numbers of personnel, almost all respondents that talked about this topic seemed to agree that there is still a lot to be done when it comes to dementia. As researchers we need to be honest and mention that some respondents used the words of "horror" and "catastrophe" in relation to care for persons with dementia in the Luxembourg hospitals, because their health deteriorated with their stay in the hospital. Unfortunately, we were not able to receive the hospitals' point of view on this important matter.

In the international thinking about dementia-friendly hospitals, Nicci Gerrard is an important name (Gerrard, 2019) (see § 4.4. for her other work relating to dementia care). Her father John Gerrard received a diagnosis of dementia and continued to live on his own. But during a hospital stay, he and other patients had to be isolated and things took a dramatic turn for the worse. Nicci Gerrard recognised that it was not just the result of the disease, but also bad hospital/dementia care. She subsequently launched the John's campaign in the UK, inviting all hospitals to subscribe a dementia friendly hospital charter.²⁸ This included for example giving family caregivers of a person with dementia the same visiting opportunities as are common in paediatric wards. By being issued a badge, they are recognised by staff. A great majority of UK hospitals actually did sign this charter.



²⁸ <https://johnscampaign.org.uk/>

(Lister Hospital, UK - photo: John's Campaign)

For Flanders, we published an inspiration guide on dementia-friendly hospitals (May 2024), in cooperation with and at the same time as the Flemish Alzheimer Liga published their guide for family caregivers. The brochure as developed in Luxembourg (2018) can be a stepping-stone to work towards dementia-friendly hospitals throughout the country.

Some respondents noted that the problem of delirium is not always recognised throughout the hospitals. Geriatric services may know the clinical picture, but no clinical pathway is established for dealing with delirium. The admittance to the hospital (for whatever reason) may cause a delirium in the person with dementia, who may then receive medication that is not apt to their situation. More training and knowledge, as well as following international guidelines, is needed on specific elements of dementia in order to be able to correctly assess the patient's shape and condition, as well as to avoid overuse of medication.

3.3.3. Fixation: also chemical (medication)

The fight against mistreatment and foreseeing a framework regarding fixation were both foreseen in the dementia plan. The quality law of 2023 refers to a concept of good treatment ('bientraitance'), which we assume will be further developed in practice when the quality control and ethical committees are installed. Mistreatment, abuse, neglect are topics that might be hard to discern in practice when the person with dementia cannot voice their concerns. Mistreatment can be reported to various instances: the care organisations themselves, Senioren-Telefon, the new ethical committee that is being or will be installed in the care institutions, the 'service d'information et médiation pour les personnes âgées', MIFA, the judges. It would be recommended to study whether these instances are known to the people concerned, whether or not they are used, and for what reason. Luxembourg University and partners carried out a research on the topic in 2010 (Ferring et al., 2010), an update on this important topic is needed. In hospitals, the process towards accreditation entails implementing good-quality care with respecting patients' dignity. This could be a way forward to look into the topic.

Reflections

In Flanders, attention goes out to so-called 'derailed care': when people, be it professional or informal carers, are unaware of the type of behaviour that dementia may cause ('challenging behaviour') this can test the carer's patience. Expressions such as "he does it on purpose!" or "if this lasts any longer, I will lose control..." are then often-heard. Indeed, when carers are under a lot of strain, sometimes they lose their temper or self-control and may misbehave towards the person with dementia. This is often not out of bad will, but rather out of lack of knowledge and/or overstrain. Formation on dementia as well as on self-care and stress management then becomes crucial to avoid situations of derailed care (so-called psychoeducation, see § 4.2.).

Avoiding mistreatment is one thing, providing for 'good treatment' is another. Developing a concept of person-centred care and a framework for good dementia care can help in this regard. The 'manuel psycho-gériatrie' can be a first step, our Flemish framework on good dementia care (see annex 2) may offer further inspiration.

Mistreatment is often linked with fixation, although these two concepts are not the same. When we asked respondents about fixation, all were, on the one hand, very firm that physical fixation was not practiced in care institutions. On the other hand, the topic of (over)use of medication was raised multiple times. This was, however, not considered by our respondents to be a form of fixation. In

practice and research in other countries, we see that professional caregivers may opt for medication to quiet down people with dementia, because they have no time to look into or offer attention to the behaviour of the person and his underlying needs, because they feel powerless, because there is not enough personnel on the work floor. Medication can deteriorate the person's health and should always be prescribed with caution (see § 4.8.).

In Flanders, a research team is supporting the Flemish government to design an integrated directive on measures that restrict freedom.²⁹ Based upon (inter)national research and literature, they distinguish between 3 types of fixation: physical, mechanical and medicamentous fixation.

Some respondents in Luxembourg had the impression that people with dementia (but also elderly more generally) seemed to receive more and more often medication. It would therefore be a good idea (1) to define what forms of fixation are considered and (2) to examine the (over)use of medication. The Interministerial Working group as foreseen in the coalition agreement 2023-2028 (p.70), even though more focused on negligence and mistreatment, seems to offer a good first step in that regard. Fixation for now seems to be discussed and regulated in Luxembourg only the field of psychiatry. Debates should be stimulated between these fields, taking at the same time into account that not that long ago, dementia was considered to be a mental illness, not in the least in society. This brings us to the following point: societal views on what dementia is.

3.3.4. Social denial, stigma

Already in 2013, the working groups elaborated on the fact that there was still a taboo around dementia, and that people were reluctant to bear witness about their experiences. From our interviews, we understood this is still the case to this day. In Flanders, we find testimonials form strong communication material. Several times our respondents commented (in general) "in Luxembourg, everybody knows everybody". Bringing a very personal testimonial as a person with dementia or family caregiver may then be more difficult and possibly related to the shame.

Within the context of developing the dementia plan, testimonies were recorded, which offered an insight view of the dementia process and how people deal with it. Respondents that were involved in making these interviews found that these testimonies were very insightful and wondered why not all were taken over in IZD's website (see § 3.2.1.). Although, respondents were, as mentioned before, content with the work done by IZD to bring dementia more to the foreground within society, they also confirmed that it is still a taboo. Awareness campaigns and television programmes are thus still needed (see § 4.4.).

Although the 'Demenzfreundliche Gesellschaft' was already mentioned in the 2013 dementia plan, we have not come across a lot of information in this regard. ALA did mention that they started cooperating with their local community in which their care institution is based (Erpeldingen an der Sauer) to get to a dementia-friendly community and IZD's 2023 report refers to their consultant role in 'Demenzfründlich Gemeng'. It seems that after 10 years, this idea of 'Demenzfreundliche Gesellschaft' is still in an embryonal state. We also understood that there is still a debate ongoing about whether or not to include people with dementia in the ClubActiv gatherings.

Reflections

Might the taboo also cause the lack of research on dementia? We understood that when research is done on the topic, it is mostly because individual researchers are interested and try to find resources

²⁹ [Kennisclips - Richtlijnen \(preventie van\) afzondering en fixatie - Steunpunt Welzijn Volksgezondheid & Gezin](#)

to be able to do so. It was also mentioned that the creation of the Luxembourg Centre for Systems Biomedicine (with prof. Heneka), could lead to research and advise towards doctors with regard to medical topics, which will be important when considering the developments with regard to medication (see § 4.6.). Psycho-social research into the importance of person-centred care and related topics seems to be marginal. When a society is serious about breaking the taboo and putting people at the centre, research into these topics is nevertheless paramount.

The Flemish CED developed a knowledge agenda, based on signals from people in the field of dementia care, persons with dementia and family caregivers. We then translate this into possible research topics which universities can address. This nourishes the debates as well as mutual cooperation and strengthening of research, practice and policy-making.

In Flanders we have learned that for dementia-friendly societies it's very important to think clearly about a long-term strategy from the beginning. How can you integrate dementia-friendly policy into various local policy areas? If you don't do this, as a city or municipality you risk creating isolated islands. Moreover, a strong dementia-friendly policy doesn't just consider people who are in the early stages of dementia. It's a policy that also allows people in later stages to continue participating and remain part of society. A priority is that people with dementia themselves can help shape how their municipality or city looks. Moreover, focus shouldn't lie with the condition, but with the capabilities that people with dementia have. And that's why we see it as a movement, rather than a label. Collaboration between people with dementia, their caregivers, local government, care organisations, and the local elderly council are crucial for the success of dementia-friendly initiatives. But one should also consider a broader group of partners there, because what is done for people with dementia can also be very valuable for other people in vulnerable situations.

3.4. Link with other national plans in Luxembourg

We were asked to not only look at the 2013 dementia plan, but to also make reference to other plans and developments that may have influenced or enhanced the implementation of the dementia plan. Without wishing to be exhaustive, we refer to action plans that are related to the measures that were foreseen in the dementia plan. In any case, it is always important to link to action plans in other domains, not only to avoid unnecessary overlap, but certainly also to enhance cooperation and cross-fertilisation (see also § 4.1.).

Prevention is mostly addressed through the creation of PDP and activities such as ClubActiv. Two other policy plans have been mentioned that focus on the use of alcohol and cardio-vascular diseases. The first axis of the 'PALMA plan' focuses on promoting healthy behaviour and includes an Interministerial working group to implement and follow-up the actions of the plan.³⁰ The plan on cardio-neuro-vascular diseases 2023-2027 includes an axis on prevention and avoidance of risk factors.³¹ The GIMB programme on the importance of movement was also mentioned as important for the prevention field.³² Some respondents think there is no use in developing a separate prevention approach for every condition. In Flanders, we have learned that a central theme that

³⁰ <https://sante.public.lu/fr/espace-professionnel/plans-nationaux/plan-palma.html>

³¹ <https://sante.public.lu/fr/publications/p/plan-national-cardio-neuro-vasculaires.html>

³² [Gesond iessen - Méi bewegen - Luxembourg](#)

spans various domains can strengthen your message and we therefore opted for “what is good for your heart is good for your brain” (see § 4.7.).

A mental health plan has been developed, in the wake of the national suicide prevention plan³³, with the aim of encompassing “mental health in all policies” (p.3).³⁴ The plan has a chapter on prevention and ensuring a good health. The starting-point is a bio-psycho-social model which states that health and well-being are influenced by multiple factors, including the social reaction towards the condition. Elderly people are considered as a vulnerable group. We would argue that people with dementia are even more vulnerable, considering the fact that the condition can lead to (further) isolation and loneliness. This nevertheless does not entail that dementia as such is a mental illness, as was commonly said in earlier days.

When it comes to the rights of the person, the reform of the civil code is important. Activities in this regard tend to be heavily influenced by article 12 of the United Nations Convention on the rights of persons with disabilities (CRPD), which need to be transposed into national laws. The debate on legal competence comes to the fore: how can a person be supported to be able to make as many decisions as possible? How and when do they need support to do so? The aim of the national action plan 2019-2024 was to move towards an inclusive society and ensuring that every person’s rights are protected.³⁵ This fits well with the aims described when it comes to people with dementia: moving towards an inclusive, dementia-friendly society and guaranteeing the protection of the person with dementia as well as enabling them to exercise their rights.

As far as we know, there is no ‘caregivers plan’, as it exists in Flanders. The plan is focused on the recognition, acknowledgement and support of carers, be it in society, the care sector, working-field or education. With this plan, the Flemish government wants to sensitise society and make informal carers more visible. We understood that the recognition of the statute of the carer under the ‘assurance-dépendance’ has led to positive changes in practice in Luxembourg, because carers are more seen. Developing a carer plan, or at least giving a full-fledged consideration in a dementia plan, can further strengthen the recognition of the important role informal carers play in supporting the person with dementia (see § 4.2.).

We understood that the PAN bien vieillir, currently under development, will include elements on prevention, loneliness, participation in society and the importance of educating carers. This will be an important addition to the plans mentioned above. Dementia could be a point of attention in that plan, since the condition heightens the vulnerability of elderly. Nevertheless, as we will argue in chapter 4, as long as dementia is still unrecognised in society, it deserves a separate policy plan.

3.5. Overall reflections on the implementation of the 2013 dementia plan

The original set up of the working groups as well as the 2013 dementia plan were concentrated on two main areas: the improvement of the quality of life of patients and informal caregivers, and taking

³³ <https://sante.public.lu/fr/espace-professionnel/plans-nationaux/plan-prevention-suicide-2015-2019.html>

³⁴ [Plan National Santé Mentale Luxembourg \(PNSM 2024-2028\) - Portail Santé - Luxembourg \(public.lu\)](#)

³⁵ [Plan d'action national de mise en oeuvre de la Convention relative aux droits des personnes handicapées 2019-2024 - Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil - Le gouvernement luxembourgeois](#)

action on the social challenge of dementia. These axes are still valid today, also internationally (as will be described in the next chapter of this report).

3.5.1. Continuity of care

When it comes to prevention, Luxembourg was innovative to have already included the topic in their 2013 dementia plan. Since there is no cure yet for dementia, prevention remains crucial. Extending the PDP programme beyond Parkinson and focusing more on primary prevention will broaden the scope, as is needed (see § 4.7.). Furthermore, the link should be made between a dementia plan and more general prevention policies, since risk factors are important for the whole population and initiatives could reinforce one another's messages (Salemme et al., 2024).

Active ageing is promoted through e.g. the ClubActiv, but there is still debate on the extent to which people with dementia can participate in these activities. Practices therein vary, depending on the locality, coordination and other elements. We noted that people with dementia generally remain "out of the picture": there seems to be no tradition of including them in debates or policy-making, although they are often keen to do so, given adequate support (e.g. in Flanders and other European countries this is the case).³⁶

The freedom of choice which is considered to be this important in Luxembourg, impedes a more standardised approach to timely diagnosis since doctors can use the instrument they want and there seems to be no substantiate coordination (see § 3.3.1.). This was however already mentioned in 2013 to be a crucial element. Not much progress has been made. Maybe the evolutions with regard to possible medication can lead to an acceleration of willingness of doctors to cooperate towards a general approach. But, a care diagnosis entails more than 'just' giving medication. It also should encompass effects on daily activities and discussions about advanced care planning.

The recognition of the statute of 'aidant' under the 'assurance-dépendance' has led to an improvement in practice since carers can get some financial compensation. Be it that especially when it comes to young-onset dementia, when both the person and their carer are often still working, this will surely not suffice. Maybe more importantly, we got the impression that this recognition has helped to break down the taboo of the condition and has risen the respect for the carer's situation.

Some measures have been taken to support family members, such as 'repit', 'garde de nuit' and 'Nuetswaach', but family has not been questioned whether these measures answer their needs. It struck us that, in general, almost no research has been done on the topic of dementia in Luxembourg, especially not psycho-social research. More specifically, it was already mentioned in the 2013 plan that the families' needs for relief would be evaluated, but this has not been done. How can one, on the one hand, support families, if you do not ask them what would help them? On the other hand, psychoeducation exists but seems to be underused. Since we know that this can be of great



³⁶ [European Working Group of People with Dementia | Alzheimer Europe](#)

help for carers and can enable persons to live longer at home (see § 4.2.), it would be good to examine why carers do not seem to find the way to this offer, and what communication needs to be enhanced in this regard.

3.5.2. Mobilisation for a societal challenge

Participants in the working groups in the run-up to the dementia plan were already very aware of the importance of including people with dementia within society. With ageing populations, more people will live with dementia and thus the societal challenge will only increase. The 2013 plan focused on the rights and protection of people with the condition, as well as social denial of illness. A judicial reform is underway which will address the topics of legal competence of the person with dementia, striking a good balance between protecting and helping them. Lessons can be drawn from the convention on the rights of persons with disabilities.³⁷ Both from international research and policy, the argument is being made to use these frameworks as a starting point to build a human rights approach for persons with dementia and dementia care (Dixon et al., 2020; Panagiotidou et al., 2024). In the first place, persons with dementia want to be seen as 'normal' people and they should be treated as such, not only when it comes to exercising their rights but surely also as being seen as 'full' members of society. Although the creation of IZD was an important advancement in this regard, dementia remains a societal taboo that should be addressed (see § 4.4.).

3.5.3. Overall evaluation

When looking at the 2 main axes of the dementia plan, we can conclude that although efforts have been made to improve practice and legislation, there is still a lot to be done to face the challenges of dementia in an ageing population. In order to do so, having a specific dementia plan proves to be a necessary tool to avoid that this vulnerable group dissipates in general policies, as is pointed out in international advice on developing dementia plans (see § 4.1.). Especially when the taboo is still existent in society, a specific policy on dementia shows that policy-makers are serious about addressing the topic.

The 2013 dementia plan was mostly elaborated in cooperation between the ministry of family and the ministry of health. Dementia is, however, a complex phenomenon that effects various life domains of people involved. We therefore believe Luxembourg should look beyond the ministries of family and health to include areas such as education, work, transport and research. People with dementia, their carers and professionals need an integrated approach to the challenges they are faced with.

In Flanders, we are faced with a multi-layered government and many ministries having responsibilities that relate to dementia. For instance, dementia care is mostly the responsibility of the Flemish ministry of welfare, while allowing family caregivers to build a temporary care unit in their garden is the responsibility of the ministry of environment. Or, while dementia care is a Flemish responsibility, establishing a dementia friendly hospital care is the responsibility of the Belgian government. In our experience, many opportunities are missed if different parts of (different levels of) government have no strategic alignment on issues, and a lot of energy can be wasted. An overarching, common dementia plan with Interministerial Committees and cooperation between these different domains of authority is crucial, as is also shown in international policy-making, which is the subject of § 4.1. Chapter 4 offers international evidence for the points of attention risen in the current chapter.

³⁷ <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>

4. International developments in dementia care and their relevance for Grand Duchy of Luxembourg



(Photo: Leo de Bock)

In this chapter, we describe a number of key international developments in research, practice and policy making on dementia care and explore the possible relevance of these for the Grand Duchy of Luxembourg. This refers to the third part of our mission (see § 1.1.): to take into account the current state of scientific knowledge, public health priorities and the framework of the global public health action plan against dementia 2017-2025, in order to identify critical points and guide national priorities.

4.1. Dementia policy plans internationally

Other governments and international policy actors have also published dementia policy plans. The global action plan (GAP) on the public health response to dementia was published by the WHO to cover the period 2017-2025.³⁸ This GAP includes 7 themes:

- Dementia as a public health priority, including monitoring legal safeguards and the importance of foreseeing financial resources;
- Dementia awareness and friendliness in society through awareness campaigns and dementia friendly initiatives;

³⁸ [Global action plan on the public health response to dementia 2017 - 2025](#)

- Dementia risk reduction;
- Dementia diagnosis and support, providing for a continuity of care (care pathways) and person-centred approach;
- Support for dementia carers, foreseeing support and training programmes;
- Information systems, such as registers;
- And dementia research.

The WHO is currently working on an evaluation through the Dementia Global Observatory. Preliminary results show that the targets as set in 2017 are not attended. Discussions within the Executive Board and with the Member States in 2025 will prove whether Member States want to continue the GAP and the actions foreseen. ADI therefore “calls upon WHO member states to recognise the imperative for sustained efforts to address dementia effectively and vote unanimously to extend the Global action plan by 10 years until 2035” (Alzheimer's Disease International, 2024).

The WHO European framework for action on mental health 2021-2025³⁹ advises the following when it comes to mental health for older adults (WHO, 2022):

- Integrate mental health in programmes promoting healthy ageing in order to tackle isolation and loneliness in older people and to prevent development of mental health conditions such as depression.
- Support development of national dementia plans for expanding early diagnosis, treatment and care for older people with dementia.

The WHO guide (WHO, 2018) states that “A comprehensive, multisectoral public policy response aimed at addressing the needs of people with dementia, their carers and families is needed to improve quality of life, enhance equitable access to services and reduce stigma and social isolation.” (p.4) Since people with dementia have complex needs, the solutions span various policy domains. Addressing people’s needs requires cooperation between various government actors as well as relevant stakeholders. A dementia plan signals the importance a government attaches to the topic and ensures a good use of resources. The WHO guide explains: “the main components of a dementia plan act to raise public awareness and create mutual understanding about dementia, address population needs, reduce the burden of dementia, and protect the human rights of people with dementia, their carers and families”, topics that had been raised in the 2013 Luxembourg plan.

A stand-alone plan has the advantage of emphasising dementia as a key priority for the government. Coordination with other plans, such as regarding mental health, ageing, carers, is then crucial. Dementia may be included in other plans, such as on mental health or non-communicable diseases, but this runs the risk of fragmentation and lack of dedicated resources. As long as dementia is not known or misunderstood in society, a separate dementia plan is of preference.

When developing a plan, it is important to listen to various stakeholders, not in the least people with dementia (“nothing about us, without us”). Alzheimer’s Disease International therefore (still to this day) “advocates for standalone national dementia plans encompassing all seven action areas of the Global action plan as the most robust way to manage the many challenges dementia poses to healthcare systems, governments and the people directly impacted by the condition” (Alzheimer's Disease International, 2024).

³⁹ [WHO European framework for action on mental health 2021–2025](#)

Various countries have a dementia plan. We have scanned some recent plans and overviews⁴⁰ and have distinguished tendencies and points of attention for a national plan. We integrated this with the WHO's global dementia strategy and Luxembourg's dementia plan considerations:

- Foresee a dedicated dementia plan: a 5-10 year strategic framework; give it a public health priority status; ensure cross-sectoral collaboration; actionable, measurable goals; long-term perspective on dementia management; and a coordinator to coach (the implementation of) the dementia plan (independent from Ministries) (see for example the Dutch dementia strategy);⁴¹
- Multi-ministerial cooperation: align with WHO's holistic approach; coordinate across health, social services, research, and policy sectors; and ensure a comprehensive, integrated dementia response, by ensuring a designated ministry takes the lead in the follow-up of the plan;
- An epidemiological foundation: develop robust dementia registers; conduct comprehensive prevalence studies; use WHO guidelines for data collection and analysis; and create a baseline for strategic planning;
- Foresee a timely diagnosis pathway: implement WHO-recommended screening protocols; train healthcare professionals in timely detection; develop clear referral and support systems; and emphasise early intervention strategies;
- Public awareness and risk reduction: integrate WHO's prevention recommendations⁴²; design targeted public health campaigns; connect with existing health promotion programs;
- Policy inclusion: involve people with dementia in policy development; create participatory mechanisms; and reflect WHO's person-centred care philosophy;
- Caregiver support: develop comprehensive support systems; provide training, respite care, psychological support; and align with WHO recommendations on caregiver assistance.

Recent unpublished research by WHO strongly indicated that dementia-specific policy plans have a stronger effect and guarantee implementation. And as ADI states (Alzheimer's Disease International, 2024): "One of the most important reasons for countries to have long-term national dementia plans is that once a plan and a budget have been set for a reasonable number of years (at least five), the plan becomes impervious to political change. This means that people living with dementia and their families are less likely to see their access to services, treatment and support start, change, or disappear with the fluctuation of political tides." This proved to be the case in Luxembourg, where the plan of 2013 was somewhat put aside after a change of government, even though – as was shown in chapter 3 – actions have been implemented. Of course, links can be made with more general ageing plans, as was done in Malta.⁴³

Given the rather limited effect of the 2013 policy plan, it is recommended that the plan is given more 'power' and updated more regularly, as dementia and dementia care comprise an active sector in which a lot happens globally. Also, whatever logical structure is used for the body of the text, it is necessary to conclude with a top-10 of foreseen actions and prioritise them (recommendations in this regard are found in chapter 5), where needed with an adequate budget. The current plan of 2013 lists 21 actions but does not include a ranking of what is important and what is secondary, nor

⁴⁰ [National Dementia Strategies | Alzheimer Europe](#)

⁴¹ [National Dementia Strategy 2021-2030 | Publication | Government.nl](#)

⁴² [Risk reduction of cognitive decline and dementia: WHO guidelines](#)

⁴³ [Malta launches its new dementia strategy for 2024-2031 | Alzheimer Europe](#)

any budget estimations. The WHO guide can be of inspiration to design the various steps and include different actors throughout the process.⁴⁴

4.2. Ageing in place & supporting family caregivers

Moving to a nursing home is a decision that people with dementia and their family caregivers only make as a last resort. They often do not realise how much quality of life they can gain from such a move, they think about the costs involved, about the nursing home only being one step away from end of life. There is also a societal 'push' towards ageing in place, towards living at home as long as possible.

There are a small number of factors that facilitate or impede ageing in place for persons with dementia. Those involve sleep disturbances (mixing up day and night activities), dealing with incontinence and the resilience of the family caregivers involved.

For sleep disturbances, research is available and colleagues at the university of Leuven have translated this into a guideline and instrument (Spruytte et al., 2018; Van Vracem et al., 2016). For dealing with incontinence of community-dwelling persons with dementia, mostly by family caregivers, there is some international research (Cole et al., 2019; Cole et al., 2022) and in participation with the Belgian foundation on Alzheimer research (<https://stopalzheimer.be/fr/>), we have just committed Flemish researchers to translate that into a guideline and instruments for family caregivers specifically in Flanders. Results are expected by late summer 2025.

On the resilience of family caregivers, there is a whole library of research available. However, especially the work of Mary Mittelman is useful as she for over thirty years studied instruments to increase the resilience of family caregivers (Mittelman, 2013; Mittelman et al., 1996; Mittelman et al., 1993; Mittelman et al., 2021). This long period of research enabled her to calculate that supporting family caregivers through psychoeducation enabled the person with dementia to live up to 1.5 year longer at home, with quality of life!

Mittelman and her colleagues calculated what it would save the state of Minnesota (population almost 5 million) if they offered the support programme for family carers on a large scale (Foldes et al., 2017 ; Long et al., 2014): \$996 million in direct care costs (medical care, residential care) spread over 15 years. Luxembourg has a population about 10 times smaller than Minnesota, but saving \$99 million (and a lot more in terms of quality of life), should sound like an opportunity.

In Flanders, we were inspired by the work of Mittelman and used her work as inspiration to develop our own psychoeducation.⁴⁵ It consists of a series of ten meetings of two hours for about ten family caregivers, always the same participants. In that way, there is not only room for information but also for sharing emotions, as a context of trust is generated in the first sessions. We developed the train-the-trainer, the manual and presentation materials for the trainers and the manual for the participants. This psychoeducation is then organised by e.g. hospitals and health insurance organisations. This intervention has also been exported to The Netherlands, including a 'cultural' translation.

⁴⁴ See also [Resources \(globaldementia.org\)](https://globaldementia.org) for various national dementia plans.

⁴⁵ <https://dementieennu.info/>

There are other interventions that strengthen the resilience of family caregivers of dementia. In addition to the above, we refer to iSupport, an intervention developed and maintained by the WHO, made available in several countries/languages (Corrêa et al., 2024; Pot et al., 2019). Similarly, there is the intervention 'partner in balans'⁴⁶ from the Alzheimer Centrum Limburg, University of Maastricht. This has and is also being translated for different countries (Boots et al., 2016; Christie et al., 2020; Scheibl et al., 2024).



These interventions have been evaluated and updated where needed. However, this has been done for intervention A or B or C or ... We have communicated recently with the authors of these interventions: there is no comparative evaluation available that suggests organisation X or country Y should best choose intervention A or B or C or ... That is a weakness of evaluation research focusing solely on one intervention.

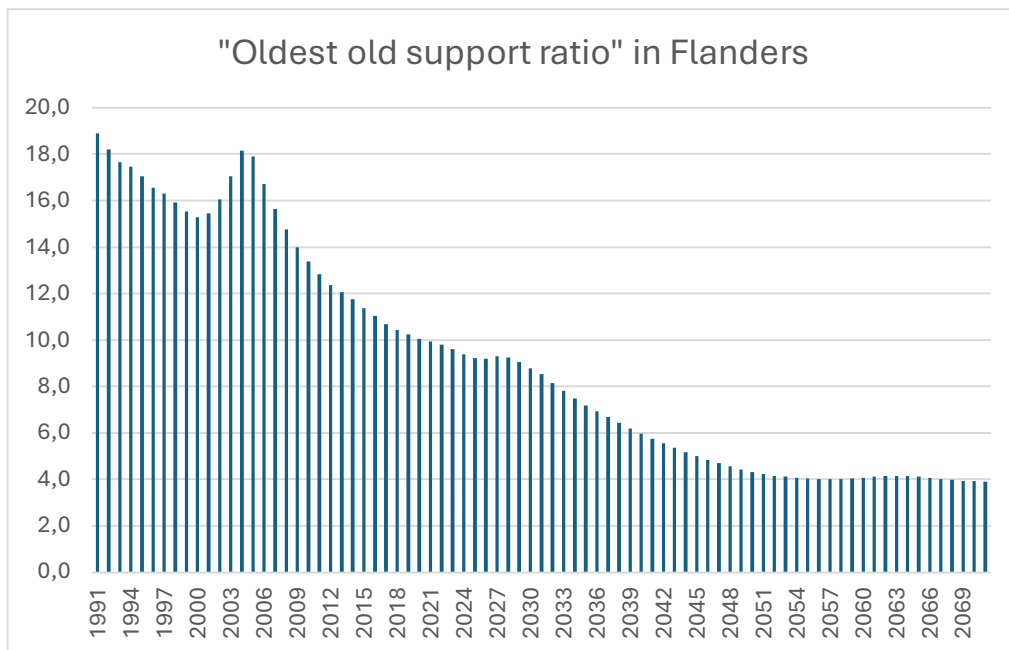
Of course, beyond interventions to strengthen the resilience of family caregivers, demographic evolutions are important as well. These cast doubt on a possible increase of family caregiving. Apart from higher life expectancy and consequently an ageing population, the second major demographic development is a decrease of children per woman. As a result, between 1950 and 2100, family structures became and will become more 'horizontal' and less vertical: "Overall, we project that the number of living kin for individuals will decline dramatically worldwide" (Alburez-Gutierrez et al., 2023). Recent Dutch research hints this development could even increase (more couples having no children) as a result of societal pessimism, concerns about climate change, geopolitical instability, ... (Ivanova et al., 2024).

To project the potential reservoir of family caregivers in future, the 'oldest old support ratio' was developed (Herrmann et al., 2010). The premise is that mostly 50- to 74-year-olds care for those over 85. Those who are younger are too busy with caring for their own children and work. Those who are older have more demand for informal care than supply. No distinction is made here between men and women, although it is known that the principle of "the new man" is slow to translate into informal care.

In The Netherlands, researchers applied that oldest old support ratio. Conclusion: "The demographic potential for informal care will decline rapidly after 2020" (Kooiker et al., 2018). For Belgium, we

⁴⁶ <https://www.partnerinbalans.nl/>

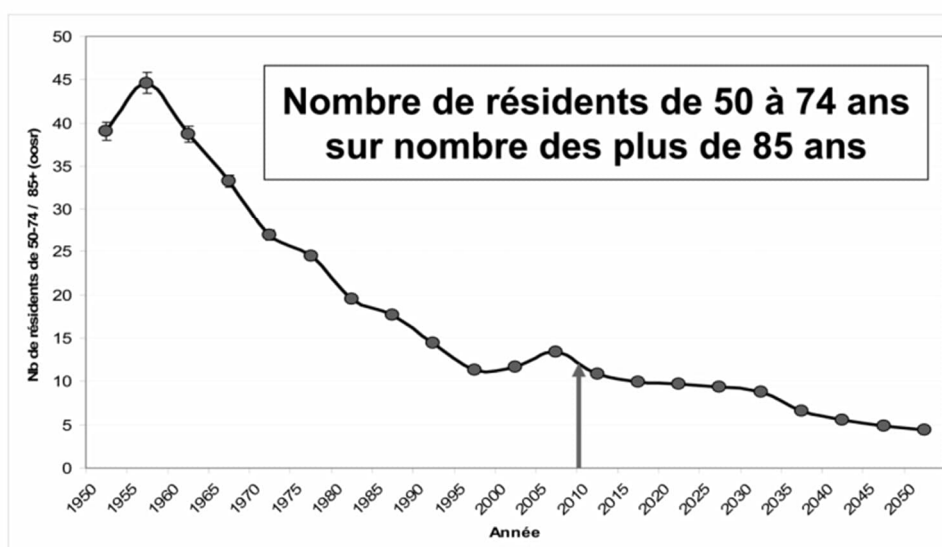
made the same analysis for the coming decades (Steyaert et al., 2020). Looking at the Federal Planning Bureau's population projections, the trend on potential reservoir of family caregiving is also sharply downward. In 1991, there were about nineteen potential informal caregivers 'available' for every person over 85. By 2020, that will have halved. Toward 2070, this reduces further to four people for every 85-plus.



Source: (Steyaert et al., 2020)

In France, the same demographic development is foreseen:

Le taux de soutien aux très âgés en France



Source: (Michel et al., 2010)

It should not be too difficult to do this exercise for Luxembourg as well, if population projections for the coming decades are available by age. However, interpreting the graph that would result from this may be harder. In one of our interviews, it was mentioned that the expectation is that the population in Luxembourg would grow towards one million inhabitants as a result of more (young) foreigners entering the labour market and becoming residents. That development might result in a population structure that is less heavy at the top, compared with other Western countries. But it should be noted that those entering Luxembourg will most likely have no family ties with the oldest population, making 'family' caregiving less likely. They may still engage in other types of informal caregiving (e.g. caring communities), but those are a less powerful resource than family caregiving.

4.3. Small-scale long-term care settings

The situation of lack of extra capacity in residential care, reluctance to move and a growth of the number of elderly persons results in the need for more innovative forms of living at old age, scenarios between staying in your own home and nursing homes (Brouwers et al., 2023; Verbeek et al., 2022). Most known in Flanders are the assisted living flats, often linked to a local service centre (serving lunch, organising activities), which are similar to the 'Résidence Seniors' of Servior which we visited in May 2024, and probably other service providers in Luxembourg.

On the forefront of the rather classical nursing home, there is a strong development towards small-scale normalised living, units of about 8 residents. Shopping and meal-preparation is done with the residents, they wake up and go to bed at their own rhythm, ... Dutch research confirmed this normalised living supports quality of life and the small-scale size helped to make normalised living achievable (Verbeek, 2011).

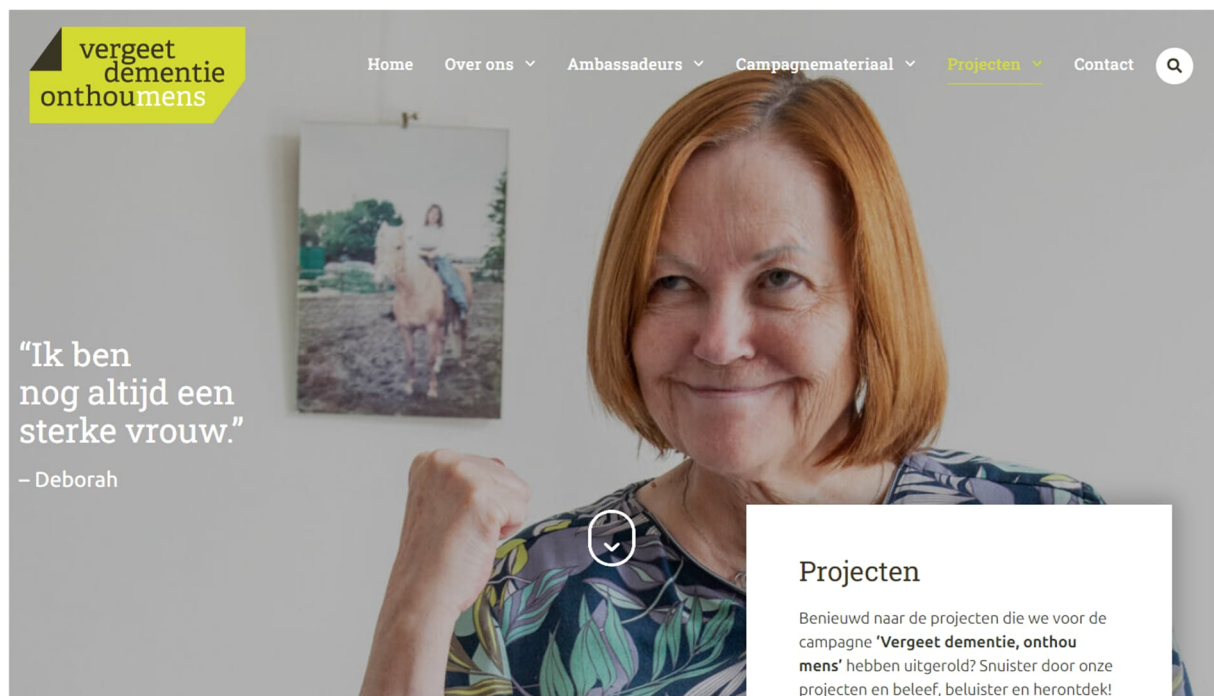
But the upcoming 'boomer' generation has still other expectations about their living conditions at later age. Those alternative scenarios could involve intergenerational or intra-generational co-housing, or 'green care', if possible outside nursing homes, if needed within them (Brouwers et al., 2023). Each of these scenarios focuses on small-scale living, a homelike environment and support of the autonomy. However, despite available research and innovative best-practices, no 'magic bullet' has yet been found. Small initiatives are successful but demand lots of budget and a group of active citizens, which makes them not suitable for large implementation, on a level the ageing population needs.

4.4. A more nuanced perception of dementia

The British journalist Nicci Gerard (better known as the female part of the thriller author Nicci French) wrote a book about her father having dementia (Gerrard, 2019). As a journalist (The Guardian) she is well-aware of the power of words. In an interview with us in 2021, she said media too often "are adding insult to injury" because they use words and pictures downgrading persons with dementia, as if a diagnosis immediately implies total loss of memory and control, and time of death is near.

Baldwin van Gorp, professor of journalism at the university of Leuven, analysed the 'frames' news media use(d) to communicate about dementia. Frames are not only constructed by the words being used, but also by the titles, the photographs, ... More importantly, he also constructed 'counterframes' which express a more nuanced image of dementia (Van Gorp & Vercruysse, 2012;

van Gorp, Vercruysse, et al., 2012). In Flanders, our work towards regular news media was substantially influenced by this research. We used the counterframes to produce photographs, video testimonies and cartoons. We have worked for several years at developing and updating a website with testimonials, photographs and sensibilisation materials for offering the general public a more nuanced view on dementia. At the same time, this is a useful tool for journalists and professionals as they can download (for free) pictures and posters to use in their communications: *Vergeet dementie, onthou mens*.⁴⁷



Besides media campaigns, television programmes have an impact on the societal debate as well. In Flanders, 'Restaurant Misverstand' (restaurant misunderstanding) has run for three seasons: people with young dementia work together with a well-known chef in a pop-up restaurant, with the aim of showing how life continues after the diagnosis and that people can still have a qualitative life. A colleague of the Flemish CED was involved in guiding and supporting the people with dementia throughout the process and ensuring that the programme offered a nuanced view. Such a TV programme brings the condition into the living room of the public at large and offers a low-threshold manner for opening talks. The programme received an Emmy award, which again drew a lot of (positive) media attention. We also cooperated with the producers of the well-known television soap 'Thuis' (home) so that when a character in the series was diagnosed with dementia, she and the challenges for her and her family caregivers were portrayed in a nuanced manner. Key messages about dementia and dementia care can thus also be embedded in fiction-media.

In 2024, the Flemish government subsidised a series of film screenings throughout Flanders of the movie 'Human forever'. This movie was produced by a young Dutch man, Teun Toebes, who lived in a care institution with people with dementia for three years and then travelled throughout the world to film various care institutions. The movie offers a very nuanced and hopeful picture of (living with)

⁴⁷ <https://onthoumens.be/>

the disease. Our government considered the movie screening and a debate afterwards guided by the CED to be a good tool to help instigate the public debate in a nuanced manner and to offer professionals a view on person-centred care. We organised 9 sessions in movie-theatres throughout Flanders, to which professionals from (home-)care institutions, organisations for informal caregivers, local politicians, schools and others were invited. In total, 1.790 people attended these sessions, they received information about dementia and the activities of the (regional) CED. Recently, the movie was broadcasted on Flemish television and on ARTE.



ARTE

with
English
subtitles

We have to admit that in regular Luxembourgish news media, there was, for what we have seen between July and end of November, little news about dementia or dementia care, even though the initial refusal and later acceptance of lecanemab to the EU market (apart from a small article in L'essentiel mid-November) and the publication of the 3rd report from The Lancet commission on prevention gave plenty of opportunity to address the issue.

Our searches in Luxembourg newspaper archives yielded few results from the past years. Some of the news item we found were negative, others nuanced, but mostly, we noticed the absence of news. In Flanders, The Netherlands, UK (the news we follow daily), there is abundant information on dementia. Some is serious (such as The Guardian or the few quality newspapers), others are hyped and focuses on drama (person with dementia abused ...) or spectacular 'breakthrough news' (new drug found ...). Media are amplifiers for messages and public perception of issues like dementia. But media can also be supported and coached to avoid hyped news and contribute to nuanced public perception about dementia.

Our work at the Flemish CED teaches us that it takes a while (1) before people in the field know who you are and (2) before the word gets out what dementia is. Information-raising activities need a continuous effort in order for projects to be established and sustainable. Organisations such as Info-Zenter Demenz that can compile good practices, bring together various actors in the field and stimulate cooperation and innovation proves to be crucial.

4.5. Advance care planning

Dementia is in the short term not life-threatening, the average life expectancy after diagnosis is about 8 years, although with great variety (Brodaty et al., 2012). But dementia does shorten lives and people with dementia will die with dementia, not necessarily from dementia (Vandormael et al., 2018). In several Western countries laws are in place to allow citizens to look forward and express their preferences and wishes for their end of life. For Luxembourg, this is « Loi du 16 mars 2009 relative aux soins palliatifs, à la directive anticipée et à l'accompagnement en fin de vie » and « Loi du 24 juillet 2014 relative aux droits et obligations du patient ».

Thinking about end of life and writing down wishes in advance directives can be a very bureaucratic process, with little communication. That was however never the aims of advance directives, they were to be the end result of open and regular communication between patient, doctor(s) and family, especially in a care-oriented relational approach (Gastmans et al., 2022). This process is referred to as 'advance care planning' and includes thinking about tomorrow's care (Opgenhaffen et al., 2022). In this way, you can discuss what is important to you, your wishes and what you want to be taken into account. Especially at times when you are reflecting on your future such as in the case of a diagnosis of dementia or the death of a loved one, starting this process can be helpful, and the initiative could equally come from the general practitioner as from the patient (Piers et al., 2018).

In advance care planning, it is important not to wait too long. Admission to a nursing home often goes hand in hand with an already serious loss of communication. And while starting advance care planning a couple of weeks after admission (to allow the resident to settle in the new accommodation first) is good practice, a lot of time has already been lost.

Ideally, the GP should give his patients ample opportunity to open the conversation about end of life, without needing a serious reason to do so and without obliging the patient to actually enter into that conversation (at that time, or later). This however calls for GPs to take the time for such talks with their patients, which is difficult in countries like Belgium and Luxembourg where reimbursement is not foreseen, and these talks do not fit in a regular 10' time slot for a consultation. Society is not encouraging doctors to engage in advance care planning.

Neither is society encouraging patients/citizens to think and talk about end of life. There is a taboo on open talks about this subject. In The Netherlands, as an example, 80% do not talk about this, despite e.g. the national newspaper weekly running a column from or on a person near death (van Es, 2013) or a popular football-journalist openly publishing columns about his own end of life (de Lange, 2015). Consequently, the Netherlands is one of a few countries which actually organises campaigns to stimulate open communication about end-of-life. They e.g. have the 'day of the care of tomorrow' on the 30th of October where citizens are invited to talk with family, friends and colleagues about growing older and needing care. The slogan is "talk today about tomorrow".⁴⁸

In Flanders, we have a smaller campaign called 'doodgewoon' ('deadly normal'), organised by our colleagues of Palliative Care Flanders. Other initiatives also support talking about end of life, such as the recently published photo-book that portrays thirteen persons just before and after their death (Rutten et al., 2024). University of Brussels set up a website, in cooperation with people with dementia, so they themselves can, throughout their dementia process, look at various steps and

⁴⁸ <https://praatvandaagovermorgen.nl/>

topics and discuss it with their carers. It could also be a tool for home care professionals to address the topic.⁴⁹



The combination of dementia and end-of-life care composes a double taboo. If we want citizens/patients to engage in advance care planning, we need such campaigns, and we need 'outreaching' doctors, be it general practitioners or specialists.

4.6. Disease modifying treatments

At the time of writing, there is no pharmaceutical cure available that cures or even slows down dementia. Over the past years, several products have however been launched which hint at scientific progress. In 2019 Biogen introduced aducanumab (brought to market as Aduhelm) and received permission from the US Food and Drug Administration (FDA) in summer 2021. In summer 2022, Biogen introduced lecanemab (brought to market as Leqembi), which it developed together with the Japanese company Eisai.

In January 2023, authorization for Leqembi was given by FDA. FDA did however note that all patients should first have to undergo genetic testing for the presence of the ApoEε4 gene, which would increase the risk of brain haemorrhages when using this drug. In addition, regular MRI scans would be necessary to detect risk of brain haemorrhages. These are not pills, but a drug that needs biweekly IV-administration. Eisai is working on a subcutaneous autoinjector for lecanemab, to avoid the costs (and staff involved) of this IV-administration. It also explores another drug, Remternetug, which is administered through simple injection (Mahase, 2024).

⁴⁹ <https://www.vroegtijdigezorgplanningbijdementie.be/>

Leqembi has been approved in Japan, China and Israel. The European Medicines Agency (EMA) in summer 2024 refused admission to the European market because it considered the risk of side-effects too high in relation to the limited beneficial effects. Some weeks later, the Medicines and Healthcare products Regulatory Agency in the UK approved lecanemab, but NICE indicated it would not fund it through NHS (Kmietowicz et al., 2024) which reduces availability to the private health care market. Costs for the drug and the surrounding care are estimated to come around 50.000 € yearly. Australia also refused admission of the drug to their market.

Also, new research results were published just after this decision and were based on a 3-year usage of lecanemab, rather than the initial 18 months. As expected, results in term of slowing down the dementia pathway were better. Moreover, it was shown that the negative side effects mostly occurred in the first six months of usage, suggestion the closely monitoring of patients by regular MRI-scans would only be needed in the period after the start of the medication. Other research suggested that the regular MRI-scans could be reduced to a couple of minutes without risk, reducing the demand for machine and staff time. This is however very preliminary research and for people with dementia, rather more than less time might be needed to go through the process in a not too stressful way.

To illustrate how dynamic these developments are at the moment, mid-November 2024, only some months after refusing admission, the EMA gave authorisation for the marketing of lecanemab under very specific circumstances. Estimations are that it would only be applicable to about 1 out of 10 patients with dementia. It is now up to the EU-member states, including Luxembourg, to organise their own evaluation and assess whether this drug and the surrounding costs would be reimbursed. And yes, that includes an assessment of how many persons potentially might benefit from this drug. So the very recent parliamentary question of Ricardo Marques (Chrëschtlech-Sozial Vollekspartei) on this topic for the minister of health and social security is very relevant.

In May 2023, results were published about another drug, known as donanemab, from the company Eli Lilly. It was approved for use in the United States and Japan in summer 2024. There is no decision yet on this drug in Europe nor the UK.

In early 2024, Biogen also announced that it was discontinuing research and production of aducanumab to give all focus to lecanemab. Mid-October 2024 Roche announced it was discontinuing research on bepranemab, another Alzheimer disease modifying treatment. Its drug gantenerumab already failed trials in 2022. Eisai on the other hand announced they were working on yet another drug, which they hope to make available by 2030. And Roche is working on trontinemab, which they say is designed to get past the blood-brain barrier implying lower doses would be needed (and consequently less adverse risks). Research on this drug are however in early stages.

Hope and disappointment follow each other in a rapid way. Some of these drugs currently come with some effect on slowing down the development of the Alzheimer disease. For the time being, this effect is small and not noticeable to the patient nor the treating doctor(s). Additionally, there are some adverse effects which makes selection and monitoring of patients complicated and expensive. Additionally, health economists warn that given the total costs, given the current (known) pricing and other costs involved, as well the estimation of the gained quality-adjusted life year (QALY), we are far away from an affordable treatment (Jönsson et al., 2023).

While awaiting next generation(s) of these drugs with more effect and less risks for the patients, it should be noted that the necessary care infrastructure to fully make use of these drugs is currently not in place. Several researchers therefore argue we should assess the preparedness of our health care systems for disease-modifying therapies such as lecanemab and donanemab (Belder et al., 2023;

Cooper et al., 2024; Dobson et al., 2024). After the EU-approval of lecanemab, Philips announced it expected the market for MRI-scanners to boom. Producers are preparing for that, are governments as well?

Having said that, medical care has seen many breakthrough innovations over the last decades. We all remember the photo taken at the Yalta conference at the end of the second world war, with Winston Churchill, Franklin D. Roosevelt and Joseph Stalin. President Roosevelt at the time had a high blood pressure of >300/190 mm Hg, to die of a heart attack soon afterwards. Roosevelt thus became “a textbook case of untreated hypertension progressing to target organ failure and death from stroke. In the 1940s, treatment of elevated BP was not deemed appropriate unless malignant or accelerated hypertension was present” (Moser, 2006, p. 16).

So, in summary, progress is being made regarding developing pharmaceutical interventions to slow down dementia, at least for the disease of Alzheimer. But we're unfortunately a long way away from the dream of being able to deal with dementia like we since many years can do for high blood pressure: easy painless diagnosis, cheap drugs with minimal side effects and easy monitoring within the context of a GP-practice, in combination with advice on lifestyle (food, weight, ...).

4.7. Brain-healthy lifestyle

However, over the past decade, substantial epidemiological research has emerged to indicate that developing dementia is not only the result of old age, gender and 'bad luck', but also of brain-healthy lifestyle. The three reports of the dementia commission of The Lancet illustrate and strengthen the consensus about the potential of reducing future dementia by investing now in prevention (Livingston et al., 2024; Livingston et al., 2020; Livingston et al., 2017). The potential risk reduction was initially 30%, became 40% in 2020 and is currently 45%. Any producer of a pharmaceutical drug with that effect, would see their shares skyrocket in the stock market.

Dementia happens in 'slow motion', the damage in the brain cells may take 10, 15 to 20 years before it impacts memory and behaviour. This implies that lifestyle at middle age (40 to 75 years old) has a substantial influence on the risk to develop dementia.

When the third report from The Lancet commission on dementia was published end of July 2024, it made frontpage in the most read Flemish newspapers, on radio and television news. This wasn't spontaneous, but (partly) of the efforts of our CED to continuously work on good contacts with journalists and alerting them when news is about to be published. We might be wrong, but we didn't see this publication being reported on in the Luxembourg news media such as Le Quotidien, Lëtzebuerger Journal or rtl.lu. An organisation with focus on advocacy could have avoided that.

In several countries campaigns have been organised to raise awareness about a brain-healthy lifestyle. The Netherlands works with “wij zijn zelf het medicijn” (“we are the drug ourselves”).⁵⁰ Alzheimer's disease published an infographic on the 12 risk factors that the second Lancet report identified. It is available in several languages.⁵¹ An update covering the 14 factors of the third Lancet report is ready and will be made available soon.

⁵⁰ www.wezijnzelfhetmedicijn.nl

⁵¹ <https://www.alzint.org/resource/dementia-risk-factors-infographic/>



Source: Livingston et al. A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission

www.alzint.org



Source: ADI website

In Flanders we choose to boil down the numerous risk factors into one slogan and our campaign focuses on “twee voor de prijs van één” (two for the price of one), with byline “what is good for the heart, is also good for the brain”.



Source: www.2voordeprijsvan1.be

More can be done on this risk awareness in the general population in Luxembourg by developing and implementing a similar campaign oriented towards the general population.

With all of these campaigns, there are two main challenges, beyond getting the message to as many persons as possible. The first challenge is to avoid 'blaming the victim'. The insights in dementia risk factors are far too young (about 10 years) to point the finger at current patients regarding lifestyle. But more importantly, healthy lifestyle is a social challenge, far more than a personal challenge. Therefore, campaigns should focus on society rather than individuals, use the so-called s-frame, rather than an i-frame (Chater et al., 2023). For example, the Dutch "wij zijn zelf het medicijn" (we are the drug ourselves) was initially working on "you are the drug yourself" (the i-frame), later to shift to the s-frame.

The second challenge is to reach out to high-risk groups, such as persons with low health literacy. If not, public health campaigns risk increasing health inequalities. The strategy to avoid this is called 'proportionate universalism' (Carey et al., 2015). The campaign is universal, for the general public, but in its implementation, it is proportional towards these high-risk groups. For example, in our "twee voor de prijs van één" campaign, we put extra effort in getting it in a popular newspaper rather than a quality newspaper, and getting the campaign in the free monthly magazines our social security organisations sent out to their members.

4.8. Antipsychotics

Although there is currently no disease-modifying treatment, persons with dementia are often prescribed antipsychotics (e.g. haloperidol) to address 'the behavioural and psychological symptoms of dementia' (BPSD) such as aggression and agitation. Although these drugs are regularly used, there is international doubt about their efficacy and adverse effects (such as increased risk of falls and cardiovascular mortality). In fact, the advice is that antipsychotics should only be used for severe situations where non-pharmacological interventions have failed to improve the situation (Tampi et al., 2020). Even in these situations, they should be used for a short-term period only and patients should be monitored for side effects. Prescriptions should have a limited time span, so as to guarantee renewal happens with appropriate assessment of the situation. Special attention is needed when it comes to Lewy Body dementia: here antipsychotics should be contra-indicated because of risk for frequent and severe extrapyramidal disturbances (e.g. inability to sit still, involuntary muscle contractions). In short, with antipsychotics, it is like with corticoids and morphine: very good and useful medication, if you use it properly. Inappropriate use has given it a bad reputation.

Several of our respondents signalled there seems to be a growing use of antipsychotics in Luxembourg, both for patients with dementia and more generally. The prescription culture among doctors has been described to us as being too liberal, with effects both on the quality of life of patients and national budgets. CNS can look up concrete figures to check this issue and if needed corroborate the debate.

Overconsumption of antipsychotics is also an issue in Belgium: "Antipsychotics are often prescribed for problem behaviour in patients with dementia, but given the associated risks of these drugs, non-pharmacological interventions are the recommended first step. Data show that by 2021, 5.5% of the population aged 65 years and older will have received antipsychotic drugs (≥ 1 Defined Daily Dose). Belgium scores close to the average compared to other European countries. The problem seems

especially acute in residential care homes. Among people aged 65 years and older in residential care homes, 27.3% were given antipsychotic drugs administered, compared to only 4.4% among people aged 65 and over, who did not reside in residential care centres. Reducing the overuse of antipsychotics in residential care centres remains an area of work for Belgium. The use of antidepressants was also particularly high in residential care centres. 48.3% of people aged 65 and over in residential care homes were taking antidepressants (≥ 1 Defined Daily Dose), compared with 18.1% in people aged 65 years and older who did not reside in residential care centre." (Gerken et al., 2024, p. 123).

Our respondents in Luxembourg also indicated that apart from antipsychotics, persons with dementia are also increasingly prescribed benzodiazepines (e.g. lorazepam). The medical doctors in our team were surprised and found this very inadequate. This should be checked and if needed corroborate. Recommendations and best practices could be published by the Conseil scientifique du domaine de la santé.

4.9. Young-onset dementia

In several Western countries special attention goes to young-onset dementia, where the first clear signs occur below the age of 65. This is a rather limited group of persons (fortunately) but with special needs. They are often still dependent on income from work (not yet at pension age), might still have a mortgage on their house and/or children in (higher) education. Also, their most likely family caregivers are still participating in the labour market, making informal caregiving less obvious.

In most countries this group is, given the demographic developments, not increasing the next decades as the population below 65 remains rather stable (Hendriks et al., 2023; Hendriks et al., 2021). However, they are a generation with higher education, and they and their family caregivers are more vocal, reaching out to the media and becoming visible. This is the context in which the aforementioned television programme *Restaurant Misverstand* was made in the Netherlands and Flanders (see § 4.4.).

For Luxembourg, we again have to refer to the prevalence estimations of Alzheimer Europa which foresee 591 persons with young-onset dementia in 2025 and 653 in 2050 (Alzheimer Europe, 2020, pp. 60-61). No special care arrangements for this group were mentioned during our interviews. Given this was not the focus of our work, we cannot assess whether more action is needed in this area.

4.10. Commercialisation of dementia care

In Belgium and The Netherlands, a part of 'the market' of dementia care is taken up by commercial actors. This can be big organisations operating a number of nursing homes, such as Vulpia or Emeis (previously known as Orpea). Another scenario for commercialisation of dementia care is individual nurses on the payroll of nursing homes being offered a higher wage (and a car to go with it) to transfer to an interim agency and continue working in the same sector, referred to as project-nurse. Sometimes they start working in the same nursing home they worked in before, but at a cost that is 1.4 times higher. Already, about 7% of all care staff in Flemish nursing homes works in this way. In the Netherlands, the scenario is more often an individual who starts working as a 'zzp' ('zelfstandige zonder personeel' or 'self-employed worker without employees'), but the result is the same.

The political discussion about this development focuses on three issues. Firstly, despite the variety in how and how much, the bottom line is that public money is transferred to private shareholders. Both Flanders and the Netherlands are working on policy measures to cap such transfers. Secondly, these commercial actors tend to focus on the most lucrative segments of 'the market', known in economics as 'cherry picking'. The nurses working as interim for instance are reluctant to work nights or weekend shifts. Thirdly, these commercial initiatives tend to evade the installed mechanisms on quality control.

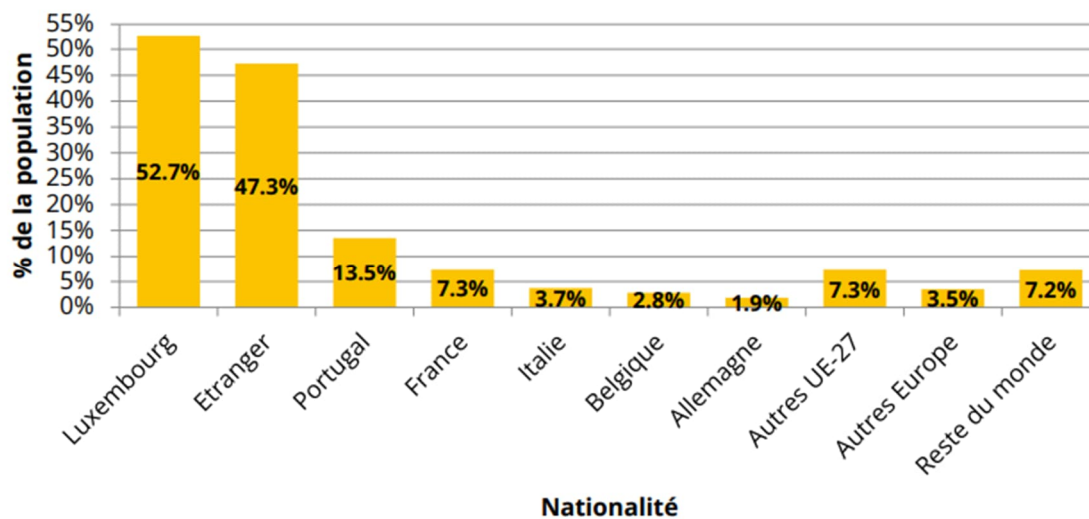
During our interviews, care providers indicated us that this development is also emerging in Luxembourg. Especially in the home care, where less infrastructure is needed, there seems to be a growing number of these commercial actors, focusing on the more populated areas to diminish time and costs lost on mobility, but consequently not offering services in less populated areas. It is clear that this makes the challenge bigger for organisations covering the whole country, also regions with lower population density.

4.11. Towards a society with superdiversity

Another important demographic development on top of the ageing population, is the increase of ethnic minorities. Since the middle of the 20th century, we have in Flanders/Belgium seen waves of immigrant workers (coal mines, steel industry) from Italy and later from Turkey and Morocco. This resulted in a Flanders with diversity. However, over the past decades we have further developed into a region characterised by superdiversity (Geldof, 2016). This was largely a development in cities with e.g. Antwerp being a majority-minority city (more inhabitants with migration background than without). But more recently, the superdiversity is spreading to rural communities (Geldof et al., 2023). More importantly, the diversity (the large contingents with background in Italy, Turkey and Morocco) and the superdiversity are also 'rising' in the population pyramid and consequently in the elderly and the group of persons with dementia. This poses extra challenges in providing good dementia care, such as language and cultural specificities (e.g. regarding food or end-of-life).

We did observe that the diversity of the population in Luxembourg seems to be more 'Western' than in other West-European countries, with most people with a migration background coming from the directly neighbouring countries and Portugal. This may make diversity a less challenging issue, also in elderly/dementia care, although language issues will remain.

GRAPHIQUE 4 : UNE POPULATION DE PLUS EN PLUS COSMOPOLITE



Sources : STATEC, CTIE

Source: (Statec, 2024)

The number of people with dementia who also have a migration background will increase exponentially in the coming decades. The prevalence of dementia among people with a migration background is higher than among their European peers. People with a migration background are 2 to 4 times more likely to develop dementia and also at a somewhat younger age (Parlevliet et al., 2016). This is partly because risk factors for getting dementia are significantly more prevalent among them, such as diabetes, chronic stress, depression, high blood pressure and low literacy.

Nevertheless, the general knowledge of people from migrant backgrounds regarding this condition is extremely low. Forgetfulness and other symptoms that may indicate dementia are more likely to be attributed to old age. Appropriate tailored information for this target group is desirable. Moreover, we see that in different cultures dementia is a taboo subject. This leads to people being ashamed of it, excluded or not seeking appropriate care and support themselves. Making dementia discussable is a must, preferably in the mother tongue.

When dementia is suspected in a person with a migrant background, making a diagnosis is often challenging. Indeed, regular screening tools take little or no account of low literacy, a language barrier and/or cultural differences. Adapted screening is of great importance to make an accurate diagnosis. The MMSE as a screening instrument is less suitable for people with a migration background. More truthful results are achieved with the Cross-Cultural Screening (CCD) from the Netherlands (Goudsmit et al., 2017) or the Rowland Universal Dementia Assessment Scale (RUDAS).

4.12. Labour market shortages

The ageing population is an important demographic development, but the shrinking labour market is equally important. Many ageing societies see their population above the pension age growing, while the population at working age remains stable or even declines. This is currently an important issue in e.g. the Netherlands (Wetenschappelijke Raad voor het Regeringsbeleid, 2021), in Norway and in Belgium (Steyaert, 2023). In Flanders, the population above pension age will increase with 25%

between 2020 and 2040, while the population at working age only increases by 3%. In the French-speaking part of Belgium, this is respectively + 35% and -3%.

This raises the question whether the coming decades the budget will suffice to organise elderly/dementia care, but more importantly whether there will be enough staff. With these demographic developments, that is highly uncertain.

Many solutions have been suggested to solve this 'demographic timebomb' in the labour market such as supporting family caregivers (see § 4.2.), building compassionate communities, reducing bureaucracy, investing in 'warm technology' (Ijsselstein et al., 2020), making work in the care sector more attractive, ... More broadly, measures could include reducing part-time work, raising the pension age, import of staff from outside the EU. But in Norway, The Netherlands and Flanders, where the stress on the (care) labour market is well known, still no master plan is in place to actually tackle the issue. In Flanders, several nursing homes already have to close one or more wards, resulting in longer waiting lists as well as more vulnerable elderly persons having to cope at home.

The Flemish government has two initiatives to promote working in the broad care sector. One is our 'care ambassador' (currently Candice De Windt) and the other initiative is the 'day of care'⁵² where hundreds of care organisations have an open-house and welcome the general public to take a look into their daily work. For over a decade, this 'day of care' is organised annually on a Sunday mid-March and is embedded in a week-long media campaign on radio, newspapers and with a free printed magazine available in every pharmacy.

It remains to be seen what the erosion of Schengen and the announced border controls by Germany and France will have as an effect on cross-border labour. Even without the lack of effective border controls, this can still have an effect. Remember the theorem of Thomas, dating from 1928: "If men define situations as real, they are real in their consequences". American banks in the 1930's may not have been broke, but they went broke because everybody believed they were and demanded the money on their savings accounts back. Likewise, the perceived hassle rather than the real hassle of border controls, can be a disincentive for cross-border commuting.

This growing stress in the (care) labour market might be an issue for Luxembourg as well. It wasn't the central focus of our work, but we heard strong concerns. On an optimistic side, the high GDP and the volume of workers from neighbouring regions in Belgium, Germany and France could make this less of a burning issue, at least for now. On a more pessimistic side, the observation was made by several respondents that the burden of daily traffic and associated expenses currently works as a growing disincentive for staff crossing the border into Luxembourg. Several of our respondents noted they also see the younger generation having another view on 'work-life balance'. On top of that, a high percentage of the current workforce in the care sector is nearing pension age. In one of our interviews, a care provider indicated their organisation is currently not planning to build a new extra nursing home because the likely scenario would be it becomes an empty building due to lack of staff.

We understood that the 'Confédération des organismes prestataires d'aides et de soins' (COPAS) will shortly be publishing a report on the labour market for elderly care, and a round table « Pérennitéit vun der Fleeg ! Genuch Mataarbechter ? » involving several ministries has already taken place early November 2024.⁵³

⁵² www.dagvandezorg.be

⁵³ <https://www.copas.lu/wp-content/uploads/2024/11/Communique-de-presse-Table-ronde-COPAS-du-7-novembre-2024.pdf>

5. Recommendations



(Photo: Leo De Block)

The ageing of Western societies and the stable/shrinking labour market are enormous demographic challenges. In that context, the growing group of persons with dementia deserve the best care a country can organise. Based on our work of the past months, we have the following recommendations to achieve this challenge, in order as we see priorities for Luxembourg:

1. While the growth of life expectancy is a good development, it unfortunately implies age-related illnesses such as dementia becoming more common and a growing challenge for society. A policy plan specifically on dementia gives this challenge more visibility and reflects the sense of urgency that is needed. Our first recommendation is therefore to establish a new policy plan specifically for dementia, specifying what is (or will be) already in place in other policy plans such as the 'plan bien vieillir'. International experience shows that with only more generic policy plans, the topic of dementia gets diluted and real impact is avoided, while dementia is becoming a top-priority tendency in an ageing society. Include a top-10 of foreseen actions and prioritise them, if possible with necessary budget. Four to six years is a good timing for such a plan.
2. We have too little information to assess the issue of inter-government cooperation in Luxembourg, but make the recommendation that any future energy on dementia care goes hand in hand with guaranteeing a strategic alignment of all actors involved. Dementia is a complex phenomenon that effects various life domains of people involved and thus actors should

be found also outside the care sectors. This is yet another reason to have a separate dementia plan, so ministries have a hands-on document to cooperate.

3. The 2013 dementia policy plan seems to be little known within Luxembourg. During our interviews, we noticed it was not ready knowledge for our respondents and it tended to have little result on the daily practice of dementia care. Hence our recommendation to give the next policy plan more publicity and visibility, to make it an active policy plan. Foreseeing a coordinator proves to be a great asset to ensure the plan's liveliness.
4. Following what comes out of international research and using that to improve the quality of dementia care is one thing, involving those directly involved in dementia care in Luxembourg is yet another thing. An often-heard statement in our area of work is "nothing about us, without us". We therefore recommend that Luxembourg organises a working group of persons with dementia and their family caregivers which can act as an advocacy group and express their needs and viewpoints.

Such a working group needs support from professional staff, who not only provides practical help in organising meetings, but can strengthen their voice, act as a megaphone, guarantee independence from care providers. People with dementia should also be included when drawing up a new dementia plan. Of course, there is also a supplementary advisory role for the 'Conseil supérieure des personnes âgées' that was formalised in august 2023.

5. Any policy plan needs the best available data. One important element in relation to dementia, is prevalence figures for now and the coming years/decades. The risk model that Alzheimer Europe published (Alzheimer Europe, 2019) can rather easily be applied to population data, once they are available by gender and age groups. If those can be matched with location, prevalence data can even be made available to cantons or local authorities to support local policy plans.

We recommend that Luxembourg looks into the available demographic data and constructs the best possible trends on future prevalence of dementia (see chapter 2). Without such data, capacity planning for home care and long term care is powerless. Luxembourg should also assess if and how the developments we have described regarding labour market (the 'demographic timebomb') and family caregiving (see chapter 2) are relevant.

6. We recommend Luxembourg looks into guaranteeing the consistency of the quality of medical care for patients with dementia and their family caregivers in the hospitals, given the strong words some of our respondents used (see § 3.3.2.). Additionally, work can be done on becoming dementia friendly hospitals.
7. Luxembourg has done great effort to develop a training manual on quality of care. We recommend to follow-up how training is implemented in practice, looking beyond the certificates of people that followed the training, also investigating the effects on people with dementia. This involves capturing the nuances and complexity of quality elements of dementia care which are hard to quantify (see § 3.2.2. and 3.2.4.).
8. We recommend expanding work on prevention beyond the current efforts focusing on PDP. Every dementia case that is prevented or delayed, is a gain for individuals and society. Work on prevention can be expanded by organising public awareness campaigns for the general population, getting the brain healthy lifestyle in regular (news) media, and building liaisons with all general practitioners and other health care providers (see § 4.7.).

9. We recommend establishing a media strategy to facilitate news related to dementia and dementia care getting in the mainstream Luxembourg (news) media, contributing to a nuanced perception of dementia (see § 4.4.).
10. Given the increase of persons with dementia (consequence of the ageing of society) and the pressure on budgets and labour staff, ageing-in-place will increase. It is important to guarantee quality of care outside long term care, and that is a challenge as there are no professionals 24/7 around. Supporting the family caregivers is quintessential. We gave some examples (see § 4.2.) on how they are supported in other Western countries. We recommend Luxembourg to develop and implement a similar supporting infrastructure for family caregivers in a structured and comprehensive way. Not one psychologist here and a social worker there, as seems to be the current situation, but a coordinated approach throughout the country.
11. We recommend Luxembourg considering a campaign to promote working in the care sector with specific focus on elderly/dementia care. The Flemish 'day of care' may be an inspiration for such a campaign (see chapter 2).
12. We recommend Luxembourg to look into potential over-usage of antipsychotics and develop programmes to bring use in line with international recommendations (see § 4.8.).
13. Given the rapid and exiting development in the area of disease-modifying drugs, Luxembourg should evaluate the preparedness of its health care system for if and when such drugs come to market. The timeline for that is unpredictable, but it will have severe implications, not only in terms of budget, but also the necessary health care infrastructure to screen and monitor patients and administer the drugs. We therefore recommend Luxembourg to assess the preparedness of their health care system for disease-modifying therapies, as well as their budgetary implications (see § 4.6.).
14. We recommend Luxembourg joins international working groups in order to follow up international developments. The international working group of governmental experts on dementia of Alzheimer Europe offers ample of opportunities to learn and exchange about dementia policy-making. The WHO GAP will decide in 2025 how to proceed with dementia policies throughout the world, offering concrete inspiration and examples. On the map of Europe, Luxembourg is the only non-member of Alzheimer's Disease International, another important international hub for information exchange.

Annex 1, staff involved

Jan Steyaert, PhD

Jan Steyaert trained as sociologist and received his PhD in 1995. He then worked as researcher in the Netherlands, working on social policy for the city of Eindhoven, the Dutch ministry of health, welfare and sport and European Commission. Since 2013, he works at the Flemish Centre of Expertise on Dementia, following international research and translating that to Flemish dementia care. Among the topics of special interest are primary prevention, prevalence data, family caregiving and advance care planning. He is also guest professor at the University of Antwerp, faculty of social sciences and member of the Expert Advisory Panel of Alzheimer Europe.

Inge Vanfraechem, PhD

Inge Vanfraechem has a PhD in criminology (KULeuven, 2006). She has worked at the University of Leuven on mediation in criminal cases, managed EU projects on the topic, and has worked for the National Institute of Criminalistics and Criminology (Belgian Ministry of Justice). She has ample experience in managing and coordinating (research) projects, as well as cooperating with various administrations. Since 2022, she works at the Flemish Centre of Expertise on Dementia as coordinator of the Flemish dementia plan.

Jurn Verschraegen

Jurn Verschraegen trained as a nurse and started his work in nursing homes. He has been director of the Flemish Centre of Expertise on Dementia since it was established. He contributed to the three dementia plans of the Flemish Government. Topics of interest: dementia policy, psychoeducation, young onset dementia, small-scale normalized living, quality of living and care, ... He is also a guest lecturer at several colleges.

Joke Pauwelyn, MD

Joke Pauwelyn worked as a general practitioner (KU Leuven 1993) in a group practice in the west of Flanders for over 30 years and currently coordinates the network of reference doctors on dementia (DRA) in Flanders. She is a research assistant and a trainer at Psychofarmaca@Ugent of the Ghent University where she teaches medical students at the Department of Public Health and Primary Care. She is also a participant of BelPep, the Belgian Psychotropics Expert Platform.

Jan de Lepeleire, MD, PhD

Jan de Lepeleire is emeritus professor in the Department of Public Health and Primary Care, Catholic University of Leuven, and worked for 34 years as general practitioner. His PhD (2000) was about the diagnosis of dementia in general practice. He was responsible for the training of coordinating physicians and dementia reference physicians.

Malika El-Jafoufi

Malika El-Jafoufi is a project and training officer at the regional CED in Antwerp. She graduated in family sciences in 2022 with a major in adults and the elderly. She wrote her bachelor's thesis on people from a migration background with dementia. She also graduated in 2022 as one of the first ten informal care coaches, a European project ism Samana. In addition, she followed the training as a dementia reference person (2023) and Diversity reference person (2024). Malika El-Jafoufi also sits on the advisory board of the MEDIMEG project. The project focuses on understanding and promoting culturally sensitive medical decision-making in the Flemish super-diverse society.

Annex 2, Flemish Centre of Expertise on Dementia

All of these persons work for the Flemish Centre of Expertise on Dementia. Our organisation and the 9 regional centres are based on a person-centred care vision with respect for individuals' life stories, needs and preferences. We do this by sharing useful knowledge with people throughout the health and welfare sector: informal caregivers, volunteers, healthcare professionals, researchers and people with dementia. This knowledge is inspired by literature and best practices, preferably using a bottom-up approach.

The Flemish CED is partner organisation of the Flemish government on topics and activities related to dementia, dementia care and dementia prevention. Our main office is located in Antwerp, but we also have nine regional offices, with a total of about forty staff. After some local initiatives emerged near the end of the twentieth century, we were formally established in 2000. The main work on this report and the interviews were done by two of our staff. In addition, other colleagues advised on drafts of this report. You will find all their short bios in annex 1.

Although our work involves many activities, two main elements need to be emphasised. Firstly, we yearly train about 150 so-called reference persons. These people have already completed their training as nurse, occupational therapist, social worker, ... and worked some years in dementia care, but then receive an extra eleven days of training which we and our regional offices organise. This training focuses not only on dementia and dementia care, but also on coaching teams and organisations towards better dementia care. In that sense, these reference persons are experts as well as change agents. We organise coaching initiatives for dozens of organisations yearly, where these reference persons are key ambassadors for growing towards good dementia care, based on the second important element in our work.

Secondly, on the demand of one of the previous ministers of welfare, health and family, we developed a reference framework on good dementia care (Dely et al., 2018). The key question was 'What is quality of life, housing and care for people with dementia?'. This framework was published in 2018 and is still the reference work for Flemish nursing homes, day care services and hospitals. We currently started work on an update. An extensive summary of the 2018 edition is available in English on our website: [You and me together we are human](#).



We focus on today's persons with dementia with their needs and abilities. This also means that we constantly keep our eye on the quality of life of people with dementia. We love clear simplicity, so that the people caring for a person with dementia are optimally informed of the current developments in science, care and support. That is why we like to look ahead and we want to be a leader in our field in Flanders. We want to stimulate debate on how to organize care and support to improve the daily lives of vulnerable people. And every now and then, we dream that dementia will be treatable one day, that each person will experience his or her care as excellent. Meanwhile, we try to build on a better quality of life for people with dementia and their families today.

A more extensive description of our organisation and our 9 regional offices can be found, in English, at <https://www.dementie.be/wp-content/uploads/2024/11/our-international-presentation-folder.pdf>.



Annex 3, semi-structured interview

Avez-vous, ou votre organisation, participé à la rédaction du plan d'action 2013 en matière de démence ?

De quelle manière avez-vous, ou votre organisation, participé à la mise en œuvre de ce plan d'action ?

Quel a été votre focus ou celui de votre organisation dans le cadre de cette mise en œuvre ?

Quelles mesures ont été efficaces, quelles mesures ont été moins fructueuses pour vous ou votre organisation ? Quels ont été les facteurs critiques de succès ou les seuils ?

Si vous pouviez contribuer à un nouveau plan d'action en matière de démence, quelle mesure figurerait en tête de votre liste, de quoi le Luxembourg a-t-il besoin de toute urgence ?

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Were you, or your organisation, involved in writing the 2013 dementia policy plan?

In which way were you, or your organization, involved in the implementation of this policy plan?

What was the focus for you or your organization in that implementation?

What measure was effective, where did you or your organization succeed less well? What were critical success factors, or thresholds?

If you were to contribute to a new dementia policy plan, what measure would be high on your list, what does Luxembourg need most urgently?

Annex 4, whom we interviewed & site visits

Site visits, as part of the May 2024 NSDG-meeting and otherwise:

- May 2024, site visit to SERVIOR: «Op der Rhum » - Luxembourg
- May 2024, site visit to Centre Grande-Duchesse Joséphine Charlotte - Junglinster
- May 2024, site visit to Maison de Séjour et de Soins « Beim Goldknapp », Erpeldange-sur- Sûre
- October 2024, site visit to Home pour personnes âgées « Sacré-Cœur », Luxembourg

Meetings & interviews, autumn 2024:

- Castor Aguilera, directeur des soins, Département des Aides et Soins, Croix-Rouge luxembourgeoise
- Laura Aubert, Alzheimer's Disease International (ADI)
- Prof. em. Jean-Pierre Baeyens, Solvay Brussels School of Economics
- Jacqueline Becker, Division Personnes âgées, Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil
- Dr Alexandre Bisdorff, neurologist at the Department of Neurology at the Centre Hospitalier Emile Mayrisch, Esch-sur-Alzette
- Pierrette Biver, directrice des soins et directeur général adjoint, Stéftung Hëllef Doheem
- Dr Guillaume Bourgeois, Direction de la santé
- Alain Brever, chargé de direction, Gero – Kompetenzzentrum für den Alter
- Raymond Coenen, chargé de direction SERVIOR – « Op der Rhum »- Luxembourg
- Christine Dahm-Mathonet, chargée de direction, Info-Zentrum Demenz
- Lydie Diederich, directrice générale, Association Luxembourg Alzheimer
- Christian Enschedé, directeur général, Home pour personnes âgées
- Madelène Fasol, family caregiver
- Dr Carine Federspiel, directrice générale ZithaSenior & vice-présidente Association Luxembourg Alzheimer
- Jean Georges, executive director, Alzheimer Europe and board member of ALA
- Dianne Gove, 'frontalier' & Alzheimer Europe
- Prof. Michael Heneka, directeur Luxembourg centre for systems Biomedicine (LCSB), Université de Luxembourg
- Sylvia Herbrink, care management coordinator, ParkinsonNet – Réseau de compétences maladies neurodégénératives
- Dr Sarah Huberty, Division Personnes âgées, Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil
- Dominique Janasiewicz, coordinateur projets, Recherche et développement, Santé / Aides et Soins – Croix-Rouge luxembourgeoise
- Elisabeth Kampa, directrice adjointe, direction droit civil, Ministère de la Justice
- Dr Anne Kaysen, chargée de projet of PDP, University of Luxembourg
- Marc Kayser, chargé de direction, Home pour personnes âgées « Sacré-Cœur », Luxembourg
- Prof. Sebastian Köhler, Maastricht University
- Pascale Kolb, responsable partenariat et information, l'administration d'évaluation et de contrôle de l'assurance dépendance
- Prof. Anna Kornadt, Faculté des Sciences Humaines, des Sciences de l'Education et des Sciences Sociales (FHSE), université de Luxembourg

- Prof. Rejko Krüger, coordinator of PDP, University of Luxembourg
- Dr Jean-Claude Leners, société médicale Luxembourgeoise de gériatrie et gérontologie
- Prof. Anja Leist, Faculté des Sciences Humaines, des Sciences de l'Education et des Sciences Sociales (FHSE), université de Luxembourg
- Prof. Gill Livingston, London University College
- Denis Mancini, directeur opérationnel, Association Luxembourg Alzheimer
- Romain Mauer, Conseil Supérieur des Personnes âgées
- Nicolas Maron, Département Assurance Dépendance, Caisse Nationale de Santé
- Laura Muck, responsable de la cellule Qualité, Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil
- Jennifer Olivarez, responsable de l'unité qualité et contrôle, l'administration d'évaluation et de contrôle de l'assurance dépendance
- Stefan Raskop, directeur des soins, Centre Grande-Duchesse Joséphine Charlotte - Junglinster
- Dr Florence Romano, Direction de la santé
- Dr Séverine Rosant, Service « Nomenclature-Conformité-Analyse-Prospective (NCAP), Caisse nationale de Santé
- Claude Sibenaler, responsable Division Personnes âgées, Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil
- Dr Jean-Paul Steinmetz, Association Luxembourgeoise géranto-gériatrie
- Tom Streicher, chargé de mission qualité, l'administration d'évaluation et de contrôle de l'assurance dépendance
- Dr Marie-Paule Theisen, Conseil Supérieur des Personnes âgées
- Sophie Thomé, chargée de mission, Club Aktiv Plus, Gero – Kompetenzzentrum für den Alter
- Vibeke Walter, responsable, geroAktiv, Gero – Kompetenzzentrum für den Alter
- Dr Murielle Weydert, Direction de la santé
- Carole van der Zande, chargée de direction, Club Aktiv Plus An der Loupescht - Junglinster
- Michaela Zuniga, Division Personnes âgées, Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil

Annex 5, list of consulted documents

- 2013, Rapport final du Comité de pilotage en vue de l'établissement d'un plan d'action national « maladies démentielles »
- 2017, Règlement grand-ducal du 13 décembre 2017 déterminant le contenu de la documentation de la prise en charge et les indicateurs de qualité de la prise en charge
- 2018, Les patients atteints de démence à l'hôpital
- 2020, Plan d'Action Luxembourgeois contre le Mésusage de l'Alcool (PALMA)
- 2020, Plan d'action national de mise en oeuvre de la Convention relative aux droits des personnes handicapées 2019-2024
- 2023, Plan national maladies cardio-neuro-vasculaires
- 2023, Plan National Santé Mentale
- 2024, relevé des services pour personnes âgées au Luxembourg

Background documents :

- Accord de coalition 2023-2028
- Accord de coalition 2018-2023
- Programme gouvernemental 2013
- Loi du 23 août 2023 portant sur la qualité des services pour personnes âgées
- 2021, Statistiques Être senior au Luxembourg
- 2021, Les seniors au Luxembourg : Profils socio-économiques singuliers, des enjeux majeurs pour le pays
- 2024, La démographie luxembourgeoise en chiffre et 2024, State of health in the EU - Country profile 2023, OECD – State of health in the EU Luxembourg
- 2022 : Service de continuité des soins de médecine générale dans les structures d'hébergement pour personnes âgées
- Loi du 15 août 2023 portant sur le congé d'aidant
- Code de la sécurité sociale : assurance-dépendance livre V
- Guide pratique assurance-dépendance
- Rapport d'analyse prévisionnel de l'assurance dépendance 2023
- Loi du 24 juillet 2014 relative aux droits et obligations du patient
- Loi modifiée du 8 mars 2018 relative aux établissements hospitaliers et à la planification hospitalière
- Règlement grand-ducal du 25 janvier 2019 déterminant les exigences et les normes auxquelles doivent répondre les services hospitaliers d'urgence des hôpitaux (et filière gériatrique)
- Règlement grand-ducal du 13 janvier 2019 déterminant le contenu minimal du dossier individuel du patient hospitalier et du résumé clinique de sortie
- 2018 Plan cadre National Gesond iessen, méi bewegen (GIMB)
- Plan national maladies cardioneurovasculaires 2023-2027
- Plan d'action luxembourgeois contre le mésusage de l'alcool (PALMA)
- Santé.lu Dossiers thématiques Démence
- Liste des services de Info-Zenter Demenz : rubrique Diagnostic, thérapie, rééducation gériatrique
- 2024, Formation continue professionnels secteur extrahospitalier du GERO-Kompetenzzentrum für den Alter
- 2024, Formation continue pour les professionnels du secteur hospitalier du Centre DeWidong
- Formations pour les médecins - Association luxembourgeoise pour la formation médicale continue (Alformec)
- 2021, Conseil scientifique du domaine de la santé - Prévention en médecine générale : Fiche pratique pour l'adulte

- 2023, Recommandations du Conseil scientifique du domaine de la santé pour le dépistage des facteurs de risques et le dépistage des fragilités des personnes âgées de plus de 75 ans consultant dans un service d'urgence
- Site Agence eSanté : Le DSP (dossier de soins partagé)
- 2024, Luxembourg Centre for Systems Biomedicine (LCSB) Research Group Translational Neuroscience
- 2022, National Centre for Excellence in Research on Parkinson's Disease (NCER-PD) L'étude « Vieillir en bonne santé »
- Santé.lu- information sur le rôle des médecins référents
- CNS - Nomenclature des actes et services des médecins et règlement grand-ducal modifié du 21 décembre 1998 arrêtant la nomenclature des actes et services des médecins pris en charge par l'assurance maladie.
- 2022, brochure d'information sur le système de santé luxembourgeois (site internet Sante.lu)
- Carte sanitaire 2023 - Information sur les données d'activité hospitalières
- 2022, CHL, hôpital accrédité par la JOINT COMMISSION INTERNATIONAL (JCI)
- 2023, HRS : ACI - une accréditation niveau or pour des équipes en or
- Code civil : Chapitre III et IV : sauvegarde de justice, curatelle et tutelle
- 2023, Projet de loi Projet de loi relatif au mandat de protection future
-

Annex 6, abbreviations

- ADEM, agence pour le développement de l'emploi
- ADI, Alzheimer's Disease International
- AEV, actes essentiels de la vie
- ALA, Association Luxembourg Alzheimer
- ALGG, Association Luxembourgeoise géronto-gériatrie
- CED, Flemish Centre of Expertise on Dementia
- CNS, la caisse nationale de santé
- COPAS, confédération des organismes prestataires d'aides et de soins
- CSPA, conseil supérieur des personnes âgées
- GAP, global action plan from WHO
- GERO, centre de compétence gérontologique
- GP, general practitioner
- IZD, Info-Zenter Demenz
- MCI, mild cognitive impairment
- MIFA, Ministère de la Famille, des Solidarités, du Vivre ensemble et de l'Accueil (now MFSVA)
- MISA, Ministère de la Santé (et de la Sécurité Sociale) (now M3S)
- MJU, Ministère de la Justice (now MJUST)
- OMS, organisation mondiale de la santé (= WHO)
- PDP, programme démence prévention
- SCD, subjective cognitive decline
- SMLGG, société médicale Luxembourgeoise de gériatrie et gérontologie
- WHO, world health organization (= OMS)

Annex 7, references

- *Accord de coalition 2023-2028 « Lëtzebuerg fir d'Zukunft stäerken »* (2023). Luxembourg.
- Alburez-Gutierrez, D., Williams, I., & Caswell, H. (2023). Projections of human kinship for all countries. *Proceedings of the National Academy of Sciences*, 120(52), e2315722120. doi: 10.1073/pnas.2315722120
- Alzheimer's Disease International. (2024). From Plan to Impact VII. Dementia at a crossroads. London: Alzheimer's Disease International.
- Alzheimer Europe. (2019). *Dementia in Europe yearbook, estimating the prevalence of dementia in Europe*. Luxembourg: Alzheimer Europe.
- Alzheimer Europe. (2020). *Alzheimer in Europe yearbook 2019: estimating the prevalence of dementia in Europe*. Luxembourg: Alzheimer Europe.
- Anderson, J. A., Hawrylewicz, K., & Grundy, J. G. (2020). Does bilingualism protect against dementia? A meta-analysis. *Psychonomic Bulletin & Review*, 27, 952-965.
- Belder, C., Schott, J., & Fox, N. (2023). Preparing for disease-modifying therapies in Alzheimer's disease. *The Lancet Neurology*, 22(9), 782-783.
- Boots, L. M., et al. (2016). Development and initial evaluation of the web-based self-management program "partner in balance" for family caregivers of people with early stage dementia: an exploratory mixed-methods study. *JMIR research protocols*, 5(1), e5142.
- Brodaty, H., Seeher, K., & Gibson, L. (2012). Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia *International Psychogeriatrics*, 24(07), 1034-1045.
- Brouwers, M., et al. (2023). An overview of innovative living arrangements within long-term care and their characteristics: a scoping review. *BMC Geriatrics*, 23(1), 442.
- Carey, G., Crammond, B., & De Leeuw, E. (2015). Towards health equity: a framework for the application of proportionate universalism. *International Journal for Equity in Health*, 14, 1-8.
- Castanet, V. (2022). *Les fossoyeurs*: Fayard.
- Chater, N., & Loewenstein, G. (2023). The i-frame and the s-frame: How focusing on individual-level solutions has led behavioral public policy astray. *Behavioral and Brain Sciences*, 46, e147.
- Christie, H. L., et al. (2020). Developing a plan for the sustainable implementation of an electronic health intervention (partner in balance) to support caregivers of people with dementia: case study. *JMIR aging*, 3(1), e18624.
- Cole, L., & Drennan, V. M. (2019). Living with incontinence: the experience of people with dementia. *Dementia*, 18(5), 1826-1839.
- Cole, L., et al. (2022). Experiences of intimate continence care and the impact on the family dyad relationship for people living at home with dementia and their co-resident family members. *Dementia*, 21(5), 1556-1573.
- Cooper, C., et al. (2024). Preparing for disease-modifying dementia therapies in the UK. *Nature Reviews Neurology*, advance access. doi: 10.1038/s41582-024-01022-1
- Corrêa, L., et al. (2024). Adaptation, testing, and use of the "iSupport for Dementia" program in different countries: a systematic review. *Dementia & Neuropsychologia*, 18, e20230097.
- de Lange, A. (2015). *Het is tijd, laatste berichten van Albert de Lange*: Boom.
- De Lepeleire, J., & Heyrman, J. (1999). Diagnosis and management of dementia in primary care at an early stage: the need for a new concept and an adapted procedure. *Theoretical Medicine and Bioethics*, 20(3), 213-226.
- Dely, H., Verschraegen, J., & Steyaert, J. (2018). *Ik, jij, samen MENS. Een referentiekader voor kwaliteit van leven, wonen en zorg voor personen met dementie*. Antwerpen: EPO.
- Dichter, M. N., et al. (2016). *QUALIDEM User Guide*. Witten/Amsterdam: DZNE/VUmc.

- Dixon, J., Laing, J., & Valentine, C. (2020). A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia*, 19(2), 221-236.
- Dobson, R., et al. (2024). Eligibility for anti-amyloid treatment: preparing for disease-modifying therapies for Alzheimer's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 95(9), 796-803. doi: <https://doi.org/10.1136/jnnp-2024-333468>
- Erifon, D. (2023). *Vie, vieillesse et mort d'une femme du peuple*: Flammarion.
- Eurostat. (2024). Higher life expectancy at birth for women in all EU regions. <https://ec.europa.eu/eurostat/en/web/products-eurostat-news/w/ddn-20241105-1>.
- Ferring, D., & Gross, S. (2010). Freiheitsentziehende Maßnahmen und Gewalt in der Altenpflege. *RBS-Bulletin, Themenheft nr. 1*, 56.
- Foldes, S. S., et al. (2017). Medicaid Savings From The New York University Caregiver Intervention for Families with Dementia. *The Gerontologist*, advance access.
- Frisoni, G. B., et al. (2024). European intersocietal recommendations for the biomarker-based diagnosis of neurocognitive disorders. *The Lancet Neurology*, 23(3), 302-312. doi: [https://doi.org/10.1016/S1474-4422\(23\)00447-7](https://doi.org/10.1016/S1474-4422(23)00447-7)
- Gastmans, C., van der Steen, J., & Achterberg, W. (2022). Societal and Ethical Views on End-of-Life Decision in Dementia. In M. Vandenbulcke, R.-M. Dröes & E. Schokkaert (Eds.), *Dementia & Society. An Interdisciplinary Approach* (pp. 233-249). Cambridge: Cambridge University Press.
- Geldof, D. (2016). *Superdiversity in the heart of Europe. How migration changes our society*. Leuven: Acco.
- Geldof, D., et al. (2023). *Superdivers Vlaanderen, geografie van een nieuwe realiteit*. Brussel: ASP.
- Gerkens, S., et al. (2024). *Performantie van het Belgische gezondheidssysteem: rapport 2024 (KCE Reports 376A)*. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE).
- Gerrard, N. (2019). *What dementia teaches us about love*: Penguin.
- Goudsmit, M., et al. (2017). The Cross-Cultural Dementia Screening (CCD): A new neuropsychological screening instrument for dementia in elderly immigrants. *Journal of Clinical and Experimental Neuropsychology*, 39(2), 163-172. doi: 10.1080/13803395.2016.1209464
- Hendriks, S., et al. (2023). Global incidence of young-onset dementia: A systematic review and meta-analysis. *Alzheimer's & Dementia*, 19(3), 831-843.
- Hendriks, S., et al. (2021). Global prevalence of young-onset dementia: a systematic review and meta-analysis. *JAMA neurology*, 78(9), 1080-1090. doi: 10.1001/jamaneurol.2021.2161
- Herrmann, F., Michel, J.-P., & Robine, J.-M. (2010). Worldwide decline in the oldest old support ratio. *European Geriatric Medicine*, 1(1), 3-8.
- IJsselstein, W., Tummers-Heemels, A., & Brankaert, R. (2020). Warm technology: a novel perspective on design for and with people living with dementia. *HCI and Design in the Context of Dementia*, 33-47.
- Info-Zenter Demenz. (2023). Rapport d'activité. Année 2023 (pp. 21).
- Ivanova, K., & Balbo, N. (2024). Societal pessimism and the transition to parenthood: a future too bleak to have children? *Population and Development Review*, 50(2), 323-342. doi: <https://doi.org/10.1111/padr.12620>
- Jack Jr, C. R., et al. (2024). Revised criteria for diagnosis and staging of Alzheimer's disease: Alzheimer's Association Workgroup. *Alzheimer's & Dementia*, 20(8), 5143-5169. doi: <https://doi.org/10.1002/alz.13859>
- Jönsson, L., et al. (2023). The affordability of lecanemab, an amyloid-targeting therapy for Alzheimer's disease: an EADC-EC viewpoint. *The Lancet Regional Health–Europe*, 29.
- Kmietowicz, Z., & Mahase, E. (2024). Lecanemab: Benefits of Alzheimer's drug are "just too small" to justify cost, says NICE. *BMJ*, 386, q1853. doi: 10.1136/bmj.q1853

- Kooiker, S., & de Jong, A. (2018). Het demografisch potentieel voor mantelzorg zal na 2020 snel dalen. *Sociale vraagstukken*, <https://www.socialevraagstukken.nl/het-demografisch-potentieel-voor-mantelzorg-zal-na-2020-snel-dalen/>.
- Livingston, G., et al. (2024). Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. *The Lancet*. doi: 10.1016/S0140-6736(24)01296-0
- Livingston, G., et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*. doi: [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)
- Livingston, G., et al. (2017). Dementia prevention, intervention, and care. *The Lancet*, online. doi: [https://doi.org/10.1016/S0140-6736\(17\)31363-6](https://doi.org/10.1016/S0140-6736(17)31363-6)
- Long, K. H., et al. (2014). Estimating the potential cost savings from the New York University Caregiver Intervention in Minnesota. *Health Affairs*, 33(4), 596-604.
- Mahase, E. (2024). Alzheimer's disease: what treatments could be rolled out in the next few years? *BMJ*, 387, q2477. doi: 10.1136/bmj.q2477
- Michel, J.-P., Robine, J.-M., & Herrmann, F. (2010). Demain, qui va prendre soin des personnes âgées ? Le taux de soutien aux très âgés. *Bulletin de l'Académie nationale de médecine*, 194(4-5).
- Ministère de la Santé. (2018). *Les patients atteints de démence à l'hôpital*. Luxembourg.
- Mittelman, M. S. (2013). Psychosocial interventions to address the emotional needs of caregivers of individuals with Alzheimer's disease. In S. H. Zarit & R. C. Talley (Eds.), *Caregiving for Alzheimer's Disease and Related Disorders* (pp. 17-34).
- Mittelman, M. S., et al. (1996). A family intervention to delay nursing home placement of patients with alzheimer's disease: A randomized controlled trial. *Journal of the American medical association (JAMA)*, 276, 1725-1731.
- Mittelman, M. S., et al. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers. *Gerontologist*, 33(6), 730-740.
- Mittelman, M. S., et al. (2021). Longitudinal study: understanding the lived experience of couples across the trajectory of dementia. *BMC Geriatrics*, 21, 1-10.
- Moser, M. (2006). Historical perspectives on the management of hypertension. *The Journal of Clinical Hypertension*, 8, 15-20.
- Opgenhaffen, T., et al. (2022). Care Planning and the Lived Experience of Dementia. In M. Vandenbulcke, R.-M. Dröes & E. Schokkaert (Eds.), *Dementia & society. An Interdisciplinary Approach* (pp. 211-231). Cambridge: Cambridge University Press.
- Pacht, L., et al. (2024). *Les seniors au Luxembourg. Des profils socio-économiques singuliers, des enjeux majeurs pour le pays*: Statec.
- Panagiotidou, N., et al. (2024). Towards Establishing Quality Standards on Human Rights for Services in Dementia Care. *International Journal of Older People Nursing*, 19(5), e12643.
- Parlevliet, J., et al. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. *International Journal of Geriatric Psychiatry*, 31(9), 1040-1049.
- Perquin, M., et al. (2015). Prevalence of dementia and cognitive complaints in the context of high cognitive reserve: a population-based study. *PLOS ONE*, 10(9), e0138818.
- Piers, R., et al. (2018). Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliative Care*, 17(88).
- Pot, A. M., et al. (2019). iSupport: a WHO global online intervention for informal caregivers of people with dementia. *World Psychiatry*, 18(3), 365-366.
- Rutten, A., & Van Leuven, B. (2024). *Ik heb geleefd*: Lannoo.
- Salemme, S., et al. (2024). Universal prevention of dementia in Italy: a document analysis of the 21 Italian regional prevention plans. *The Journal of Prevention of Alzheimer's Disease*, 11(6), 1525-1533. doi: 10.14283/jpad.2024.144

- Scheibl, F., et al. (2024). Adapting a Dutch web-based intervention to support family caregivers of people with dementia in the UK context: Accelerated experience-based co-design. *JMIR Formative Research*, 8(1), e52389.
- Schröder, V., et al. (2024). Programme Dementia Prevention (PDP): a nationwide program for personalized prevention in Luxembourg. *Journal of Alzheimer's Disease*, 97(2), 791-804.
- Social Protection Committee (SPC), & European Commission (DG EMPL). (2021). *Long-term care report, Vol. 2, Country profiles*. Luxembourg: Publications Office of the European Union.
- Spruytte, N., Van Vracem, M., & Van Audenhove, C. (2018). *Nachtrust bij dementie : stappenplan voor een niet-medicamenteuze aanpak*. Brussel Politeia.
- Statec. (2024). Une croissance démographique réduite en 2023 *Statnews*, 16.
- Steyaert, J. (2023). Dreigende crash voor ouderenzorg? 'De demografische tijdbom tikt'. *Sociaal.Net*, <https://sociaal.net/achtergrond/ouderenzorg-dreigende-crash-demografische-tijdbom-tikt/>.
- Steyaert, J., et al. (2020). Hoe vangen we het toekomstig tekort aan mantelzorgers op? *Sociaal.Net*, <https://sociaal.net/achtergrond/hoe-vangen-we-het-tekort-aan-mantelzorgers-op/>.
- Tampi, R. R., et al. (2020). Antipsychotics in the management of behavioral and psychological symptoms of dementia: maximizing gain and minimizing harm. *Neurodegenerative Disease Management*, 10(1), 5-8. doi: 10.2217/nmt-2019-0036
- van Es, G. (2013). *Het laatste woord, de kunst van leven met de dood*: Nieuw Amsterdam.
- Van Gorp, B., & Vercruysse, T. (2012). Frames And Counter-Frames Giving Meaning To Dementia: A Framing Analysis Of Media Content. *Social Science & Medicine*, 74(8), 1274-1281.
- van Gorp, B., Vercruysse, T., & van den Bulck, J. (2012). Toward a more nuanced perception of Alzheimer's disease: designing and testing a campaign advertisement. *American Journal of Alzheimer's Disease and Other Dementias*, 27(6), 388-396.
- Van Vracem, M., et al. (2016). Nachtelijke onrust bij personen met dementie in woonzorgcentra: een verkennende veldstudie. *Tijdschrift voor Gerontologie en Geriatrie*, 47(2), 78-85.
- Vandormael, S., et al. (2018). Insights on dying, dementia and death certificates. *Archives of Public Health*, 76(16).
- Verbeek, H. (Ed.). (2011). *Redesigning dementia care : an evaluation of small-scale homelike care environments (PhD)*. Maastricht: Universiteit Maastricht.
- Verbeek, H., & Mitchell, G. (2022). Changing the long-term care spectrum. *BMC Geriatrics*, 22(1), 303. doi: 10.1186/s12877-022-02909-8
- Wetenschappelijke Raad voor het Regeringsbeleid. (2021). *Kiezen voor Houdbare Zorg. Mensen, middelen en maatschappelijk draagvlak*. Den Haag: WRR.
- WHO. (2018). Towards a dementia plan: a WHO guide. Geneva: World Health Organization.
- WHO. (2022). WHO European framework for action on mental health 2021-2025. Copenhagen: WHO regional office for Europe.
- Wolters, F. J., et al. (2020). Twenty-seven-year time trends in dementia incidence in Europe and the United States: The Alzheimer Cohorts Consortium. *Neurology*, 95(5), e519-e531.