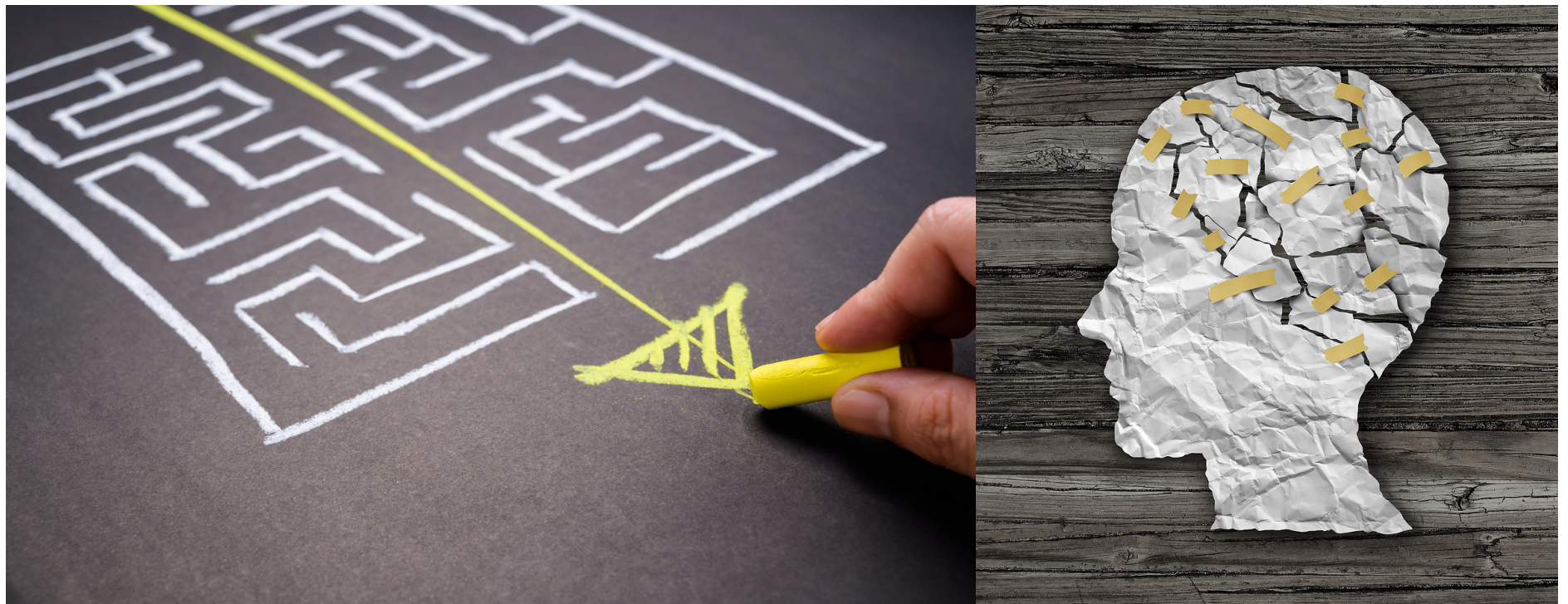


YOUNG-ONSET DEMENTIA: PAVING THE WAY FOR AN INTEGRATED CARE PATHWAY IN BELGIUM



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All experts and stakeholders consulted within this report were selected because of their involvement in the topic of Young-onset dementia. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report'.

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- **The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.**
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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
AD	Alzheimer Disease
ALS	Amyotrophic lateral sclerosis
ASAPP	'Aide et Soutien aux Aidants Proches et aux Personnes atteintes de la maladie d'Alzheimer ou troubles apparentés'
bvFTD	Behavioural variant frontotemporal dementia
CBD	Cortico-basal degeneration
CM2R	Memory Resource and Research Centres ('Centres Mémoire de Ressources et de Recherche') (France)
CNR – MAJ	National Reference Centre for Young Alzheimer's Patients ('Centre National de Référence – Malades Alzheimer Jeunes') (France)
CSF	Cerebrospinal fluid puncture
CT	Cranial computed tomography
DAIzG	German Alzheimer Society ('Deutsche Alzheimer Gesellschaft') (Germany)
DRA	'Dementie referentiearts'
EMR	Electronic medical record
EOAD	Early-onset Alzheimer's disease
FAZODEM	'Farmaceutische zorg voor personen met dementie'
FIM	Functional Independence Measure
FTD	Frontotemporal dementia
FTE	Full-time equivalent
FTLD	Frontotemporal lobar degeneration
GP	General practitioner
HCP	Healthcare professional
HAS	High Authority of Health ('Haute Autorité de Santé') (France)



KCE	Belgian Health Care Knowledge Centre
LOAD	Late-onset Alzheimer Disease
LOD	Late-onset dementia
MeSH	Medical Subject Heading
NICE	National Institute for Health and Care Excellence
MMSE	Mini-Mental State Examination
MRI	Magnetic resonance imaging
MRPA	Home for elderly people ('Maison de repos pour personnes âgées')
MRS	Nursing home ('Maison de repos et des soins')
MS	Multiple sclerosis
NICE	National Institute for Health and Care Excellence
NIHDI	National Institute for Health and Disability Insurance ('Rijksinstituut voor Ziekte- en Invaliditeitsverzekering'/'Institut National d'Assurance Maladie-Invalidité')
NPS	Neuropsychiatric symptoms
PDU	Psychotropic drug use
PET	Positron emission tomography
P-MND	'Plan Maladies neuro-dégénératives'
PNFA/SD	Progressive non-fluent aphasia and semantic dementia
PPA	Primary progressive aphasia
PSP	Progressive supranuclear palsy
PRECODE	Prevalence recognition and care pathways in young onset dementia
RHAPSODY	Research to Assess Policies and Strategies for Dementia in the Young
RCT	Randomised clinical trial
ROB	'Rustoord voor Bejaarden'



RVT	Nursing home ('Rust- en verzorgingstehuis')
SIGN	Scottish Intercollegiate Guidelines Network
TAP	'Tijdige, accurate en gepersonaliseerde'
UK	United Kingdom
YOAD	Young-onset Alzheimer disease
YOD	Young-onset dementia
ZonMW	'Zorgonderzoek Nederland Medische Wetenschappen'



■ SCIENTIFIC REPORT

1 INTRODUCTION

1.1 Young-onset dementia

The Medical Subject Heading (MeSH) thesaurus defines dementia as follows: “*an acquired organic mental disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The dysfunction is multifaceted and involves memory, behaviour, personality, judgment, attention, spatial relations, language, abstract thought, and other executive functions. The intellectual decline is usually progressive, and initially spares the level of consciousness.*” In other words, dementia is a neurodegeneration that causes a progressive decline in people’s ability to think, reason, communicate and remember, and can also affect personality, behaviour and mood.

The risk of dementia increases with age: the prevalence of dementia in men globally is estimated to be 0.5% among those aged 40–69 years, 6.5% among those aged 70–84 years, and 23.5% among those aged 85 years and older. The corresponding figures for women are 0.6%, 8.5% and 30.5%, respectively.¹ In Belgium, it is expected that the population ageing will result in an increase from around 190 500 cases in 2019 to 330 500 cases in 2050.¹

When symptoms develop before the age of 65 years, dementia is called young-onset.^a The age cut-off is a social construct arrived at by consensus rather than being driven by a qualitatively different underlying disease process. It is usually the age of work retirement. Young-onset dementia (YOD) differs from late-onset dementia (LOD) on various aspects which will be described in more details in chapter 2 & 3. First, YOD comprises a more

^a The terms ‘early onset’ or ‘working age’ dementia are also used, but can be confusing: ‘early onset’ can be interpreted as the early stages of dementia, and ‘working age’ is more open to interpretation as the retirement age is more flexible. Hence the term young-onset dementia is preferred. (<https://www.dementiauk.org/about-dementia/young-onset-dementia/what-is-young-onset-dementia/>)



heterogeneous range of dementias, resulting in more diverse clinical patterns including cognitive, psychiatric and neurological symptoms.² Moreover, awareness of the existence of YOD is lower than for LOD, including among healthcare professionals. As a result, people living with YOD can be misdiagnosed, with their symptoms misattributed as depression or other mental health issues. The correct diagnosis can be delayed by several years, translating in late appropriate patient care.³ Second, the earlier timing of symptom onset brings different social, financial, and occupational challenges compared to LOD presentations, since people with YOD are often still reliant on full-time employment income and sometimes have other caring responsibilities (e.g. children, ageing parents).⁴

1.2 Need for a specific care pathway

Given these specificities, it is generally admitted that developing a specific care pathway for people with YOD is relevant. In May 2022, the Belgian Chamber of representatives stated that best practices regarding a care pathway for people with YOD should be the subject of inquiry to develop such a pathway in Belgium.

The Belgian Healthcare Knowledge Centre (KCE) was tasked with examining the matter. This report aims to identify the needs of people with YOD as well as the gaps in care provision to prepare an appropriate Belgian care pathway. An overview of the disease, including diagnosis, Belgian epidemiology, and care management, is presented in Chapter 2. Chapter 3 contains a literature review on the needs of people with YOD and their caregivers. A multi-faceted analysis of the current Belgian care provision is presented in Chapter 4. After a review of national dementia policy plans in four neighbouring countries in Chapter 5, recommendations for a care pathway in Belgium are presented in Chapter 6. It should be noted that this report is the result of a health system research and does not constitute a guideline for good clinical practice. For example, we will analyse in the context of this project the concrete possibilities of an early detection of YOD (training of frontline caregivers, accessibility to the electronic medical record, referral to a specialised centre for diagnosis, etc.), and not the evidence-based validity of specific biomarkers, because this latter information will influence little the care pathway. Moreover, as the main goal was to pave

the way for a care pathway, we concentrated on its underlying principles and main implementation components, and less on the economic and financial aspects. For recommendations based on current evidence for best practice in the assessment, care and support of adults with dementia, we refer the readers to national (EBM PracticeNet (2017) and the joint guideline by KU Leuven and Expertise Centre Dementia Flanders (2020)) and international guidelines (NICE (2018) and SIGN (2023)), as there are currently no clinical guidelines specific to YOD.⁵⁻⁸



2 DISEASE OVERVIEW

2.1 Key points

- The aetiology of young-onset dementia (YOD) is more diverse than for later-onset dementia (LOD), often involving rarer diseases or being secondary to other conditions of neurological, infectious or toxic (e.g. alcohol) nature. An autosomal dominant genetic mutation is retrieved in 15% of the cases.
- The symptoms are also more diverse. Beyond the cognitive impairments also observed in LOD, YOD may display behavioural and personality changes, language impairment, and executive dysfunction.
- The frequent lack of awareness regarding YOD in the public and healthcare professionals, together with the symptomatic overlap with non-degenerative primary psychiatric disorders can delay the diagnosis by several years.
- People with YOD have significantly increased mortality compared to the general population, and increased risk of suicide.
- We estimated the number of YOD patients in Belgium around 7300 cases, among whom 67% are in age band 60-64y. Around 4% of all dementia cases would be YOD. Around 800 new cases of YOD are expected every year.
- Post-diagnosis care is often fragmented, with services delivered across aged care, healthcare, and social care sectors.
- Age-appropriate, holistic, multidisciplinary management of cases is recommended.
- Non-pharmacological interventions are central and include cognitive rehabilitation, psycho-educational and social interventions, and environmental support.

This section aims to highlight aspects of the disease that are important for establishing an appropriate care pathway. The answer to each question is based on a narrative review of the literature.

2.2 How does YOD differ from dementia in older individuals?

2.2.1 Causes

Alzheimer's disease is thought to be caused by the abnormal build-up of proteins in and around brain cells. One of the proteins involved is called amyloid, deposits of which form plaques around brain cells. The other protein is called tau, deposits of which form tangles within brain cells. The causes probably include a combination of age-related changes in the brain, along with genetic (ApoE4 gene), environmental, and lifestyle factors. As in older patients, the most common form of YOD is the typical amnesic presentation of young-onset Alzheimer's disease (AD), characterised by progressive impairment of episodic memory that impacts the ability to acquire new information, recall recent events, and orient oneself in time and place.⁴

The two other most frequent causes of YOD are frontotemporal lobar degeneration resulting in a frontotemporal dementia (FTD) and vascular problems, typically small vessel disease, transient ischaemic attacks or strokes, resulting in a so-called vascular dementia.² Risk factors for vascular dementia are arterial hypertension, smoking, high blood cholesterol, lack of exercise, overweight or obesity, diabetes, excessive alcohol consumption, and atrial fibrillation. Neurodegenerative lesions in FTD are close to the ones observed in Alzheimer's disease. A family history is the only known risk factor for FTD. Behavioural variant frontotemporal dementia (bvFTD) is the most common subtype of FTD, wherein insidious changes arise in personality and behaviour, followed by the primary progressive aphasia (PPA), involving a decline in speech and language abilities.⁴



The aetiology of YOD is more diverse than LOD. While AD is involved in 60% of LOD cases, it represents only 30% of YOD cases (Table 1).⁹ The prevalence of FTD is much higher before 65 years (12% of YOD vs 3% of LOD). YOD is more likely to be caused by a rarer disease (e.g. Lewy body dementia), or to be secondary to other conditions of neurological (e.g. Huntington disease, Parkinson disease, multiple sclerosis), infectious (e.g. HIV, neurosyphilis) or toxic (e.g. alcohol) nature.^{2, 10} Alcohol abuse would be involved in around 10% of the cases. People with intellectual disability are recognised as having increased risk for developing dementia, and most people with Down syndrome will exhibit symptoms consistent with AD by age 65 years. About 15% of all YOD cases are caused by an autosomal dominant genetic mutation (50% of people with onset <45 years).²

A thorough diagnostic focus is necessary to identify all curable pathologies.

2.2.2 Clinical patterns

The first symptoms are more diverse than in older individuals and often include behaviour, language and personality changes, and executive dysfunctions.²

2.2.2.1 Alzheimer's disease (AD)

Initial symptoms of Alzheimer's disease (AD) are short term memory impairment, disorientation and word-finding difficulties, as in late-onset dementia. However, several variants of AD can be observed in YOD, each with specific symptoms (Box 1).²

Box 1 – Symptoms of variants of AD (adapted from Loi et al. 2023²)

- **Posterior cortical atrophy:** visual problems (ocular motor apraxia, simultanagnosia), apraxias and Gertsman syndrome (acalculia, finger agnosia, agraphia, left–right disorientation)
- **Frontal AD or behavioural/executive AD:** symptoms similar to behavioural variant FTD (bvFTD)
- **Primary progressive aphasia:** language difficulties such as word-finding difficulties and decreased repetition of sentences.

A recent high quality systematic review including 42 studies reported that people with young-onset AD (YOAD) had significantly poorer baseline cognitive performance and faster cognitive decline but longer survival times than people with late-onset AD (LOAD).¹¹ However, there was no evidence that YOAD patients differ from people with LOAD in terms of symptom onset to diagnosis time, activities of daily living, and neuropsychiatric symptoms (depression, anxiety, apathy). There were insufficient data to estimate overall effects of differences in quality of life.¹¹

Regarding the poorer baseline cognitive performance, YOAD patients exhibit non-amnesic cognitive syndromes that affect domains such as language and visuospatial abilities, whereas LOAD patients typically present mainly episodic memory complaints. YOAD also present with more non-cognitive symptoms such as depression and anxiety, and they may use association areas to compensate for their cognitive difficulties. As a result, they may delay seeking assessment until symptoms become more pronounced and begin to significantly affect their daily lives, potentially explaining the lower baseline scores observed at presentation.¹¹



2.2.2.2 Other types of YOD

The symptoms are more diverse in YOD than in LOD also because the causes of dementia are more diverse. For example, patients with FTD often present with impulsive or inappropriate behaviour, executive problems, and language impairments. With bvFTD, the patient can present with loss of empathy, disinhibition, changes in appetite, apathy, repetitive or stereotyped behaviours, and rigidity. The patients suffering from progressive supranuclear palsy may experience falls, and gait, balance problems, and vertical supranuclear gaze palsy.²

Of note, the impact of onset age on symptom progression in dementia other than AD is still poorly understood.¹²

2.2.3 Survival

A retrospective cohort of 386 Australians with YOD reported that the median survival after symptom onset was 11.3 years for Alzheimer's disease, 10.6 years for FTD, 12.3 years for VD, and 18.8 years for Huntington's disease.¹³ Overall, people with YOD had significantly increased mortality (5 to 8 times), compared to the general population. This is in line with the results from another cohort study reporting that overall people with YOD lose 10 to 15 years of life expectancy.¹⁴ YOD people have prolonged survival compared to LOD, but life expectancy is decreased dramatically.^{11, 14}

It is also worth mentioning that the risk of suicide is increased substantially in YOD people in comparison with the general population,¹⁵ but this is also the case for LOD.¹⁶ These results highlight the importance of suicide risk screening and support, particularly at the time of diagnosis.

2.2.4 Impact on patients and families

YOD provokes more working, social, family, and economic consequences than LOD. The specific needs of patients and carers are presented at length in Chapter 3. Of note, there is a lack of studies on social and indirect costs.¹⁷


Table 1 – Differences between YOD and LOD

Aspect	Young-Onset Dementia (YOD)	Late-onset dementia (LOD)
Age of Onset	Before age 65	After age 65
Common Causes	More diverse causes:² - Mainly Alzheimer disease (AD, ≈30%), vascular dementia (VD, ≈20%), frontotemporal dementia (FTD, ≈12%),⁹ - Lewy body dementia (≈10%) - Neurological diseases (e.g. multiple sclerosis, Parkinson's disease, Huntington's disease, Creutzfeldt Jakob disease) (≈20%) - Infectious diseases (neurosyphilis, HIV) - Alcohol-related dementia (≈10%) - Down syndrome, intellectual disability	Mainly Alzheimer disease (AD, ≈60%), vascular dementia (VD, ≈17-30%), frontotemporal dementia (FTD, ≈3%),
Symptoms	More diverse symptoms in relation to diverse causes:² - Short-term memory impairment, word-finding difficulties, disorientation - Behavioural and personality changes: apathy or disinhibition, loss of empathy, repetitive behaviours, depression - Language impairment: anomia, aphasia, alexia - Executive dysfunction: apraxia, rigidity, falls, balance problems	Memory loss, confusion, difficulty reasoning, disorientation
Diagnostic challenges	Frequently misdiagnosed (e.g. as stress, anxiety, or depression), delayed diagnosis (average lag time: 4.4 years)^{3, 18}	Easier to diagnose due to age-related expectations of cognitive decline Average time between symptom onset and diagnosis is smaller
Impact on life	Affects career, family responsibilities, and finances; often raising children and working when diagnosed	Often retired and less likely to have young children; financial planning may already be in place
Social and emotional impact	Profound emotional toll, especially for younger family members and work disruption	Significant, but potentially less disruptive to daily life and family roles
Prognosis and management	People with YOAD experience faster cognitive decline than LOAD	Slower progression, with more established care and support options
Financial burden	Greater due to loss of income, need for early retirement, and care costs at a younger age	Can still be significant, but often mitigated by retirement savings and insurance



2.3 How frequent is YOD in Belgium?

We don't have good comprehensive numbers/estimates for the Belgian population. To estimate the frequency of YOD in Belgium, we extracted crude prevalence rates in high-income countries by age range from a good quality systematic review (published in 2021) including 95 unique studies^{b,9}. For each age band of 5 years between 30 and 65 years, we multiplied the crude incidence rate by the Belgian population (direct standardisation). This yielded the number of cases of dementia expected in Belgium by age range. The age-standardised prevalence rate was obtained by summing up all cases and dividing it by the total Belgian population between 30 and 65 years (5 325 852 in 2021 according to Statbel^c). We did the same computations for incidence based on crude rates extracted from another good quality systematic review including 47 studies^d, except the crude incidence rates were not specific to high-income countries as such stratification was not provided.¹⁹ We did not standardise the results by sex as there was generally similar prevalence and incidence between males and females.^{9, 19}

Results are presented in Table 2. The age-standardised prevalence in Belgium is estimated at 137.1 (95%CI: 93.9; 201.3) per 100 000 population between 30 and 64 years, corresponding to around 7300 cases overall (95%CI: 5000; 8489). Thus, YOD would represent around 4% of all dementia cases in Belgium, if we use as denominator the prevalence reported in point 1.1.¹ The vast majority of these cases (83%) are between 55 and 64 years (67% in age band 60-64 years). AD counts for approximately one third of the cases (54.1 per 100 000 population in

Europe), followed by vascular dementia (19.5 per 100 000 population in Europe) and frontotemporal dementia (2.9 per 100 000 population in Europe).⁹ There were not enough studies on dementia with Lewy bodies and Parkinson disease to get a pooled estimate. Of note, three studies on alcohol-related dementia included in the review by Hendriks et al. (2021) reported prevalence estimates from 4.9 to 16.3 per 100 000 for 30 to 64 years of age, i.e. from 3% to 10% of all cases.⁹ The age-standardised incidence rate in Belgium is estimated at 15.0 (95%CI: 9.7; 25.0) per 100 000 population between 30 and 64 years, and corresponding to around 800 new cases of YOD every year (95%CI: 518; 1329), most of them (80%) in the age range 55-64 years (50% in the age band 60-64 years).

It must be underlined that these are estimates subject to certain limitations. First, the number of studies was greater in the age band 60-64 years, therefore, estimates in younger age bands are less precise. Second, retrospective registered-based studies tend to report lower rates than prospective studies, and they represented 1/3 and 1/2 of prevalence and incidence studies, respectively. Third, there was substantial heterogeneity across the studies included in the meta-analyses, and this was reflected in the wide confidence intervals, e.g. overall prevalence rates in high-income countries go from 206.0 to 557.0 per 100 000 population. To yield more accurate and comparable prevalence estimates in the future, efforts should be made to conduct more cohort studies and to standardise procedures and reporting of prevalence studies.⁹ Despite these limits, the estimates provide a valid estimate of the burden of the disease in Belgium.

^b Eighty-one studies reported prevalence estimates on all types of YOD. Of these, 21 studies were excluded from meta-analyses: 11 studies reported solely on specific ethnic subpopulations, and 10 studies lacked numerator or denominator data. The number of eligible studies ranged from 4 in the age band 30 to 34 years to 45 in the age band 60 to 64 years.

^c Statbel population figures can be found at <https://statbel.fgov.be/fr/themes/census/population/age#panel-13>

^d Only 41 studies contributed to meta-analysis

**Table 2 – Age-standardised prevalence and incidence of YOD in Europe and expected case numbers in Belgium**

Age range, y	Crude prevalence rate of dementia, per 100 000 (95%CI)	Belgian population (2021)	Expected prevalent Belgian cases (95%CI)	Age-standardised prevalence rate in Belgium, per 100 000 (95%CI)	Crude incidence rate of dementia, per 100 000 (95%CI)	Expected incident Belgian cases (95%CI)	Age-standardised incidence rate in Belgium, per 100 000 (95%CI)
30-34	5.9 (3.3; 10.6)	755 100	45 (25; 80)	-	0.9 (0.1; 7.2)	7 (1; 54)	-
35-39	5.9 (3.6; 9.4)	744 183	44 (27; 70)	-	1.0 (0.2; 4.8)	7 (1; 36)	-
40-44	23.9 (12.9; 44.5)	749 373	179 (97; 333)	-	3.2 (1.0; 9.9)	24 (7; 74)	-
45-49	43 (25.9; 71.2)	753 006	324 (195; 536)	-	5.2 (2.0; 13.8)	39 (15; 104)	-
50-54	81.3 (59.4; 111.1)	785 883	639 (467; 873)	-	13.6 (7.8; 23.7)	107 (61; 186)	-
55-59	148.5 (117.5; 187.6)	803 728	1194 (944; 1508)	-	24.7 (17.4; 35.1)	199 (140; 282)	-
60-64	663.9 (441.8; 996.4)	734 579	4877 (3245; 7319)	-	56.6 (39.7; 80.7)	416 (292; 593)	-
All	338.9 (206.0; 557.0)	5 325 852	7301 (5000; 8489)	137.1 (93.9; 201.3)	35.3 (24.0; 51.7)	799 (518; 1329)	15.0 (9.7; 25.0)

Crude prevalence rate estimates in high-income countries are from Hendriks et al. 2021;⁹ Crude incidence rate estimates in high-income countries are from Hendriks et al. 2022;¹⁹ Belgian population is from Statbel^e

2.4 When should YOD be suspected (primary care level)?

As already explained, the early presenting symptoms of YOD are more variable than LOD (see Table 1), and this results in delayed recognition and diagnosis often by several years.^{3, 20} For example, the behavioural variant of FTD (bvFTD) shows significant symptomatic overlap with non-degenerative primary psychiatric disorders including major depressive disorder, bipolar disorder, schizophrenia, obsessive-compulsive disorder, autism spectrum disorders and even personality disorders.²¹ A substantial proportion of patients with bvFTD receive a prior psychiatric diagnosis, and patients with primary psychiatric disorders can be wrongly diagnosed with bvFTD.^{21, 22}

The INSPIRED study in Australia reported that longer time to dementia diagnosis occurred in people who were younger at symptom onset, when mild cognitive impairment or depression was present, and in dementias other than AD and FTD.¹⁸ This is why the awareness of healthcare providers and families regarding the early signs of the disease is key. Elements that should be considered warning signs and prompt a more thorough investigation are presented in Box 2.²

^e Statbel population figures can be found at <https://statbel.fgov.be/fr/themes/census/population/age#panel-13>

**Box 2 – Warning signs of YOD (adapted from Loi et al. 2023²)**

- Behavioural/psychiatric changes in someone of middle age who has no previous psychiatric history
- Cognitive/behavioural/psychiatric changes in a person with a family history of young-onset dementia
- Behaviour changes that are not consistent with previous personality
- Progressive neurological symptoms or seizures
- Minimal improvement of psychiatric symptoms following psychotherapy or psychotropic medications

A systematic approach to clinical history taking, examination and investigation in YOD is needed. Tools exist to streamline such organised assessment. For example, a guideline, based on a modified e-Delphi consensus survey involving 23 international expert clinicians, proposes 48 elements of inquiry for a comprehensive assessment of YOD (year 2020).²³ The elements are grouped in pre-assessment and communication, history taking, family history, physical examination, risk assessment, psychiatric assessment, neuroimaging, neuropsychological assessment (not just the Mini Mental State Examination^f), and support to end of life (Box 3).

Many brief cognitive tests are available that can be used in non-specialist settings, including primary care: the Mini Mental State Examination (MMSE), the Mini-Cog, the Addenbrooke's Cognitive Examination 3 (ACE3), the Mini-ACE, the Clock Drawing Test (CDT), the Rowland Universal Dementia Assessment Scale (RUDAS), etc.⁶ The most used is probably the MMSE. These tools are not diagnostic on their own, but can be used to identify people who might benefit from referral for specialist dementia assessment. Domains assessed include attention, temporal orientation, memory (immediate and delayed recall), visual motor skills, executive function, judgement and language. There is no evidence to recommend one cognitive test over another.⁶ Moreover, the assessment of dementia should take into account a collateral history (eg from family members or carers) and clinical examination (mental state and focussed physical examination), and not be solely reliant on cognitive assessment.

^f The Mini-Mental State Examination (MMSE) may be within normal limits for some persons with YOD (e.g. in case of frontotemporal dementia). Alternative screeners should be considered (e.g. Addenbrooke's Cognitive Examination III revised)². Loi SM, Cations M, Velakoulis D. Young-onset dementia

diagnosis, management and care: a narrative review. Med J Aust. 2023;218(4):182-9.

**Box 3 – Quality indicators for a comprehensive assessment of YOD (adapted from O'Malley et al.²³)**

Group of indicators	Statements considered as “absolutely essential” or “very important” by 80% of the experts consulted
• Pre-assessment and communication	• Multiple professionals are required over time to allow flexible assessment with support to end of life • Diagnosis of YOD is a clinical judgement and has a profound impact on the future, so it important to convey this to patient and their family and remain open to the need to review and potentially modify opinion • Establishing rapport to enable open reporting of symptoms • The assessment should start with counselling to ascertain what patient and supporters require • Ensuring the patient has capacity
• History taking	• To ask an informant (e.g. wife/husband) for a collateral history • To understand the symptom type and the mode of onset • More information about loss of sympathy/empathy towards others, disinhibited behaviour, change in food preferences and changes in personality • To enquire about changes in physical health • If there have been any changes in activities of daily living • To ask about changes in behaviour • To consider previous medical conditions • To take a drug history • To ask about sleep • To take an alcohol history
• Family history	• To ask if a first degree relative has had young onset dementia • To obtain a three-generation history of young onset dementia from the patient • To have a full medical history (including cardiovascular history)
• Risk assessment	• To evaluate risks, for example driving or in the work place
• Psychiatric assessment	• A thorough psychiatric history should be conducted • Ask about past psychiatric symptoms • Include mental state examination • Exclude symptoms of mood disorder • Exclude psychotic symptoms



Group of indicators	Statements considered as “absolutely essential” or “very important” by 80% of the experts consulted
- Neurological assessment - Neuropsychological assessment - Neuroimaging - Support to end of life	- Establish if there is a known history of learning disability - Include mental state examination - A thorough neurological assessment should be conducted: eye movements, cerebellar signs, tongue or limb fasciculation, frontal signs, extrapyramidal features, motor skills, praxis, parkinsonism - An Addenbrooke's Cognitive Examination-III (ACE-III) is useful to understand the cognitive profile - Patterns of cognitive deficits rather than the score itself provide clues to disease aetiology on the ACE-III - Detailed neuropsychology testing should be considered if there is under-performance on screening measures - MRI head to agreed dementia protocol - Support is required from diagnosis to end of life care

Another international Delphi study established a consensus among YOD experts about the information that is essential for health professionals providing care and services to people with YOD and their support persons (year 2022).²⁴ Fifty-eight statements were listed (72% with a high to very high consensus). In summary, health professionals should be aware and understand that:

- people with YOD require age-appropriate care programs and accommodation options that take a whole family approach
- YOD is aetiologically diverse, distinct from a mental illness, and has a combination of genetic and non-genetic contributing factors
- specialised, multidisciplinary services both in terms of diagnosing YOD and in providing ongoing support are needed

The NICE guideline on dementia (2018) also makes consistent recommendations for the initial assessment of dementia in non-specialist settings.⁵ Although this guideline is primarily about overall dementia, the authors were aware of the problem of early dementia as a chapter is dedicated to the problem, although this does not lead to specific recommendations.

Finally, although a number of risk factors are well known, screening for dementia is not recommended because reliable predictive models are not yet available, as showed by a recent Cochrane review including 20 studies, 19 of which had a high risk of bias.²⁵



2.5 How is YOD diagnosed (specialist level)?

2.5.1 Neurological examination and cognitive testing

Once a patient with suspected YOD is referred to the neurologist, a thorough neurological examination and cognitive/neuropsychological testing should occur. NICE recommends using validated criteria to guide clinical judgement.⁵ This assessment should be repeated in the first years after a YOD diagnosis. Some dementias, such as bvFTD, are difficult to diagnose at one timepoint and individuals may perform within normal limits on neuropsychological testing, so they are often misdiagnosed as having a psychiatric condition. Repeated assessments are important to confirm or specify a diagnosis.² Currently in Belgium, only one neuropsychological examination is reimbursed over the life time.

2.5.2 Imaging

A magnetic resonance imaging (MRI) can detect cerebral atrophy, e.g. hippocampal atrophy in AD. Functional imaging such as fluorodeoxyglucose positron emission tomography (PET) can identify dementia-related changes. New molecular neuroimaging technologies can increase the accuracy of the diagnosis. For example, a negative amyloid- β PET can exclude AD in persons with cognitive impairment,² or a normal 18F-fluorodeoxyglucose PET can exclude bvFTD.²¹ Routine use of amyloid PET in the diagnosis of dementia or mild cognitive impairment is not recommended.⁶

Describing in detail the use and merits of imaging techniques to diagnose dementia goes beyond the scope of this report, especially since most techniques are not YOD-specific. Relevant information can be found in synthesis documents such as the NICE or the SIGN guidelines.^{5, 6, 26}

2.5.3 Cerebrospinal fluid biomarkers

Analysis of cerebrospinal fluid via lumbar puncture can measure A β 40, A β 42, total tau (t-tau) and phosphorylated tau (p-tau) as indicators of AD.² Neurofilament light chains (a component of the axons) in cerebrospinal fluid could also help differentiating between psychiatric conditions and dementia.^{21, 27, 28} Some predictive biomarkers can also be measured in the

plasma (e.g. p-tau 181, p-tau 217, A β 40, and A β 42).²⁹ Once again, these tests are not specific to YOD, and NICE or SIGN guidelines can be consulted for a comprehensive dementia assessment strategy.^{5, 26}

2.5.4 Genetic factors

As an autosomal dominant genetic mutation is retrieved in 15% of YOD cases, genetic testing is recommended especially when the dementia occurs in very young individuals (<45 years), there is a family history of YOD, and in case of FTD.³⁰⁻³³ However, there is currently no optimal single genetic investigation that simultaneously identifies the different genetic variants resulting in YOD.³⁴ In addition, some genetic risk factors have unclear significance. A genetic counselling before testing and receiving results is therefore required.²

2.6 What are the post-diagnostic services needed?

2.6.1 General principles

Post-diagnosis YOD care is often fragmented, with services delivered across aged care, healthcare, and social care sectors.³⁵ Post-diagnostic care for younger people with dementia should be tailored, flexible, affordable and provide meaningful engagement.² An assessment of the specific disabilities and needs experienced by the person must occur rapidly after the diagnosis. It will help to guide non-pharmacological treatment and care, and share with the patients all relevant information. People with YOD may benefit from a multidisciplinary approach including psychology or counselling, functional assessment with home modifications and help with activities of daily living, speech pathology, physiotherapy and/or exercise physiology, home support (e.g. cleaning, cooking), financial management, and assistance with advance care planning.²

The fundamental elements of best practice were listed by Stamou and Carter^{36, 37} and are summarised in Box 4.

**Box 4 – Good practice principles for post-diagnostic services³⁶**

- Personalised age-appropriate needs-led services delivered in a timely and uninterrupted manner and using a person-centred approach
- Family-oriented services that address the individual and collective needs of all those affected by YOD
- Clear, affordable, effective, and easily accessible diagnostic and post-diagnostic care pathways across the experience with YOD
- Coordination and collaboration between services to provide continuity and address the changing needs of younger people and their families over time
- Evaluation models are needed for the implementation of national guidelines on good practice

However, it should be noted that there is currently limited empirical evidence with respect to widely accepted models of best practice.³⁶

NICE also makes a number of recommendations regarding care coordination for patients with dementia. Although not specific to YOD, they appear relevant also for these patients:⁵

- Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.
- Named professionals should:
 - arrange an initial assessment of the person's needs, which should be face to face if possible,
 - provide information about available services and how to access them,
 - involve the person's family members or carers (as appropriate) in support and decision-making,
 - give special consideration to the views of people who do not have capacity to make decisions about their care,

- ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate,
- develop a care and support plan, and:
 - agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals
 - specify in the plan when and how often it will be reviewed
 - evaluate and record progress towards the objectives at each review
 - ensure it covers the management of any comorbidities
 - provide a copy of the plan to the person and their family members or carers (as appropriate).
- When developing care and support plans and advance care, request consent to transfer these to different care settings as needed.
- Service providers should ensure that information (such as care and support plans and advance care) can be easily transferred between different care settings (for example home, inpatient, community and residential care).
- Staff delivering care and support should maximise continuity and consistency of care. Ensure that relevant information is shared and recorded in the person's care and support plan.

It is very important that all relevant information is shared with the patients and caregivers. A neat checklist for information provision at the times of diagnostic and post-diagnostic is provided in the Scottish Intercollegiate Guidelines Network (SIGN) guideline.⁶

A UK survey of people with YOD and carers (n=236) was carried out to understand the characteristics of support services they experience as helpful (Angela study).³⁷ In summary, three main characteristics emerged from the interviews: person-centredness (positive attitude, flexibility, collaborative, user-friendly materials, and in-person); functional consistency,



i.e. services organised consistently with needs (age-appropriate, holistic, responsive, and accessible); and organisational coherence (service integration, specialist services and service continuity).³⁷ Services were considered positive by people with YOD if they met three main needs: maintaining autonomy, allowing the person to be himself/herself, and enhancing connectedness with families, social circles and local communities.³⁸

2.6.2 *Providing a diagnosis of dementia*

Announcing a diagnosis of dementia is obviously a critical moment in the life of the patient and his/her family, and special care must be provided. The SIGN guideline (2023) provides a number of relevant recommendations about this:⁶

- A multidisciplinary team including the GP, the dementia specialist and other professionals aware of all relevant information about the patient's case may all be involved in discussing and providing a diagnosis of dementia.
- The discussion should include the patient and his/her carers. The role of the carers in supporting person with dementia and the healthcare professional by assisting with communication and recall of the discussion should be acknowledged.
- Healthcare professionals should consider discussing a dementia diagnosis in stages, over more than one session or as an ongoing process, allowing time for the information to be absorbed.
- Healthcare professionals should ensure that the discussion of a diagnosis of dementia should include positive and hopeful, yet realistic, messages; information on prognosis and sources of support; information on wellbeing and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia.

2.6.3 *Addressing reversible causes of secondary YOD*

A proportion of YOD cases may result from a reversible cause, such as:²

- Alcohol-related would count for 3% to 10% of YOD cases⁹
- An inflammatory, infectious (e.g. HIV, neurosyphilis), or metabolic (e.g. hypothyroidism) disease
- A poisoning by heavy metals
- An obstructive sleep apnoea

Other potentially modifiable risk factors for dementia (not specifically YOD) include hearing impairment, orthostatic hypotension, stroke, diabetes, obesity, high cholesterol levels, smoking, heart disease and depression.³⁹

In the presence of a reversible cause, the primary goal of patient care is to eliminate as much as possible this cause, following recommendations for good practice specific to each health problem.



2.6.4 Pharmacological interventions

There are no pharmacological treatments specifically recommended for YOD. Even for LOD, more randomised clinical trials (RCTs) are required to address the uncertainty surrounding the efficacy of medications including cholinesterase inhibitors, memantine and anti-amyloid beta monoclonal antibodies.⁴⁰⁻⁴³

Treatment for low mood and anxiety should follow general treatment guidelines, including psychotherapy and antidepressants with short term benzodiazepines for depression and anxiety.²

The first-line approach to the management of behavioural symptoms is non-pharmacological. However, sometimes a pharmacological treatment may be required as an adjunct, e.g. benzodiazepines for sleep disturbance, agitation and anxiety or risperidone for aggressive behaviour dementia.⁴⁴ Pharmacological treatments should be used wisely, particularly the antipsychotics as they are associated with major risks (extrapyramidal symptoms, stroke).²

2.6.5 Non-pharmacological interventions

In a recent narrative review including 16 primary studies⁹, Kim et al. 2024 presented five categories of non-pharmacological interventions for people living with young-onset dementia and their caregivers (search date: 20/03/2022).⁴⁵ We follow hereunder the same typology while adding additional examples or references, where relevant, particularly for clinical trials (Table 4).^h *Our comments on the quality of the evidence are written in italics.*

2.6.5.1 Cognitive rehabilitation

Rehabilitation refers to a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions. Interventions can include memory rehabilitation, concentration-enhancing training or using memory aids such as memos and diaries. Although rehabilitation cannot stop the progression of dementia, its importance in improving functional abilities and promoting health and quality of life has gained international recognition in recent years.⁴ YOD rehabilitation may be delivered by psychologists, occupational therapists, speech and language therapists, nurses, social workers, and physiotherapists. The core features of YOD rehabilitation services are the ability to provide age-appropriate and specialist support, integration within existing services, and continuity of care. When setting up interventions, understanding each individual's cognitive and behavioural profile (e.g. apathy subtype) is pivotal to effective personalised care (Table 3).⁴

⁹ The included 16 studies were published from 1996 to 2022. The studies were conducted in various countries: three studies were conducted in Norway. Additionally, two studies were conducted in the United Kingdom, the United States and the Netherlands, respectively. The remaining six studies were each conducted in a different country, and one multinational study was also conducted.

^h We searched MEDLINE for RCTs carried out in a population of YOD patients. The search string in MEDLINE/Pubmed was ((young-onset OR early-onset) AND dementia), with filters: randomised controlled trials; publication date: after 2004. It retrieved 16 hits, 6 of which were relevant and referring to 3 unique RCTs.

**Table 3 – Cognitive rehabilitation tailored to dementia cause**

Conditions	Symptoms	Cognitive rehabilitation
Amnesic young-onset Alzheimer's disease (EOAD)	Memory loss, disorientation	Cognitive rehabilitation can be delivered using techniques such as modelling, action-based learning, and graded activity. Once learned, assistive technology such as digital calendars, simplified TV remotes, mobile phones, and stove timers can help people with EOAD to orient and navigate around the neighbourhood or local shops, complete shopping tasks (e.g. form grocery lists to assist memory for purchasing items), improve safety within the household, and provide reminders to complete everyday tasks. Vocational rehabilitation may also be considered, with some evidence indicating safe, supported engagement in workplace contexts such as retail.
Behavioural frontotemporal (bvFTD)	variant dementia Functional decline across basic and complex activities of daily living, in parallel with behaviour and cognitive changes	• The occupational therapy-based intervention, Tailored Activity Program (TAP), may help maintain everyday functioning and reduce behaviour symptoms in FTD. TAP involves working collaboratively with family carers to prescribe personalised activities for behaviour management. • Positive Behaviour Support (PBS) therapy is a multicomponent plan involving a review of the person–environment fit, teaching positive skills that are functionally related to the target behaviour, considering antecedents, promoting desired behaviour, and providing strategies for how to react to the behaviour when it occurs.
Primary progressive aphasia (PPA)	A range of speech and language changes that impact social relationships and engagement.	Word retrieval therapies, which can be effectively delivered either face to face or via technology-supported methods. People with PPA may also benefit from developing and practising scripts (script training) to support anticipated conversations.
Posterior cortical atrophy (PCA)	Severe impairment in everyday skills and self-care tasks compared to those with typical (difficulty using the telephone, putting a coat on, preparing a hot drink, handling money, and using electrical appliances). Problems with reading due to visual disorientation (e.g. becoming lost on the page) and visual crowding (e.g. words and lines of text cluttering up).	Evidence-based recommendations for the rehabilitation of PCA are scarce

The information content is abstracted from Suarez-Gonzalez et al. 2024⁴



Kim et al. retrieved 5 studies, 4 of which were case reports. Each study included between 1 and 5 participants, and none was a RCT. The applied interventions included memory rehabilitations or concentration-enhancing training. Participants generally showed partial improvement or preservation of cognitive function, but one study reported neither improvement in cognitive function nor difference from the LOD group.

No relevant or reliable conclusion can be drawn from such small-scale non comparative studies.

2.6.5.2 Physical/social activities

Kim et al. retrieved 4 studies exploring group activities in a zoo, in a hardware store, in a soccer field and in a garden. Applying physical/social activities consisting of social gatherings and gardening activities led to a positive effect as a qualitative result, although it did not show statistically significant changes in well-being. A positive effect also resulted from supporting the desire for employment by giving people living with YOD a 'buddy' role such as guiding customers in stores, and connecting colleagues or friends through vocational activities.

All these studies were exploratory, with very small samples and no comparative design, so no firm conclusions can be drawn.

2.6.5.3 Psycho-educational interventions

Psycho-educational interventions for dementia aim to enhance the quality of life of carers, family members and people with early stage dementia by providing them with the necessary information and strategies to effectively manage their psychological symptoms.⁴⁵ Three studies provided participants with information about treatment, symptoms, resources, services, disease-related problems and/or problem-solving strategies for coping. The participants in all three studies were exclusively carers. Participants in the 3 studies expressed positive satisfaction with the interventions.

Only one of the studies was a randomised unblinded controlled pilot study, the RHAPSODY study (Table 4).⁴⁶ The RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) project is a European initiative to improve care for people with YOD by providing an internet-based information and skill-building program for family carers. The e-learning program focuses on managing problem behaviours, dealing with role change, obtaining support, and looking after oneself.⁴⁶ The evaluation included 61 participants and was set to prepare a subsequent trial testing an information and support programme for caregivers. Results indicated modest improvements in reported stress and negative reactions to patient memory symptoms among caregivers using the programme compared with a wait-list control group after 6 weeks. No statistical difference between groups in caregiving self-efficacy, caregiver burden, health-related quality of life was retrieved. Good acceptability by caregivers and healthcare professionals was confirmed in a more recent study in the Netherlands.⁴⁷ Another online pilot study evaluated the good acceptability of RHAPSODY-Plus intervention, i.e. RHAPSODY combined with individually tailored support sessions with health professionals (social worker or clinical psychologist).⁴⁸

Pivotal trials assessing the added value of such approaches are still lacking.

2.6.5.4 Psychosocial interventions

Psychosocial interventions are defined here as interventions that aim to improve a person's mental health and overall functioning in society mainly through counselling or support groups. There were two studies which used psychosocial interventions as their programme, mainly focusing on holding a group session for emotion processing.

The first study was a cluster RCT with a stepped wedge design conducted in hospital environment with people living with YOD in the Netherlands (n=274; Table 4).⁴⁹ It compared usual care with the effects of a series of psycho-social interventions being applied by carers when neuro-psychotic symptoms were apparent. No significant effect in physically aggressive behaviours, physically non-aggressive behaviours or verbally agitated



behaviours, neuropsychiatric symptoms (NPS), particularly agitation and aggression, and psychotropic drug use (PDU) were reported.⁴⁹

The second study conducted online meeting of carers, confirmed the positive responses of the participants, and described the factors required for successful intervention. *It was small scale (n=10) with limited extrapolation.*

We retrieved a third more recent study (Table 4).⁵⁰ It is a cluster RCT of a psychosocial intervention aiming at improving a sense of usefulness and engaging in meaningful activities (SPAN, n=35) against usual care (n=26). There was no statistically significant differences in empowerment, quality of life, neuropsychiatric symptoms, disability, or apathy of the patients.

2.6.5.5 *Environmental support*

Environmental support can be defined as interventions aimed at enhancing safety, security, social participation, mobility, and physical and cultural activities. Among the interventions, assistive technology (AT) has been highlighted as a solution to delay the need for service or hospitalisation (such as item/object locators, white boards with written messages, reminders and memory clocks). Only two small-scale non-comparative pilot studies were retrieved by Kim et al. 2024.⁴⁵ In both studies, participants generally showed positive responses on using AT.



Table 4 – RCTs of psychosocial interventions to improve health of YOD patients

Author	Trial	Methods and results
Bielderma et al. 2024 ⁵⁰	SPAN	- A cluster-randomised controlled trial of a psychosocial intervention aiming at improving a sense of usefulness and engaging in meaningful activities (SPAN, n=35) against usual care (n=26). - There was no statistically significant differences in empowerment (operationalised by self-management abilities using the SMAS-30; primary outcome), quality of life, neuropsychiatric symptoms, disability, apathy; and, for the family caregiver, quality of life, emotional distress, sense of competence
Appelhof et al. 2019 ⁴⁹ Van Duinen et al. 2019 ⁵¹ Van Duinen et al. 2020 ⁵²	BEYOND-II	- A cluster randomised controlled trial was conducted using a stepped wedge design. Thirteen YOD special care units were randomly assigned to three groups, which received the intervention at different time points. Four assessments took place every 6 months during a period of 18 months (274 participants) - The intervention consisted of an educational program combined with a care program, which structured the multidisciplinary process of managing neuropsychiatric symptoms (NPS), particularly agitation and aggression, and psychotropic drug use (PDU). - No significant differences were found in any of the dimensions. The intervention had no effect on the nursing staff neither (burnout, job satisfaction, job demands).
Kurz et al. 2016 ⁴⁶ Metcafe et al. 2019 ⁵³	RHAPSODY	- An online information and skill-building programme developed specifically for young onset dementia carers (RHAPSODYⁱ) was evaluated in a pilot randomised controlled trial with 61 participants to assess user acceptability and satisfaction. Group A (intervention) were gain immediate access. After 6 weeks, group B (waiting-list control) were also given access. Assessment was conducted at Week 6 (mid-point) and at Week 12. - Overall caregivers reported finding the programme easy to use, useful, and relevant. User activity on the programme was moderate (one visit per week on average). Results indicated modest improvements in reported stress and negative reactions to patient memory symptoms among caregivers using the programme compared with a wait-list control group after 6 weeks. No statistical difference between groups in caregiving self-efficacy, caregiver burden, health-related quality of life.

ⁱ The RHAPSODY project (Research to Assess Policies and Strategies for Dementia in the Young), a consortia of six European countries (England, France, Germany, Netherlands, Portugal, and Sweden), set out to develop a web-based multimedia, information, and skill-building programme for carers of people with YOD and to evaluate it in a pilot study. The finished programme features seven modules covering the nature of YOD, medical explanations, common problems and solutions, management of cognitive and behavioural symptoms, adapting to relationship changes, available care and support, and self-care suggestions. The multimedia format combines written and video content, case-studies, presentations from professionals, and downloadable materials.



2.6.6 Work and vocational rehabilitation

People diagnosed with YOD encounter significant challenges associated with employment, and individual and family finances. Multi-agency support is often needed to promote the continued employment of younger people with dementia, starting with accommodations and changes in role, before transitioning into early retirement.² A whole-of-family approach to the management of YOD is needed to ensure that families have adequate access to financial resources, respite, social and educational opportunities, and psychoeducation.²

There is a need for specific information and guidance for healthcare professionals around employment rights, income support and welfare benefits and the pension status for this group of people. Additionally, healthcare professionals should be cognisant of the additional financial burden people face in YOD when advising on services which incur out-of-pocket costs.⁵⁴

2.6.7 Advance care planning

Given the complex care needs and more rapid disease trajectory in YOD, planning together with the patient palliative care and preferences for end of life should be considered from the time of diagnosis, and be incorporated into routine dementia care.⁵⁵⁻⁵⁷ SIGN guidelines recommends to offer early and ongoing opportunities for people living with dementia (not specific to YOD) and people involved in their care to discuss and to make an advance statement about their wishes, preferences, beliefs and values regarding their future care, advance decisions to refuse treatment, their preferences for place of care and place of death. It is also important to explain that they will be given chances to review and change any advance statements and decisions they have made.⁶

2.7 Discussion

As illustrated in the sections above, there is a paucity of data on the various aspects of YOD. Evidence on what works in real-life practice is currently scarce.³⁸ However, this does not mean we are entirely without options to support those affected by YOD. For example, cognitive rehabilitation in AD patients can significantly improve their occupational performance levels and satisfaction with goal attainment.^{58, 59} Although there is virtually no evidence of such approach in YOD (see section 2.6.4.1), there is no obvious reason to think that management of AD should differ between younger and older patients. Similarly, the NICE guideline (2018) on dementia contains a chapter on the needs of patients with YOD, but makes no specific recommendations for this group, i.e. the recommendations apply to both YOD and LOD.⁵ Similarly, the package of interventions for dementia rehabilitation recently released by the WHO also does not separate YOD and LOD.^j The lack of evidence should therefore not prevent us from providing the best possible care for these patients, but it does underline the importance of evaluating practice and care programmes adapted to the needs of patients with YOD (from diagnosis to post-diagnosis support services) in the most serious and scientific way possible. This also concerns web-based interventions.⁵⁷ For developing care programs that are tailored to the needs of YOD patients, it is critical to acknowledge that YOD often involves other underlying aetiologies that are less prevalent or not represented in late-onset dementia (LOD) studies. These differences can influence symptom presentation, progression, and treatment responses. Recognizing and integrating these unique characteristics is essential when determining what interventions work best for whom in real-life practice.⁵⁷

^j <https://iris.who.int/bitstream/handle/10665/370504/9789240071131-eng.pdf?sequence=1>



3 CARE NEEDS AND EXPERIENCES OF PEOPLE WITH YOUNG-ONSET DEMENTIA AND THEIR CAREGIVERS: A RAPID REVIEW OF THE LITERATURE

3.1 Key points

- This rapid review summarises the care needs and experiences of people diagnosed with YOD and their caregivers from 2015 on. The needs and experiences are classified by biological needs, health care services needs, psychological needs, social needs and spiritual needs. A total of 17 publications were included. These comprise seven primary studies and six reviews addressing both YOD patients and their caregivers and/or their children, and four reviews focusing exclusively on caregivers/children of patients with YOD.
- Individuals with YOD experience unique difficulties compared to patients suffering from LOD, including career disruption, altered family roles and increase social isolation. The early onset brings profound psychological distress due to a loss of autonomy and future aspirations.
- Spouses or partners often face dual roles in caregiving and household management, causing emotional and physical strain. Financial stress is common, with caregivers often needing to reduce work hours, highlighting a need for financial support and workplace accommodations. Children of YOD patients often assume caregiver roles, leading to emotional distress, social isolation, and uncertainty. Psychological support and counselling are essential for these children.

- Public education and training on YOD are crucial for reducing stigma and improving support. Specialised training for healthcare providers is necessary to meet YOD-specific needs.
- Policies should support comprehensive, integrated care for YOD patients and families, involving multidisciplinary teams and a coordinating healthcare professional knowledgeable in YOD. Patients and caregivers benefit from age-specific, flexible support services that adapt to the disease's progression and encourage both formal and informal peer support networks.

3.2 Introduction

Young-onset dementia (YOD), defined as dementia diagnosed before the age of 65, presents unique challenges that requires distinct care approaches compared to late-onset dementia. Individuals with YOD often face difficulties related to their life stage, such as employment concerns, financial instability, and the impact on dependent children. As a result, both individuals with YOD and their caregivers experience significant emotional, social, and practical burdens that are often overlooked in traditional dementia care. It is uncertain to what extent the current needs of people with YOD and their caregivers, including children, are met and whether they are satisfied with the available services and access to care. Understanding these aspects is crucial for developing appropriate interventions and person-centred care that address their specific needs.

Therefore, this rapid review aims to synthesise existing literature on the care needs and experiences of individuals with YOD and their caregivers. The goal is to inform the development of tailored care strategies that effectively address the unique challenges faced by this population.



3.3 Methods

This chapter aims to describe the care needs and experiences of people diagnosed with YOD, their caregivers and their children. The research question was formulated using the PICOTS (Population, Intervention, Comparator, Outcomes, Timing, Study design) framework (Table 5).

An initial search on Medline using general search (Medical Subject Heading – MeSH) terms and a filter for systematic literature reviews identified two relevant systematic literature reviews that partially addressed our research question.^{60, 61} These reviews included comprehensive literature searches up to the end of 2015, covering 27 articles in one and 304 studies in the other.

Given the thoroughness of these previous reviews, we decided to conduct a rapid review of the literature. We used these reviews as the starting point for our literature search and screened the literature from 2015 onwards. We focused on primary studies and systematic literature reviews related to patients with YOD. Additionally, we only included systematic literature reviews to describe the needs and experiences of caregivers and children of YOD patients.



Table 5 – Inclusion/exclusion criteria and relevant keywords/search concepts

	Inclusion criteria	Exclusion criteria	Relevant keywords and search concepts
P	People diagnosed with YOD and their caregivers/children YOD is defined as dementia of which symptoms develop before the age of 65	People diagnosed with late-onset dementia (>65 years) and their caregivers/children	Dementia/ • AIDS Dementia Complex • AD • Aphasia, Primary Progressive • Primary Progressive Nonfluent Aphasia • Creutzfeldt-Jakob Syndrome • Dementia, Vascular • Dementia, Multi-Infarct • Diffuse Neurofibrillary Tangles with Calcification • Frontotemporal Lobar Degeneration • Frontotemporal Dementia + • Primary Progressive Nonfluent Aphasia • Huntington Disease • Kluver-Bucy Syndrome • Lewy Body Disease • Mixed Dementias Neurocognitive disorders/ Young-onset: age of onset/ AND (Middle Aged/ OR Young Adult/ Caregivers/ AND Family/ Spouse Caregiver Family Caregiver Informal Caregiver
I	Use of care and other services	-	-
C	-	-	-
O	<i>Primary:</i> experiences, needs, problems, satisfaction, and accessibility		Health Services Needs and Demand/ Health Services Accessibility/ Needs Assessment/ Patient Satisfaction/



T	First search identified two relevant systematic literature studies (published in 2016): - therefore we only include studies published between 2015 and current.		
S	Patients with YOD: all types of scientific study designs will be included: qualitative, quantitative, systematic literature reviews. Caregivers: only systematic literature reviews	Patients with YOD: editorials Caregivers: all other types of study designs	-

3.3.1 Literature search and selection

We followed the KCE Process Book for conducting the search^k. The following electronic databases were searched: (i) Ovid® Medline, (ii) Research Rabbit, (iii) EMBASE, and (iv) APA PsycInfo® (Table 6). Search queries were developed by assistance of a medical information specialist and adapted to each database. The online tool Research Rabbit was used to identify articles similar to Millenaar et al. (2016) and Sansoni et al. (2016).^{60, 61} The search strategies for these databases are documented in Appendix 1. Search in these databases was supplemented by collecting additional references from different sources (external experts, exploratory searches in the bibliographical databases, identification of cited references and looking into the bibliography of key references). To be eligible, a study needed to describe the care needs and/or experiences of people diagnosed with YOD (defined as dementia with symptoms developing before the age of 65). Only full articles published in English, Dutch or French were included. To increase the relevance of the results for the Belgian context, we only included studies conducted in high-income OECD countries.^l Because the primary aim of this rapid review was targeted on patients with YOD, we included both primary studies and systematic literature reviews for this

group. For caregivers and/or children of YOD patients, we included only systematic literature reviews. Letters, editorials, commentaries and abstracts were excluded. A time limit was applied from 1 January 2015 to 5 January 2024.

Table 6 – List of sources searched for studies

Source (Interface)	Set	Date of search
MEDLINE (OVID)	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to December 01, 2023>	2023-12-04 (Subject headings) 2023-12-22 (Text word)
Research Rabbit		2023-12-08
Embase (Embase.com)		2024-01-05
PsycInfo (OVID)	APA PsycInfo <2002 to January Week 1 2024>	2024-01-05

^k <http://processbook.kce.fgov.be/>

^l High income (World Bank, dd 4 January 2024) and OECD countries (alphabetically): Australia, Austria, Belgium, Canada, Chile, Czechia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland,

Ireland, Israel, Italy, Japan, Korea, Latvia, Lithuania, Luxembourg, Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, United Kingdom and United States of America.



All identified references were imported in Endnote X.8, the duplicate search results were detected based on title match using the build-in tool from EndNote, and supplemented by manual identification after sorting on Title. A total of 1400 records were provided for screening. References from research Rabbit were checked to ensure they did not come from predatory publishers. Studies were screened by two researchers (WC and JD) using the PICOTS in- and exclusion criteria in Rayyan®. The initial screening was based on title and abstract. In a second step, the remaining papers were screened by reading the full-text by the same two researchers.

3.3.2 Data extraction

For each study, we extracted the following descriptive data: country, study design (only for primary studies), time frame, population, sample and inclusion/exclusion criteria. Afterwards, each included publication was read in-depth, and the care needs and experiences were thematically coded using the software package NVivo®. This data-extraction and coding was performed by one researcher (JD). Because the aim of this review is to quickly gain comprehensive knowledge on the topic, we decided to simplify the methods compared to traditional systematic literature reviews, by not subjecting the methodological quality of the included studies to a critical appraisal.

3.4 Results

3.4.1 Overview of selected studies

The procedure of the screening process is summarised in Figure 1. A total of 17 publications were included in this rapid review. These comprised seven primary studies and six reviews addressing both YOD patients and their caregivers and/or their children, and four reviews focusing exclusively on caregivers/children of patients with YOD. Among the primary studies, four used a qualitative research design and two employed a quantitative cross-sectional survey design. The reviews covering both YOD patients and caregivers utilised various methods: two scoping reviews, one qualitative meta-synthesis, one systematic literature review, one rapid literature review and one integrative review. The reviews focusing only on caregivers/children of YOD patients included one qualitative systematic literature review, one scoping review, one meta-ethnographic review, and one systematic literature review. More details about the included publications can be consulted in Table 7.

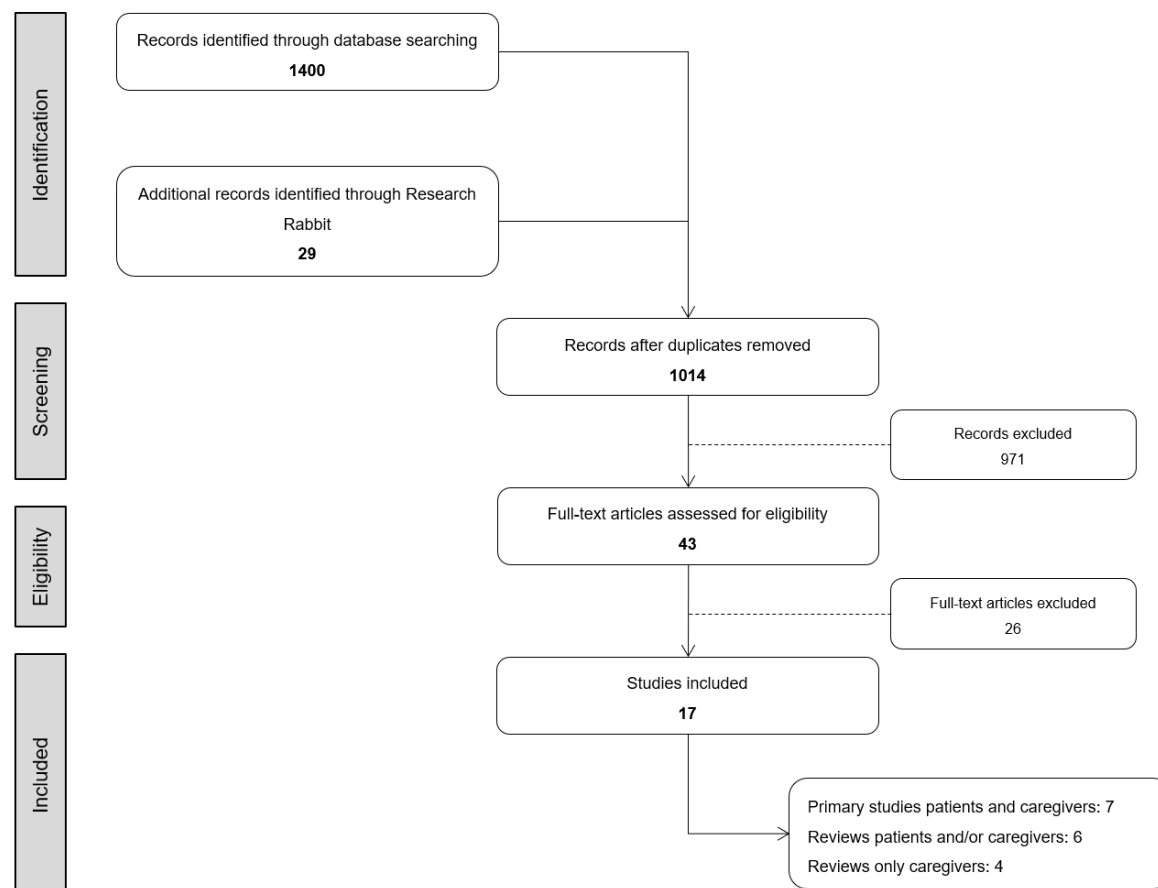
**Figure 1 – Flow chart of the screening process**



Table 7 – Study characteristics of the included publications

Author (year)	Country	Study design	Time frame	Population	Sample	In- and exclusion criteria
PRIMARY STUDIES – PATIENTS (AND CAREGIVERS)						
Rimkeit et al. (2017) ⁶²	NZL	Qualitative design	n/a	People with YOD who anticipate or experience residential old age services	n = 10 ^m	Purposive sampling was employed using hospital data which identified 28 people aged under 65 years who had been diagnosed with dementia and were eligible for old age services. Ten people with younger onset dementia were selected for a maximum variety of experiences.
van Vliet et al. (2017) ⁶³	NLD	Qualitative design: focus groups	n/a	People with YOD and caregivers	Patients n = 18 Caregivers n = 21	Inclusion: participants were eligible to participate if (1) dementia was diagnosed, (2) symptom onset was before the age of 65 years, (3) they were living in the community, and (4) a healthcare professional of the participating organisation deemed them able to participate in a group discussion. Family caregivers were relatives, partners, or friends who had a significant personal relationship with, and provided a broad range of assistance to, a person with YOD for at least three months and/or more than 8 hours per week. Family caregivers were not necessarily related to the participating persons with YOD.
Mayrhofer et al. (2021) ⁶⁴	GBR	Cross-sectional online survey design	August – October 2019	People with YOD ⁿ	n = 55	Inclusion: patients have to be diagnosed below the age of 65.
Stamou et al. (2021) ⁶⁵	GBR	Quantitative design: cross-sectional semi-structured survey	August 2017 – September 2018	Explore positive real-life practices of post-diagnostic support among people with YOD and caregivers	n = 233	Inclusion: people received a diagnosis of dementia, as defined by DSM-5, before the age of 65, or cared for a younger person with dementia. Exclusion: people with dementia caused by HIV, traumatic brain injury, Down's syndrome, Huntington's disease or alcohol-related dementia were excluded as they usually access different specialist services.
Broders et al. (2022) ⁶⁶	CAN	Qualitative design	n/a	Women with YOD	n = 5	Inclusion: any woman living with a diagnosis of some type of YOD, providing they were able to give their consent to participate, and would feel comfortable

^m Nine people with YOD were interviewed and 11 family or community support persons.

ⁿ Of the 55 respondents, 71% (n = 39) received assistance of family or caregiver when completing the survey.



Author (year)	Country	Study design	Time frame	Population	Sample	In- and exclusion criteria
Ikeuchi et al. (2022) ⁶⁷	JAP	Qualitative design	September 2018 – February 2019	People with YOD with full-time employment or who have recently left the labour market	n = 11	articulating and sharing their experiences of living with dementia with a researcher. Inclusion: People under the age 65 years with dementia with full-time employment or having left employment within one year of receiving a diagnosis of YOD, consent obtained from both the participant and their family members and able to talk about their experiences from the onset of their illness to the present and able to cooperate with this study.
Van Rickstal et al. (2022) ⁵⁶	BEL	Qualitative design	August – December 2019	Explore views on advance care planning of people with YOD and their family caregivers	n = 20	Inclusion: For persons with dementia: (i) being formally diagnosed with young- or late-onset probable AD (based on strictly applied standard diagnostic criteria; e.g. NIA-AA criteria), (ii) having a score of minimum 16 on the MMSE, (iii) being diagnosed for at least 6 months (for reasons of sensitivity to grieving stage after diagnosis), (iv) being 18 years of age or older, (v) speaking Dutch and (vi) signing written informed consent (themselves + caregivers' consent as witnesses is required) For family caregivers: (i) being the primary caregiver of a person formally diagnosed with young- or late-onset probable AD, (ii) being 18 years of age or older, (iii) speaking Dutch and (iv) signing written informed consent (and providing consent for person with dementia, as witness).
REVIEWS – PATIENTS (AND CAREGIVERS)						
Ritchie et al. (2015) ⁶⁸	n/a	Integrative review	n/a	Persons with dementia in the workplace	n = 6	n/a
Millenaar et al. (2016) ⁶⁰ °	n/a	Systematic literature review	Inception November 2015	People with YOD and their caregivers	n = 27	Inclusion: studies were included if they focused on individuals with dementia onset before the age of 65 years or their informal caregivers; focus on care needs or

° Part of the European RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) study: for more information, see section 5.3.



Author (year)	Country	Study design	Time frame	Population	Sample	In- and exclusion criteria
						experiences with services; and availability of the full-text article in English, Dutch, French or German. Exclusion: Articles that focused solely on people with Huntington's disease or on dementia after acquired brain damage, HIV, alcohol abuse or Down's syndrome were excluded.
Sansoni et al. (2016) ⁶¹	AUS EUR GBR USA CAN Other	Rapid review	literature	2000 - 2016	People with YOD	n = 304 Inclusion: (1) a primary or comparative focus on YOD and (2) relevance to the service needs and service provision for people with YOD.
Andrew et al. (2018) ⁶⁹	GBR (2) USA (1) GBR, USA (1) SWE (1) AUS (1)	Scoping review	2000 – 2017	People who experience onset of YOD symptoms while in paid employment	n = 6	Inclusion: quantitative, qualitative and mixed method peer reviewed research investigating the relationship between participation in paid work and dementia Exclusion: literature reviews, opinion-based literature and editorial publications, studies investigating correlation between type of work and risk of developing, and studies investigating correlation between cognitive reserve and presentation of dementia.
O'Malley et al. (2021) ^{70 p}	GBR (3) USA (1) NOR (1) FRA (1) n/a (1)	Scoping review	Inception – 15 November 2018	People with YOD and their family members and/or informal caregivers	n = 8	Inclusion: qualitative or mixed method research that directly involves people living with YOD, investigations of the lived experiences of YOD and where themes surrounding diagnosis are reported, research that involves speaking directly to those affected by YOD (i.e. those diagnosed and/or their family members/carers), articles published in English.
Bannon et al. (2022) ⁷¹	NOR (8) GBR (5) ENG (6) NLD (3)	Qualitative meta-synthesis	Inception – January 2020		n = 43	Inclusion: article is written in English, published in a peer-reviewed academic journal, concerns original research and primary data collection, used any type of qualitative methods for data, collection or qualitative analysis of data (including mixed-methods), concerns

^p Part of the Angela Project, a three-year research study carried out in the UK (for more information, see section 1.1).



Author (year)	Country	Study design	Time frame	Population	Sample	In- and exclusion criteria
	AUS (4) CAN (3) IRE (1) COL (1) BRA (1) USA (1) FRA (1) SCT (1) BEL (1) ENG, FRA, DEU (1) CAN, USA (1) n/a (1)					patients or informal caregivers to patients with a diagnosis of YOD (patients aged 65 and under), relevant to patients' and/or caregivers' experiences, needs, and/or preferences for psychosocial support resources in the postdiagnosis period, article published during or after year 2010. Exclusion: article does not concern primary data collection (e.g. opinion article or literature review), used quantitative methodology only for data collection and analysis, concerns patients or informal caregivers to patients with a diagnosis of later-onset dementia (patients aged 65 and older) or a non-YOD diagnosis, not relevant to patients' and/or caregivers' experiences, needs, and/or preferences for psychosocial support resources in the postdiagnosis period.
REVIEWS – CAREGIVERS ONLY						
Cartwright et al. (2021) ⁷²	GBR (7) NOR (3) NLD (1) AUS (2) USA (1) CAN, USA (1)	Qualitative systematic literature review	Inception – 23 March 2020	Individuals whose parent has a diagnosis of YOD	n = 15	Inclusion: published in English in a peer-reviewed journal, study population consisted primarily of the children (including those both under and over the age of 18 years and stepchildren) of people living with YOD (defined as dementia diagnosed before the age of 65 years), or the data from children could be separated from that of other participants, stated aim of the study concerned individual experiences, caring experiences or implications of caring on the children, qualitative or mixed methods, primary research. Exclusion: published in non-peer-reviewed journals, grey literature or were unpublished theses, not an empirical article (e.g. was a review, conference abstract or protocol), solely quantitative data collected.
Karnatz et al. (2021) ⁷³	EUR(22) USA/CAN (24) AUS (16)	Scoping review	Inception April 2017	– Caregivers of people with frontotemporal lobar degeneration (FTLD)	n = 69	No limitations were made regarding the type of study, including posters and congress publications, and publication date; articles were excluded if they were in a language other than English or German. All studies that focused on caregivers that included an FTLD cohort as



Author (year)	Country	Study design	Time frame	Population	Sample	In- and exclusion criteria															
						well as interventions that assessed caregiver burden in the said cohort were included. When we searched the ScienceDirect database, the following filters were applied: for “ALS caregiver burden” and “aphasia caregiver burden”, the topic “dementia” was set to exclude a large number of articles addressing other aspects of these diseases.															
Tookey et al. (2021) ⁷⁴	CAN (2) GER (1) NOR (1) USA (2) AUS (2) GBR (1) SWE (1) NLD (2)	Systematic literature review	January 2003 – July 2019	Caregivers of people with frontotemporal dementia (FTD)	n = 12	Inclusion: quantitative, qualitative, and/or mixed method studies; non-interventional studies; reported results relating to needs, experience or coping strategies of informal carers of adults with FTD; sample were informal family carers of adults with FTD; English language or translation available articles; peer reviewed; published between June 2003 and June 2019. Exclusion: pooled samples of carers of FTD with other dementias; no reported diagnosis of FTD; case series or case report, review studies, letters to the editors, professional opinions, dissertations or conference abstracts; reported only carer burden; reported only comparison findings between FTD and other dementias; focus only on patient (not carer).															
Poole et al. (2022) ⁷⁵	GBR (9) NOR (3) AUS (2) NLD (1) USA (1)	Meta-ethnographic review	n/a	Children who have a parent with YOD	n = 16	Table 1. Inclusion and exclusion criteria for systematic search. <table><tr><th></th><th>Inclusion</th><th>Exclusion</th></tr><tr><td>Research design</td><td>Qualitative, quantitative or mixed methods studies</td><td>Review papers, opinion papers</td></tr><tr><td>Quality</td><td>Peer-reviewed empirical studies</td><td>Unpublished or gray literature, non-peer-reviewed sources</td></tr><tr><td>Concepts</td><td>Experience or impact of having a parent with young onset dementia</td><td>Epidemiology or genetics, interventions or treatments</td></tr><tr><td>Sample</td><td>Children of people who were diagnosed with dementia under the age of 65. No upper or lower age limit for child.</td><td>Children of people with late-onset dementia, other family caregivers, patients with dementia, children of people with other physical or mental health conditions</td></tr></table>		Inclusion	Exclusion	Research design	Qualitative, quantitative or mixed methods studies	Review papers, opinion papers	Quality	Peer-reviewed empirical studies	Unpublished or gray literature, non-peer-reviewed sources	Concepts	Experience or impact of having a parent with young onset dementia	Epidemiology or genetics, interventions or treatments	Sample	Children of people who were diagnosed with dementia under the age of 65. No upper or lower age limit for child.	Children of people with late-onset dementia, other family caregivers, patients with dementia, children of people with other physical or mental health conditions
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Research design	Qualitative, quantitative or mixed methods studies	Review papers, opinion papers																			
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Author (year)	Country	Study design	Time frame	Population	Sample	In- and exclusion criteria														
Wiggins et al. (2023) ⁷⁶	GBR (9) NOR (3) USA (3) AUS (2) NLD (1)	Systematic literature review	Inception – 10 May 2022	Asymptomatic relative of a person with YOD and onset of YOD in the affected person before age of 65	n = 19	<table><tr><th colspan="2">Table 2 Inclusion and Exclusion Criteria.</th></tr><tr><th>Inclusion</th><th>Exclusion</th></tr><tr><td><i>Population</i> Asymptomatic relative of a person with young onset dementia (YOD) AND onset of YOD in the affected person before age of 65</td><td><i>Population</i> Caregivers or spouses not at potential genetic risk Onset of dementia in affected family member after the age of 65 Included population not differentiated from excluded population (e.g if results about spouses and children are not distinguished) Age of onset of the affected person is not specified</td></tr><tr><td><i>Intervention</i> Family member with YOD onset before age 65</td><td><i>Intervention</i> Family member diagnosed with late-onset dementia</td></tr><tr><td><i>Comparison</i> N.A</td><td><i>Comparison</i> N.A</td></tr><tr><td><i>Outcome</i> Articles presenting data on the experiences, needs, challenges, social or psychological impact of having a relative diagnosed with YOD</td><td><i>Outcome</i> Articles that do not differentiate the experiences of asymptomatic family members and spouses Articles which do not include information on the experience or psychological or social impact of having a family member with YOD</td></tr><tr><td><i>Study design</i> Empirical peer reviewed studies (qualitative, quantitative & mixed methods) Articles written in English No date restrictions were imposed</td><td><i>Study design</i> Reviews, editorials or opinion pieces Unpublished research or poster presentations Empirical studies that are not peer reviewed or have been retracted Articles not in English</td></tr></table>	Table 2 Inclusion and Exclusion Criteria.		Inclusion	Exclusion	<i>Population</i> Asymptomatic relative of a person with young onset dementia (YOD) AND onset of YOD in the affected person before age of 65	<i>Population</i> Caregivers or spouses not at potential genetic risk Onset of dementia in affected family member after the age of 65 Included population not differentiated from excluded population (e.g if results about spouses and children are not distinguished) Age of onset of the affected person is not specified	<i>Intervention</i> Family member with YOD onset before age 65	<i>Intervention</i> Family member diagnosed with late-onset dementia	<i>Comparison</i> N.A	<i>Comparison</i> N.A	<i>Outcome</i> Articles presenting data on the experiences, needs, challenges, social or psychological impact of having a relative diagnosed with YOD	<i>Outcome</i> Articles that do not differentiate the experiences of asymptomatic family members and spouses Articles which do not include information on the experience or psychological or social impact of having a family member with YOD	<i>Study design</i> Empirical peer reviewed studies (qualitative, quantitative & mixed methods) Articles written in English No date restrictions were imposed	<i>Study design</i> Reviews, editorials or opinion pieces Unpublished research or poster presentations Empirical studies that are not peer reviewed or have been retracted Articles not in English
Table 2 Inclusion and Exclusion Criteria.																				
Inclusion	Exclusion																			
<i>Population</i> Asymptomatic relative of a person with young onset dementia (YOD) AND onset of YOD in the affected person before age of 65	<i>Population</i> Caregivers or spouses not at potential genetic risk Onset of dementia in affected family member after the age of 65 Included population not differentiated from excluded population (e.g if results about spouses and children are not distinguished) Age of onset of the affected person is not specified																			
<i>Intervention</i> Family member with YOD onset before age 65	<i>Intervention</i> Family member diagnosed with late-onset dementia																			
<i>Comparison</i> N.A	<i>Comparison</i> N.A																			
<i>Outcome</i> Articles presenting data on the experiences, needs, challenges, social or psychological impact of having a relative diagnosed with YOD	<i>Outcome</i> Articles that do not differentiate the experiences of asymptomatic family members and spouses Articles which do not include information on the experience or psychological or social impact of having a family member with YOD																			
<i>Study design</i> Empirical peer reviewed studies (qualitative, quantitative & mixed methods) Articles written in English No date restrictions were imposed	<i>Study design</i> Reviews, editorials or opinion pieces Unpublished research or poster presentations Empirical studies that are not peer reviewed or have been retracted Articles not in English																			

n/a: not available



3.4.2 Biological needs

Biological needs vary depending on the underlying disease, but a common demand of patients is the relief of their physical symptoms (e.g. pain, fatigue, dyspnoea, lack of appetite, constipation).⁷⁷ However, none of the publications we reviewed identified biological needs of patients with YOD or their caregivers and/or children.

3.4.3 Health care services needs

According to Paulus et al. (2012)⁷⁷, health care services needs typically refer to single and reliable healthcare provider (usually the GP), as well as care collaboration and integration and shared expertise among providers, regardless of the care setting.

3.4.3.1 Health care services needs of people with YOD

Diagnosis is long process

A major challenge faced by individuals with YOD is obtaining a timely and accurate diagnosis. Research indicates that it typically takes about 4.5 years from the onset of early symptoms to receiving a formal diagnosis, compared to approximately 2.8 years in late-onset dementia.³

The complexity of YOD subtypes often results in overlapping symptoms, making differential diagnosis challenging.^{60, 61} Also, delays in diagnosis, initial misdiagnosis or misattribution of symptoms to psychiatric disorders are commonly reported in the literature.^{60, 61, 66, 68, 70} Lack of familiarity with and enquiry of symptoms that may be more typical in rarer dementia types may lead to symptom dismissal, or misattribution to primary psychiatric disorders (particularly depression, stress or burn out), causes frustration for patients and a sense of having to fight to be heard.⁷⁰ This is in the literature attributed to a lack of knowledge or alertness about YOD among health care professionals. For example, the fact that the individual is still working seems to influence clinicians. However, it is not uncommon for dementia in younger people to present with non-cognitive symptoms (e.g. psychosis, mood disturbances, personality changes) and for day-to-day activities and

functioning to be well-preserved.⁷⁰ Additionally, the **absence of a clear diagnostic pathway** contributes significantly to the prolonged duration of the diagnostic process.⁶¹

Furthermore, patients themselves may unintentionally prolong the diagnostic process.⁷⁰ O'Malley et al. (2021)⁷⁰ illustrated that some individuals and their families initially ignore early prodromal symptoms wishing to maintain normalcy in their lives, or avoiding associating symptoms with dementia out of a desire to preserve hopefulness (ignorance is bliss).

Emotional shock

Receiving a diagnosis of YOD can evoke a mixture of reassurance and destabilisation. For instance, O'Malley et al. (2021)⁷⁰ describes that while the diagnosis ends a period of doubt for the patient, it also destabilises by disrupting their previously maintained equilibrium. Nevertheless, there is consensus in the literature regarding the emotional shock experienced upon receiving a YOD diagnosis.^{61, 78} People often feel overwhelmed and receive a flood of information at the moment of the diagnosis, leaving little space to process the shock. Access to **face-to-face emotional support immediately after diagnosis** is highlighted as highly beneficial.⁷⁰ Moreover, providing advice and information specific to the younger age of the patient and how to cope with symptoms can help patients comprehend their condition and adapt to live with the diagnosis.⁶⁵

Difficulties in finding and accessing support services

Once diagnosed, patients with YOD often struggle to timely apply for support due to a **complicated, non-transparent system filled with barriers**.⁷⁰ The process is lengthy and usually requires repeated assessments.⁶⁴ Additionally, many services and supports are only available to those over 65, excluding younger individuals with dementia from qualifying for assistance.⁶⁶

Consequently, these patients may miss out on essential benefits, leading to financial and legal difficulties (see section 3.4.5.1). Patients with YOD feel that external support gives a sense of security, which is an important



prerequisite for staying active as long as possible.⁶³ Therefore, it is important to help patients and families navigate the system, understand relevant legislation, and access available benefits. In the study of Mayrhofer et al. (2021)⁶⁴ participants required assistance from professionals, such as financial advisors and charity volunteers, to manage the benefits system effectively.

Persons with YOD, but also their caregivers, prefer **services tailored to the stage of the illness, their age and current functioning**.⁷¹ They appreciate support that addresses their specific challenges (for instance, parenting while having YOD). Both groups express a need for “gentle support” to help them cope with the diagnosis and the transition to being care partners.

Need for coordinating care professional

In this respect, individuals with YOD emphasise the importance of having a **fixed care coordinator** who can help them access services tailored to their evolving needs.⁶⁵ This role is ideally fulfilled by a health care professional (e.g. physician, nurse, occupational therapist, etc.) who is connected to collaborative networks of services.⁶⁵ Also caregivers find it important to have someone to talk to who knows their relative with YOD and is familiar with their situation.⁷²

Importance of autonomy and empowerment

A common concern among YOD patients is the fear of losing choice and control in their daily life.^{62, 63} Many patients with YOD may miss their “normal” life in which they could effortlessly perform daily tasks (such as driving a car, going to work, and doing housework). Parenting and partner roles also change (see section 3.4.5.1). Loss of autonomy and social roles is linked to the loss of feeling useful.⁶³

In addition, there is a fear that using services designed for the frail and elderly will limit their choices or even leave them feeling imprisoned with no choices at all. This loss of choice, especially regarding activities that promote physical fitness and meaningful engagement, can lead to feelings of anger and anxiety.⁶²

Loss of empowerment is often due to being excluded from decision-making, sometimes by well-meaning caregivers or service staff. For example, Van Rickstal et al. (2022)⁵⁶ found that participants in their study were largely unaware of advance care planning and did not engage in it. Many YOD patients express a strong desire to stay engaged and maintain control over their lives as much as possible.⁶¹ Therefore, YOD patients and caregivers emphasise the **importance of autonomy, empowerment, and dignity in care provision**.⁵⁶

Need for purposeful and age-appropriate services

The sudden transition from an active working life to changing work arrangements or even having to stay at home full time can lead to a profound sense of loss of purpose. Together with the loss of future perspective and social isolation that often accompanies it, **the need for purposeful and age-appropriate support programs to regain a sense of self-esteem and identity** is important.⁶³ People with YOD are frequently directed to services designed for late-onset dementia, as these are more established or accessible. However, these services often lack emotional and supportive therapy to address the grief, anxiety and anger that arises from experiencing a condition out of synchronisation with younger age.⁶²

Access to age-appropriate services is positively experienced, but this relies heavily on health care professionals who are knowledgeable about the availability of these services.⁶⁵

Patients with YOD generally prefer **to stay home for as long as possible**.⁵⁶ A strong community support system can help delay the need for institutional care.⁶¹ Despite caregivers' fears about eventually needing to transfer their relatives to residential care, institutionalisation can sometimes be necessary. However, patients and caregivers often feel that the residential care system, as it is organised now, does not adequately meet the needs of younger people with dementia.⁵⁶



3.4.3.2 *Health care services needs of caregivers and children of people with YOD*

Difficulties in diagnostic process

Caregivers and children of patients with YOD report similar issues with the diagnostic process as patients themselves.^{60, 61, 74, 76} Early recognition and referral are identified as major areas for service improvement. Recognising and attributing early symptoms is important because subtle and gradual behavioural and personality changes can be misinterpreted. For example, by partners, which may negatively affect the marital relationship.^{61, 74} Misdiagnosis and delays in accurate diagnosis lead to uncertainty and confusion.^{60, 72}

Caregivers describe the experience of receiving a diagnosis as shocking and confusing. Despite this difficult experience, some caregivers may feel relief upon receiving a diagnosis because it opens the door to receiving support from services.⁷⁴

Need for support

In a study conducted in 2014 identified in the review of Karnatz et al. (2021)⁷⁶, it was revealed that 58% of the caregivers of people with YOD do not receive any kind of support. Caregivers experience that there is a lack of referral to support services, resulting in the feeling of “falling between the cracks of the system”.^{60, 61, 74} Similar to patients with YOD, the long diagnostic process delays access to support services.⁶⁰ Poole et al. (2022)⁷⁵ highlighted that the timing of support initiation is crucial; while support may be unnecessary in the early stages, it becomes more relevant as the condition progresses.

However, especially children of people with YOD often feel “powerless” because their needs are not always recognised due to their age or separately from those of their parent. This is particularly true for asymptomatic family members who are not the spouse but still provide care to their relative.^{72, 75} These family members often feel unsupported or even dismissed by health care professionals, as they are not seen as the “primary

caregiver”.⁷⁶ Resources or formal support services for these caregivers are either not offered, or when provided, not always appropriate.^{72, 76}

Additionally, caregivers often prefer to connect with YOD peers rather than caregivers of patients with late-onset dementia, as their situations differ significantly. For example, despite both being the child of the patient, the needs of a teenager whose parent suffers from YOD differ greatly from those of an adult caring for a parent with late-onset dementia.⁶²

Bannon et al. (2022)⁷¹ identified three essential themes for support services for caregivers: (i) support in adjusting to caregiver responsibilities, (ii) skills to identify individual needs and prioritise self-care and (iii) strategies to reduce the emotional impact of caregiving.

Guilt and grief

The availability for age-appropriate programs is also important for the caregivers, they often feel guilt and grief when placing their spouse or parent in a service or program not specifically dedicated for their age group.⁶⁰

3.4.4 *Psychological needs*

Paulus et al. (2012)⁷⁷ divides psychological needs into two separate categories: (i) need for information and (ii) need for psychological support.

The need for information involves providing tailored information about treatment options and the potential progression of the disease. This information should be adapted to both the patient and the stage of their illness. Many patients prefer to have a relative or a friend present when receiving this information, which is particularly crucial in cases of dementia.

The need for psychological support refers to assistance in managing emotions related to the chronic condition (e.g. fear, frustration, depression, distress).



3.4.4.1 *Psychological needs of people with YOD*

Need for information

The literature highlights a significant level of unmet need among patients with YOD for clear information.^{60, 61, 63, 65, 69, 70} Despite the efforts of major dementia advocacy organisations to provide comprehensive information, both patients and caregivers still find clear information and advice lacking.⁶¹ For instance, research indicates that it is crucial to provide clear information to YOD patients and their families, especially at the point of diagnosis.⁶¹ Patients with YOD often describe the diagnostic process as lacking empathy and being traumatic.

Additionally, patients report that the diagnostic assessments are poorly structured, making them seem unprofessional and confusing.⁷⁰ Effective communication during assessments and explanations is essential, as it significantly impacts patient wellbeing and empowerment.⁷⁰ A sensitive, collaborative, and enabling approach to both assessment and disclosure of the diagnosis is crucial, allowing ample opportunity for discussion when the individual feels ready to know more.

Understanding how much information a person and their family want about the diagnosis is complex, as preferences vary.⁷⁰ Some find information empowering, while others may choose not to know more. Some YOD patients may value opportunities to receive detailed information through educational courses on YOD. These courses help them understand future challenges and prepare accordingly.⁶⁵

Also, the importance of information on available and age-appropriate services and the process of available benefits is highlighted (see section 3.4.3.1).⁶⁵

Need for psychological support and peer support

Sharing experiences with a partner or others with dementia is highly valued.⁶³ Being open with towards family, friends, and neighbours is generally seen as positive. Some patients report that this openness leads to

greater understanding from those around them and makes them feel more secure in their daily activities.⁶³

Another psychological (and also social) need is the desire for services that create age-appropriate, inclusive networks and social companionship for meaningfully engagement with other YOD patients.^{60, 61, 65, 71} Peer support groups provide an accepting social environment, fostering new relationships and offering support from others who understand their challenges and can help them cope.^{60, 65}

3.4.4.2 *Psychological needs of caregivers and children of people with YOD*

Need for information

Some caregivers find that receiving information is one of the most helpful forms of support.^{60, 72} However, they are often not consulted by professionals or asked to express their needs, leading them to search for information on their own.⁷² While some successfully find useful information online, others find the information overwhelming and not specific to their relative's diagnosis.⁷² Caregivers particularly value **information about available financial resources and age-appropriate support groups**.

Need for psychological support and peer support

Having a relative suffering from YOD has a significant psychological impact on family members.^{61, 72-75} They often experience distress, guilt, grief, self-blame and "emotional chaos", leading some to need psychological support.^{60, 61, 72, 73, 75, 76} Caregivers may feel hurt and upset by changes in their relationship with their loved one, while others feel embarrassed or ashamed by their behaviour. These feelings of shame often stem from discrimination, marginalisation and stigma (see section 3.4.5.1).⁷² Additionally, some caregivers hide their own feelings to protect their relatives and avoid adding further strain.⁷⁵

Like patients suffering from YOD, their caregivers also have a need for peer support (groups).^{60, 71-73} These groups facilitate the development of problem-focused coping strategies to help change their situation and overcome



obstacles.⁶⁰ Those who attend peer support groups generally find them helpful, feeling less isolated and more understood.⁷² However, many caregivers struggle to access suitable support groups, often encountering ones that are not age-appropriate, such as being the only young person in the group.^{72, 73} While caregivers generally prefer face-to-face support, online formats are also acceptable, particularly for teenagers.^{71, 72}

3.4.5 Social needs

Social needs are a major concern for people living with a long term disabling condition, in particular to keep their independence.⁷⁷ They may require assistance with activities such as housekeeping, shopping, and transportation. Additionally, preventing social isolation is a significant concern, along with the need for financial and administrative support.

3.4.5.1 Social needs of people with YOD

Changing relationships

Social relationships are important for people with YOD to feel a sense of purpose and usefulness.^{56, 60, 63} However, there are often high levels of unmet needs in this area.⁶¹ People with YOD report being less engaged in social activities due to losing social contacts (e.g. friends) and a lack of understanding from their environment.^{63, 66} One possible strategy to address this need is to increase awareness and public knowledge about YOD (see next section).⁶³

Patients value services that promote active social participation or leisure and recreation activities.^{60, 63, 65} Sometimes, new friendships form through advocacy activities, local support organisations, or peer support groups.⁶⁵

Lack of awareness and visibility

Public perception of YOD and dementia in general is still clouded by stigmatisation and taboo, which negatively affects patients' self-esteem.^{56, 60, 61} These stigmas usually revolve about people assuming that individuals with YOD are unable to understand or do certain things.⁵⁶

Therefore, people with YOD value services that allow them to have their voices heard and to make a difference in other's lives. This is often achieved through opportunities to participate in research projects, partnerships or networks related to YOD, which can **provide a fulfilling sense of contribution**.⁶⁵

YOD and work life

Patients suffering from YOD may often experience confusion at the beginning of their cognitive decline (prior to diagnosis). They might try to downplay these symptoms at work, attributing memory problems to work stress or ageing rather than the underlying cause of YOD.⁶⁷

This can lead to diminished confidence in their own ability in the work place, resulting in stress, anxiety and emotional trauma which further impacts physical health and abilities, especially if there are bad reactions from colleagues or employers.^{67, 68}

YOD patients emphasise that continuing to work contributes significantly to their wellbeing by providing a sense of usefulness, satisfaction, enjoyment, pride and social participation.⁶⁹ This preference for **maintaining a work role** is not differentiated by age.⁶⁹ Workplaces that offer peer support, simplify existing roles or provide alternative roles can create positive opportunities for ongoing occupational participation.⁶⁹ However, Andrew et al. (2018)⁶⁹ note that there are disparities between workplace practices and legislative policies designed to protect employees with a disabilities. Additionally, support needs to be balanced, as excessive support from colleagues can make patients feel helpless or disempowered.⁶⁷



Although patients prefer to work for as long as possible, some employers advocate for early or medical retirement without considering the occupational preferences of their employees, assuming that their time would be better spent on domestic and leisure activities.⁶⁹

As the condition progresses, establishing a new identity beyond the worker role may become necessary. Therefore, patients seek often other meaning roles (see next section).^{63, 69}

Need for meaningful daytime activities

Patients suffering from YOD prefer to **engage in meaningful daytime activities** as much as possible, even if they can no longer work.⁶⁰ These activities can relate to their previous occupations, household chores or through participation in leisure and recreation activities. In this way, they feel a sense of usefulness, accomplishment, in control, meaningful and part of something.⁶³

Financial impact and need for financial support

The diagnosis of YOD generates significant financial consequences for patients, or those living in the same household but also for adult children and relatives.^{61, 64, 65, 68, 69, 73, 74}

Patients often face higher care costs and the loss of two incomes when their caregiver has to reduce or give up their job to provide care. This double loss also affects associated pensions for both parties.^{64, 68} In addition, when patients have to stop work, they are often still paying off mortgages and supporting children who have not yet completed their education.⁶⁸ These consequences can lead to immediate financial strain and long-term anxieties about managing present and future needs.⁶⁴

Services that **address these financial challenges** are highly valued.⁶⁵ Supportive measures may include helping patients to continue working after being diagnosed, help with applying for benefits, flexible working options from employers and income assistance from workplace insurance schemes to lower the financial burden of employers.^{65, 69}

Especially these last two occupational adaptation strategies help maintain the occupational identity.⁶⁹ However, patients with YOD often face unpredictability about eligibility for financial support, making assistance with benefit applications crucial.⁶⁴

3.4.5.2 Social needs of caregivers and children of people with YOD

Difficulties in balancing caregiving responsibilities with personal responsibilities

Systematic literature reviews consistently highlight the challenges caregivers face in balancing caregiving responsibilities with personal responsibilities (such as employment, parenting and future planning). These challenges create a number of practical challenges day-to-day life and long-term goals.^{60, 61, 71-75} Some issues are unavoidable when living with and supporting a relative with YOD, while others arise from the caregivers' own decisions to manage their feelings about YOD.⁷⁵ In addition, young children of parents with YOD report taking on demanding caregiving roles while also dealing with the developmental challenges of growing up.^{60, 61} For instance, these children often experience disrupted sleep due to their parent's nighttime behaviour or their own worries, leading to difficulties in concentrating in school and negatively affecting educational achievement.

Relatives often feel that their lives are "on hold", delaying life events to spend more time with their loved ones or to fulfil their caregiving roles.⁷⁵ This includes postponing moving away from home, having their own children, and making decision about further education and work that enable them to stay closer to their parent or support the family.⁷⁵

Changes in relationships

Caregivers face challenges due to the symptoms of YOD, which profoundly change the dynamics of their relationship with the person with YOD, causing caregivers to redefine their self-identity.^{60, 73, 74} Studies reveal an association between this transformation and a growing emotional disconnect in the relationship. Caregivers grieve the loss of the person with YOD, their shared



bond, and their former identity as a spouse or child, which is gradually replaced by the role of caregiver.⁷³⁻⁷⁵ Particularly with children of people with YOD, many of these children take on additional responsibilities and provide care to their parents, resulting in a role reversal where they feel they are “parenting their parent”.⁷⁵

Other relationships were also affected by YOD, often resulting in emotional distancing.⁷⁵ Caregivers spoke about friendships becoming more superficial and extended family members withdrew as they struggled to relate to the situation. Conflict within families may be common, as disagreements arise between children and their siblings or well-parents regarding the care of their parent with YOD. However, not all relationship changes are negative.⁷⁵ Some children of people with YOD feel emotional support from friends, partners or siblings in similar situations. Some caregivers even feel closer to their well-parent by sharing caregiving responsibilities and providing mutual support. In some cases, there are also improvements in a previously strained relationships with the parent with YOD.

Sense of isolation

Isolation and loneliness are common among caregivers of people with YOD, due to these changes in relationships and difficulties in addressing their own needs while fulfilling their caregiving role.^{61, 72} For instance, they may have less time to spend with friends, or their personal experiences or their relatives' behaviours may not be understood or accepted by others leading to social distancing.⁷² Additionally, as care recipients become more dependent, caregivers' insight into their needs may decrease, leading to communication breakdowns and making meaningful interactions challenging.⁷⁴ Cartwright et al. (2021)⁷² also mentioned that caregivers in some cases feel that their peers are unsympathetic, ill-informed or do not want to deal with their difficulties, leading to reluctance in seeking their support. Just like people suffering from YOD (see section 3.4.5.1), caregivers also have the desire to be part of age-appropriate peer support groups.⁷¹

Raise public awareness

Multiple reviews on the needs of caregivers and/or children refer to the importance of increasing public awareness, knowledge and understanding about YOD, as well as educating health and social care professionals.⁷²⁻⁷⁴ As a result of a lack of awareness and visibility of YOD in society, asymptomatic family members sometimes experience a sense of shame or guilt related to their relative being stigmatised or marginalised within the community (see section 3.4.5.1).⁷⁶

3.4.6 Spiritual needs

Spiritual needs extend beyond religion and encompass the search for meaning, moral values, and personal identity.⁷⁷

3.4.6.1 Spiritual needs of people with YOD

Acceptance and sense of purpose

Acceptance of the diagnosis is found to be crucial for YOD patients in moving forward with their lives.⁶⁶ However, the process of acceptance varies among patients, which some find it easier than others.⁶⁶ Some patients view the diagnosis of YOD not as the end of their life, but rather as the beginning of a new chapter or even describe it as a “blessing in disguise”.⁶⁶ Acceptance is particularly linked to regaining a sense of purpose, such as resuming work or social participation.^{60, 67}

Some YOD patients also discovered a sense of purpose by stepping into new roles, like advocacy work in health and social care organisations, public speaking, participation in public consultations, etc.⁶⁶

Uncertainty for the future

Uncertainty about the future complicates medical-decision making for both YOD patients and their caregivers (see also section 3.4.6.2). One frequent concern is the unpredictable nature of the disease's progression.⁵⁶ The unique trajectory of each individual's illness makes advance care planning difficult, as respondents are unsure which decisions to prepare for. Some



caregivers suggest that advance care planning should be adaptable to accommodate the disease's erratic progression and address patients' concerns about its binding nature. This uncertainty often leads to a "day-to-day" mindset, where both patients and caregivers focus on living in the present and learning to cope with the disease on a daily basis.

3.4.6.2 *Spiritual needs of caregivers and children of people with YOD*

Uncertainty for the future

The progression of YOD can often be unpredictable, creating a level of uncertainty for family members. They may not be sure how the disease will affect their relative or their caring responsibilities. Wiggins et al.'s (2023)⁷⁶ literature review highlights that family members sometimes delay making plans because they feel uncertain about the future due to their caregiving responsibilities and the unpredictable nature of the disease progression in their relative.

In addition, uncertainty is also linked to not knowing one's own genetic status and the risk for developing YOD themselves. Young carers may have concerns about who will care for them if they develop YOD in the future. Due to these layers of uncertainty reported above, many asymptomatic family members feel like they are putting their lives "on hold". This includes making adjustments to future plans, such as education, career and family planning. For instance, some may decline scholarship opportunities due to caregiving responsibility, postpone significant life events like moving out of the their home, or overlook their own health and fertility. However, Wiggins et al. (2023)⁷⁶ emphasises that the studies reviewed do not delve deeply into the various aspects of uncertainty, highlighting the need for further research to better inform counselling in this area.

3.5 Discussion

The rapid review on the needs and experiences of individuals diagnosed with YOD, their caregivers, and their children reveals several significant insights and common themes. This discussion synthesises the findings, highlighting key areas of concern and suggesting directions for interventions. The results of this review are consistent with previous literature (before 2015) and articles published after our own literature search.^{36, 60, 61}

Despite similar symptoms, individuals with YOD face distinct challenges compared to those with late-onset dementia. The early onset of the disease typically occurs during a critical phase of life, disrupting careers, family roles, and social relationships. These disruptions can lead to significant psychological distress, as individuals struggle with the loss of autonomy and future aspirations. Furthermore, the stigma and lack of awareness surrounding YOD can exacerbate feelings of isolation and loss of purpose and usefulness. Important unmet needs identified include difficulties in the diagnostic process, limited access to support services, and the need for more information. This has also mentioned by guidelines of the Young Dementia Network and NICE (UK): 42% of people who are diagnosed with YOD receive no services whatsoever in the first weeks following diagnosis.⁷⁹

Caregivers of individuals with YOD, who are often spouses or partners, experience a substantial burden. The dual roles of caregiving and managing household responsibilities can lead to emotional and physical strain. The review highlights the need for tailored support systems to address the specific stressors, such as counselling services, (peer) support groups, and respite care options specifically designed for YOD contexts. Additionally, the financial impact on caregivers is significant, as they may need to reduce working hours or leave employment entirely to provide fulltime care. Financial support and workplace accommodations are critical areas that require attention to alleviate this burden.

Children of parents with YOD face unique challenges, including role reversal, where children become caretakers for their parents, can lead to emotional distress, uncertainty for the future, and social isolation. The review underscores the importance of providing psychological support and



counselling for these children to help them cope with their altered family dynamics and responsibilities. Therefore, it is important to highlight the value of a family-based approach which is especially meaningful and unique in the context of YOD. This approach sets YOD care apart from the interventions typically used in LOD care.

There is also a clear need for systemic changes to better support individuals with YOD and their families. Increasing public awareness and education about YOD can reduce stigma and improve social support networks. Healthcare providers should receive specialised training to recognise and address the unique needs of YOD patients and their families.²⁴ Policies and care programs that offer timely, accessible and comprehensive care – integrating medical, psychological, and social services – are essential. Collaborative care models that involve multidisciplinary teams with a coordinating healthcare professional (such as a case manager or key worker) can contribute to meet all aspects of the patients' and families' needs effectively. The Young Dementia Network recommends that this coordinating healthcare should have specialised knowledge, skills and experience with the impact of YOD.^{79, 80} Their roles include:

- Coordinating services, organisations and people, helping to connect the person living with YOD to local group networks and support services
- Providing or facilitating access to specialist advice and support about YOD specific needs (e.g. employment, financial obligations and future financial planning)
- Acting as a liaison between clinical services and the person's community and home
- Providing information, practical and emotional support for family members, and connecting them with others for mutual support
- Ensuring continuity of support
- Helping the person living with YOD understand their condition and actively engage in their care plan and journey

This coordinating professional can be embedded in various organisations or care structures depending on local infrastructure and funding arrangements, such as primary care, local mental health teams, neurology departments or even the voluntary sector.⁸⁰

Both persons with YOD and caregivers prefer support services that are age-appropriate, specific to YOD subtypes, inclusive, accessible, consistently available and relevant to the illness's progression stage. These services should also be flexible and individualised, allowing time for both the individual with YOD and their caregivers to process the diagnosis at their own pace. Programs that offer formal and informal peer support and educational resources can also be beneficial in helping patients and caregivers/children understand and manage their experiences.

Overall, this rapid review highlights the profound impact of YOD on individuals, caregivers and children. It underscores the urgent need for tailored support systems, increased awareness, and comprehensive care models to address the unique challenges posed by YOD. By focusing on these areas, stakeholders can improve the quality of life for those affected and mitigate the broader societal impacts of this condition.



4 YOUNG-ONSET DEMENTIA CARE IN BELGIUM

4.1 Key points

- There is a fragmentation of training, funding, information provision, services and facilities.
- Currently, there is no national dementia strategy in Belgium.
- The Flemish dementia plan (2021-2025) is a general strategy to organise dementia care, with some specific actions for patients with young-onset dementia (YOD).
- Only Flanders has a dementia expertise centre, whereas the other regions lack structured support and expertise for young-onset dementia.
- Twelve memory clinics have a convention with the NIHDl for an annual budget of € 123 850 per clinic. In the period 2019-2021, 11.4% (98/857) of newly admitted patients were under 65 years of age. YOD patients can benefit from 35 cognitive rehabilitation sessions for a maximum period of 4 years, with the aim of maintaining the patients as long as possible at home.
- There are multiple other uncoordinated initiatives for the management of dementia. Some of them have been undertaken to make residential facilities more accessible for patients with (young-onset) dementia.
- Various bottlenecks in the patient journey were identified through stakeholders interviews:
 - Physicians often miss young-onset dementia in younger patients due to its rarity and lack of training, leading to delays or to misdiagnosis as stress or burnout when issues first appear at work.
 - Healthcare professionals often lack knowledge and training specific to YOD, leading to misdiagnosis and over-reliance on medication rather than behavioural approaches.
 - There is no clear pathway for patients: after diagnosis, patients typically receive intermittent follow-up without a coordinated care plan.
 - Patients and family often feel they can manage alone, delaying care until symptoms worsen, which complicates effective management.
 - Delays for initial appointments and necessary follow-up tests are long, causing stress and uncertainty for patients.
 - Limited specialised care facilities mean some patients must travel far, leading to treatment drop-out.
 - YOD patients face high costs for non-reimbursed exams and treatments, with age restrictions on financial support leading to inequity in access to care.
 - This lack of reimbursement limits data collection on diagnostic tests (e.g. lumbar puncture), which hinders understanding and evidence-based treatment strategies.
 - Caregivers receive limited support, especially young family members, who lack a defined support system for dealing with the impact on their lives.
 - Young dementia patients are often declared unfit for work early, without efforts for workplace accommodations, reducing their societal engagement and sense of normalcy.



4.2 Aim and methods

This chapter describes on the one hand the organisation of dementia care in Belgium, covering both general dementia care and more specific care options for YOD, and on the other hand the bottlenecks in the current patient journey.

Increased interest in YOD by policy makers and researchers has led to the establishment of specific facilities, services and organisations to care for people with dementia at a younger age (<65 years). In addition, several disease-specific initiatives aimed at providing support, raise awareness and provide information to the general public, family members and healthcare professionals.

Several methods were used to develop this overview of the current health care landscape such as desk research, a (pragmatic) literature review (including grey literature) and scoping interviews with stakeholders. For this, we conducted several exploratory interviews to identify the difficulties in the care pathways for people with young-onset dementia in Belgium. We engaged with key informants in Belgium and interviewed them using a semi-structured interview guides (Appendix 2). Recorded interviews were transcribed and analysed using NVivo. When no recording was available, we used notes taken during the interviews.

The information on the current management of patients with young-onset dementia contributed to the next section describing the situation (section 4.3). In section 4.4, we focus on the bottlenecks identified by stakeholders and their proposals for future improvements: in total, we conducted 12 individual interviews and 1 group interview (consisting of 15 interviewees) (Table 8).

Table 8 – Number of interviews per type of stakeholders

Type of stakeholder	French-speaking	Dutch-speaking
General practitioners representatives	1	3
Policy maker	/	1
Administration	1	/
Expertise centre	/	2 (director + expert)
Memory clinics with convention	1 neuropsychologist	1 neurologist
Memory clinics without convention	2 neurologists	/
Patient representatives	2	1

4.3 Organisation of dementia care in Belgium

4.3.1 Political context of the care provision in Belgium

Through six state reforms, Belgium evolved into a federal state composed of communities and regions. The competences for health and health care were transferred (in part) to the federated entities, resulting in a rather complex institutional structure with seven regional ministers and one federal minister being responsible for healthcare organisation.⁸¹ “*Health and welfare*” has gradually been transferred to the federated entities through the successive state reforms (Table 9). This has led to the assignment of care for the elderly, including care for persons with dementia, to the jurisdiction of the three federated entities. In Belgium, these entities comprise the Minister of Welfare, Public Health, and Family in Flanders (*Minister van Welzijn, Volksgezondheid en Gezin*), the Minister for Social Action and Health (*Ministre de l’Action sociale et de la Santé*) in Wallonia, and the Minister for Social Affairs and Health (*Ministre des Affaires sociales et de la santé*) in the Brussels-Capital Region.



Table 9 – Short overview of the tasks on federal level and by the federated entities (Flanders, Wallonia and Brussels-Capital region) in Belgium, related to the organisation of health care

Federal level	Federated entities
• Organisation of the financing of hospitals and nursing homes ○ Staff costs ○ Nurses ○ ... • Costs of outpatient care ○ General practitioners ○ Medical specialists ○ Physiotherapists ○ ...	• “Health and welfare” ○ Care for the elderly (e.g. care for persons with dementia) ○ Recognition of hospitals, nursing homes, residential care facilities and psychiatric institutions ○ Care provided at home

As the care of persons with dementia is situated on the intersection of health care and social assistance, it poses a complex organisational challenge. The federated entities are responsible for the recognition of hospitals, nursing homes, residential care facilities and psychiatric institutions. Additionally, the federated entities are responsible for care provided at home (e.g. standard quality of care, accreditation, regional organisation). However, the federal government, through the National Institute for Health and Disability Insurance, NIHDI (RIZIV – INAMI), is responsible of the financing of the care provided by hospitals and nursing homes (e.g. nurses, paramedical staff costs) within the framework of mandatory health and disability insurance. It also covers the costs of outpatient care provided by general practitioners, specialists, physiotherapists and home nurses. This fragmented organisation has led to important regional and structural differences within the Belgian healthcare system.

4.3.1.1 Structural and regional differences

An example of these regional and structural differences is the Flanders Centre of Expertise on Dementia, funded by the Flemish government.⁸² A short presentation can be found on their website.⁹ This expertise centre is an umbrella organisation with multiple local expertise centres spread across Flanders. These local centres of expertise are based on person-centred care with respect for individual needs and preferences and share useful knowledge with people throughout the health and welfare sector (e.g. informal caregivers, healthcare professionals, people with dementia, ...).

Furthermore, the expertise centre of dementia is a point of contact for (Flemish) policy makers, stimulates the debate for a better organisation of dementia care, keeps track of the international literature, evaluates (international) best practices for the Belgian context and disseminates best practices through their local network and partner organisations (e.g. *Alzheimer liga Vlaanderen*, *Vlaamse ouderenraad*, *Vereniging van Vlaamse Steden en Gemeenten*, *Vlaams Agentschap Zorg en Gezondheid*, King Baudouin Foundation).⁸³

As examples of actions, the expert centre identifies preventive measures and coordinates prevention campaigns (e.g. 10 000 steps, ‘*Vergeet dementie, onthou de mens*’) in collaboration with its partner organisations. Besides prevention campaigns, the expert centre has played an important role in disseminating evidence, raising awareness among the general public and educate the general public, health professionals and care organisations (e.g. guidelines, *Farmaceutische zorg voor personen met dementie* [FAZODEM] project^r). Importantly, this organisation focuses on dementia, but some local expertise centres have developed specific expertise in young dementia and support local, specific activities for this patient population (e.g. expertise centre MEMO and ORION).⁸⁴

⁹ Flanders Centre of Expertise on Dementia: <https://www.dementie.be/wp-content/uploads/2020/01/our-international-presentation-folder.pdf>

^r This project trained pharmacists to timely recognise early symptoms of dementia and communicate this information to GP's, optimise drug treatment and improve informal care through targeted advice.



4.3.2 Lack of national dementia strategy

Overall, there is currently no overarching federal Belgian dementia plan. While a dementia strategy has been developed and implemented in Flanders (*“Dementieplan Vlaanderen 2021-2025”*), such an implemented and up-to-date plan is currently lacking in Wallonia, with the latest version dating from 2010.^{85, 86}

The current Flemish dementia plan (*“Dementieplan Vlaanderen 2021-2025”*) is an updated version of two previous plans: *“Dementieplan Vlaanderen (2010-2014)”* and *“Update Dementieplan (2016-2019)”*. It has the following goals: **prevent dementia, improve the quality of care and provide the necessary support** for (informal) caregivers of people with dementia.⁸⁵ Further (regional) actions and initiatives should aim to create a dementia-friendly society, hence safeguard **patients’ autonomy and social participation** (e.g. promote awareness among the general public and health professionals).

Importantly, the current Flemish dementia plan is a **general strategy** to organise dementia care in which some specific actions for patients with YOD are described (Box 5).⁸⁵ However, these actions need further development, implementation and evaluation. Additionally, financing, reimbursement and nomenclature are mostly decided on a federal level, which complicates the allocation of budgets on a more regional level.

Box 5 – Specific actions for persons with young-onset dementia, as defined in the Flemish dementia plan (2021-2025)

- *Vlaams Agentschap Zorg en Gezondheid* is evaluating the current residential care landscape for people with young-onset dementia and their needs. Regulation will be amended so persons with young-onset dementia and being in the category D of dependency* can also receive reimbursement for residential care in one of the residential care centres with specific recognition.
- The current supportive measures for persons with young-onset dementia who still live at home (e.g. buddy system, home care) will be studied and evaluated for needs or gaps.
- The Flemish government will take initiative to cooperate with the federal government to develop a specific care path for people with young-onset dementia.
- The Flanders Centre of Expertise on Dementia will make occupational physicians more aware of the theme young-onset dementia to allow work place or schedule adaptations to the specific needs of persons with young onset dementia.

*: Category D means that the patient has been formally diagnosed with dementia by a specialist physician in neurology, psychiatry, or geriatrics



4.3.3 Conventions from the National Institute for Health and Disability Insurance (NIHDI)

In the Belgian healthcare system, agreements with the NIHDI, or 'conventions', are often used to finance multidisciplinary care approaches (e.g. diabetes, respiratory diseases, rare metabolic diseases).⁸¹ These conventions define the activities and financing of the (multidisciplinary) centres and health care professionals that have signed such an agreement. Among the current NIHDI conventions, two are relevant for this report:

- the conventions on neurodegenerative diseases (one for patients with multiple sclerosis (MS) or amyotrophic lateral sclerosis (ALS) and a second for patients with Huntington's disease,
- the convention on memory clinics.

4.3.3.1 NIHDI convention related to neurodegenerative diseases

Specific NIHDI conventions are in place for patients with advanced-stage neurodegenerative diseases (i.e. MS or ALS, and Huntington's disease).⁸⁷ The convention provides patients with one of the above conditions with subsidised places in hospitals or residential care facilities for either short-term care (e.g. to stabilise their current situation, to relieve their carers) or long-term care when traditional care and residential facilities are no longer able to provide appropriate care for due to the progression of the disease.⁸⁷ Eligible patients must meet a number of criteria (Box 6). When a patient is deemed eligible, standardised fees for care and residence are paid to the hospitals or residential care facilities under the convention.⁸⁷ The convention aims to strengthen cooperation and continuity of care between hospitals and residential care facilities. To this end, a liaison function (by a paramedical health professional or a social worker) and medical supervision (by a neurologist or a neuropsychiatrist) will be provided, visits to residential

facilities and training will take place to ensure quality of care. The convention also calls for special attention to be paid to the information needs of patients and their families, (psychological) support and support in daily activities (e.g. advance care planning) (Table 10).

Box 6 – Patient eligibility criteria for the NIHDI convention on neurodegenerative diseases

- Patients over 18 years of age with advanced MS, ALS or Huntington's disease who don't further benefit from a traditional rehabilitation programme (due to the advanced stage of the disease).
- Patients do not require acute care.
- An objective evaluation of "advanced disease" should be available (i.e. FIM-scale^s is used in MS and ALS, and an adapted version of Shoulson and Fahn scale^t in the Huntington's disease).
- Patients need to be institutionalised in one of the facilities under convention to be eligible for this programme.
- An expert physician and a reference person of the convention decide after anamnesis whether a patient is eligible to be included in the programme.

^s The Functional Independence Measure (FIM) is an ordinal scale with 18 items: 13 motor and 5 cognitive items, scored on a 7-level scale (1 = total assistance, 7 = total independence).

^t The scale derived from the Shoulson and Fahn scale is available in the convention, measuring functional capacity for 5 criteria (occupational activities, ability to manage financial affairs, household tasks and activities of daily living, and place of care) according to 5 levels of severity for each.



In addition to the financial compensation, this convention offers additional advantages in the care of people with neurodegenerative diseases, as a result of the development of a partnership between a residential care facility and the reference hospitals. First, it **facilitates the collaboration** between reference hospitals and residential care facilities (e.g. liaison function). Secondly, it aims to **improve the expertise and quality of care** provided

by these residential care facilities as a result of the offered support, expertise and training from these reference hospitals. Finally, the convention provides for **additional reimbursement** to the institutions under convention to cover extra costs (e.g. transport, material).

**Table 10 – Overview of the programme and requirements for hospitals and residential care facilities under the NIHDl convention related to neurodegenerative diseases**

Topic	Description
Content of the programme for residential care facility	• Offer psychosocial support to patient and their relatives, provide correct information on the disease to the patient and families (e.g. clinical course, needs) and provide information (including on advance care planning, life goals and palliative care). • Offer multidisciplinary care in a residential care facility adapted to the clinical course of the disease to provide patients with the best quality of life possible. • Liaison between hospital and residential care facility to support the care of professionals dealing with complex individual problems of patients. • Medical supervision of the specialist from the reference hospital, with whom they formed a partnership.
Partnership	• The programme is based on cooperation between a residential care facility and a reference hospital. • The liaison professional (e.g. paramedical staff, nurses, social worker) should visit the residential care facility at least 12 times per year. • Every patient in the programme has a liaison file shared between the hospital and the residential care facility.
Infrastructure	• The convention specifies the number of conventioned beds to be provided by hospitals and residential care facilities. • These units should meet the specific needs of people with MS/ALS/Huntington's disease (infrastructure).
Staffing	• Each convention (MS/ALS or Huntington's disease) specifies the full-time equivalent (FTE) in care personnel (e.g. nurse, physiotherapist, occupational therapist, ...) who should be available per patient. • A reference person should be designated. • 0.05 FTE per patient on staff with a liaison function from the reference hospital. Liaison personnel should visit the residential care facilities at least 12 times per year. • Depending on the convention (MS/ALS or Huntington's disease), the convention specifies the additional FTE care personnel per patient in the hospital unit (in the reference hospital). • The convention specifies the medical supervision by a specialist in neurology and/or neuropsychiatry (in FTE per patient); this supervision includes visits to the residential care facility at least 6 times per year, but exceptions exist to have only 2 visits (under certain conditions).



4.3.3.2 NIHDI convention related to memory clinics

4.3.3.2.1 General

Memory clinics are multidisciplinary centres that play an important role in the diagnosis (new diagnosis and second opinion), medical management, education and cognitive rehabilitation for people with early-stage dementia. The ultimate goal is to enable the beneficiaries to live at home or at the home of a caregivers as long as possible, outside of any institutional environment, with the highest possible autonomy and the best possible comfort of life for themselves and their caregivers. Generally, patients are referred to a memory clinic by a physician (e.g. general practitioner, neurologist, geriatrician, psychiatrist) and the available personnel is specialised in dementia care which enables them to provide individually tailored care for persons with dementia. In addition, the memory clinics can provide a second opinion and specific expertise in complex cases (e.g. frontotemporal dementia).

In Belgium, the term “memory clinic” is not an official or protected title. This results in several memory clinics across the healthcare landscape, with some of them under convention, adhering to the rules and recognition criteria of the convention, while others are not required to adhere to these (quality) standards.⁸⁸ Belgium currently counts 12 memory clinics under convention with some specific structural and staffing requirements. The geographical spread was set to ensure maximum accessibility. These memory clinics offer a multidisciplinary cognitive rehabilitation programme for patients (Table 11, Table 12, Table 13, Table 14).⁸⁸

Table 11 – Memory clinics participating in the NIHDI convention

	License no	Hospital	Place
Flanders	009	Ziekenhuisnetwerk Antwerpen vzw	2660 Hoboken
	371	Ziekenhuis Oost-limburg	3600 Genk
	012	AZ Sint-Blasius	9200 Dendermonde
	322	Universitaire Ziekenhuizen K.U.L.	3000 Leuven
	290	Algemeen Ziekenhuis St. Lucas	8310 Brugge
Brussels	143	Universitair Ziekenhuis Brussel	1090 Jette
	403	Cliniques Universitaires St. Luc	1200 Woluwe-St-Lambert
Wallonia	010	Grand Hôpital de Charleroi	6061 Montignies-sur-Sambre
	257	Klinik St. Josef	4780 St-Vith
	707	Centre Hospitalier Universitaire de Liège	4020 Liège
	168	Vivalia - Centre Hospitalier de l'Ardenne	6800 Libramont
	039	Clin. Universitaires U.C.L. de Mont-Godinne	5530 Yvoir

The article 6 of the NIHDI convention stipulates that the therapeutic staff includes at least the following functions, each carried out by one or a maximum of 2 persons, meeting the conditions set out in Article 7:

1. Specialist doctor (geriatrician, neurologist, neuropsychiatrist and/or psychiatrist).
2. (Neuro)psychologist.
3. Occupational therapist.
4. Social worker.
5. Secretary

The article 7 defines the functions of each staff member (Table 12).

**Table 12 – Staff function under the NIHDI convention for memory clinics**

Staff	Functions
Medical doctor	The specialist doctor(s) (Article 6, point 1) shall prove, through their professional experience and any scientific publications, their expertise in the field of dementia, its consequences and its treatment. One and only one of these doctors shall act as coordinator. In addition to the tasks arising from their role as specialist doctor, they shall assume the medical direction of the multidisciplinary team for all matters relating to the application of this agreement. He/she is particularly responsible for • the coordination of the multidisciplinary team, • the quality and proper organisation of the care provided, • the relevance and coherence of each individual programme, • the experience, competence and continuing education of each member of the therapeutic team, in the function that he exercises in application of the convention, • the topicality and medical validity of the concepts on which the care programmes are based, • the quality of the data in the annual report and the punctuality of their transmission.
Psychologist	The holder(s) of the position of psychologist have a graduate (master) in psychology; at least one of them has received in-depth training in neuropsychology and at least one of them meets the legal requirements for practicing clinical psychology. They can prove their experience in caring for patients with dementia. They have sufficient medical knowledge in this area. Depending on their skills, they focus on summarising previously conducted cognitive tests and performing additional tests, delivering the cognitive rehabilitation programme, training and informing beneficiaries and their caregivers on all psychological and neuropsychological aspects of dementia. They provide specialised psychological support to beneficiaries, their caregivers and their loved ones.
Occupational therapist	The holder(s) of the occupational therapist function demonstrate their experience in treating and educating patients with dementia. They are mainly responsible, on the one hand, for re-teaching beneficiaries to perform certain daily acts, and on the other hand, for planning the necessary adaptations to the beneficiaries' living environment and for supervising the implementation of these adaptations on site. They can contribute to the realisation of cognitive assessments, for the parameters that concern their specialty.
Social worker	The holder(s) of the social worker function are social nursing practitioners or social workers with in-depth knowledge of the organisation of social security and social legislation in Belgium and sufficient medical knowledge of dementia. They propose concrete solutions to the social problems that arise for the beneficiaries, as direct consequences of dementia. In this context, they help them with administrative formalities; they liaise with the various stakeholders in the care network, and with social and administrative services.
Administrative worker	The holder(s) of the secretary function have sufficient knowledge of dementia to enable them to adequately welcome beneficiaries and their carer(s). During their working time under the agreement, they devote themselves exclusively to reception and administrative tasks directly related to the application of this agreement.



Strangely enough, the social worker position is not part of the staffing requirements stipulated by the convention, and thus not part of the pricing of the rehabilitation sessions (Table 13). It seems this was done on purpose because the global budget was capped and it was decided to fund only the staff directly involved in the rehabilitation (personal communication NIHDI). It is therefore unclear whether a social worker properly fulfils the tasks assigned to this position under the terms of the agreement in each centre.

Table 13 – Staffing requirements under the NIHDI convention for memory clinics

Discipline	FTE
Physician specialist ¹	0.20
Psychologist	0.30
Therapists A1	0.50
Administrative worker	0.20

¹ The physician specialist can be a geriatrician, neurologist, neuropsychiatrist and/or psychiatrist and has a coordinating function of the memory clinic

The multidisciplinary therapeutic team meets at least once a month. These meetings contribute to the coherence of its operation and its interventions with the beneficiaries, as well as to the sharing and updating of its members' knowledge in all useful areas. They are placed under the supervision of the physician in charge. Each meeting gives rise to the drafting of a written report, containing at least the names of the participants, the list of topics discussed and the names of the beneficiaries whose cases were discussed. This written report is kept by the institution.

^u Over the 2019-2021 period, the mean age was 74.7 years; 46% were males; 69% had primary or secondary education degree. In 64% of the cases, the caregiver was a spouse living with the patient, and in 24% a child not living with the patient.

Cognitive rehabilitation programme

Patients are deemed eligible for the cognitive rehabilitation programme if they have received a (recent) diagnosis of dementia and are able to remain at home, alone or with an informal caregiver, for at least 12 months. The prescription for rehabilitation is issued by the specialist doctor (neurologist, geriatrician or psychiatrist) who made the diagnosis or by the beneficiary's general practitioner. This prescription must always mention the diagnosis of early dementia (including its aetiology), and the name and NIHDI identification number of the specialist doctor (neurologist, geriatrician or psychiatrist) who made the diagnosis and established the treatment plan.

There is no age limit, i.e. memory clinics can be used by patients with YOD. This is already the case. In 2019-2021, 11.4% of newly admitted patients (98/857) were under 65 years of age.^u In 2018, the maximum number of rehabilitation sessions was increased to 35 for people under 65 years, instead of 25 sessions for people over 65 years (Table 14).^v The location or frequency of the sessions is tailored to the individual needs of the patient and the progression of the disease. However, once a rehabilitation programme has started (e.g. the date of the agreement with sickness fund) it should be continued without interruption for 4 years; no rehabilitation sessions can be performed outside this 4-year period.

The first sessions are assessment sessions. They are intended to supplement the medical examinations and cognitive tests carried out previously, in order to accurately assess the skills preserved and those that have been lost. The following sessions have a rehabilitation purpose in the strict sense. At least one assessment session or one rehabilitation session should take place at the patient's home.

^v Note CSS 2018/384

**Table 14 – Description of the different phases of a cognitive rehabilitation programme, offered by the memory clinics under NIHDI convention**

Phases	Aim	Number of sessions	Time period
Anamnesis	Evaluate the lost and remaining cognitive functions through cognitive tests and medical evaluation	Max. 1 session	First year
Rehabilitation	Focus on specific goals and adaptive strategies mentioned in the convention: • teach the beneficiaries alternative strategies that will enable them to perform certain activities of daily living using their preserved skills, • train the caregivers who will help the beneficiaries in their daily life, • inform the beneficiaries and their caregivers about the disease, its progression and its consequences, • advise and supervise adaptations to the daily environment that will help to overcome cognitive difficulties, • provide psychological support to the beneficiaries and their caregivers.	Not defined by convention	First year
Maintenance	Maintain (or regain) the strategies learned/gained during the rehabilitation phase	Max. 15	Next 3 years

To help the beneficiaries to remain as independent as possible, various complementary approaches are implemented:

- Learn or relearn practical life skills (e.g. money management, facilitating spatial orientation).
- Learn or relearn a useful activity (e.g. cooking, telephoning, washing) or moments of relaxation and leisure (e.g. games, reading, contact with others).
- Systematise the use of memory aids to compensate for memorisation difficulties (e.g. diary, calendar).
- Support and help families in their care (e.g. information on the disease).
- Carry out home visits to detect real daily difficulties and to overcome them with adaptations, assistance and strategies.
- Provide psychological support to the beneficiaries and their caregivers.

Funding

Since 2012, memory clinics under convention have been evaluated as part of a pilot project with an initial budget allocation of € 1 054 000. **In 2024, the global budget is set at € 1 486 205. This budget is equally shared among the 12 clinics, i.e. € 123 850 per clinic, with no consideration of the size of the catchment area** and actual consultation rate (personal communication NIHDI). During the same calendar year, each clinic may provide **billable rehabilitation services up to a maximum of 875 billing units, with an average cost per unit of € 141.5**. In calculating this number, a session in the clinic is worth 1 billing unit and a session at home is worth 1.75 billing units for the 1st session during a day, and 1 billing unit for the 2nd possible session during the same day.

The insurance contribution to the cost or “price” of any rehabilitation service provided for in this agreement is a flat rate that covers all costs incurred in providing this service to a beneficiary. It is due for any service that complies with the conditions provided for in the agreement. For any beneficiary, the insurance contribution to the cost of rehabilitation services is subject to the



prior approval of the College of Medical Directors or the medical advisor of the insurance organisation to which the beneficiary is affiliated or registered.

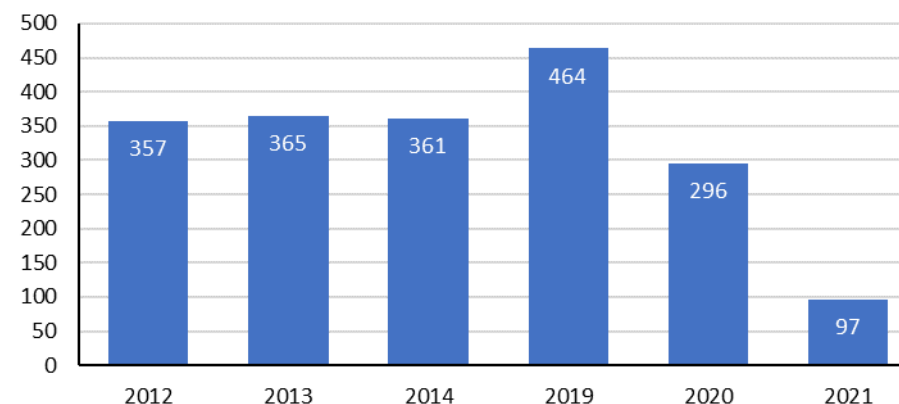
The salary cost of the staff employed under the agreement is entirely borne by the institution on the basis of the reimbursement of the cost of services received under this agreement.

4.3.3.2.2 Performance of memory clinics

They are obligated to provide data bi-annually to the College of Medical Directors (*“College van artsen-directeurs – Collège des médecins-directeurs”*) to allow the assessment of the quality of care. Furthermore, the board of medical directors has established a protocol outlining operational goals and therapeutic objectives, based on international evidence and clinical guidelines. This protocol serves to ensure the quality of care and standardise treatment across the memory clinics. These 12 memory clinics were selected by the College of Medical Directors in 2011 based on defined selection criteria: the structural and staffing requirements defined in the convention and most importantly geographical location. Furthermore, the application file of each candidate was evaluated based on personnel, therapeutic programme, prior experience, (clinical) network, research and accessibility. The following section will describe the data that is periodically reported by the memory clinics to NIHDI to evaluate their functioning.

The last batch of data was received in the spring of 2022, covering the period 2019-2021 (but the data for 2021 is incomplete due to a misunderstanding).

Figure 2 – Total number of new patients who started treatment at a memory clinic under NIHDI convention per year



More newly admitted patients were treated in 2019 compared to the first years of the convention, but no real conclusions can be drawn about the numbers for 2020 (e.g. impact of the COVID pandemic) and 2021 (e.g. incomplete data due to miscommunication) (Figure 2).

The number of patients (in total and per clinic) is not reported. Only the number of annual sessions is available. Of note, the maximum number of sessions allowed (covered by the provisional budget) is not met. For example, in 2019 there were 5532 sessions whereas 10 500 billing units are available (53%). It is unknown if this percentage was higher in more recent years as results of the period 2022-24 will only be known in 2025.



Figure 3 – Total number of rehabilitation sessions performed at home or at the memory clinic during the first year of the rehabilitation programme

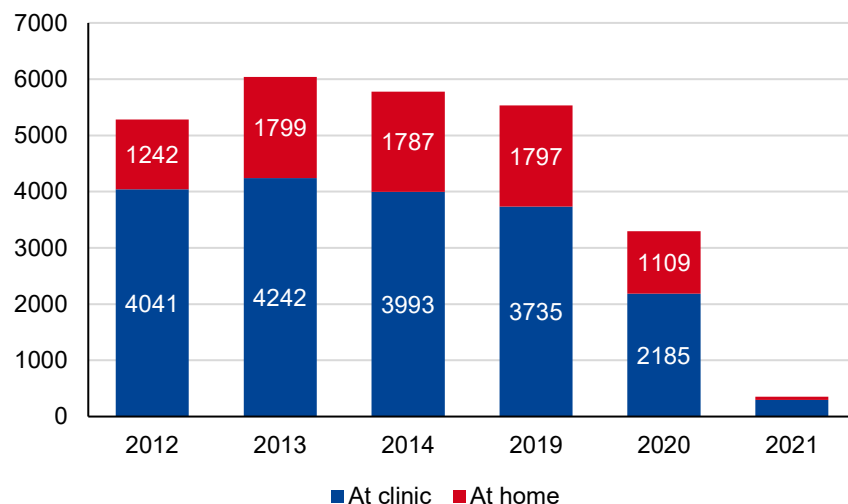
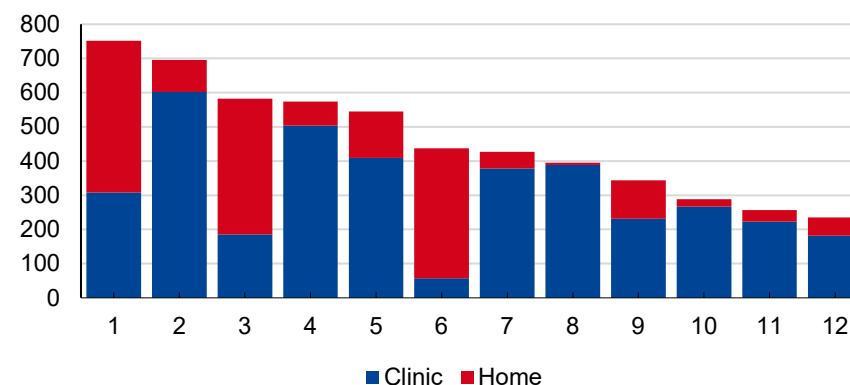


Figure 4 – Distribution of the total number of rehabilitation sessions per memory clinic in 2019



Most rehabilitation sessions take place in the memory clinics, although some centres provide more rehabilitation sessions at home (Figure 3). We looked at the latest complete data from 2019 (i.e. not influenced by Covid-19 or incomplete). During that year, there were 5532 sessions of cognitive rehabilitation, 32.5% of which were organised at home. There was an important variability between the memory clinics in the split between *at home* and *in clinic* sessions (Figure 4). Secondly, there was an important difference in the total number of rehabilitation sessions between the memory clinics and, more importantly in the number of sessions per newly admitted patient during the first year of rehabilitation, which can vary from 6 (clinic n°11: 257 new patients in 2019; average number of clinic visits per patient during 1st year: 6; average number of home visits per patient during 1st year: 1) to 19 (clinic n°1: 752 new patients in 2019; average number of clinic visits per patient during 1st year: 13; average number of home visits per patient during 1st year: 6).

**Table 15 – Reasons to early stop the rehabilitation programme**

	2012-2014 N (%)	2019-2021 N (%)	Total N (%)
Total number of new patients	1083 (100.0)	857 (100.0)	1940 (100.0)
Early stop of programme^w	221 (20.4)	214 (25.0)	435 (22.4)
<i>Refusal of the patient</i>	61 (5.6)	75 (8.8)	136 (7.0)
<i>Institutionalisation</i>	54 (4.9)	66 (7.7)	120 (6.2)
<i>Death</i>	12 (1.1)	28 (3.2)	40 (2.1)
<i>Intercurrent somatic problem</i>	26 (2.4)	15 (1.8)	41 (2.1)
<i>Transport problem</i>	10 (0.9)	13 (1.5)	23 (1.2)
<i>Refusal of informal caregiver</i>	18 (1.6)	11 (1.3)	29 (1.5)

About 20% (20.4% in 2012-2014) and 25% (in 2019-2021) of newly admitted patients discontinue the rehabilitation programme less than 6 months after starting. The main reasons for such early discontinuation in both cohorts are patient refusal or institutionalisation (Table 15).

^w Early stop of the program is defined as halting the rehabilitation program less than 6 months after the first session.

Table 16 – The living environment of a patient 1 year after the start of the rehabilitation programme

	2012-2014 N (%)	2019-2021 N (%)	Total N (%)
Total number of patients who started the programme during the year	1083 (100.0)	857 (100.0)*	1940 (100.0)
Living at home after the programme	973 (89.8)	566 (66.0)	1539 (79.3)
Living in residential care after the programme	76 (7.0)	94 (11.0)	170 (8.7)

*: In the period 2019-21, 4% of patients died over the first year, and status at the end of the 1st year was unknown for 20%

About 66% (2019-2021 period) of patients are still living at home one year after starting rehabilitation. However, these figures should be treated with caution because: 1) the follow-up of patients starting in 2021 is unclear (the period covered is 2019-2021); 2) the COVID-19 pandemic changed care-seeking behaviour and care provision, and 3) the data were incomplete in 2020-21. A higher proportion of patients were living at home after one year of the rehabilitation programme in 2012-2014 than in 2019-2021 (Table 16).

So far, the pilot project has received a positive evaluation based on the data and the (limited) evaluation of the College of Medical Directors. To come to this conclusion, the living environment of a patient after 1 year of the rehabilitation programme is considered as a main outcome to evaluate the efficacy of the rehabilitation programme. At the same time, the results are considered insufficient to generalise the range of services offered by the current memory clinics (personal communication NHDI). In addition, the evaluation highlighted that there is no need for additional memory clinics,



although they considered adding 1 additional memory clinic for Walloon Brabant, as this province currently has no memory clinic.

As it can be seen above, there is no qualitative evaluation of the cognitive rehabilitation itself. For example, it is not clear whether a social worker truly fulfils the tasks assigned to this position under the terms of the agreement. The score of satisfaction of patients and caregivers with the service is generally high, but a social desirability bias cannot be excluded.

4.3.4 Management of YOD

4.3.4.1 Diagnosis and referral

In this paragraph, the importance of **awareness campaigns and education** should be highlighted. A first step to a correct and timely diagnosis is the awareness of the general public and primary care workers (e.g. general practitioner (GP)), as it has been noted that the first problems and symptoms of YOD often occur at work or at home (e.g. concentration problems, forgetfulness, behavioural changes). It is therefore important that relatives, colleagues and (primary) health care providers are aware of the symptoms of YOD, awareness campaigns are thus of the utmost importance to improve the delay in diagnosis.

To improve diagnosis in primary care, two **guidelines** have been developed: “*Diagnostiek van dementie in de huisartsenpraktijk*” and “*Multidisciplinaire richtlijn m.b.t. de samenwerking in de zorgverlening voor thuiswonende oudere personen met dementie en hun mantelzorgers*”.^{7, 8} Both of these guidelines are aimed at primary care workers (e.g. GPs, nurses, physiotherapists, occupational therapists, social workers) with recommendations on how to recognise dementia based on anamnesis, clinical evaluation and associated risk factors.^{7, 8} Furthermore, the guidelines offer advice on when primary care workers should refer patients to specialists. Importantly, **both guidelines explicitly state that they do not apply to patients with YOD, as they require a more specific approach and/or tools.**⁸

If an initial evaluation in primary care leads to a suspicion of dementia, patients are often referred to **specialists** (e.g. neurologist) working in a general or university hospital with or without a recognised memory clinic (see section 4.3.4.2.3) to confirm or refute this suspicion. Patients will then receive an intake anamnesis, neuropsychological evaluation (Box 7) and medical imaging to evaluate atrophy and structural changes of the brain. If indicated, some extra evaluations can take place (e.g. functional imaging, biomarkers, PET-scan with contrast, genetic testing).

Box 7 – Neuropsychological evaluation

Since 2011, NIHDI reimburses under nomenclature number 477573 a **one-time neuropsychological evaluation** for suspected dementia.⁸ This evaluation, focused on assessing cognitive functions in patients suspected of early dementia, can **only be charged by neurologists, psychiatrists, and geriatricians**. They may do so only when the patient has been referred to them by their GP or another specialist.

This evaluation entails a validated, thorough neuropsychological examination covering primary cognitive functions typically affected in dementia syndromes, including attention, memory, language skills, visual-spatial abilities, and executive functions. The examination must last a minimum of 45 minutes. The specialist may delegate the technical aspects of the exam to a qualified neuropsychology assistant. To use nomenclature number 477573, the specialist must supplement this neuropsychological evaluation with a specialised diagnostic assessment for dementia (nomenclature code 102992 or 102933 by an accredited physician-specialist).



4.3.4.2 Care provision after diagnosis of YOD

Dementia care in Belgium is organised on several levels ranging from supportive measures at home to (temporary) residential care and institutionalisation. Therefore, we have categorised the existing facilities according to the following three levels: extramural care, transmural care and intramural care.

Extramural care and supportive measures

Around 70% of people with dementia continue to live at home, relying entirely or partly on **informal caregivers**.⁸⁹ To assist these caregivers, the Federal and Flemish government have introduced several initiatives (e.g. law of 12 may 2014 and law of 17 may 2019). Although not specifically targeted to the YOD condition, these laws are available to informal caregivers supporting patients with various conditions. They aim to provide caregivers more social rights and help relieve some of their caregiving burden (Table 17). A number of organisations, often receiving public subsidies, offer information and support to caregivers.^x

Table 17 – Initiatives within the legal framework to support informal caregivers of persons with YOD

Supportive measures and rights	
Federal level	• A person who provides care to someone with impaired independence will be able to request an official recognition as “informal carer” to the compulsory health insurance and as a result will have access to a series of social rights (e.g. paid care leave, flexible working conditions). • Informal carers have an extended full-time leave scheme, 18 months instead of 12 months, for medical assistance. • The administrative burden will be alleviated for informal carers. • In 2020, a new carer’s leave was introduced allowing carers to take a carer’s leave of 6 times 1 month (for a full-time employee) over the duration of a career with a financial compensation of € 1400 gross per month from the National Employment Office (<i>RVA, ONEM</i>). Employers cannot reject the request for leave, there is no seniority requirement and employees benefiting from the leave are immune to dismissal. Self-employed workers can receive an allowance of € 1606 gross per month if they stop completely their professional activity. They are allowed to do it maximum 12 months over the duration of their career. Job seekers can also apply for an exemption from their obligations and receive an allowance of € 14.71 per day for a maximum period of 48 months.
Regional and municipal level	• In Flanders, a carer allowance (“<i>mantelzorgpremie</i>”) is available at the level of several Flemish local authorities. Each local authority sets the eligibility requirements and the lump sum attributed to the informal carer. • Municipalities in Brussels and Wallonia also propose an annual lump sum, and other advantages^y

^x Aidants Proches website, list of organisations supporting informal caregivers: <https://www.aidantsproches.brussels/structures-soeurs/>

^y Aidants Proches website: <https://www.aidantsproches.brussels/espace-media/soutiens-aux-aidants-proches-via-les-communes-bruxelloises/>



Secondly, informal caregivers can get additional information on their (social) rights at several patient organisations (e.g. *Alzheimer Liga Vlaanderen* or *Ligue Alzheimer*) or in organisations for informal caregivers (e.g. *Steunpunt Mantelzorg*, *Aidants-Proches*) which support all informal caregivers, and represent their interests. Besides these organisations, specific initiatives are

aimed at persons with YOD, their families and informal caregivers to offer support after diagnosis (Table 18) and provide them with information. In comparison to late-onset dementia, these initiatives should pay extra attention to the family situation, partners and (young) children.

Table 18 – Non-exhaustive list of available initiatives that support YOD patients and informal caregivers of patients with YOD in Belgium

Initiative	Description
<i>Praatcafé dementia</i> ⁹⁰	An initiative from the regional expert centres in Flanders to bring together persons with dementia and their family, with peer contact as central theme. This talking group gives the opportunity to share experiences in an informal setting and are organised 4-6 times a year (bi-monthly). In some instances, a keynote speaker is invited who covers a dementia specific theme.
<i>Alzheimer café</i>	The <i>Alzheimer Café</i> is a friendly, non-medical meeting place where people can ask questions about living with the disease. The group also helps to break down taboos and loneliness. These <i>cafés</i> are organised by Alzheimer Belgium.
Family groups ⁹¹	This initiative of the <i>Alzheimer Liga Vlaanderen</i> . “ Family groups ” aimed at stimulating contact with peers. It consist of talking groups with a moderator on a specific theme of dementia. These family groups are also specifically organised for people with YOD , which makes them more specific to this subgroup than other initiatives.
<i>Baluchon Alzheimer Belgique</i> ⁹²	This organisation/initiative offers respite care to informal caregivers. Informal caregivers can hire a caregiver (a “ <i>Baluchonneuse</i> ”) 2 times a year for a period of minimal 3 days to maximal 14 days. This caregiver is trained in dementia care and will provide the routine 24-hour care as explained by the informal caregiver and maintains a care journal. The only prerequisite is the fact that the caregiver will move in and ask a day price, some sick funds reimburse part of this sum. This initiative is more known and used in Wallonia than in Flanders.
<i>Dementie en nu</i> ⁸²	Psycho-education tool, developed by the Flemish dementia expert centre and <i>Alzheimer Liga Vlaanderen</i> , which offers a specific module for YOD and is aimed at informal caregivers of people with dementia and covers different themes: e.g. empathy with dementia, communication, finances, coping mechanisms.
Buddy system/ organisations	A volunteer assigned to a person with (young-onset) dementia, together they will participate in (adapted) activities. These activities are often not related to care or perceived as care by the person with dementia (e.g. <i>Het Ventiel</i>).
<i>Groupe battants</i>	Support group, who organises activities, talking groups, offers support and psychoeducation for people with YOD, their families and informal carers.
<i>Auguste et les autres</i>	Support group, who organises activities, talking groups, offers support and psychoeducation for people with YOD, their families and informal carers.



As shown by Table 18, several support groups for informal caregivers and relatives are established. More recently, support groups for persons with (young-onset) dementia themselves are started. To participate in such a support group, the patient is first evaluated by an expert, to ensure the person is not in a too advanced stage of dementia. The expert also assesses the interest of the person with dementia and his ability to express himself, before enrolling them.

Besides informal caregivers, patients with dementia can also rely on **home care services**.^{93, 94} The offered services include (routine) daily care and/or small medical interventions (e.g. wound care, injections) to improve and prolong the quality of life of a patient at home. To ensure the dementia care expertise in home care, **some home care services utilise a reference person** (e.g. *Wit-Gele kruis – Croix jaune et blanche*). These are specialised carers who offer advice and expertise to colleagues who encounter specific problems associated with dementia in their daily care tasks. Home care services are financed by the compulsory health insurance (sickness funds), according to a lump sum that varies according to the care needs.

Family care services (e.g. “*Familiehulp vzw*”, “*Fédération aide & soins à domicile*”) offer household help (e.g. cleaning, cooking, basic help with personal hygiene, administrative help...) to people who are unable to carry out these tasks themselves. Family care services may be part of a sickness fund (private service), offered through the OCMW – CPAS (public service) or organised by the regional authorities. In addition to home care services, this help is offered to facilitate elderly or ill persons to live as long as possible in their own home environment, thereby postponing residential care. Importantly, family care services are aimed at elderly or vulnerable people and not specifically persons with (young-onset) dementia. Some home care workers are supervised by dementia reference persons within the organisation (e.g. *Familiehulp vzw*), who have followed an additional training provided by the Flemish dementia expert centre.⁹⁵

The care and home help coordination centers (“*Centres de coordination et de soins*”, *CASD*) coordinate home care and family care services for anyone who, for a short or long period, suffers from reduced autonomy. As second-line workers, they ensure the proper organisation of services and benefits by consulting with the first line (general practitioners, etc.) and following **an intervention plan adapted to the beneficiary**. Their objectives remain above all the preservation of the beneficiary's quality of life and the maintenance of their autonomy. In Wallonia, AVIQ is responsible for the administrative and budgetary management, monitoring and evaluation of these centres.^z

The integrated home care service (“*Service intégré de soins à domicile*”, *SISD*) organises and supervises home care services that require the intervention of professional practitioners from different disciplines (doctors, physiotherapists, nurses, etc.) in a pre-defined geographical area.

In Wallonia, AVIQ is responsible for the administrative management and evaluation of integrated home care services (13 in total).^{aa}

Finally, reference physicians for dementia (“*Dementie referentiearts*” [*DRA*]) are currently being implemented in Flanders, in accordance with the goals defined in the Flanders dementia plan 2021-2025. There are currently around 141 000 people with dementia in Flanders and the Brussels Region. This number is expected to double by 2070. As part of the pilot project for dementia reference physicians, the first group of students started their training as dementia reference physicians in October 2023. In this way, Flanders wants to focus on increasing knowledge about dementia among current and future physicians. The pilot project is part of the 2021-2025 dementia plan, which emphasises the role of the GP in the early recognition of signs of dementia, the diagnosis and care diagnosis, the treatment and the follow-up of the patients (Box 8).

^z AVIQ website: <https://www.aviq.be/fr/soins-de-sante/soins-et-aides-domicile/coordination-soins-et-aide-domicile>

^{aa} AVIQ website: <https://www.aviq.be/fr/soins-de-sante/soins-et-aides-domicile/service-integre-de-soins-domicile-sisd>



Box 8 – Role of the reference physician for dementia (DRA)

In the Flanders Dementia Plan, a dementia reference physician is a general practitioner, geriatric psychiatrist, geriatrician or neurologist who advises fellow physicians who have questions about patients with dementia. At the macro level, the dementia reference physician signals policy challenges in consultation with the regional Dementia Expertise Centres. At the meso level, he/she has an awareness-raising role and works together with the primary care zone, local policy makers and care facilities. He/she also has an advisory role to the primary care zone and actively shares his/her expertise on dementia. At the micro level, the dementia reference physician is available to advise fellow physicians.

In December 2023, around 90 physicians (e.g. general practitioners, neurologists) finished the educational programme (approximately 24 hours). The aim of the training is to provide physicians with tools to support fellow physicians in recognising signs of dementia at an early stage, making the correct (care) diagnosis and following up on complex and changing care needs. The training was developed in collaboration with the Flanders Dementia Expertise Centre, the chronic care expertise group of Domus Medica and committed experts from the field. A new group of physicians started the training in 2024. The role of these reference physicians would be **to support primary health care physicians and to be a contact point for primary care workers within their region**. However, their function is not yet officially recognised and still needs to be implemented in clinical practice with concrete remuneration and tasks.^{bb}

Lastly, a specific pilot project was set up called the **ASAPP project** (*“Aide et Soutien aux Aidants Proches et aux Personnes atteintes de la maladie d’Alzheimer ou troubles apparentés”*) as part of the Protocol 3 from the NIHDI.^{96, 97} This pilot will run until 2024 and consists of several projects that focus on the development of alternative care options and support programmes for frail elderly people in Brussels and Wallonia regions.⁹⁶ The ASAPP project is aimed at people with neurodegenerative diseases and loss of autonomy (e.g. Alzheimer’s or related diseases). The main objectives are to i) help patients and their informal carers to stay at home (e.g. prevent institutionalisation), ii) maintain their autonomy and iii) improve their quality of life. To achieve this, the programme contributes to the well-being of patients and their informal carers at home by helping them to manage their condition through multidisciplinary and personalised intervention at the patient’s home by an occupational therapist, a psychologist or a case manager, depending on needs. Importantly, **one of the inclusion criteria is that the patients should be older than 60 years old, which can possibly exclude persons with YOD.**⁹⁶ This pilot project stimulates professionals in home care to set up a formal and informal support network; it is free of charge to beneficiaries and will be evaluated as part of the Protocol 3 evaluation. Protocol 3 is funded by the federal government (14 million euros in 2023) and a scientific consortium made of researchers from 4 Belgian universities evaluate the projects and their results. In the long-term, projects from Protocol 3 are supposed to be incorporated in the upcoming intergovernmental plan of integrated care.

Transmural care

Transmural care encompasses the gap between home care (extramural care) and residential care (intramural care). The main services for people with YOD in transmural care include: day care centres and short-stay centres.

^{bb} Jan De Lepeleire, KU Leuven, and Jurn Verschraegen, Dementia Expertise Center Flanders; personal communication, 10 October 2024.



Day care centres are tailored to people who have lost (some of) their self-sufficiency, do not need intensive medical care and can still live at home, but for whom home care is temporarily unavailable or need help in their daily life activities. They can spend a day or several days a week in a day care centre and return to their own homes at the end of the day. Besides the protective and supportive environment for people, some day care centres offer (adapted) activities to stimulate cognitive abilities and self-sufficiency (e.g. reading memory exercises, singing, cooking). Importantly, individuals are only eligible to apply for a day care centre if they have been diagnosed with difficulties by a doctor. Most day care centres work with prices per day – or in some cases with hourly rates – and the sickness funds reimburse part of the cost.

Short-stay centres can provide temporary accommodation for short periods of time (maximum 60 consecutive days and 90 days in total per calendar year). This accommodation can be provided by day or at night or both.

It should be noted that waiting lists and the accessibility to day care centres is very regionally dependent; the interviews with stakeholders revealed some having long waiting list with others still having places available. Furthermore, some day care centres have developed specific expertise in (young-onset) dementia and can offer more personalised and adapted activities.

Intramural care

Sometimes when informal care, home care and transmural care do not offer sufficient support, institutionalisation becomes inevitable. People with dementia can find support in two types of intramural facilities: permanent residence (nursing homes, rest and nursing homes, psychiatric nursing homes) and temporary residence (general hospitals, memory clinics, and psychiatric hospitals).

In Belgium, there are two main types of residential facilities for elderly people: homes for elderly people (*"Rustoord voor Bejaarden [ROB]"* - *"Maison de repos pour personnes âgées [MRPA]"*), providing nursing care and support services to elderly people with mild or moderate limitations in their daily activities, and *nursing homes ("Rust en verzorgingstehuis [RVT]"* – *"Maison de repos et des soins [MRS]"*) for individuals who are severely limited, but do not require acute care. Every nursing home must have a coordinating and advisory physician who is responsible for the coordination of physiotherapy, wound and pharmaceutical care.

These care facilities are mainly for people aged over 60, but initiatives have been undertaken to make them more accessible for patients with YOD. A pilot project in Flanders granted 23 nursing homes a specific recognition for YOD care, which equals around **200 subsidised places for people with YOD (Box 9)**.⁹⁸ In Wallonia, it is estimated that about a third of the approximately 300 institutions offers an adapted unit for patients with cognitive problems.^{cc} This is a specific architectural unit that accommodates people with cognitive disorders day and night. This unit is integrated into a rest and care home, and has a maximum capacity of 30 residents. The adapted unit promotes individual autonomy through the participation of residents in daily life activities and collective autonomy through the implementation of adapted leisure and therapeutic activities. The AVIQ regulations provide that people living in an adapted living unit have an individualised life project.^{dd}

^{cc} AVIQ; personal communication.

^{dd} AVIQ website: <https://www.aviq.be/fr/hebergement/aines/accompagnement-des-troubles-cognitifs-en-maison-de-repos>

**Box 9 – Special accreditation for residential care homes for the care and support of people with YOD in Flanders⁹⁸**

Programming: for each province, one housing unit for YOD patients is allocated per 15 000 inhabitants in the 30-64 age group. The Flemish minister may set additional rules to ensure balanced distribution of housing units throughout each province.

Accreditation conditions: a residential care home receive special accreditation to set up care for YOD patients for a minimum of 5 and a maximum of 12 units, provided it meets the following conditions:

- Units form a distinct architectural section separate from other care units;
- Units adhere to all standard approval conditions for residential care, except where specified otherwise;
- Care homes collaborate with a recognised dementia expertise centre.

Eligibility criteria for admission: a user is eligible if he/she (i) is diagnosed with YOD, (ii) is classified in dependency category Cd^{ee} or D^{ff} (based on the Katz scale) and (iii) requires intensive interdisciplinary care. YOD patients living in this facility receive a discount of 25 euros per day on the invoice price.⁹⁸

Staffing requirement: in addition to the full-time equivalents required in a residential care home, the care home should have 0.5 full-time equivalents of additional staff members per ten users who meet all the following conditions:

- have a qualification as a social worker, social nurse, remedial educationalist or master in psychology, or an equivalent qualification;
- possess the certificate reference person dementia.

Some recent initiatives in residential care aim to create an environment that more closely resembles a home setting. In Flanders, small-scale normalised living initiatives, known as “*kleinschalig genormaliseerd wonen*”, have been established since 2007 as part of a research project. In these settings, small communities of up to 15 people live together in an environment designed to feel more like a regular home than a nursing facility, allowing residents to retain maximum control over their daily lives. These initiatives promote a flexible, professional, and interdisciplinary approach to staffing and are integrated within a broader continuum of residential care. Such environments generally better accommodate individuals with YOD compared to traditional residential care facilities. While other healthcare providers have since adopted similar models, no specific legal requirements or oversight mechanisms currently regulate these initiatives.

^{ee} Category in which patients are ranked who:

- are psychologically dependent: they are disoriented in time and space, and dependent to wash and dress themselves, and dependent because of incontinence, and dependent for transfer and movement or to go to the toilet or to eat; or
- those for whom the diagnosis of dementia has been established or confirmed on the basis of a specialised diagnostic bilan for dementia performed by a physician-specialist in neurology, psychiatry or geriatrics, with written report, and who are dependent to wash and

dress, and are dependent due to incontinence, and are dependent for transfer and movements or to go to the toilet or to eat.

^{ff} Category in which patients are ranked who are

- physically dependent: they are dependent to wash and dress themselves, and are dependent for transfer and movement or to go the toilet or;
- psychologically dependent: they are disoriented in time and space and are dependent to wash or dress themselves.



Since 2010, the NHDI funds ½ FTE of a specially trained dementia care referent in residential care facilities for older people.⁹⁹ This dementia referent can be a nurse, a physiotherapist, a psychologist, a social worker, or other primary care provider. The training must last at least 60 hours and must be validated by the FPS Public Health. The Alzheimer Ligue, for example, organises this training.^{hh} Its mission is to encourage the creation of networks involving relevant stakeholders active in the field: the dementia expertise centre, the geriatric day hospital with which a functional link is created, the coordinating physician, other reference persons in the field of dementia. It is also about raising awareness among staff and management to continue to seek ways to improve the quality of life of people with dementia, as well as proposing management ways to improve the quality of life of staff who care for or work alongside people with dementia, in particular through the organisation of supervision by external experts.

4.4 Bottlenecks in the current patients' journey

In this section, we present a synthesis of the insights provided by the stakeholders we met. Since we did not initially aim for a detailed analysis, we did not seek authorisation to use the interviewees' quotations.

4.4.1 The diagnostic process

Interviewees agreed that the earlier the disease is detected and the better the risk factors are managed, the better the chances of early treatment and prevention of deterioration. A primary bottleneck identified by the stakeholders lies in the diagnostic process, which is estimated to take 2 to 4 years. The diagnosis of YOD is challenging to establish for several reasons.

First, it raised from the interviews that the physicians often overlook young-onset dementia due to its low prevalence and their lack of training and awareness of the occurrence of dementia in groups other than the elderly. YOD is often an exclusion criterion. Healthcare professionals want to be

sure that no other condition could be causing the observed cognitive impairment before thinking about dementia, and the variability of symptoms exhibited in different patients makes the diagnosis more difficult, i.e. each dementia patient shows a different range of possible symptoms, one showing more behavioural problems, the other more cognitive. In addition, the diagnostic process is lengthy because the risk of error is higher in younger patients and multiple examinations are required. These examinations are not always available within a short time frame and are not always reimbursed (see further details). Waiting times for neurology consultations are also significant. The diagnostic delay could also be due to a psychological barrier, e.g. YOD confronts doctors with their own vulnerability.

Second, people with YOD might hide their cognitive decline from those around them, allowing them to function relatively well for a long time, further delaying diagnosis. Often, their difficulties first manifest at work, where decreased productivity and efficiency, unusual behaviours (e.g. a punctual person who gets often late), or even mistakes, are noticed. Consequently, when a person seeks medical attention for atypical problems such as personality change or withdrawal, these symptoms are often mistakenly attributed to stress, burnout or psychiatric problems.

4.4.2 Lack of a clear care pathway

Once the diagnosis is made, either during a hospital stay or in a neurologist's office, interviewees reported that there is no structured care pathway. Typically, patients are advised to attend follow-up appointments every six months. During these visits, the neurologist conducts tests to check for disease progression, including the MMSE test to assess cognitive abilities. However, there is no comprehensive care plan in place. In Belgium, according to at least one interviewee, there is a notable lack of institutions and trained professionals with expertise in supporting people with YOD. For example, organisations such as AVIQ in the Walloon region and Iriscare in

⁹⁹ Circular MRPA-MRS 2011/8 <https://www.health.belgium.be/nl/node/29081>

^{hh} <https://alzheimer.be/nos-activites/formations/a-destination-des-professionnels/formation-referent-demence/>



Brussels lack the expertise to fully understand the extent and consequences of young-onset dementia, including the major neurocognitive disorders and the comprehensive needs that results from this condition. In contrast, Flanders has an expertise centre for dementia with some local expertise centres that aim to provide healthcare professional (HCP) with expertise, training and some coordination of care.

Patients presenting with memory issues are likely to be directed to memory clinics. However, young-onset dementia often manifests through behavioural disturbances, and in such cases, doctors are uncertain about appropriate referrals.

According to interviewees, the care provided, even in memory clinics under NIHDI convention, is neither specific nor well organised. It includes treating the underlying causes, addressing or preventing comorbidities, encouraging cognitive stimulation through activities such as sports and the arts, and promoting social interaction. Measures are also taken to discourage activities that further deteriorate brain health, such as smoking.

They also pointed out that there is currently no case management or coordination of care after diagnosis. The case manager should avoid the patient repeating his/her story several times.

However, in Flanders they are currently trying to tackle this problem with the implementation of dementia reference physicians (and got extra budget for this in 2023). This leads one interviewee to point out that in other countries, decisions about care are structural and not a succession of (regional) plans. Doing it this way undermines the ability to provide a clear pathway.

4.4.3 *Difficulties in engaging patients to seek care*

A major challenge in managing this type of disease, as reported by interviewees, is that patients often exhibit anosognosia. In the early stages, they do not perceive themselves to be seriously ill and do not feel the need to seek care. They may feel that although they are not quite well, they are still able to manage their own lives. Patients often think, "I'm not yet at the stage where I can't recognise my children; I can still take care of myself."

They tend to postpone seeking help, planning to do so only when their condition worsens.

This attitude may be reinforced by partners who prefer to wait until the situation becomes unmanageable. However, it was clear from the interviews that it is crucial to initiate care as early as possible. Delaying intervention increases the risk that, once the disease has progressed significantly, it will be too late to achieve effective management or slow the deterioration.

4.4.4 *Expertise and structural issues*

4.4.4.1 *Long waiting times from initial contact with a healthcare professional to care*

Interviewees reported significant delays between the initial contact with a healthcare professional and the start of care. Patients often face long waiting times to see a specialist, compounded by the difficulty of scheduling appointments within a professional agenda for those who are still working. In addition, to receive a reimbursed neurological assessment, patients must first obtain a prescription from a neurologist, which further prolongs the diagnostic process. If general practitioners could prescribe these assessments, one could assume that the diagnostic pathway would be simplified and speeded up.

There are waiting times not only for the initial consultation, but also for the scheduling of further examinations, which depend on the availability of radiology services, such as MRI scans. The delay between the initial request for care and the eventual diagnosis and treatment is a crucial quality parameter according to interviewees. On the one hand, it is very tough for patients to wait for their "definitive" diagnosis by imaging. They live uncertainty in the period of time between the initial request and the final diagnosis. It is therefore important to keep this time as short as possible in order to reduce psychological distress. On the other hand, due to the agnostic nature of the disease, rapid organisation of treatment and follow-up after diagnosis is essential, as patients tend to lose awareness of their condition.



When patients are referred to a specialised care centre (i.e. a memory clinic), particularly in French-speaking regions, the likelihood of them actually attending is low, as mentioned by interviewees, if the centre is too far away. This issue is exacerbated by the small number of centres in these regions.

Overall, stakeholders noted that addressing these structural and logistical barriers is critical to improving the timely diagnosis and management of patients with young-onset dementia.

4.4.4.2 *Inadequate care*

A current lack of knowledge about young-onset dementia among healthcare professionals, including caregivers, nurses, neurologists, and general practitioners, was highlighted in the interviews. Some general practitioners are sceptical about the diagnosis simply because they are unfamiliar with the disease. While some theoretical training on the diagnosis and symptoms is provided by certain local expertise centre, this training is very regionally dependent and mainly based on local initiatives by expertise centres (in Flanders), which are not specific to younger patients. According to the stakeholders we met, such training should, be included in the curriculum for future healthcare professionals.

Due to the lack of trained personnel, individuals with dementia lack cognitive stimulation and age-appropriate activities. There are no specialists available to support young patients, especially when behavioural problems suddenly arise. This poses a safety risk to staff and complicates patient care. As a result, interviewees stated that patients are often prescribed antipsychotics rather than benefiting from the expertise of professionals who understand behavioural approaches and can implement various activities to alleviate these issues.

Cognitive-behavioural units could provide care for people with severe behavioural problems and focus on addressing these issues without resorting to medication. Such units should cater for people with young-onset cognitive disorders without being day-care centres like those available for the elderly. Stakeholders mentioned that it is crucial to keep these patients physically, socially, and relationally active as the disease progresses.

Improving their mental health would reduce the burden of home care, which is not medically intensive but is very demanding on a daily basis. These people do not require hospitalisation but living with them can be extremely challenging.

However the lack of treatment facilities means that patients may have to travel long distances for their follow-up care. The distance between home and treatment centres is a barrier to consistent care and, according to interviewees, explains many early drop-outs. Patients do not drop out of treatment because they find it irrelevant but because long journeys for a non-curative follow-up can lead to understandable reluctance.

In the absence of the proximity of such non-residential care centres, people can no longer stay at home. They have no alternative but to be institutionalised, and if they are not, their cares run the risk of becoming exhausted. When home care is no longer possible, people should have access to age-appropriate housing. They should not be forced into nursing homes for the elderly, as these environments are not suitable. Young patients feel out of place in a nursing home, and living among the elderly can be distressing because it reminds them of their own mortality, which they are not ready to face. In addition, even with more activities, these facilities remain closed environments that limit the patients' freedom.

Stakeholders mention that it is essential to find alternative care facilities for individuals when home care is no longer feasible. These alternatives should meet the needs of younger adults, with programmes that respect and adapt to individual needs. This is particularly important as, from 2029, access to nursing homes and residential care homes will be restricted to people over the age of 70. Exceptions will be allowed, but only in large institutions. It should be noted that such initiatives are already emerging, but very local and regional, with long waiting lists (and others with no waiting list at all). These are good examples that can be looked at and further expanded.

Meeting the specific needs of younger adults requires the development of specialised programmes that are more flexible and individualised. Creating such facilities will ensure that these patients receive appropriate care and support, preserving their quality of life and autonomy for as long as possible.



4.4.5 *Issues due to healthcare reimbursement*

4.4.5.1 *Access to care*

The loss of family income, combined with the cost of maintaining a family and multidisciplinary care, as well as low sickness benefits, risks pushing some families into poverty. Facilitating access to examinations and treatments is therefore crucial. However, young people with dementia benefit less from reimbursement than other patients because of the current regulations.

Uncertainty about non-reimbursed options and their impact on the disease

While some doctors may be tempted to prescribe certain tests or treatments, they may refrain from doing so due to the lack of reimbursement by NIHDl, or because they are not sure of the appropriateness or effectiveness in the absence of evidence. It is therefore a challenge for them to determine what they can offer.

Age as a limiting criterion

The convention provides reimbursement for a rehabilitation programme at memory clinics and gives financial support to certain *WZC – MRS* "beds" that have a partnership with YOD reference centres (e.g. lower daily rate) and better support (e.g. more expertise and adapted environment). In these centres, young people with dementia can choose to receive on-site medical support from a psychiatrist and/or neurologist for a fixed daily fee.

The number of rehabilitation sessions, included in the convention, and thus provided by one of the 12 memory clinics under convention with the NIHDl, is determined by the patient's age. They also have a fixed duration of 4 years. The criterion used is the time of entry into the care pathway, not the time of diagnosis. Therefore, if a patient is diagnosed by a neurologist before the age of 65, but decides to start treatment at the age of 66 due to various delays (e.g. patient acceptance, spouse availability), they will lose the right to the higher number of sessions granted for the early onset of their disease.

Conversely, due to their age, patients with young-onset dementia do not have access to the same care reimbursements as older individuals. For example, they cannot enter a geriatric care programme aimed at people aged 75 on average, even though they require a similar multidisciplinary approach. This raises questions about the equity of access to care.

Diagnosis as a gateway to certain treatments

In order to obtain reimbursement for treatments such as physiotherapy or occupational therapy, it is necessary to submit a request to the mutual insurance company's consulting physician. In the early stages of the disease, however, the symptoms are more varied and the diagnosis is not easy to establish. One examination that helps refine the diagnosis is a lumbar puncture to measure cerebrospinal fluid biomarkers, and in the future, blood biomarkers. This examination is not reimbursed. Patients are reluctant to undergo it, especially since it does not currently alter the medical approach.

Currently, certain medications are only reimbursed for specific conditions. For example, Rivastigmine is reimbursed for patients with moderate to severe AD but is also prescribed for patients with Lewy body disease.

Limited interventions in number and time, designed for diseases progressing over a shorter period due to advanced age

Young-onset dementia is a progressive disease that requires long-term support, at the pace of the disease's progression, given the young age of the patients. Limiting interventions in time seems inappropriate, according to interviewees. Currently, cognitive rehabilitation programmes only provide reimbursement for one neurological assessment in a lifetime. While this may be sufficient for older patients with a disease that progresses over a relatively short period of time, young patients would benefit from a second reimbursed neuropsychological assessment for ongoing monitoring. Many patients currently present with mild cognitive complaints, and an initial assessment often concludes with a prodromal condition, necessitating follow-up and usually a comparative neuropsychological assessment.



4.4.5.2 State of knowledge : lack of data to evaluate the effectiveness of non-reimbursed diagnostic tests and treatments

There is a debate about whether the disorders classified as "young-onset dementia" constitute one or several diseases. Defining this requires data generated by examinations. The more physicians limit examinations, the more we remain in a general approach that does not allow us to understand what we are really dealing with. For example, the cost-benefit of lumbar puncture examinations for diagnosing, treating, and monitoring patients with young-onset dementia is unknown. Sufficient data are needed to determine whether it refines the diagnosis and therapeutic approaches based on specifics rather than simply categorising the pathology as 'Alzheimer's,' despite possible different processes. Without reimbursement, the examination is rarely prescribed, and the data needed to assess its cost-effectiveness is lacking.

The same applies to treatments: some non-pharmacological approaches, such as speech therapy, seem to have an impact according to interviewees. For some people with neurocognitive disorders such as aphasia, speech and language therapy allows them to continue to communicate with their loved ones, which is essential.

4.4.5.3 Insufficient financial support for informal caregivers

When a patient refuses cognitive care, the caregiver who needs more support and advice from a neuropsychologist receives the same number of reimbursed sessions or the same number as caregivers of institutionalised patients. It is difficult for the spouse of a young patient or the child of a parent living alone to get leave from work. Children of people with YOD can also be

greatly affected by their parent's state of health in their own 'child life', for example, if they want to study in good conditions. At present, they do not benefit from any special status or support to help them with this difficulty.

4.4.5.4 Hospital level

Healthcare providers are feeling pressure on their profitability across all healthcare sectors. Interviews suggest that this is particularly acute in neurology and the cognitive disorders sector, which are time-consuming without "valued medical acts." As a result, it is a challenge for services to maintain financial balance. For example, under the NIHDI convention, sessions are well funded compared to other types of follow-up, but home visits are underfunded (mainly due to traffic in Brussels).

4.4.6 Lack of keeping patient integrated in the society

Young people with dementia wish to continue living as normally as possible. However, they are quickly declared unfit for work, even though adjustments could be made to help them remain active. Currently, there are no specific provisions for integrating these people or maintaining their participation in society. There are no measures to motivate employers to keep them in work, for example by offering them adapted work.

4.4.7 Suggestion for improvement

From the interviews, we identified several needs of people with young-onset dementia. Interviewees also suggested several recommendations to address unmet needs. These are presented in Table 19.


Table 19 – Needs of people with young-onset dementia and suggestions for improvement in Belgium (from the interviews)

UNMET NEED domains	Suggestions for improvement
Specific approach for people with YOD	• Similar to existing national dementia plans, create a specific YOD-focused strategy • Address research, funding, caregiver support, and community services • Create Cognitive behavioural therapy (CBT) units for younger patients providing physical, social and relational activities
Diagnosis: Need for earlier diagnosis	• Raise public awareness: ◦ Promote public awareness campaigns about risk factors for YOD. Encourage healthy lifestyles, brain health, and risk reduction strategies • Empower GPs and healthcare professionals about YOD ◦ Tailored training sessions should cover early signs, differential diagnosis, and the unique challenges faced by younger patients ◦ Highlight the importance of timely intervention and person-centred care: early screening initiatives can identify at-risk individuals and facilitate timely interventions ◦ Equip GPs with the skills to administer basic cognitive tests. Early detection relies on their ability to recognise subtle cognitive decline. Regular training updates are essential ◦ Create dedicated sections within electronic medical records (EMRs) to track functional aspects. Document changes in daily living, cognitive abilities, and quality of life
Organisation of care: No clear pathway and drop out	• Develop expertise in Wallonia • Empower GPs to actively participate in YOD care. They should collaborate closely with memory clinics, share information, and engage in joint decision-making • Extend the interdisciplinary convention to include case managers • Enlarge local offer
Psychological support	• To provide comprehensive support, consider integrating psychologists within memory clinics (note: this is already a requirement for memory clinics to enter the NIHDI convention). Their expertise in cognitive assessment, emotional well-being, and coping strategies can significantly benefit patients and their families
Better support and patient-centredness	• Recognise the vital role of informal caregivers (family members, friends) and actively involve them in care planning • Beyond clinical knowledge, emphasise attitudinal training for GPs. Accreditation programmes should reward compassionate communication, empathy and understanding
Accessibility of care	• Patients with cognitive impairments should be better reimbursed for additional physiotherapy sessions (more than the current 18 annually), as these sessions help maintain their autonomy and quality of life, especially if they are motivated to maintain or resume weekly sports activities. Group sessions are also valuable for psychosocial aspects.



5 INTERNATIONAL COMPARISON: ORGANISATION OF CARE AND SUPPORT IN FOUR COUNTRIES

5.1 Key points

- This chapter reviews the current national dementia plans in 4 neighbouring countries: England, France, Germany, and the Netherlands.
- There is no national plan specifically for people with YOD, but the national plans for dementia care include some references (specific actions, centres, initiatives...) for young patients. This supports the recommendations of the National Institute for Health and Care Excellence (NICE) (2018) stating that it is less appropriate to have a separate set of recommendations for people with YOD, rather than highlighting their specific needs in recommendations for patients of all ages with dementia, where appropriate.
- The main objectives of the national plans are to support and empower people of all ages with dementia and their informal carers, and to enable people with dementia to remain a valuable part of society (including professional activities).
- Some actions or strategies are targeted at younger people with dementia: reference centres (France, the Netherlands), case managers or dedicated professionals to support patients and their carers (Netherlands, England), while other are targeted at people with dementia of all ages (e.g. memory clinics for diagnosis and management).

- There is a lack of specific data, evidence and evaluation of activities for people with YOD in the national plans. In addition, information on the effective implementation of the plans was difficult to obtain (e.g. whether they were implemented – and which parts, at what level and to what extent).
- Limitations: Local initiatives or initiatives outside of the national plan that may also provide care and support to people with YOD are not included in this chapter; nor are general practices that apply to everyone, although they may help people with YOD.

5.2 Methods

The aim of this chapter is to describe the organisation of care and management of people with YOD in neighbouring countries, such as expected in a national strategyⁱⁱ. This would enable us to draw lessons relevant to the Belgian context. Specifically, the question we want to answer is: *What are the current national plans for the care of people with YOD?* We want to improve our understanding of what is being proposed in a selection of countries in order to identify any lessons that could be learned for the management and support of people with YOD in the Belgian context.

To answer this question, we conducted a review of existing plans in a subset of neighbouring countries. National plans for the care of people with YOD are generally not published in peer-reviewed journals. Therefore, we decided to conduct a grey literature review, focused on a limited number of countries that have established a national dementia plan. We carried out an initial exploratory search to identify the countries to be included. Countries were selected because i) they had a national dementia plan in place, and ii) published documents (grey literature, reports, policy briefs, etc.) were available. We selected four countries: England^{jj}, France, Germany and the

ⁱⁱ In this chapter, we will use the term plan or strategy interchangeably.

^{jj} England was selected over the United Kingdom (UK) because the national plan is implemented at that level.



Netherlands. As a starting point for our data collection, we used the available national plans or strategies.

For each country, we searched the grey literature, in particular websites of government institutions or ministries, professional health care organisations or patient organisations. To standardise the data collection, we created an extraction table divided into three sections: i) general information (name of plan, period, responsible institution, funding, aim), care pathway (target population, public awareness and prevention, screening and diagnosis, management and treatment) and iii) evaluation (timing, type of evaluation, indicators, results). We then extracted the information on each national plan into this table, which was reviewed and validated by a country representative

recognised for his/her expertise in the (organisation of) care for patients with YOD (Appendix 3). These experts were selected through our reading of national strategies (their names were mentioned) or through contacts with national organisations (ministries, national centres or associations with expertise in dementia care). In addition to our review, we asked the country representatives to clarify certain points and/or identified gaps and whether other important (national) documents/reports were missing from our analysis (e.g. evaluation, reported data). The search for documents took place between September and December 2023, the validation by the national experts took place between December 2023 and March 2024. Below, we summarise the main findings from these four national plans, with a focus on overlapping themes and/or differences.

Table 20 – General information of the national plans in the four selected countries

	England ⁹⁹	France ¹⁰⁰	Germany ¹⁰¹	The Netherlands ¹⁰²
Name of the plan (English)	The Major Conditions Strategy: Case for change our strategic framework (expected in its final version in 2024)	Roadmap for Neurodegenerative Diseases (Axis 3/sheet 6: Design and implementation of a response adapted to the specific needs of young Alzheimer's patients)*	National dementia strategy	National dementia strategy
Name of the plan (national language)	The Major Conditions Strategy: Case for change our strategic framework	Plan Maladies neuro-dégénératives (P-MND)	Nationale Demenzstrategie	Nationale dementiestrategie
Period covered	To be published in its final version in 2024	2021-2022*	Sept. 2020-Dec. 2026	2021-2030
Published by	Department of Health and Social Care	Ministry of Health and Prevention	Federal Ministry for Family, Seniors, Women and Youth	Ministry of Health, Welfare and Sport's
Targeted condition(s)	6 major conditions, including dementia	Neurodegenerative disorders	Dementia	Dementia
Targeted population	Patients of all ages	Patients of all ages	Patients of all ages	Patients of all ages

*The National Neurodegenerative Diseases Plan 2024-2028 is expected in 2024.



Box 10 – The example of the National Reference Centre for Young Alzheimer's Patients in France

The National Reference Centre was created following the 2008-2012 National Plan for Alzheimer's Disease^{kk}, which identified the need for specific initiatives for young patients. Its missions are organised around 4 key areas:

- **Care**, by improving the diagnosis (including genetic diagnosis and reducing the time to diagnosis) and follow-up of young patients according to their needs, and providing access to clinical and pharmacological protocols.
- **Management of the disease**, by informing occupational and general practitioners to help with rapid diagnosis, helping to raise awareness of specific needs (such as socio-professional difficulties), defining accommodation needs, etc.
- **Research**, by setting up a cohort of young patients to define specific characteristics and needs, identifying unknown genes in rare familial forms, improving imaging techniques, encouraging studies and trials, etc.
- **Public health**, by proposing new guidelines, identifying problems and promoting new solutions.

In practical terms, the National Reference Centre for Young Alzheimer's Patients is involved in the diagnosis of patient, support for care and research through its 3 sites (Lille-Bailleul, Ile de France, Rouen, which is specialised in genetics). It also develops partnerships between professionals and coordinates memory support networks.

In addition to the National Reference Centre for Young Alzheimer's Patients, there are other centres (for patients of all ages, including young patients): the Memory Resource and Research Centres [CM2R – *Centres*

Mémoire de Ressources et de Recherche], the regional memory consultations [*consultations Mémoire de Territoire*] and the local memory consultations [*consultations Mémoire de Proximité*]. The CM2R (between 1 and 3 per region) are associated with university hospitals, while the memory consultations are more numerous throughout the country. All these structures have to meet certain criteria in terms of staffing and missions. Young patients have at least one contact with the CM2R (professionals in these centres are qualified in the care of young patients) and they can be followed up in a CM2R or referred to a memory centre. The National Reference Centre supports the local expertise of the CM2R and the memory consultations throughout France.

There is also a national reference centre for patients suffering from one of four rare neurological disorders caused by the degeneration of nerve cells in the frontal and temporal cortex and affecting young patients: frontotemporal degeneration (FTD), progressive non-fluent aphasia and semantic dementia (PNFA/SD), progressive supranuclear palsy (PSP) and cortico-basal degeneration (CBD). The aim of this National Reference Centre for Rare or Young-onset Dementias (based in Paris) is to ensure that these 4 diseases are treated in the same way throughout France, by coordinating a nationwide network.

(<http://cm2r.enamax.net>, <http://www.alzheimer-genetique.fr>, <http://www.centre-alzheimer-jeunes.com>, <https://cref-demrares.fr/>, <https://www.centre-alzheimer-jeunes.fr/>, Personal communication CNR-MAJ)

^{kk} The Alzheimer's Plans have evolved into the Neurodegenerative Diseases Plans or 'Roadmap'.



5.3 Main takeaways of national plans

5.3.1 General guidance on dementia care

In the four selected countries, there are differences both in the **names** of the plans and in the conditions they target (Table 20): the Netherlands and Germany have a national "strategy", while France has a "roadmap".¹⁰⁰ In England, a new "strategy on major conditions" is expected, replacing the previous Prime Minister's Challenge on Dementia and, before that, a "National Dementia Strategy".^{99, 103, 104} All have a national scope, as this was a selection criterion for inclusion in this international comparison. These plans are issued by official institutions such as ministries: the Ministry of Health, Welfare and Sport's in the Netherlands, the Ministry of Labour, Health and Solidarity in France or the Department of Health and Social Care in the United Kingdom (for England), and the Federal Ministry for Family, Seniors, Women and Youth in Germany. Although the names are different, **they all provide general guidance on the care and support to be provided.**

In terms of **conditions**, the Netherlands and Germany target 'dementia'; France has developed a broader plan targeting 'neurodegenerative diseases', which includes, but is not limited to dementia (e.g. multiple sclerosis is also targeted). In England, previous strategies have targeted dementia and the new plan expected in 2024 will have a broader scope: it will target six major conditions, one of which will be dementia. This new plan will have a transversal vision of the care to be provided to the population, rather than a more fragmented vision by each individual pathology (the six targeted conditions are cancer, heart disease, musculoskeletal disorders, mental ill-health, dementia and respiratory diseases).

However, none of the selected countries has a specific national plan dedicated exclusively to young people with dementia, but all have included some focus on this group in their plan, as they recognise the specific needs of this subpopulation. This focus on young patients may be more or less

prominent according to the country. This can be illustrated as follows: in the Dutch strategy, people with YOD are mentioned as a specific patient group within each of the main themes of the strategy (i.e. to promote the cooperation in dementia research, to empower people with dementia to remain valuable part of the society, to improve support for people with dementia and their relatives). In France, one axis of the roadmap focuses on the design and implementation of a response adapted to the specific needs of people with young-onset AD and the maintain of the National Reference Centre for Young Alzheimer's Patients (*Centre National de Référence – Malades Alzheimer Jeunes [CNR-MAJ]*) (Box 10).^{100, 105, 106}

In the four countries, YOD is defined as a dementia below the threshold age of 65 years¹¹. However, it's not always explicit whether the threshold refers to the age of onset of symptoms or the age at which care is received.

All these national strategies aim to **outline the care and support to be provided** in the case of dementia (or more broadly, neurodegenerative disease in France and one of the six 'major conditions' in England). They provide general orientations but in England, implementation plans have also been published for previous versions of the strategies, providing practical support^{103, 107, 108}, as in Germany, where the strategy includes an implementation plan with specifically stated goals and deadlines, which are revised and evaluated through annual stakeholder meetings.

These plans have been updated (some of them several times) emphasising an environment where appropriate care for people with dementia of all ages matters. None of the plans in the four countries is a first attempt to propose a national vision for the care and support of people with dementia: all take place in a context where dementia care has already been the subject of previous strategies that have been updated, sometimes over more than 10 years (such as in England) or 20 years (in France). Little is known about the level of funding of the plans, and the economic assessment. It is also worth mentioning that in France (Box 10) and the Netherlands, **"reference**

¹¹ In France, some earlier documents mention 60 years as a threshold.



centres" have been set up to coordinate dementia care and research at a macro level.

5.3.2 *Main objectives of the national plans*

All four national plans share a common goal: **to support people with (young-onset) dementia and their informal carers** during the course of the disease and/or to improve the care provided. Improving or supporting care includes preserving people's autonomy, helping them to stay at home with the highest possible quality of life, and supporting their informal carers or relatives.

Some specific objectives or components can also be mentioned. For example, in France, the roadmap has proposed the creation of a regional network adapted to the care of young patients, taking into account, on the one hand, their specific care needs and, on the other hand, the need to limit the geographical distance from their families and relatives. They also want to improve the care of young patients in health care institutions (e.g. residential care facilities) through the creation of multidisciplinary teams, better education and training of health professionals and appropriate/adapted units. The aim is to improve patients' quality of life and autonomy, reduce their psycho-behavioural problems and improve their end of life care.

In all four countries, **informal carers are seen as essential partners** in the care of people with dementia, and actions are being taken to empower them and increase their knowledge. In England, for example, a document published by NHS England on the Well Pathway for Dementia (2016)¹⁰⁹ explicitly includes carer respite, and the National Institute for Health and Care Excellence (NICE) recommendations (2018) also recognise the specific needs of carers of people living with YOD. In some countries, such as England, some **patient organisations** play also an important role.^{79, 80} For example, the Young Dementia Network (England) has published

recommendations for implementing guidelines or pathway; this Network is an online influencing community, whose aim is to "improve the lives of people living with YOD and their families now and create positive change for a better future"; their approach has several components, including working with people with lived experience, professionals and organisations, campaigning for improvements in policy, practice and services; providing opportunities to increase knowledge and connection between people with lived experience and professionals; and creating empowering resources for patients and professionals^{mm}. The network has produced a range of resources for people with YOD, their caregivers, clinicians and service commissioners and developersⁿⁿ.

The Dutch plan mentions the goal of **empowering people with dementia to remain a valuable part of the society**. In Germany, they want to develop and maintain dementia-inclusive communities to enable people with dementia to participate in society; dementia friendly communities to improve awareness and social action were also part of the previous English strategy. In France, raising awareness on dementia in society and developing the skills of health professionals are operational objectives of the French National Reference Centre. One example of being or remaining a valuable part of society is, maintaining a **(professional) activity**, which is an important need for people with YOD (see section 3.4.5.1). However, this is hardly mentioned in the four national plans: as described above, they focus on care and support, research may be included, but maintaining or returning to work is not a priority in these national strategies. This does not mean that there are no initiatives in these countries: either there are local initiatives outside the national plan or, there are "general rules" related to the work environment, not specific to the needs of people with YOD. In France, for example, the occupational physician can be involved to obtain some support, such as the adaptation of the workplace or a reassessment of the work project. According to the German national plan, one of the main objectives of the management of people with YOD is to advise patients, their

^{mm} From the Young Dementia Network website: <https://youngdementianetwork.org/about-the-network/what-is-the-young-dementia-network/>

ⁿⁿ See website <https://youngdementianetwork.org/resources/>



informal carers and employers to improve the chances of remaining in gainful employment and to empower people to adapt workplaces to the specific needs of people with YOD. In its recommendations, the NICE committee recognises that, based on their experience, some younger people living with dementia can continue to work for many years with reasonable adjustments (the work can be considered either paid or voluntary).⁵ In addition, the patient organisations in the different countries (such as Alzheimer's Society) provide information to workers about their rights and options.

Lastly, all four countries have reported on the importance of developing (inter)national research consortia and to coordinate **scientific research** on (young-onset) dementia. In the Netherlands, an important point is the establishment of research consortia and structural financing of a research agenda by *Zorgonderzoek Nederland Medische Wetenschappen (ZonMw)* for the following 10 years.⁹ One example is "YOD INCLUDED"^{oo}, which aims to develop knowledge and expertise on the biomedical and psychosocial cause(s) of dementia, the pathophysiology, diagnosis and patient-centred, individualised care for people with YOD. In Germany, the national plan aims to promote "excellent research" on dementia, while in England, research was one of the domains to develop (with dementia care, support, and awareness) as expected in the next plan (to be published in 2024). In France, research on (young-onset) dementia is a mission of the National Reference Centres and of the 28 Memory Resource and Research Centres, and research is also one of the 10 axes of the Roadmap for Neurodegenerative Diseases (although this roadmap is not specific to people with YOD). The fragmentation of research structures in France as well as their funding and evaluation makes it difficult to evaluate a specific field of research such as neurodegenerative diseases; however, a challenge formulated at the end of the previous plan (2014-2019) was to strengthen and better coordinate research on neurodegenerative diseases.¹¹⁰

5.3.3 Lack of (national) data, evidence and knowledge on YOD

As mentioned above (Chapter 2), there is little high quality evidence on YOD. Therefore, the current state of scientific knowledge is rarely mentioned in the national plans. There is little mention of how these plans were developed and **how the evidence or research was used** to draw them up. The national plans we analysed described some of the (scientific) context, showing for example the extent of the disease (number of people affected, impact on daily activities and specific needs). For example, in France and Germany, the context included the estimated number of patients or their specific needs, and in the Netherlands, the research consortium has provided national Dutch data. In England, some of the previous plans (i.e. the Well pathway for dementia and the Prime Minister's challenge) were built using the NICE recommendations^{pp}. **However, the data reported in the national plans are mostly aggregated data on people with dementia, making it difficult to disentangle information on people with YOD and their specific needs.**

Currently, (national) data and evidence on YOD are difficult to obtain, and when available, are mostly estimates. To meet this demand for data and evidence, some countries, such as the Netherlands, are developing research consortia and are registering more and more data that will be available to enrich future dementia plans.

There is also little information about who has been involved and consulted in drawing up the plans. **Patient organisations and experts in the field** were mentioned as being involved in the development of some plans:

- German stakeholders from states, municipalities and relevant fields, German health associations and patient associations (such as the

^{oo} 'YOD INCLUDED' is one of five multidisciplinary research consortiums discussed in the Dutch national dementia strategy and funded by *ZonMw*.

^{pp} The recommendations from NICE have also been used by patient associations (such as the Young Dementia Network) to develop their own recommendations to support young patients (see earlier in this chapter).



German Alzheimer Society or *Deutsche Alzheimer Gesellschaft* [DAIzG]) and the scientific community were involved^{qq}.

- In the Netherlands, the regional dementia networks, health professionals, insurers and patient organisations will be involved in the next steps following the development of the Dutch plan.
- In France, stakeholders (patient organisations) and experts were involved in the development of the plan (i.e. the roadmap is the result of extensive dialogue between representatives of the Ministry and patients organisations, after an initial proposal presented by the Ministry and fed by proposals from the associations).
- In England, although the Major Conditions Strategy is still awaited and it is not yet known to what extent YOD will be included, efforts have been made to involve people with dementia and their families in a participatory process to review this strategy.

In summary, stakeholders, patient organisations and professionals have been involved at some points in the development or the review of national plans, but detailed information on the extent of their involvement and their actual impact is not clearly presented.

5.3.4 Evaluation of the national plans

Information on the evaluation of the national plans varies between the four countries, such as the level of detail of the evaluation indicators (process or outcome): in some national plans, the indicators to be measured are well detailed and mostly outcome indicators have been documented, if indicators are documented at all. **The evaluation plans, where they exist, are not specific to young people with dementia**, except for some specific indicators, which is consistent with the absence of national plans for people with YOD. For example, in England, the indicators related to YOD are

published in the Memory Services National Accreditation Programme as standards to be met in relation to assessment and referral of patients, resources and staffing, psychological interventions, and joint working and liaison (e.g. “There is a named lead within the service for people with YOD”, “The team signposts younger people with dementia to structured activities such as vocational rehab, employment support and workplace adjustments” or “The service can refer on to specialist services for rare or YOD and/or complex care needs”).¹¹¹ In general, assessment reports are not easily accessible to the general public or health care providers.

In France, the expected evaluation process of the 2021-2022 plan is well documented, including a person responsible for the implementation of each measure, who regularly (every six months) sends a progress report and an update on the indicators monitored to be discussed by a monitoring committee; a steering committee is also expected to send an annual report to the relevant minister. The types of indicators to be measured are documented: outcome and impact indicators, caregiver satisfaction indicators, process and resource indicators. The new plan will be updated in 2024 and the evaluation process is not yet known^{rr}, but the evaluation of the previous plan (2014-2019) is available online¹¹⁰. A first finding of this evaluation is the difficulty in identifying its specific impact, as it was part of a series of successive plans (Alzheimer's, Parkinson's, rare diseases, etc.). A second finding is the variability in the degree of achievement of the actions, some of which are close to 100%, while others are zero, which was to be expected given the large number of actions and the excessive ambition of some of them (i.e. actions requiring societal adaptations are not feasible in the short time frame of the plan) or because the initial funding was not granted.¹¹⁰

^{qq} Due to the political organisation in Germany, some regions had dementia plans in place before the national plan was developed; these regional plans have fed into the national plan.

^{rr} At the time of writing this section (March 2024).



In England, a new strategy is also expected and the evaluation plan has not been defined in the documents currently available. Attempts have been made to review the progress of the previous plans, but this does not appear to have been comprehensive. Otherwise, evaluation was planned in the previous plans, through very elaborate and detailed outcome and process measures, including “commitments” to be achieved and “success” criteria to assess the achievement. These indicators cover risk reduction, health and care provision, dementia awareness and social action, and quality statements on the dementia pathway have been published (e.g. diagnosing well, living well, supporting well, dying well). Quality standards have also been developed by the Memory Services National Accreditation Programme, which awards accreditation to services that meet the required level of performance.¹¹¹ Data on dementia are also regularly collected from across the health care system, but people with YOD are not identified as a subgroup.¹¹²

In the Netherlands, data collection has been implemented through a registry of dementia care and support for people of all ages. The PRECODE project (Prevalence Recognition and Care pathways in young Onset Dementia) has also started a national database of patients under 70 years using memory clinic services, and a set of quality indicators on the characteristics of patients using these services has been implemented. These initiatives aim to document the care and support provided, but do not appear as an evaluation of the national plan.¹¹³

The German national plan provides for annual intermediate and final evaluations. The evaluation plan is well described, including who is in charge for which indicator and annual evaluations to follow the progress of the overall dementia plan. However, no publicly available documents were found of these temporary evaluations. An outcome evaluation is expected at the end of the plan to review the need for further development (after 2026).¹⁰¹

As we can see, **these evaluation processes are sometimes described in the national plans and are mostly theoretical, with no information on how and why these indicators were chosen.** In most cases, the results of the evaluations are **not publicly available.**

5.3.5 Broad care pathway covered

As mentioned above, **none of the four national plans is specific to young people with dementia.** The organisation and provision of care and support targets people of all ages, and where needs have been identified, there is a particular focus on this younger group because of their specificities (e.g. additional tests in people with YOD such as recommended in Germany or the Netherlands). Table 21 provides an overview of the organisation of care such as expected in the national plans.

5.3.5.1 Prevention

Prevention is mentioned in the national plans; the English Strategy on Major Conditions (expected to be published in 2024) addresses primary and secondary prevention to address wider determinants of health such as healthy eating or exercise habits, and is not specific to people with YOD. At the end of the previous plan, France recommends a better understanding of neurodegenerative diseases in order to prevent their onset and slow down their progression.¹¹⁰ In the Netherlands, the YOD INCLUDED research consortium on YOD aims to investigate the biomedical and psychosocial causes, improve clinical recognition of YOD and precursors of early symptoms, and improve the diagnostic pathway and post-diagnostic care. In the absence of a validated screening tool (Chapter 2), none of the four countries has a national **screening** programme.



5.3.5.2 Diagnosis

With regard to **diagnosis**, there are differences between the national plans or national guidelines referred to in the national plans, with some being precise and recommending specific tests and imaging.

To improve the diagnostic pathway, the Netherlands aims to nationally standardise, as much as possible, the tests that need to be carried out on patients to establish a diagnosis of dementia: the TAP (*Tijdige, Accurate en gePersonaliseerde*) Dementia Consortium of the Dementia Research Programme is responsible for this task as part of the ZonMw-programme “Memorable”. The role of the GP’s for diagnosis is also specified: the GP take the medical history and test behaviour, memory, language ability and concentration, if necessary the MME-test. If YOD is suspected, the GP will always refer the person to a specialist in a memory clinic specialised in YOD, where further tests can be performed (neurophysiological tests, blood tests, brain scans and/or possibly lumbar puncture). The Dutch guideline recommends that additional tests (e.g. cerebrospinal fluid, Positron Emission Tomography (PET) scans) should be considered for the assessment of people with YOD.

The German national guidelines for dementia care recommend the use of clinical history, medical and neurological examinations and cognitive assessments (e.g. Mini-Mental State Examination (MMSE), DemTect, Clock Drawing Test). Further tests such as blood sampling and imaging (cranial computed tomography (CT) or magnetic resonance imaging (MRI)) may be performed, and in certain circumstances, biomarker-based diagnosis (e.g. cerebrospinal fluid puncture (CSF), positron emission tomography (PET)) are recommended. These more specialised diagnostic procedures are often only available in specialised clinics. In young patients, the German guideline recommends considering additional tests: human immunodeficiency virus, syphilis, and drug screening.¹¹⁴

In France, the High Authority of Health (*Haute Autorité de Santé*) has recommended (2018) that patients with a neurocognitive disorder related to Alzheimer’s disease should be referred to a specialised centre (Box 10). Patients will undergo clinical, cognitive and medico-social assessment, imaging (MRI, PET), biological markers and genetic evaluation. Neurogenetic consultation is recommended in patients with symptoms before the age of 50 or with a family history of the disease.¹¹⁵

The new English strategy is not expected to include specific tests or imaging to be performed at the diagnosis stage (an implementation plan is also expected and may include more detail on the diagnostic process). Diagnosis of people with suspected YOD has varied across England in terms of timeliness, assessment and imaging carried out, and the service managing the diagnosis. The first point of contact is the GP, from there it depends on local arrangements and the pathway varies according to the services available in the geographical area (personal communication Dementia UK).

5.3.5.3 Referral pathway

The **referral pathway includes (acute) hospitals and/or memory clinics for diagnosis and management of the disease**. Memory clinics are never the only institutions providing care to people with (young-onset) dementia; the management of these patients also takes place in acute hospitals or with specialised HCPs, depending on the availability of the structures in the geographical environment of the patients.

In Germany, “memory clinic” is not a protected term and covers a variety of organisational forms. A key aim of management and care is to expand counselling and support structures for people with YOD and their families, as described in the national strategy. Several measures have been identified to achieve this goal, including information, counselling and continued education, empowerment and support groups.¹⁰¹

In the Netherlands, each memory clinic has its own way of working, but a process of more standardisation is currently being studied to improve this heterogeneity in care, however this approach is not yet implemented. The national plan provides a standard of care to be followed, being implemented since 2023 through monthly learning meetings (not limited to care for people



with YOD). As a national initiative, the dementia plan promote close collaboration between GPs and case managers to improve continuity of care: case managers should be involved from the end of the diagnostic process in the memory clinics and facilitate the transition to day care and/or inpatient care. There are also about 40 organisations in the country that provide care for people with YOD throughout the care pathway (in collaboration with other partners such as support groups, day care, palliative care).¹⁰²

In France, different types of specialised centres coexist to provide care: the National Reference Centre for young Alzheimer's patients (CNR-MAJ), the National Reference Centre for Rare or Young-onset Dementias, the Memory Resource and Research Centres (CM2R) and the local and regional memory consultations (Box 10). They cover the whole the territory and act as a care network for patients, with a designated referral person who is the point of contact for health professionals, nursing homes and families. The reference centres cover a wide range of activities for patients and health professionals, including multidisciplinary care and follow-up (medical, paramedical, psychological and social), therapeutic patient education programmes, training for health professionals or harmonisation and dissemination of good practice. The expertise available at the reference centres include neurologists, neuropsychologists, speech therapists, psychologists, health educators, social workers, and genetic diagnosticians.

The English "Well pathway for dementia" explicitly mentions five steps, from prevention, diagnosis, support, well living to death (2016). The first steps are about managing the disease and relate to access to safe, high quality health and social care that enables people with dementia to live normally in safe

and accepting communities, and the last step includes palliative care and preferred place of death as standards to be measured.¹⁰⁹

In the Netherlands and England, there are **specialised HCP** who help patients and their informal carers to manage the disease throughout its course and in collaboration with other health professionals: in the Netherlands, they are called case managers (nurses or social workers who have completed an additional postgraduate training) and in England Admiral Nurses (who have undergone dementia-specific training). Their role is to support and advocate for patients and their caregivers and they are seen as a point of contact; they go beyond giving advice. They are with people from diagnosis to death, helping patients and their carers navigate the care pathway, organising care and providing emotional support. In the Netherlands, these specialised YOD case managers have existed since 2018 (they have followed a specific additional training after completing the first postgraduate training on dementia and working with young people). This specific training is offered in two places in the Netherlands.

In all four countries, **patient organisations play an important role in supporting and advising people with dementia and their informal carers throughout the course of the disease.**



Table 21 – Organisation of care for people with (young-onset) dementia, according to the national plans

	England	France	Germany	The Netherlands
Public awareness	Through the community	Through the community	Through the community	Through the community
Prevention	Primary and secondary prevention (general/not focused on dementia)	Recommendation: better understanding of neurodegenerative diseases to prevent their onset and slow down their progression	No prevention reported in the national plan	Research: to investigate the causes, to improve the clinical recognition of YOD, the diagnostic pathway and the post-diagnostic care
Screening	No screening	No screening	No screening	No screening
Place of diagnosis	GPs act as gatekeeping in case of suspicion/first symptoms Memory clinics and/or acute hospitals	Memory clinics and/or acute hospitals National Reference Centre for Young Alzheimer's Patients National Reference Centre for Rare or Young-onset Dementias Memory Resource and Research Centres	Memory clinics and/or acute hospitals	GPs act as gatekeeping in case of suspicion/first symptoms If YOD is suspected: referral from primary care setting to a specialist in a memory clinic Memory clinics and/or acute hospitals
Recommended tests for the diagnosis	No specific tests or imaging to be performed	No specific tests or imaging to be performed (but the reference centres work as a network, providing the same care to young people with dementia across the country) Recommendation from the High Authority of Health (HAS): clinical, cognitive and medico-social assessment, imaging (IRM, PET), biological markers and genetic evaluation; neurogenetic consultation in patients with symptoms before the age of 50 or with a family history of the disease	Clinical history, medical and neurological examinations, cognitive assessments (e.g. Mini-Mental State Examination (MMSE), DemTect, Clock Drawing Test) In specific cases: blood sampling, imaging (CT or MRI), biomarker-based diagnosis (e.g. CSF, PET scan) In young patients: human immunodeficiency virus, syphilis, drug screening	Single test to be developed Neurophysiological tests, blood tests, brain scans and/or possibly lumbar puncture In case of suspected YOD: additional tests such as CSF, PET scans
Place of care	Memory clinics and/or acute hospitals	Memory clinics and/or acute hospitals	Memory clinics and/or acute hospitals	Memory clinics and/or acute hospitals



		National Reference Centre for Young Alzheimer's Patients National Reference Centre for Rare or Young-onset Dementias Memory Resource and Research Centres		
Management of the disease	Patient-centred care Varies across England; no standardised care Important role of the third sector/patient organisations	Patient-centred care No standardised care; wide range of activities for patients and health professionals (e.g. multidisciplinary care and follow-up, therapeutic patient education programmes, training for health professionals, harmonisation and dissemination of good practice)	Patient-centred care No standardised care Counselling and support for people with YOD and their families (e.g. information, counselling and continued education, empowerment and support groups)	Patient-centred care Close collaboration between GPs and case managers, daytime activities



5.4 Discussion

The aim of this international comparison was to describe the national plans for the care of people with YOD in neighbouring countries. To achieve this goal, we retrieved the national plans and extracted data from the available (grey) literature using a standardised approach, and asked national experts to validate our findings, answer questions and provide further information where necessary. It was not our intention to provide an exhaustive overview of the care and management of people with YOD in each of the four selected countries; local initiatives or initiatives outside of the national plan that may also provide care and support to people with YOD are not included in this chapter; nor are general practices that apply to everyone, although they may help people with YOD (e.g. rules related to the work environment). Despite the involvement of national experts, it was difficult to obtain information on practical implementation, making it difficult to understand whether they were implemented, at what level and to what extent, and to obtain information on specific data for our subgroup of interest (e.g. people with YOD). These issues are important limitations of our work.

Another difficulty was obtaining information on the evaluation of the current national plans: in each of the four countries an evaluation is planned and indicators are mentioned, although sometimes imprecisely (e.g. no information on the percentage to be achieved or the delay in achieving the milestones). However, the results of these evaluations and how they have been used to develop future plans remain unknown. The results of these evaluations, if they have been carried out, are not publicly available (with the exception of France). In addition, the national plans of two selected countries are expected to be updated in the near future (2024), which should be taken into account when reading this section. It is also always possible that we have overlooked certain features or initiatives in a national plan, so it should not be considered as an exhaustive list/overview.

We focused our literature review on the existing national plans per country and the associated grey literature, to present the national overviews. This excluded the possibility of presenting valuable local initiatives or (multicentre and international) research projects. For example, there are specific research projects on YOD that can be highlighted. A first one is the Angela project, a three-year project in the UK that aimed at improving the accuracy of the clinical diagnosis and post-diagnostic support for young people with dementia and their families/carers; the second is the RHAPSODY project (Research to Assess Policies and Strategies for Dementia in the Young), a European initiative^{ss} to improve care for people with YOD by providing an internet-based information and skills programme for informal carers.^{37, 38, 46, 47} These two research projects have been completed and their findings are available to make recommendations for improving care for people with YOD^{tt}.

We found that the national plans of the four selected countries contain little information specific to people with YOD. This is in line with the recommendations from the NICE (2018) stating that it is less appropriate to have a separate set of recommendations for people with YOD, rather than highlighting their specific needs in recommendations for patients of all ages with dementia, where appropriate⁵. The four national plans provide general guidelines, although care pathways and diagnostic tests (Netherlands, Germany) tend to be standardised and applied across the country; memory clinics for diagnosis and management of the disease are common to the four countries, and some countries have national reference centres (France, The Netherlands) or case managers to help navigate the care pathway and health system (England, The Netherlands).

^{ss} The project includes eight partner institutions from six countries: France, Germany, the Netherlands, Portugal, Sweden and the UK.

^{tt} The results of the RHAPSODY and Angela studies relevant to our research are presented in Chapter 3.



6 MAIN FINDINGS AND RECOMMENDATIONS

6.1 Main findings

6.1.1 Overview of young-onset dementia (chapter 2)

1. **Causes.** Similar to people with later-onset dementia (LOD), the main causes of YOD are Alzheimer's disease (AD), vascular dementia, and frontotemporal dementia (FTD). However, AD counts for 30%, instead of 60% in LOD, and the aetiologies of YOD are more diverse than for LOD, often involving rarer diseases or being secondary to other conditions of neurological (e.g. Huntington disease, multiple sclerosis), infectious (e.g., HIV, neurosyphilis) or toxic (e.g. alcohol) nature. An autosomal dominant genetic mutation is retrieved in 15% of YOD cases.
2. **Clinical patterns.** Beyond the cognitive impairments also observed in LOD (e.g. short-term memory impairment, word-finding difficulties, disorientation, confusion), YOD may display more diverse symptoms, such as behavioural and personality changes (e.g. apathy or disinhibition), language impairment (e.g. anomia, aphasia, alexia), and executive dysfunction (e.g. apraxia).^{uu}
3. **Diagnosis.** The frequent lack of awareness regarding YOD in the public and healthcare professionals, together with the symptomatic overlap with non-degenerative primary psychiatric disorders (e.g. major depressive disorder, bipolar disorder, schizophrenia), can delay the diagnosis by several years.^{vv}

^{uu} Of note, in people with AD symptoms are pretty much the same in YOD and LOD.

^{vv} However, a systematic review including 42 studies on AD-related YOD retrieve no evidence that those patients differ from people with AD-related LOD in terms of symptom onset to diagnosis time.

- a) **Detection of YOD.** The following elements should be considered as red flags:

- i) First-time psychiatric, cognitive, or behavioural changes in someone aged 50-64 years with no history of psychiatric disease, especially with a family history of YOD
- ii) No improvement in psychiatric symptoms (e.g. depression) despite recommended treatments and/or psychotherapy
- iii) Progressive onset of neurological symptoms (e.g. apraxia)

- b) **Confirmatory diagnosis.** Investigations to confirm the diagnosis include neuroimaging, measurement of cerebrospinal or plasmatic biomarkers (e.g. amyloid- β 40-42, neurofilament light chains), and genetic testing.^{ww} Reference centres with high performance diagnostic tools, in particular brain imaging and biology, are key.

4. Impact on patients and families.

- a) YOD provokes more work, social, family and economic consequences than LOD. In AD-related YOD, cognitive decline tends to be faster than in LOD, but that does not seem to be the case for all symptoms. The impact of onset age on symptom progression in other dementia types is still poorly understood.
- b) People with YOD have significantly increased mortality compared to the general population, and increased risk of suicide. YOD people have prolonged survival compared to LOD, but their life expectancy is decreased dramatically (by 10 to 15 years).

^{ww} However, there is currently no optimal single genetic investigation that simultaneously identifies the different genetic variants resulting in YOD³⁴. Huq A, Thompson B, Winship I. Clinical application of whole genome sequencing in young onset dementia: challenges and opportunities. *Expert Rev Mol Diagn.* 2024;24(8):659-75. In addition, some genetic risk factors have unclear significance.



5. **Frequency in Belgium.** The age-standardised prevalence of YOD in Belgium is estimated at 137.0 per 100 000 population between 30 and 64 years, corresponding to around 7300 cases. The vast majority of these cases (83%) are between 55 and 64 years (67% in age band 60-64y). We estimated that around 4% of all dementia cases are YOD. Around 800 new cases of YOD are expected every year, most of them (80%) in the age range 55-64 years (50% in the age band 60-64 years).
6. **Post-diagnosis management.** Post-diagnosis care is often fragmented, with services delivered across aged care, healthcare, and social care sectors.
 - a) **Identifying reversible causes.** It is important to address reversible causes of secondary YOD, e.g. excessive alcohol consumption which would account for 3% to 10% of cases.
 - b) **Pharmacological interventions.** We retrieved no evidence on treatments specifically targeted to YOD or its accompanying neuropsychiatric and behavioural symptoms. General guidelines on dementia, like those from NICE or SIGN, can apply.
 - c) **Non-pharmacological interventions.** We retrieved very few evidence on non-pharmacological interventions in people with YOD, even if there is a consensus that an age-appropriate, holistic, multidisciplinary management is recommended, including:
 - iv) Cognitive rehabilitation: including memory rehabilitation, concentration-enhancing training or using memory aids
 - v) Physical and social activities: encouraging engagement in social and physical activities to enhance wellbeing
 - vi) Psycho-educational interventions: providing patients and families with information about treatment, symptoms, resources, services, disease-related problems and/or problem-solving strategies for coping
 - vii) Psychosocial interventions: counselling or support groups, help with activities of daily living, ensuring that families have

adequate access to financial resources, respite, social and educational opportunities

viii) Environmental support: accommodation of home and working place to promote continued employment and life at home

ix) Advance care planning

6.1.2 Patients and caregivers needs (chapter 3)

1. **Multiple impacts.** YOD disrupt careers, family roles and social relationships. This can lead to significant psychological distress. The stigma and lack of awareness surrounding YOD can exacerbate feelings of isolation and loss of purpose and usefulness. Caregivers of individuals with YOD also experience a substantial burden as they struggle to balance caring responsibilities with personal responsibilities and/or future perspective.
2. **Unmet needs.** Important unmet needs identified include difficulties in the diagnostic process, limited access to support services, and the need for more information. Financial support and workplace accommodations are also critical areas that require attention.
3. **Options for improvement.** Tailored support systems, increased awareness of population and healthcare providers, and comprehensive care models are needed. Collaborative care models that involve multidisciplinary teams with a coordinating healthcare professional (such as a case manager or key worker) can contribute to meet all aspects of the patients' and families' needs effectively.



6.1.3 *The Belgian case: fragmentation of training, funding, information, services and facilities (chapter 4)*

1. **Policy plan.** There is currently no overarching federal dementia plan for Belgium. The Flemish dementia plan (2021-2025) focuses on preventing dementia, improving the quality of care, and supporting caregivers. **Some specific actions for patients with YOD** are described. No similar plans are available in the other regions.
 2. **Training.** In Flanders, two guidelines to improve dementia diagnosis in primary care have been developed. However, both state that they do not apply to patients with YOD. Also in Flanders, around 90 physicians (e.g. GP, neurologists,...) were trained in 2023 to be **reference physicians for dementia**, to support primary health care physicians and to be a contact point for primary care workers within their region (e.g. primary care networks). However, their function is not yet officially recognised and still needs to be formally implemented in clinical practice.
 3. **Memory clinics.** Memory clinics are multidisciplinary centres for the diagnosis, medical management, education and cognitive rehabilitation of dementia, with the aim of maintaining the patients at home as long as possible. The team must include a medical doctor, a psychologist, an occupational therapist and a social worker.
 - a) **Accessibility.** The prescription for rehabilitation at these memory clinics is issued by the specialist doctor (neurologist, geriatrician or psychiatrist) who made the diagnosis or by the beneficiary's general practitioner. There is no age limit. In the period 2019-2021, **11.4% (98/857) of newly admitted patients were under 65 years of age.**
 - b) **Cognitive rehabilitation.**
 - i) YOD patients can benefit from **35 cognitive rehabilitation sessions for a period of maximum 4 years**, instead of 25 for patients above 65 years.
 - ii) The location (in the memory clinic or at home) and frequency of the sessions are tailored to the individual needs of the patient and the progression of the disease.
 - iii) The aim of the sessions is to keep the patient as independent as possible and include: learning or learning life skills a useful activity, using memory aids, adapting the home environment, providing psychological support to the beneficiaries and their caregivers.
 - iv) The social worker and/or psychologist on the team clearly has a case manager function: he/she liaises with the various stakeholders in the care network and with social and administrative services.
- c) **Funding.**
 - i. The cognitive rehabilitation sessions are financed through a NIHDI convention with centres fulfilling specific structural and staffing requirements. Currently, twelve memory clinics are under convention, but more clinics are working outside of the NIHDI convention.
 - ii. Each clinic may provide billable rehabilitation services up to a maximum of 875 billing units per year, and the 2024 budget per clinic is set at € 123 850. So far, the maximum annual number of sessions allowed is not reached.
 - d) **Difficulties**
 - i) The number of sessions of cognitive rehabilitation is limited in number (maximum 35 sessions for YOD patients), in time (maximum 4 years) and target beneficiaries (only patients living at home). This means that after 4 years or as soon as the patient moves to a nursing home, the link with the team/case manager is broken for the patients and their caregivers. This contradicts the principle of care and information continuity.



- ii) With 12 memory clinics in the NIHDI convention, the geographical accessibility may be limited for patients in some regions, but also the financial accessibility may be heterogeneous for users of clinics inside or outside the NIHDI convention. Geographical distances are also a problem for the staff achieving the home visits.
 - iii) The current capacity of memory clinics seems sufficient as the maximum number of sessions per year is not reached. However, it should be noted that the number of new patients every year is low in comparison with the number of new cases expected. If the use of memory clinics is encouraged, the capacity could not be sufficient. Moreover, as the global budget is equally shared among the 12 clinics, the funding allocated to the clinics with a relatively low number of annual sessions (e.g. less than 500 sessions) cannot be redistributed to clinics with a greater activity volume.
 - iv) An evaluation of the memory clinics is on-going. However, the data required by the NIHDI do not allow a qualitative appraisal of users (e.g. diagnosis is not reported) and outcomes (i.e. remaining at home after 12 months is the main indicator). For example, it is not clear whether a social worker properly fulfils the tasks assigned to this position under the terms of the agreement.
4. **Initiatives for the management of dementia.** There are many initiatives for the management of dementia, some of them with specific services geared towards YOD cases:
- a) **The Flemish dementia expert centre.** This is an umbrella organisation connecting local expertise centres (some of which have developed specific expertise in YOD), disseminating best practices among healthcare professionals and raising awareness among the general public.
 - b) **Support to non-institutionalised dementia patients and their informal caregivers.**
 - i) **Legal provisions.** There are some legal provisions (at the federal and regional levels) to enhance the involvement of informal caregivers, including a financial compensation.
 - ii) **Organisations and support groups.** There are many (private) organisations which provide caregivers with information, psycho-education and support (including respite care).
 - iii) **Family care services.** These services offer household help, and may be part of a sickness fund, offered through the Public Centre for Social Welfare (CPAS/OCMW) or organised by the regional authorities.
 - iv) **ASAPP project.** The ASAPP project (*"Aide et Soutien aux Aidants Proches et aux Personnes atteintes de la maladie d'Alzheimer ou troubles apparentés"*) in Brussels and Wallonia regions provides case management, psychological support and occupational therapy for patients older than 60 years, with the main aim to help patients and their informal carers to stay at home. This pilot project is funded by the NIHDI and will be evaluated in 2024. The budget was € 14 million in 2023.
5. **Day care centres and short-stay centres.** These centres are tailored for persons who can still live at home but for whom home care is temporarily unavailable or need help in their daily life activities. They are not specific to patients with dementia or younger patients.
6. **Residential facilities for elderly people.** These include homes for elderly people and nursing homes for individuals who are severely limited. They are mainly for people aged over 60, and are not specific for patients with dementia. However, some initiatives have been undertaken to make them more accessible for patients with (young-onset) dementia.
- a) Since 2010, the NIHDI finances in each facility ½ FTE of a worker specifically trained to be a dementia referent. The dementia referent



can be a nurse, a physiotherapist, a psychologist, a social assistant, or another primary care provider.

- b) A pilot project in Flanders granted 23 nursing homes a specific recognition for YOD care, which equals around 200 subsidised places for people with young-onset dementia. In Wallonia, about a third of residential care facilities offers an adapted unit for patients with cognitive problems (max. 30 residents per unit)
- c) In residential care, some new initiatives try to provide an environment that better resembles the home environment. In “Kleinschalig genormaliseerd wonen” people (maximum 15 persons) live together, the environment resembles the normal living environment rather than a nursing home.

7. **NIDHI convention related to neurodegenerative diseases.** This convention is not specific to dementia patients, but targets patients with advanced-stage neurodegenerative diseases, some of which can result in dementia (e.g. Huntington’s disease).

- a) The convention aims to strengthen cooperation and continuity of care between hospitals and residential care facilities. To this end, a liaison function (by a paramedical health professional or social worker) and medical supervision (by a neurologist or neuropsychiatrist) will be provided, visits to residential facilities and training will take place to ensure quality of care. The convention also calls for special attention to be paid to the information needs of patients and their families, (psychological) support and support in daily activities (e.g. advance care planning,...).
- b) The liaison professional should visit the residential care facility at least 12 times per year, every patient in the programme has a liaison file shared between the hospital and the residential care facility.

8. **Bottlenecks identified by Belgian stakeholders**

- a) **Delay in diagnosis due to several factors:** lack of awareness among physicians about YOD and insufficient expertise,

minimisation of early symptoms by patients, long waiting lists to access first a neurology consultation and thereafter complementary examinations

- b) **Lack of a coherent care pathway** once YOD is confirmed: no case management or coordination of care after diagnosis, few specialised healthcare providers, few facilities tackling cognitive and behavioural problems.
- c) **Suboptimal financial accessibility to diagnosis and care:** for example, the initial assessment may require procedures which are not reimbursed (e.g. a lumbar puncture to measure cerebrospinal fluid biomarkers); only one neurological assessment is reimbursed in a lifetime whereas YOD is an evolutive condition.

6.1.4 *International comparison of National Dementia Plans (chapter 5)*

1. **National plans.** The National Dementia Plans in England, France, Germany and the Netherlands are not specifically dedicated to people with YOD, but all four contain some references (specific actions, centres, initiatives...) for young patients. This supports the recommendations of the National Institute for Health and Care Excellence (NICE) (2018), which states that it is less appropriate to have a separate set of recommendations for people with young-onset dementia than to highlight their specific needs in recommendations for patients of all ages with dementia, where appropriate. In addition, information on their effective implementation and their performance is mostly unavailable, even after consulting a national expert in each country for clarification.
2. **Landscape.** The main objectives of the national plans are to support and empower people of all ages with dementia and their informal carers, and to enable people with dementia to remain a valuable part of society (including professional activities). Some actions or strategies are targeted at younger people with dementia: reference centres (France, the Netherlands), case managers or dedicated professionals to support patients and their carers (Netherlands, England), while other are



targeted at people with dementia of all ages (e.g. memory clinics for diagnosis and management).

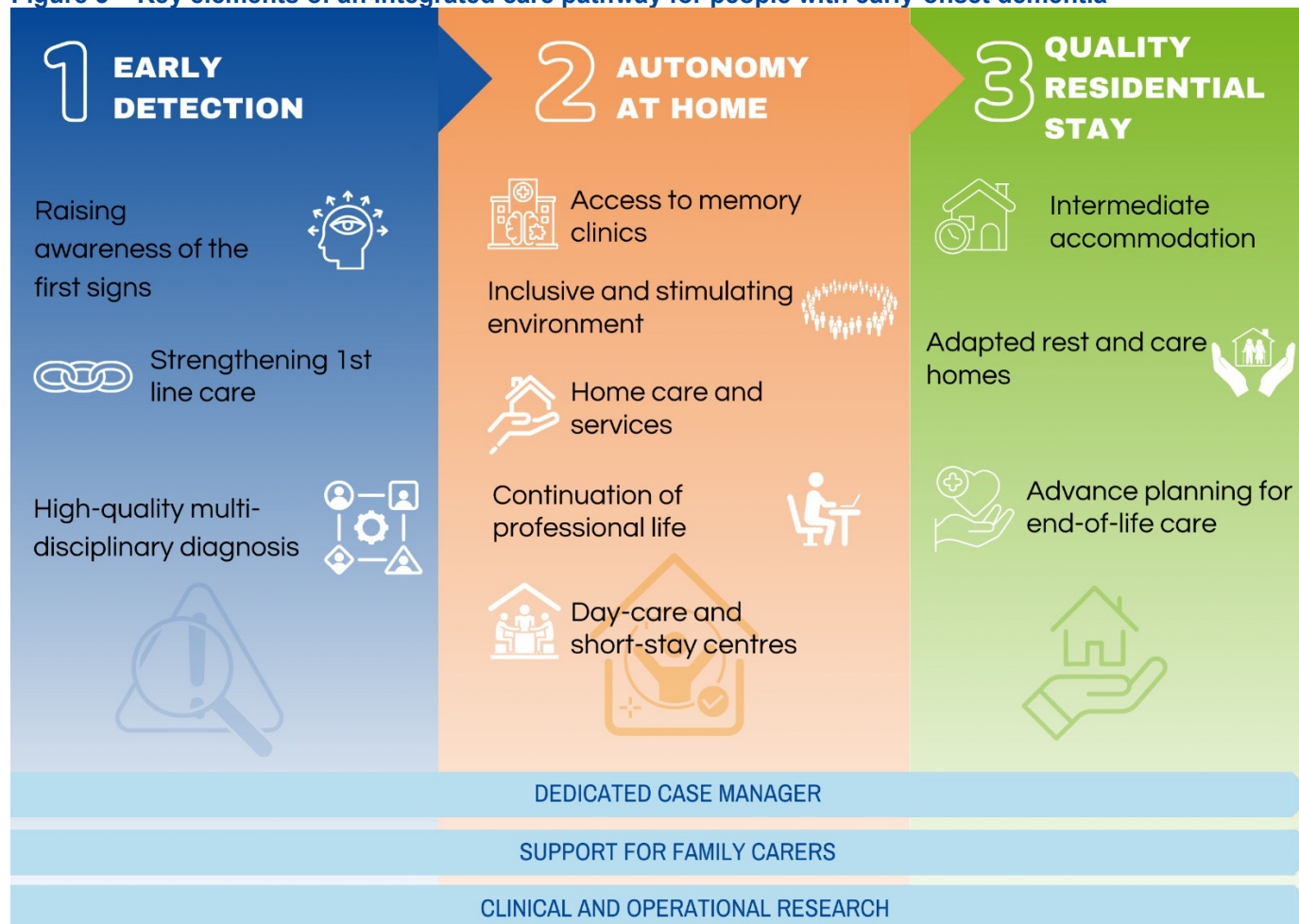
3. **Memory clinics** appear to play a central role in the diagnosis and management of patients with dementia in the four countries.
4. There is a **lack of data**, evidence and evaluation of activities geared towards people with young-onset dementia within national plans.



6.2 Recommendations

6.2.1 Overarching recommendations

Figure 5 – Key elements of an integrated care pathway for people with early-onset dementia





1. Ensure a coherent care pathway

Each patient with YOD should have access to a coherent multi-faceted care pathway/trajectory integrating early detection, coordinated diagnosis, and multidisciplinary post-diagnosis support services.

- a) Early detection requires that healthcare professionals, particularly at the primary level, be well aware of the specificities of YOD and of the instruments they can use for a coherent assessment, including an evaluation grid on red flags, risk factors and recommended confirmatory tests (among which imaging and/or biomarkers).
- b) Coordinated diagnosis implies that evidence-based examinations are realised and the results are centralised in a patient file accessible to all involved healthcare providers.
- c) Multidisciplinary post-diagnosis support includes age-appropriate, family-centred psychological support, particularly at the time of diagnosis, along with cognitive rehabilitation, psycho-educational and psycho-social interventions, and environmental support. This support should adapt to the changing needs of individuals with YOD, facilitating smooth transitions across different care settings, including home care, day care centres, residential care, and end-of-life care.
- d) An efficient case management is needed to ensure that patients and their caregivers can swiftly find their way to the information, the care and the support they need.

2. Prioritise an integrated healthcare and service provision

While recognizing the specificities of YOD, it is appropriate to adapt and optimise as much as possible the structures and procedures already in place for patients with dementia in order to achieve the best quality of care and the most efficient use of resources. A silo approach should therefore be avoided.

The care pathway for patients with YOD should be clearly outlined within a coherent and global regional/community dementia plan, e.g. the Flemish Dementia Plan 2021-2025 aiming at preventing dementia, improving the quality of care and supporting caregivers. The means and responsibilities for the implementation of the actions described in the sections below, as well as the evaluative monitoring of activities, outputs and outcomes, should be described in detail.

3. Increase the accessibility to useful and appropriate information

Knowledge and information on YOD are fragmented at all levels: the aetiology is still not well understood and is multifactorial, the symptoms and diagnosis are complex, and available types of care, places of care and support vary widely across the territory. It is, therefore, crucial to streamline reliable and useful information to make it accessible to all persons concerned (health and welfare professionals, patients, caregivers,...) at the moment they need it. This can be done following two main strategies:

- a) **Support the development of an expert knowledge centre on dementia** to develop up-to-date evidence-informed guidelines, harmonise best practices, and train professionals. This centre should also serve as a central hub for information on support resources and organisations, accessible through a user-friendly website or other information supports. The website of the *Centre National de Référence-Malades Alzheimer Jeunes* in France (<http://www.centre-alzheimer-jeunes.fr/>) or the *Jong Dementie* platform of the Flanders Centre of Expertise on Dementia (<https://www.jongdementie.be/>) are examples of what can be offered. This could also be the channel for psycho-educational interventions, such as e-learning programmes.
- b) **Ensure the presence of a dedicated and competent case manager for each patient**



Patients and families need adequate information tailored to their specific needs. Moreover, web-based information is not appropriate for everyone. Starting from the earliest symptoms, the case manager should guide the patient and family through the care pathway. Various professional profiles already endorse partly this role: the general practitioners (more details are presented below), the social workers in the memory clinics, the dementia referent in nursing homes. Case managers should receive specialised training to gain advanced knowledge and skills to deal with YOD patients and their caregivers, possess sufficient communication skills to provide continuous information, practical and emotional support, and act as a coordinator of care and social services.

6.2.2 Enhancing early detection of YOD

1. Strengthen the awareness of families about YOD

Raising awareness of people aged <65 years, and more particularly those in the 50-64 years band, about YOD can encourage early consultation. This can be done by centralising the useful information and making it easily understandable and accessible (as described under point 3 of the overarching recommendations). Neutral, non-worrying information should be favoured. Raising awareness of people aged less than 50 years is less recommended because it could trigger anxiety in a population where the disease is rare.

2. Strengthen the awareness and skills of primary healthcare providers

A strong awareness of primary healthcare providers (GPs, physiotherapists, home nurses,...) about YOD is key. **Health professionals should be trained on:**

a) The specificities of YOD:

- i) YOD is aetiologically diverse, distinct from a mental illness, and has a combination of genetic and non-genetic contributing factors

- ii) People with YOD require age-appropriate care programs and accommodation options that take a whole family approach
- iii) Specialised, multidisciplinary services both in terms of diagnosing YOD and in providing ongoing support are needed
- iv) The importance of psychosocial support and non-pharmacological interventions to manage neuropsychiatric symptoms

b) The evaluation grid they can use for a consistent assessment in case of suspicion of a dementia

- i) Existing international assessment guidance, such as the NICE (2018) and SIGN (2023) guidelines, can be adapted and disseminated, if appropriate. This could be done by the expert knowledge centre on dementia, if relevant.
- ii) Ideally, the evaluation grid should be integrated in the medical information software used by the GP, and the information collected should be recorded in the electronic medical record of the patient. Each patient should be encouraged to have a Global Medical File and agree to give access to other healthcare professionals.

c) The psychological-educational support that memory clinics can deliver, and the other sources of support available locally, in order to be able to orientate the patient towards appropriate services.

d) The training of healthcare providers can be organised at various levels:

- i) For future healthcare professionals, the topic of detection and management of YOD, including non-pharmacological interventions, should be integrated in the curriculum.
- ii) For active healthcare professionals, the training on YOD could be part of the professional accreditation scheme, and be organised by universities, professional associations or



dementia referents from the expert knowledge centre on dementia, if relevant. The national guidelines on dementia diagnosis and management could be extended and include specific recommendations on YOD (see section 1.2).

6.2.3 Enhancing the autonomy and well-being of patients at home

1. Refer each newly diagnosed YOD patient to a memory clinic

- a) **Consider lifting the time limit during which sessions can be delivered (currently 4 years)** so that patients and their family maintain access to the medical team, particularly the case manager, who has been following him/her since the beginning of the illness. However, to avoid duplication, for example when a patient moves to a nursing home, only one case manager is identified for each patient, and his contact details are recorded in the medical file. A maximum annual number of sessions can be defined. Currently 5 sessions are recommended and reimbursed per patient and per year during the maintenance phase.
- b) **Consider lifting the cap of sessions of cognitive rehabilitation per clinic**, while maintaining the overall budget. This would alleviate possible limitation of clinics with a greater volume of activity than the 875 billing units.
- c) **Consider increasing the number of memory clinics entering the convention.** Having more memory clinics spread throughout the territory could increase accessibility and allow for the mobilisation of a more local network of stakeholders. This does not necessarily translate in a greater budget as the number of sessions performed in 2019 was only 53% of the maximum allowed. However, the number of sessions per year in the 2022-2024 period is not yet known.
- d) **Improve the evaluation of memory clinics.** Results will help to define more precisely how to adapt the services to the patients' needs.

- e) **Consider increasing the budget** if the evaluation is positive and more places are needed.

1. Ensure welfare support

Patients with YOD should be duly informed of the legal welfare support they can access. This includes the intervention of home helpers, or the official recognition of close caregiver ("*aidant proche*" / "*mantelzorger*") for the partner or other family members. All legal provisions should be activated. Indirect financial support comes from provisions such as "chronic disease" status or the cost reductions associated with BIM status. Case manager is key in providing up-to-date relevant information.

2. Encourage a YOD-friendly environment for patients and their caregivers

An environment where patients with YOD can access physical/social activities, psycho-educational interventions, psychosocial interventions such as support groups, and vocational rehabilitation is likely to be beneficial to the well-being of patients, although evidence is scarce.

Family-centred initiatives to enhance the well-being of caregivers should also be stimulated, such as respite care financed through the sickness funds.

3. Facilitate continued professional work

To facilitate continued work, with adaptation of tasks, responsibilities and working hours according to needs allows patients to keep a sense of social utility. Occupational physicians should be aware of YOD and specific needs of people with YOD to recommend adaptations of the working environment. Employers should be informed and adapt tasks if acceptable for both employer and patients.



6.2.4 Allow intermediary housing solutions

For YOD patients who can no longer live at home but still have some independence, intermediary housing options should be offered. These options can be short-term, such as daycentres, or long-term, like small-scale housing initiatives (e.g. “kleinschalig genormaliseerd wonen” initiatives in Flanders). Ideally, these housing options should be age-appropriate, person-centred, community-based to maintain connections with everyday life, and designed to support quality of life and relationships with relatives and friends. It should also offer a balanced approach providing autonomy and security.

6.2.5 Enhancing the quality of care in residential facilities

1. Specific long-term residential facilities for YOD patients

When long-term residential care becomes necessary, it is essential for healthcare facilities to offer age-appropriate residential options for YOD patients. The specific requirements for these facilities – such as staffing, admission criteria, design, and available services – should be clearly outlined in legislation and regularly evaluated.

2. Ensure that dementia referents in all nursing homes are fully supported (e.g. sufficient dedicated time) to perform the duties within this function effectively

6.2.6 Encourage research

1. Evaluate the functioning of memory clinics and outcomes of YOD people using these clinics, including satisfaction, well-being, autonomy and delay to residential care.
2. Evaluate the role of the dementia referent in nursing homes.
3. Ensure a bibliographic surveillance of new high-quality studies on:
 - a) The validity of new diagnostic tools (imagery, biomarkers, genetics)

- b) The efficacy and safety of new treatments, particularly the new monoclonal antibodies
- c) The efficacy and cost-effectiveness of non-pharmacological interventions for cognitive rehabilitation and psycho-social support
- d) The added value of eHealth, digital tools and AI-assisted apps in the information and cognitive rehabilitation of patients with YOD



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