



JÖNKÖPING UNIVERSITY  
*School of Health and Welfare*

Doctoral Thesis

# Care and support for couples when one partner has young-onset dementia

Fanny Kårelind

Jönköping University  
School of Health and Welfare  
Dissertation Series No. 151 • 2026



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# Acknowledgements

When I first started, I thought I would take a straightforward approach. I would ask about the support the couples received, when it was offered, and how they felt about it. However, the couples had something else in mind. They wanted to share their stories with me, their lives as they were lived, and it soon became clear they were trying to help me understand. Looking back, it was naive to think I could stand outside their stories, untouched by what would unfold over the 18 months (and counting). Instead, I was deeply moved, and for that I am grateful beyond words.

Although my findings may sometimes sound heavy, one reviewer even called them “heartbreaking”, that is not how I see the couples. There were difficult moments, of course, but what I remember most is the sense of friendship that slowly grew between us, the humour that coloured so many of our conversations, and the lightness they brought even when speaking about hard things. The resilience and love I have witnessed have changed me forever. And they were clear about one thing: they wanted me to share the difficult parts, not to change their own path, but in the hope that it might help change someone else’s in the future. Thank you to the couples who welcomed me into their homes and have continued to meet with me over the years. Your willingness to share your lives has made this thesis possible, and I hope it does justice to what you entrusted to me.

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knowing that I can no longer insist on seeing you whenever I want, as I could when I was a student. And the truth is, I have no desire to work with anyone else, even though I understand the necessity. I have much more to say to you, but I will save that for when we meet. What I can say here is that you have shown me the kind of researcher and future supervisor I hope to become.

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# Abstract

**Background:** Young-onset dementia refers to dementia with symptom onset before the age of 65, affecting persons during a life phase typically characterised by employment, family responsibilities, and active social participation. When one partner in a couple has young-onset dementia, both partners are affected, and daily life is reorganised around the condition. Knowledge of how support is accessed and experienced in young-onset dementia remains limited. As a result, it is unclear whether available services meet the specific needs of those affected.

**Aim:** The overall aim of this thesis is to explore and describe support for persons living with young-onset dementia and their partners, and to examine how this support is experienced and adapted over time.

**Methods:** This thesis comprises four studies employing quantitative and qualitative designs. Studies I and II drew on data from SveDem, the Swedish national quality dementia registry, and included persons diagnosed with young-onset dementia (Study I, n=284; Study II, n=2,592). Study I examined post-diagnostic support offered at the time of diagnosis, and Study II analysed factors influencing the time to formal support. Studies III and IV used dyadic semi-structured interviews with couples in which one partner had received a dementia diagnosis before the age of 65 (Study III, n=11 couples; Study IV, n=10 couples). Study III addressed couples' experiences of support in daily life, and Study IV examined how their interactions with formal support systems developed over time.

**Findings:** At diagnosis, most persons were offered information and educational support, while about half were offered contact with a dementia nurse, counsellor, or needs assessor. Over time, living with another adult and having higher cognitive functioning were associated with later access to home help, day care, and care facilities. Qualitative results showed that couples living with young-onset dementia negotiated independence and support in daily life while navigating fragmented support systems with unclear responsibilities and limited coordination. Support was most meaningful when aligned with the couple's daily life and current needs. Three distinct patterns of interaction with formal support were identified: keeping formal support at a distance, initially seeking but gradually stepping back, and persisting in

seeking support despite obstacles. These patterns were influenced by service responses to early contact attempts and whether support matched the couple's circumstances.

**Conclusion:** This thesis provides both empirical and theoretical insights into support for couples living with young-onset dementia in Sweden. As partners take on increasing responsibilities, couples might seem to be coping, even when their needs are significant, risking that those needs go unrecognised. Structural fragmentation, both between memory clinics and municipal services and within them, forces couples to navigate the system on their own, often without clear guidance. The findings point to a need for more accessible, proactive, coordinated, and individually tailored support that recognises the couple as a shared unit.

# Original papers

This thesis is based on the following studies, which are enclosed as appendices.

## Study I

Kårelind, F., Finkel, D., Zarit, S.H. et al. Post-diagnostic support for persons with young-onset dementia – a retrospective analysis based on data from the Swedish dementia registry SveDem. *BMC Health Serv Res* 24, 649 (2024).

## Study II

Kårelind, F., Johansson, L., Zarit, S., Wijk, H., Bielsten, T., & Finkel, D. (2025). Factors influencing time to support in young-onset dementia: survival analysis of data from the Swedish Dementia Registry (SveDem). *Aging & Mental Health*, 29(6), 992–999.

## Study III

Kårelind, F., Bielsten, T., Zarit, S., Wijk, H., Finkel, D., & Johansson, L. (2026). Navigating Support Together: A Meaning-Oriented Dyadic Understanding of Daily Life With Young-Onset Dementia. *Dementia (London, England)*, *In Press*, 14713012261424095.

## Study IV

Kårelind, F., Johansson, L., Zarit, S., Wijk, H., Finkel, D., & Bielsten, T. How Couples Interact with Formal Support Systems Over Time: A Pattern-Oriented Longitudinal Study in Young-Onset Dementia. *In manuscript*

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# 1. Definitions and terminology

This thesis uses specific terminology throughout. The definitions below clarify how central terms are understood and used.

**Couples** refer to two partners living together in a romantic relationship in which one person has young-onset dementia. The term is used regardless of marital status. In this thesis, couples also share a household. *Couples living with young-onset dementia* reflect the impact of dementia on their shared daily life.

The term ‘**families**’ is used as a broad term to refer to the relatives of persons with young-onset dementia, including partners, children and, where relevant, extended family members. The term is primarily used when discussing broader social contexts or existing research.

**Formal support** refers to organised support services provided through healthcare and municipal systems. This includes diagnostic services, follow-up in specialist care, social services, day care, home-based support and other publicly funded support services.

**Informal caregivers** are family members or other persons, such as partners, friends, or neighbours, who provide unpaid support to a person with young-onset dementia outside formal support systems (e.g., informal support). Definitions of informal caregiving vary across the literature and are used inconsistently (Happ et al., 2024). In policy documents and parts of the research literature, the term is often used interchangeably with partners of persons with dementia. In this thesis, the term is used when referring to existing research or policy documents that apply this terminology.

**Informal support** refers to support provided outside formal systems, such as by partners, family members, friends, organisations or social networks. It may include both practical and emotional support and is not based on formal assessments or eligibility criteria.

The phrase ‘**Persons with young-onset dementia**’ is used throughout the thesis when referring to those living with the condition. In some instances, the term *‘people’* is used for grammatical clarity. Terms such as *‘patients’* are avoided. This reflects a deliberate choice to refer to those living with young-onset dementia as persons in their own right, rather than primarily in relation to a diagnosis, as labelling persons exclusively in disease terms risks erasing their personal identity (Villar et al., 2019) as this thesis focuses on their daily lives rather than their clinical situation. When referring specifically to persons participating in the interview studies, sometimes the term *‘participants’* is used to describe their role in the research context.

**Support** is an overarching term in this thesis and encompasses both formal and informal forms, including practical, social, organisational, and relational dimensions. Sometimes the phrase ‘Care and support’ is used to highlight *or* distinguish between health care services and social support services. In this context, *‘care’* refers primarily to health and medical services provided within the healthcare system.

**Young-onset dementia** refers to dementia with symptom onset before the age of 65. Several terms are used in the literature and everyday language, including early-onset dementia and major neurocognitive disorder. The latter reflects a broader shift in the Diagnostic and Statistical Manual of Mental Disorders [DSM] (American Psychiatric Association, 2013) towards neurocognitive disorder as the preferred clinical term, partly driven by the stigma associated with dementia. However, young-onset dementia is currently the most widely used term in research, supported by expert consensus (Veen et al., 2022). It remains the established term in Swedish clinical practice and quality registries, which are largely organised around the International Statistical Classification of Diseases and Related Health Problems [ICD] (World Health Organization [WHO], 2022). It is also the term that participants in the studies commonly used to describe their own condition. This thesis therefore uses the terms ‘dementia’ and ‘young-onset dementia’ throughout, while acknowledging that terminology in this area continues to evolve.

## 2. Preface

When I first came across the project on young-onset dementia in 2022, I was both curious and puzzled. Despite having spent my entire working life in healthcare and social services, I could not recall ever meeting anyone with young-onset dementia. That realisation stayed with me. How could a group of people with such extensive needs be almost invisible in settings where support is central?

Over time, it became clear to me that this invisibility exists on several levels. Dementia is still largely understood as a condition of old age, which means that younger persons with dementia often do not fit established expectations - neither in society nor within health and social care services. This insight made me want to understand more about who these persons are, how they live their daily lives, and what kinds of care and support they actually receive. Do the available services meet their needs? Furthermore, how do they themselves experience the support that is offered?

This thesis does not aim to provide complete answers to these questions. Instead, it explores care and support as they are experienced in the lives of persons with young-onset dementia and their partners. Ultimately, this work is motivated by a simple ambition: to contribute knowledge that can support persons with young-onset dementia and their families, and to identify areas where care and support systems could better meet their needs.

### 3. Introduction

Dementia is most often associated with older age. However, approximately 6-9% of persons with dementia develop symptoms before the age of 65 (Hendriks et al., 2021; Skovdahl et al., 2017), typically referred to as persons with young-onset dementia. When dementia occurs in midlife, it disrupts employment, family life, and financial commitments (Gumus et al., 2021; Sansoni et al., 2016; Spreadbury & Kipps, 2019). These disruptions rarely affect the person alone but unfold within close relationships, especially among couples who share daily life and responsibilities. Receiving a dementia diagnosis at a younger age can also carry a stigma, as dementia is typically associated with older ages (Burkinshaw et al., 2023). Additionally, as diagnostic methods continue to develop (Jack et al., 2018), the number of identified cases of young-onset dementia is expected to increase. These specific circumstances mean that persons with young-onset dementia require separate attention, both in research and support systems.

Although the number of studies on support services for young-onset dementia is increasing, knowledge remains limited on how support is experienced over time. Support services may therefore rely more on established practice than on research, which can restrict their ability to be effectively tailored to individual needs. To analyse these experiences, the thesis draws on two theoretical frameworks, Neugarten's (1970) concept of off-time events and Habermas (1987) distinction between the lifeworld and the system-world. Together, these frameworks provide analytical lenses for understanding both the individual experience of a midlife diagnosis and how couples encounter formal support.

Against this background, this thesis examines how persons with young-onset dementia and their partners encounter support, including the types of support they receive or create and how they experience it. Focus is given to whether the support provided is viewed as adequate and timely, as well as the awareness of available support among those with young-onset dementia and

their partners. By exploring these aspects, the thesis seeks to contribute to existing knowledge about young-onset dementia and identify areas where support for couples could be improved. The overall aim of this thesis is to explore and describe support for persons living with young-onset dementia and their partners, and to examine how this support is experienced and adapted over time.

## 4. Background

### 4.1. Young-onset dementia

Dementia is a condition caused by various factors that lead to a decline in cognitive function, with consequences for daily life. It is not a specific disease but an umbrella term covering conditions that affect memory, thinking, behaviour, and the ability to carry out everyday tasks (Livingston et al., 2017; World Health Organization, 2025). Even though dementia mainly occurs within the older population (over 65 years), it can also affect persons under 65, so-called young-onset dementia. Young-onset dementia, sometimes called early-onset dementia, refers to the onset of symptoms before age 65. Young-onset dementia is the most commonly used term in research, supported by expert consensus (Veen et al., 2022). Like all forms of dementia, the risk of young-onset dementia increases with age, with the majority being diagnosed between 60 and 64 years old (Hendriks et al., 2021). Young-onset dementia shares clinical features with those of later-onset forms, but its development occurs under different circumstances. A midlife diagnosis affects work, parenting responsibilities, and social activities in ways that a later diagnosis does not, shaping both the diagnosis and support experiences.

### 4.2. Epidemiological overview

According to WHO (2025) the number of people living with dementia worldwide is estimated to be 55 million. This number is expected to increase to almost 153 million by 2050 due to the rise in life expectancy and population increase (Nichols et al., 2022). Dementia is among the top 10 leading causes of death globally and a major cause of disability and dependency (WHO, 2025). This makes dementia a substantial public health issue, with major social and economic consequences that place considerable pressure on support systems worldwide.

The estimated worldwide prevalence of young-onset dementia is around 119.0 per 100,000 people for persons between the ages of 30 and 64 (Hendriks et al., 2021), which means that approximately 3.9 million persons are affected by young-onset dementia globally. The exact prevalence of young-onset dementia in Sweden is unknown, but it is estimated to affect between 9,500 and 12,000 persons (Hendriks et al., 2021; Skovdahl et al., 2017). The prevalence of young-onset dementia is growing, likely due to the increasing population and diagnostic advancements that make it easier to detect dementia earlier, resulting in a diagnosis before age 65 (Graff-Radford et al., 2021; He et al., 2025; Hendriks et al., 2021).

### 4.3. Diagnosis

Sweden's National Guidelines for dementia care (The National Board of Health and Welfare, 2017) give recommendations across different areas, including the diagnostic workup preceding a dementia diagnosis. This workup is divided into two batteries: primary and extended workup. The basic diagnostic workup includes family interviews, cognitive testing, and computed tomography (CT) structural brain imaging, which is mandatory for all persons investigated for dementia in healthcare. The extended workup is performed if the basic workup presents unexpected results or if there are complex circumstances. The components of the extended workup can vary based on an individual assessment. However, they may also include additional testing, such as a lumbar puncture to measure biomarkers, magnetic resonance imaging, neuropsychological testing, and glucose metabolism testing. The decision regarding the selected diagnostic workup is made individually by the diagnostic unit. Specialised dementia care services, such as memory clinics, often conduct extended workups (The National Board of Health and Welfare, 2017). This is particularly relevant for young-onset dementia, since these persons are more often diagnosed within specialist dementia care.

The four most common types of dementia are Alzheimer's disease (AD), frontotemporal dementia (FTD), vascular dementia, and Lewy body dementia. Alzheimer's is the most commonly diagnosed type of dementia, accounting for approximately 60-70% of all cases, followed by vascular dementia and Lewy Body dementia (Alzheimer's Association, 2023). Similar to persons

with all-age dementia, Alzheimer's disease is also the most common form of dementia under the age of 65. However, persons with young-onset dementia are more likely to be diagnosed with rarer types of dementia, such as FTD, which is the second most common dementia diagnosis among these persons (Chiari et al., 2021; Hendriks et al., 2021; Kvello-Alme et al., 2019). According to the ICD-10 classification of neurocognitive disorders, dementia is a progressive, chronic condition that affects several cognitive functions, including memory, executive functions, attention, language, social behaviour, judgement, psychomotor speed, and visuoperceptual and visuospatial abilities (WHO, 2022).

For persons with young-onset dementia, the diagnostic pathway is often lengthy and difficult. Persons who are affected by early symptoms may initially overlook them, attributing them to other factors such as stress or depression. The first signs are often noticed in the workplace, where colleagues may notice difficulties with task management, even before the affected person becomes aware of them (Grunberg et al., 2022a). This lack of awareness, coupled with the possible absence of memory-related symptoms, can complicate early identification of young-onset dementia and delay help-seeking (Chirico et al., 2022; Rabanal et al., 2018). It may only be after receiving a diagnosis that people recognise the nature of their symptoms (Grunberg et al., 2022a). Before seeking help, dementia symptoms can cause conflicts in relationships, with partners sometimes interpreting symptoms as intentional behaviour or disagreeing about their presence and severity (Grunberg et al., 2022a; Popok et al., 2022). Gradual worsening of symptoms, making it difficult to manage work and daily life, may ultimately lead the person to seek medical help (Lai et al., 2023; Rabanal et al., 2018).

Because social and cognitive symptoms are often present years before an actual diagnosis (Chirico et al., 2022; Hendriks et al., 2022; Kvello-Alme et al., 2021; Loi et al., 2021), physicians may interpret them as depression or fatigue, leading to misdiagnosis and delays in the diagnostic process (Chirico et al., 2022; Kilty et al., 2019; Loi et al., 2023; O'Malley et al., 2021; Tsoukra et al., 2021). A Norwegian population-based study showed that, on average, it takes 5.5 years to receive an Alzheimer's diagnosis before age 65 (Kvello-Alme et al., 2021). Specialised young-onset dementia services, however, have been shown to shorten the diagnostic pathway (Loi et al., 2022). These lengthy

diagnostic procedures can cause frustration and distress for persons with young-onset dementia and their families (Grunberg et al., 2022a; Millenaar et al., 2016; Spreadbury & Kipps, 2019), creating a logistical burden with multiple healthcare visits, emails, and phone calls (Grunberg et al., 2022a; Kilty, Cahill, et al., 2019). Such delays also result in delayed access to support, depriving the person and their families of the opportunity for early intervention (Millenaar et al., 2016; O'Malley et al., 2021).

Persons with young-onset dementia and their families often describe receiving the diagnosis as a shock (Bannon et al., 2022; Grunberg et al., 2022b; Lai et al., 2023), with feelings of grief, isolation, denial, and stigma (Bannon et al., 2022; Lai et al., 2023). For some, receiving the diagnosis can bring relief, confirming what they already suspected and marking the end of a long diagnostic process. The person with young-onset dementia can plan for treatment and better understand the symptoms (Grunberg et al., 2022b; Lai et al., 2023).

#### 4.4. Symptoms and progression

There are different ways to classify the stages of dementia, with one of the most common being a three-stage division: early, middle, and late. These stages reflect changes in symptoms and the level of support required for daily living. The latest stage of dementia is characterised by a nearly complete dependence on others and reduced physical activity. The time taken to progress from the early to late stages of dementia varies and is influenced by factors such as age and eventual comorbidities (WHO, 2017). In Sweden, dementia is classified into three categories: mild, moderate, and severe. This classification, like the one used by WHO, focuses on the level of dependency and support needed (The National Board of Health and Welfare, 2017).

Not all persons with dementia show memory problems in the early stages, as different types of dementia can cause varying symptoms (Alzheimer's Association, 2023; The National Board of Health and Welfare, 2017). However, about 90% of persons with dementia will experience some form of behavioural and psychological symptoms (BPSD) throughout the course of the condition. The most common BPSD symptoms are aberrant motor behaviour, agitation/aggression, and irritability, regardless of the specific type

of dementia, though symptoms such as delusions and hallucinations are more prevalent in FTD (Schwertner et al., 2022). As FTD occurs more frequently in young-onset dementia, this may partly explain the elevated rates of these symptoms among these persons (Fieldhouse et al., 2021; Rosness et al., 2016). The diverse signs and symptoms of young-onset dementia are also due to a broader heterogeneity of underlying causes (van de Veen et al., 2021). Overall, persons with young-onset dementia present a more atypical symptom profile than persons with late-onset dementia (Ducharme & Dickerson, 2015).

## 4.5. Treatment and prevention

Although there is currently no cure for dementia, pharmacological treatments are available for Alzheimer's disease to help improve cognitive function. Cholinesterase inhibitors are recommended for persons with mild to moderate Alzheimer's disease and may be continued into the severe phase due to their effect on BPSD, while memantine is indicated for moderate to severe Alzheimer's disease. Disease-modifying treatments have been introduced internationally, but are not yet approved in the European Union (Läkemedelsboken, 2024). Non-pharmacological approaches and person-centred care are considered first-line treatments for BPSD, with pharmacological treatment used only when these approaches are insufficient (The National Board of Health and Welfare, 2017). Additional medications are also available to manage symptoms such as sleep disorders, anxiety, and BPSD, though the use of antipsychotic medications has decreased in recent decades, in line with the national recommendations (Karlsson et al., 2017; The National Board of Health and Welfare, 2017; Xu et al., 2021).

When treating dementia, pharmacological treatment is only one part of overall care. In Sweden, national guidelines state that all dementia care should be person-centred, including both health and social care (The National Board of Health and Welfare, 2017). At the heart of person-centred care is seeing the person behind the diagnosis, understanding who they are, what matters to them, and adapting to their individual needs and life story. The quality of relationships between the person with dementia and those providing support is considered essential, as meaningful interactions preserve the person's sense of self and wellbeing (Kitwood, 1997). In addition to the quality of

interactions, the national dementia guidelines emphasise the importance of the physical environment as a key component of dementia care (The National Board of Health and Welfare, 2017). Access to outdoor spaces and nature is also considered an important part of the physical environment, as engaging with natural surroundings has been shown to improve mood and boost social interaction among persons living with dementia (Evans et al., 2019).

## 4.6. Needs and support in young-onset dementia

### 4.6.1. *Young-onset dementia's impact on daily life and relationships*

Although the characteristics of the condition differentiate young-onset dementia from late-onset dementia, other unique circumstances are also present. In younger ages, life-stage-specific commitments to family, work, and social activities are more common (Gumus et al., 2021; Wong et al., 2020), which can be a source of psychological distress (Bannon et al., 2021). Consequently, persons with young-onset dementia are more likely to experience symptoms such as depression and anxiety than those with late-onset dementia (Gumus et al., 2021; Wong et al., 2020). Additionally, they may feel anxious about future functional decline and fear making mistakes, and they may experience personality changes that can cause distress. Persons with young-onset dementia may also feel a sense of loss of identity in society, at work, and in their family (Popok et al., 2022; Roach et al., 2016). Driving cessation is also common, which can be problematic both in terms of loss of independence and loss of social connections (Loi, 2023).

Persons with young-onset dementia are often forced to leave employment prematurely, sometimes even before diagnosis, causing not only a sense of loss but also financial strain for them and their families (Bannon et al., 2022; Mayrhofer et al., 2021; Thorsen et al., 2020). This strain can lead to worry about finances and the ability to provide for themselves and others (Mayrhofer et al., 2021). In addition to the financial challenges of leaving employment, partners often have to reduce their working hours to support their loved ones (Bannon et al., 2022). If they are not able to do so, it can lead to anxiety about

leaving the person with young-onset dementia at home alone, generating concerns about the person's safety (Roach et al., 2016).

Informal caregivers for persons with young-onset dementia are more likely to experience caregiver burden and a lower quality of life than those caring for persons with late-onset dementia (Hvidsten et al., 2020; Lim et al., 2018), as they may experience psychological stress, including feelings of anger, fear, resentment, shame, guilt, and hopelessness or loneliness (Hutchinson et al., 2016; Håkansson et al., 2024; Wiggins et al., 2023). Caring for someone with young-onset dementia while balancing one's responsibilities and personal life can be a challenging task, especially when dealing with changes in behaviour and personality (Millenaar et al., 2016), leaving informal caregivers with little time for themselves, including self-care and hobbies. It can be an overwhelming experience, potentially leading to fatigue and burnout (Popok et al., 2022).

Persons with young-onset dementia are more likely to have children living with them, and the symptoms of dementia may result in a reduction in the parental role (Popok et al., 2022). The risk of heritability of dementia can also cause additional stress, as the person with young-onset dementia may worry whether their children will be affected in the future (Bannon et al., 2022). Children may gradually assume caregiving roles rather than receiving parental care, and as a result, neglect their own needs and social interactions (Gelman & Rhames, 2018; Wiggins et al., 2023).

The challenges faced by persons with young-onset dementia and their families are further compounded by stigma, rooted in public unawareness that dementia can affect younger persons. As a result, affected persons may conceal their diagnosis and withdraw from social life (Millenaar et al., 2016; Rabanal et al., 2018). Persons with young-onset dementia express that they feel that persons around them have difficulty understanding and coping with the diagnosis, avoiding them altogether (Bannon et al., 2022; Cations et al., 2017; Popok et al., 2022). Consequently, because persons with young-onset dementia and their families may feel uncomfortable sharing the diagnosis, they may miss out on essential support and care-seeking behaviour (Millenaar et al., 2016; Rabanal et al., 2018).

## Couples living with young-onset dementia

Among the relationships affected by young-onset dementia, the couple relationship is particularly central, as it is within this relationship that much of daily life is shared. When one partner has young-onset dementia, the relationship may face several challenges. Changes in communication can lead to misunderstandings between partners (Bannon et al., 2022). Balancing independence with support can be challenging, especially when safety concerns are involved. The person with young-onset dementia may feel that their partner is overprotective, which can lead to anger and embarrassment. Consequently, the relationship may experience a loss of intimacy, and conflicts may arise between partners (Bannon et al., 2022; Popok et al., 2022). At the same time, the relationship can serve as a shared unit for managing daily life together. Partners may adjust to changes by making joint decisions and supporting each other in daily routines (Bannon et al., 2021; Håkansson et al., 2024). In this way, the relationship may involve both strain and forms of mutual support. The way the relationship functions as a shared unit may consequently influence how relationship quality is experienced over time (Bruinsma et al., 2024). Over time, the balance of responsibilities within the relationship shifts, with the partner increasingly taking on tasks previously shared or managed by the person with young-onset dementia, which may affect how both persons experience their relationship (Håkansson et al., 2024; Yu et al., 2025).

### *4.6.2. Post-diagnostic support for persons with young-onset dementia*

When a diagnosis is eventually established, persons with dementia and their families require timely and tailored support. Yet research consistently shows that such support is not always accessible or adapted to their life circumstances (Cations et al., 2017; Giebel et al., 2020; Millenaar et al., 2016). Although a diagnosis can bring clarity, it can also raise concerns about the future, career, family, and retirement (Bannon et al., 2022; Kilty et al., 2019; Rabanal et al., 2018). Uncertainty about the progression of dementia is a source of stress for both persons with young-onset dementia and their families, making it challenging to plan for multiple future outcomes (Bannon et al., 2022). Persons with young-onset dementia and their families describe information on

expected progression and guidance on how to move forward after a diagnosis as lacking (Bannon et al., 2022), yet such information is needed to better understand and manage the condition (Millenaar et al., 2016). However, when receiving information, people tend to be overwhelmed by excessive amounts that are impossible to process (Cations et al., 2017; Rabanal et al., 2018).

Persons with young-onset dementia often describe a lack of adequate support post-diagnosis (Bannon et al., 2022; Rabanal et al., 2018), needing coordinated support and assistance in finding age-appropriate services to normalise their experience and plan for the future. Instead, they may face uncertainties and feel unsupported (Bannon et al., 2022; Grunberg et al., 2022; Kilty et al., 2019). Additionally, persons with young-onset dementia usually have fewer previous healthcare contacts due to fewer comorbidities than persons with late-onset dementia (Gerritsen et al., 2016), making it even more challenging to navigate the health and social care system.

Formal support can help persons with young-onset dementia remain at home longer, thereby delaying institutional care (Mayrhofer et al., 2018). However, a study found that over 60% of those recommended to use formal support services did not use them, with barriers including services not being adjusted to work schedules and transportation difficulties due to driving cessation (Cations et al., 2017). Support groups specifically for persons with young-onset dementia can be a valuable resource, providing information and helping to prevent social isolation (Cations et al., 2017; Rabanal et al., 2018). Connecting with others in similar situations can foster a sense of independence and empowerment. However, support groups must be tailored for younger persons, as traditional dementia support group activities may not be suitable (Rabanal et al., 2018). When support groups are not age-appropriate, this can discourage attendance (Cations et al., 2017). At the same time, age-appropriate support is sometimes not offered due to insufficient numbers to motivate the costs /effort involved (Giebel et al., 2020). These barriers reflect the broader challenge of adapting support services to the specific life circumstances of persons with young-onset dementia and their families.

### Swedish formal care and support for young-onset dementia

In Sweden, two main formal care providers share responsibility for care and support: regions, which primarily provide healthcare and municipalities,

which provide social services. Private providers are also available, governed by the same laws and regulations, and often funded by taxes.

The 21 regions are responsible for healthcare services, even though private options exist. HSL regulates all healthcare in Sweden and covers medical prevention, investigation, and treatment with the aim of providing good health and care on equal terms, prioritising those with the greatest need. For persons with young-onset dementia, these services include inpatient and outpatient services such as hospitals, (some) primary care centres, and specialist services, such as memory clinics. Memory clinics are specialised outpatient healthcare services that provide diagnostic workups and care and support for persons with dementia. Their services may differ across regions, but are delivered by healthcare professionals such as physicians, nurses, physiotherapists, occupational therapists, counsellors, and speech therapists. All regions in Sweden have at least one memory clinic (The Swedish registry for cognitive/dementia disorders [SveDem], 2024). However, the accessibility of these clinics may vary, as some regions are very large and the distance to the clinics can depend on where you live.

Municipalities in Sweden are responsible for social services, determined by a social worker's assessment, known as a needs assessor. These services cover three main areas: 1. Economic and social security, 2. Equal living conditions, and 3. Active participation in the community. Municipal services are mainly regulated by the Social Services Act [SoL] (SFS 2001:453), a framework law that imposes an obligation to provide support and services that every person may need. Each of Sweden's 290 municipalities decides how to organise these services to achieve the goal of providing reasonable living conditions for the individual. In addition to SoL, municipalities also provide services within HSL (SFS 2017:30). These services are provided by nurses, physiotherapists, and occupational therapists in the person's home (The Swedish Association of Local Authorities and Regions [SKR], and eligibility is assessed by primary care centres, based on the criteria such as the person's ability to visit them (Janlöv et al., 2023).

In July 2025, a new Social Services Act (SFS 2025:400) replaced the previous act (SFS 2001:453). The new act introduces several changes relevant to support for persons with dementia, including an explicit requirement for

municipalities to offer a designated contact person for those receiving home help services and a strengthened obligation to support those caring for a long-term ill relative. The new act also lowers the threshold for accessing support, as municipalities can now offer certain interventions without a prior individual needs assessment. This may make it easier for persons with young-onset dementia to access support earlier. As the majority of the data collection in this thesis was conducted prior to the implementation of the new act, references to the Social Services Act throughout this thesis refer to the previous act (SFS 2001:453) unless otherwise stated.

Various support services for persons with young-onset dementia are available through municipalities' social services. These include, for example, home help services, daycare centres, and care facilities (SFS 2001:453). Municipalities mainly provide home help services, but several private companies also offer these. These services are available to all, though they are not free; the fee is based on a person's income (and their partner's income if they live together). Municipalities also provide daycare services for persons with dementia, aiming to offer meaningful activities, social connections, daily routines, and respite for families. About 20% of municipalities in Sweden have specific daycare options for persons with young-onset dementia (The National Board of Health and Welfare, 2020). There are also several care facility options, such as nursing homes and respite care, some with a specific focus on dementia, including a few that target young-onset dementia. They serve as options for persons with dementia who can no longer reside in their homes (The National Board of Health and Welfare, 2017). In municipal care, much of the support provided by home help services and care facility options is delivered by assistant nurses, who form the core workforce in these settings (The National Board of Health and Welfare, 2025).

Municipalities are further responsible for services under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments [LSS] (SFS 1993:387), an entitlement law that guarantees good living conditions for people with extensive functional impairment, including services such as personal assistance and accompaniment. These services are available only for persons under 66, but they can be extended if approved before that age. However, LSS services have been shown to be challenging to

obtain for persons with young-onset dementia (The National Board of Health and Welfare, 2019).

When services are required through both social care and healthcare, municipalities and regions are obligated to prepare a coordinated individual plan (Coordinated Plan – SIP). This plan should specify what services are needed, who is responsible for each service, which services are provided by formal caregivers other than the municipality or the region, and which caregiver is responsible for the individual plan (SFS 2001:453).

### National dementia policies and guidelines

Besides legislation, several national policy documents at different levels aim to promote evidence-based approaches and facilitate the organisation and delivery of care and support within healthcare and social services.

In 2025, the Swedish Government introduced *the National Dementia Strategy 2025–2028* (Socialdepartementet, 2025), presenting an updated national framework for dementia care and support. Building on previous guidelines, the strategy emphasises the need for coordinated, evidence-based, and person-centred care across both health and social services. Particular focus is given to families and informal caregivers, who play an important role in supporting daily life and well-being for persons with dementia. The strategy emphasises providing relatives with education and support to enable sustainable informal caregiving, recognising that dementia affects not only the person but the entire family. It also places particular emphasis on young relatives, including minor children, as a group in need of tailored support.

The national dementia guidelines include recommendations for decision-makers on the support and care of persons with dementia. These include diagnostic pathways, follow-up procedures, multi-professional approaches, support services, medication guidelines, and staff education. The guidelines mention home help services and daycare activities as particularly important for helping the person with dementia remain in their home and maintain social connections. For persons with young-onset dementia, the guidelines recommend age-appropriate daycare services. However, the guidelines acknowledge that smaller municipalities may struggle to provide such services

due to their small populations (The National Board of Health and Welfare, 2017).

*A standardised intervention pathway for dementia* is a model also developed by the Swedish National Board of Health and Welfare (2019) to coordinate care and support throughout the course of the dementia, from diagnosis to end-of-life, with a focus on person-centred care. The pathway provides a structured approach to collaboration among providers, such as municipalities and regions, to ensure that persons with dementia receive the right support at the right time and maintain continuity in support services. The standardised pathway states that interventions should be adjusted over time, with a focus on preserving quality of life as dementia progresses. For persons with young-onset dementia, the model emphasises that their needs may differ from those with later onset. Special attention should be given to providing tailored support, such as adapted care facilities or age-appropriate day care services. The pathway also highlights the importance of supporting family members of those with young-onset dementia, including providing information and education about dementia, along with psychosocial support.

The national guidelines, dementia strategy, and standardised intervention pathway together create a comprehensive framework for supporting persons with young-onset dementia. However, since these policies are implemented at the local level by municipalities and regions, how this framework is put into practice can vary, leading to variation in the support services available for young-onset dementia across Sweden.

## 5. Theoretical framework

This thesis draws on two complementary theoretical perspectives: Neugarten's concept of on-time and off-time life events (Neugarten, 1970), and Habermas's theory of the system-world and the lifeworld (Habermas, 1987). These frameworks will support the interpretation of complex interactions among persons with dementia, their partners, and the societal responses to their needs.

In addition to guiding the interpretation of the findings, the frameworks also informed the overall design of the thesis. The quantitative studies adopt a system-world perspective by focusing on the structural and organisational aspects of formal support. The qualitative studies capture the intersection of the lifeworld and the system-world, focusing on how couples living with young-onset dementia understand and manage support in their daily lives. Together, these perspectives enable the thesis to explore societal conditions and lived experiences through different methodological approaches.

### 5.1. The system-world and the life world

The phenomenological philosopher Edmund Husserl introduced the concept of the "lifeworld," referring to the self and lived experiences with others in the social sphere. Husserl's theory emphasises the importance of communication and engagement with others in forming the human being (Husserl, 1970). Jürgen Habermas (1987) developed this further by introducing the concept of "the system-world" to describe societal functions, such as healthcare, and social systems that operate according to rules and procedures independent of their citizens' lifeworlds.

The system-world includes formal, regulated aspects of society, such as political and administrative institutions. This sphere is characterised by purposeful, goal-oriented action driven by rationality, with communication regulated by means-end thinking. On the other hand, the lifeworld reflects the

informal and social side of human interaction. This sphere includes norms and meaning and is crucial for social communication and mutual understanding. Here, people exchange ideas and cultural expressions spontaneously on a daily basis. Shared norms and values are formed and maintained in this sphere.

At the individual level, an increasing influence of the system-world can shift focus away from personal meaning and autonomy. Persons who previously had power and agency in their lifeworld may become increasingly reliant on standardised methods and treatments, reducing their lifeworld and increasing dependence on the system-world. Habermas argued that the system-world and the lifeworld should complement each other. Otherwise, the system-world risked dominating the lifeworld, and such an overtake may reduce the ability to meaningfully address collective challenges.

The distinction between the two worlds has been criticised for being too simplistic and for ignoring the complexities of societies. The system-world and the lifeworld are not entirely separated, and different cultural contexts may lead to different interactions, making the theory not universally applicable. Habermas' theory pays little attention to cultural variation, making it challenging to apply in practical research and policy contexts. Some critics have argued that the theory is too abstract to be helpful in such contexts (Baxter, 1987).

Despite these limitations, Habermas's distinction between the system-world and lifeworld is relevant to this thesis, as it provides a framework for examining the relationship between formal support structures and the daily lives of couples living with young-onset dementia, and how these two spheres may come into tension or alignment. Habermas's distinction between the system-world and the lifeworld offers a way to reflect on the relationship between formal structures and daily life. The system-world refers to how support is organised, while the lifeworld reflects how couples understand their daily situation and roles, which may affect how they interact with and interpret the support.

## 5.2. Neugarten's on-time and off-time events

Bernice Neugarten was a sociologist who studied ageing and the life course. Her concepts of "off-time" and "on-time" examined how individuals experience life events and transitions compared with societal norms and expectations (Neugarten, 1970).

Off-time events are described as unexpected or outside societal norms. According to cultural standards, these events may happen earlier or later than typical. Examples of off-time events include early marriage, late parenthood, mid-life career changes, or experiencing a major illness at a young age. Such events can disrupt the usual sequence of life transitions and may challenge persons in adapting to new roles or circumstances.

In contrast to off-time events, on-time events occur at expected or socially acceptable times, as defined by cultural norms. These events typically follow the conventional timeline of life transitions and align with societal expectations. Examples of on-time events include getting married in one's late twenties or early thirties, starting a career after completing education, having children in one's twenties or thirties, and retiring later in life. On-time events are often considered smoother transitions because they align with the expected progression of life stages.

Age-related norms and expectations form a system of social control, referred to as the social clock, that accelerates or slows events. In youth, one learns the "right way" and "right time" to become an adult; in middle age, one learns the "right way" and "right time" to age. These norms contribute to high predictability in society. People are aware of these social expectations and contribute to them by defining themselves as "early," "late," or "on time" for major life events.

Neugarten has faced criticism for categorising life events as either "on-time" or "off-time." It can be seen as an oversimplification of when life events occur and may not reflect the full range of individual experiences. Life events are often complex and shaped by several factors, so timing alone cannot fully explain individual variation. Despite these limitations, this framework remains useful for this thesis because it highlights how age

norms and societal expectations shape the interpretation of off-time events, including young-onset dementia.

In conclusion, being diagnosed with dementia at a young age is an unexpected and “off-time” event that occurs earlier than what is typically associated with dementia. Receiving support at a younger age may not align with what persons with young-onset dementia and their families expect in midlife. Neugarten's concepts may help clarify how the timing of a diagnosis influences expectations of support and how the relevance of support services is understood for couples living with young-onset dementia.

### 5.3. Considering the theories in combination

Integrating Habermas's distinction between the lifeworld and system-world with Neugarten's concept of off-time events enables the thesis to explore how timing, daily life, and system structures relate to experiences of support. Together, the theories provide a basis for examining how persons with young-onset dementia and their partners understand available support and how they navigate both formal and informal support.

The two frameworks complement each other in a specific way. Neugarten's concept of off-time events helps explain how the timing of a diagnosis shapes a person's expectations and experiences. Habermas's framework then provides a lens for understanding how formal support systems, structured around bureaucratic logic, may be poorly equipped to respond to the lifeworld of navigating such off-time events. To my knowledge, this combination of frameworks has not previously been applied in dementia research. Together, they therefore offer a unique approach that enables examination of both the individual experience of an off-time diagnosis and the structural conditions that shape how support is organised and received.

## 6. Rationale

Persons with young-onset dementia face significant disruptions to their daily life during midlife, often during a period shaped by employment, family responsibilities, and active social participation. These disruptions lead not only to practical and financial challenges but also to considerable emotional difficulties for both the person and their partners. However, much of the current research still primarily focuses on late-onset dementia, and support systems and services are often tailored to older adults, meaning they may fail to recognise the realities faced by couples living with young-onset dementia.

Although research on young-onset dementia is increasing, important gaps remain. Since support is closely linked to national welfare systems, Swedish research is essential to understanding how services can better meet the needs of couples living with young-onset dementia. Little is known about how support is organised at the time of diagnosis or which factors affect access to it. Existing studies tend to focus on informal caregivers rather than on the couple relationship, overlooking that support is not experienced in isolation. Yet few studies have examined couples longitudinally as the condition progresses. Moreover, cross-sectional studies can capture support only at a single point in time and cannot reveal how support needs and experiences change as dementia progresses, underscoring the need for longitudinal approaches. Understanding how couples experience and navigate support over time is therefore essential if support is to be designed in ways that are meaningful and relevant to couples living with young-onset dementia.

This thesis addresses these gaps through a combination of approaches. Registry-based studies, which operate within the system-world framework, provide a population-level understanding of the support available and when it is accessed. Longitudinal qualitative interviews with couples examine how support is experienced and navigated within the shared life-world of the relationship over time. Together, these methods address both the structural

and experiential dimensions of support, providing a more comprehensive picture than either approach alone.

## 7. Aim and research questions

The overall aim of this thesis is to explore and describe support for persons living with young-onset dementia and their partners, and to examine how this support is experienced and adapted over time. The specific research questions are:

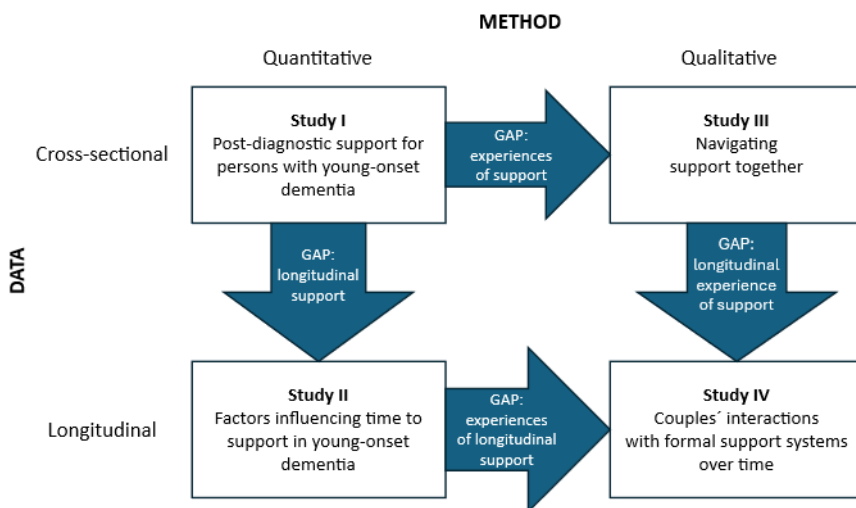
1. What support is available for persons with young-onset dementia, and what factors influence access to and use of this support? (Studies I and II)
2. How do couples, where one partner has young-onset dementia, navigate and use support in their daily lives? (Study III)
3. How do support provision and experiences of support evolve over time, and what factors influence these changes? (Studies II and IV)

## 8. Methods and materials

### 8.1. Study design

This thesis is part of a larger research project on support for persons with young-onset dementia, funded by the Swedish Research Council for Health, Working Life and Welfare (FORTE), grant number 2021-01799. In addition to the components included in this thesis, the larger project also features examining experiences and organisational aspects of care facilities for persons with young-onset dementia, as well as the professionals working in these settings. An expert group consisting of dementia nurses from municipalities, nurses from memory clinics, and a couple living with young-onset dementia was involved throughout the research process. The expert group provided clinical and experiential insights to inform, contextualise and discuss the findings.

The four studies in this thesis were designed sequentially, with each study addressing a gap identified in the previous one. As illustrated in Figure 1, the studies are organised along two axes: method (quantitative and qualitative) and data (cross-sectional and longitudinal). Study I provided a structural overview of post-diagnostic support, revealing a knowledge gap about how support is experienced, which motivated Study III. The longitudinal gap identified in Study I motivated Study II, which examined factors influencing time to support. Study II, in turn, revealed a knowledge gap regarding the longitudinal experience of support, motivating Study IV. Together, the four studies move from a structural examination of support to an in-depth exploration of how couples experience and navigate support over time (Figure 1).



*Figure 1. Sequential design of Studies I- IV, organised by method (quantitative/qualitative) and data (cross-sectional/longitudinal), illustrating how identified gaps motivated each subsequent study.*

The combination of quantitative and qualitative approaches enabled the studies to complement each other, with the registry studies uncovering the context-specific meanings and interactions of support. Rather than seeking complete integration, the studies are regarded as complementary, with different methodologies highlighting distinct aspects of support for persons with young-onset dementia and their partners.

### **8.1.1. Studies I and II**

The first two studies in this thesis are based on data from SveDem, a national quality dementia registry, described in detail in Section 8.2.1.

Study I was a retrospective cross-sectional study using baseline registrations from SveDem. Cross-sectional studies analyse data from a population (or a sample) at a single point in time. They are often used to describe sample

characteristics and to examine factors associated with different outcomes (Wang & Cheng, 2020).

Study II employed a longitudinal design using both baseline and follow-up registrations from SveDem. A longitudinal design makes it possible to investigate changes over time and to analyse factors that influence the timing of events (Caruana et al., 2015), such as when formal support is first introduced.

### **8.1.2. *Studies III and IV***

The third and fourth studies were based on qualitative interview data and focused on the lived experiences of couples living with young-onset dementia (Table 1).

Dyadic interviews were chosen as the methodological approach for Studies III and IV to capture how couples jointly construct accounts of their support experiences. Interviewing partners together makes it possible to access both individual perspectives and the co-construction of experiences in interaction. The dyadic format has been shown to enable partners to expand one another's accounts by adding detail or presenting contrasting perspectives, thereby generating richer descriptions than individual interviews (Eisikovits & Koren, 2010; Polak & Green, 2016). This approach is especially relevant in dementia research, where communication changes can affect participation and where the partner often represents the primary source of support (Hirt et al., 2024). Interviewing couples together, therefore, helped capture both perspectives without marginalising the person with young-onset dementia. Focusing on couples as the unit of analysis aligned with the aims of Studies III and IV, which explored couples' experiences of support.

Study III was an explorative qualitative study using dyadic semi-structured interviews. Explorative designs are used when little is known about a phenomenon, and the aim is to generate a new understanding (Stebbins, 2001). A meaning-oriented thematic analysis grounded in lifeworld research was selected because it enables exploration of how persons give meaning to their lived experiences (Lindberg et al., 2024).

Study IV was a longitudinal qualitative study in which each couple was treated as a case. Longitudinal designs enable repeated data collection over time, allowing the capture of how experiences evolve as circumstances change (Neale, 2021). Pattern-Oriented Longitudinal Analysis (POLA) was chosen as it enables examination of both individual trajectories and shared patterns of change across cases over time (Kneck & Auduly, 2019).

**Table 1.**

*Overview of the design, participants, data collection, and analysis in Studies I–IV*

Study	Design	Participants	Data collection	Data analysis
I	Retrospective cross-sectional study	Persons under 65 with young-onset dementia (n=284)	Quality Registry Data 2021-2022	Descriptive statistics, logistic regressions
II	Longitudinal cohort study	Persons under 65 with young-onset dementia (n=2592)	Quality Registry Data 2009-2022	Descriptive statistics, Cox proportional hazards regression
III	Explorative qualitative study	Couples living with young-onset dementia (n=11)	Dyadic semi-structured interviews	Meaning-oriented thematic analysis
IV	Longitudinal qualitative	Couples living with young-onset dementia (n=10)	Repeated dyadic interviews, participant notes	Pattern-Oriented Longitudinal Analysis (POLA)

## 8.2. Settings and data collection

### 8.2.1. *Study I and II*

Data from SveDem's national quality register were used for Studies I and II, and all registrations meeting the inclusion criteria were extracted, including both baseline and follow-up data. Table 2 provides an overview of the variables used in the analyses in Studies I and II. For both studies, the inclusion criterion was a dementia diagnosis before the age of 65. SveDem is a national quality register that has been active since 2007, with over 120,000 unique registrations to date (Svenska registret för kognitiva sjukdomar/demenssjukdomar [Internet], 2024). Its purpose is to support various stages of the registration process and to serve as a reminder and aid in follow-up care after diagnosis. SveDem oversees quality indicators for all registered persons at the registration unit and the national level. SveDem are used by specialist units, primary care centres, care facilities, and home healthcare services. The initial registration should be followed by annual updates, with the possibility of registering follow-ups up to 15 months between updates (SveDem, 2022).

SveDem collects a broad range of clinical and care-related information. Prior to analysis, I thoroughly reviewed the registry's documentation, discussed the variables and their definitions with the registry administrator to ensure an accurate understanding, and attended training provided by SveDem to further develop an accurate understanding of how the registry is used in practice. This process informed the selection and interpretation of variables used in the analyses. For Studies I and II, variables were selected based on the research questions, including clinical and support-related variables such as age, sex, dementia diagnosis, Mini-Mental State Examination [MMSE] score, medication, accommodation, living arrangements, care setting, and support variables such as home help service, daycare, counsellor, and care facility. Data originated from two modules within the register: specialist care and primary care. Although the register was established in 2007, data from 2009 onwards were used because of inconsistencies in selected variables in the initial years. Additionally, due to substantial updates to the registry in 2021, Study I uses data from 2021 to 2022.

**Table 2.***Variables from SveDem used in Study I and Study II*

Variable (SveDem)	Study I	Study II	Options
<b>Accommodation</b>	✓	✓	Ordinary housing; Care facility, temporary; Care facility, permanent – not adapted for persons with dementia; Care facility, permanent – adapted for persons with dementia
<b>Age</b>	✓	✓	Age in years
<b>Care setting</b>	✓	✓	Memory clinic; Primary care centre
<b>Children at home</b>	✓	–	Yes; No
<b>Cognitive aids</b>	✓	–	Yes; No
<b>Counsellor contact</b>	✓	✓	Yes; No
<b>Dementia nurse contact</b>	✓	–	Yes; No; No – no dementia nurse available
<b>Contact needs assessor</b>	✓	–	Yes; No
<b>Dementia diagnosis</b>	✓	✓	Mixed dementia; Dementia UNS; Alzheimer's disease; Dementia in Parkinson's disease; Frontotemporal dementia; Lewy body dementia; Mild cognitive disorder*; Alcohol dementia; Vascular dementia; Other dementia
<b>Daycare</b>	✓	✓	Yes, adapted for persons with dementia; Yes, adapted for persons with young-onset dementia; Yes, but not adapted for persons with dementia; No; Do not know
<b>Home help service</b>	✓	✓	Yes; No; Do not know
<b>(Information and Educational) Support to the person</b>	✓	–	Yes; No
<b>(Information and Educational) Support to family members</b>	✓	–	Yes; No; No – no family member available
<b>Living arrangement</b>	✓	✓	With another adult; Living alone
<b>Medications</b>	✓	✓	Number of medications
<b>MMSE</b>	✓	✓	Score (0–30); Yes; Not performed; Not testable
<b>Sex</b>	✓	✓	Male; Female
<b>Support according to LSS</b>	✓	–	Yes; No; Do not know

### 8.2.2. *Study III and IV*

Approval to recruit participants through the memory clinics was obtained from the clinical manager prior to recruitment. The clinic staff then identified eligible couples based on the specified inclusion and exclusion criteria described in 8.3.2. Potential participants received a brief oral introduction to the study, along with written information in both standard and simplified versions. Couples were asked whether they consented to me being provided with their contact details. For couples who agreed, staff recorded the names and phone numbers of both partners and sent this information to me.

Furthermore, recruitment was conducted through the Swedish Dementia Association's website, where an invitation to participate was posted. Couples interested in taking part registered on the site, and their contact details were sent to the research team. I then contacted the couples to offer more detailed information and to ask about their participation. Written informed consent was obtained during the initial meeting.

All interviews were conducted by me in the couples' homes using a semi-structured interview guide (Appendix 1). Participants selected the interview date and time. In Study III, an initial round of interviews was carried out. For Study IV, each couple participated in three additional interviews over 18 months, with approximately 6 months between interviews, for a total of 40 interviews. Interviews in Study III lasted between 33 and 102 minutes (median 63 minutes), and transcripts ranged from 7 to 24 pages (median 15 pages). In Study IV, interviews lasted between 33 and 135 minutes (median 76 minutes), and transcripts ranged from 7 to 69 pages (median 19 pages). The first interviews focused on couples' daily lives and support experiences, while the follow-up interviews explored how these experiences had changed since the previous interview. All interviews were audio-recorded and transcribed verbatim by me.

## 8.3. Participants

### 8.3.1. *Participants in studies I and II*

Study I included 284 persons registered in SveDem who met the inclusion criterion of a dementia diagnosis before the age of 65, diagnosed during 2021-2022. Study II included 2,592 persons meeting the same age criterion between 2009 and 2022, registered in SveDem, and who had at least one follow-up registration. Participant characteristics for both Studies I and II are shown in Table 3.

**Table 3**

*Participant characteristics in Study I and Study II*

<b>Characteristic</b>	<b>Study I (n=284)</b>	<b>Study II (N= 2592)</b>
<b>Sex distribution</b>	144 women, 140 men	1386 women. 1206 men
<b>Mean age at diagnosis</b>	59 years	59 years
<b>% Diagnosed between age 60-64</b>	54.9	58.4
<b>Living with another adult</b>	N = 194 (68.3%)	N = 1801 (69.5%)
<b>Most common diagnosis</b>	AD (n= 149; 52.5%)	AD (n= 1507; 58.1%)
<b>Registered by the memory clinic</b>	N = 261 (91.9%)	N = 2283 (88.1%)

### 8.3.2. *Participants in studies III and IV*

For Studies III and IV, participants were recruited from three regions in Sweden. Inclusion criteria required that one partner had received a dementia diagnosis before the age of 65, had been diagnosed for at least six months and lived in ordinary housing together with a partner. Couples in which the person

with dementia had interventions approved under LSS prior to diagnosis were excluded. In total, 11 couples were recruited for Study III.

In Study IV, the same couples were followed longitudinally, however one couple withdrew after the first interview, leaving 10 couples (20 participants) who participated in all interviews. Participant characteristics for both Study III and IV are shown in Table 4.

**Table 4**

*Participant characteristics in Study III and Study IV*

<b>Characteristic</b>	<b>Study III (n = 11 couples)</b>	<b>Study IV (n = 10 couples*)</b>
<b>Persons with young-onset dementia</b>	7 men, 4 women	6 men, 4 women
<b>Partners</b>	7 women, 4 men	6 women, 4 men
<b>Age (participants)</b>	54–68 years	54–68 years
<b>Years together</b>	10–43 years	10–43 years

\*One couple withdrew after the first interview.

At the time of the first interview, some persons with young-onset dementia were still working or on sick leave, while others had retired or were receiving sickness compensation. By the end of the study period, all persons with young-onset dementia were receiving sickness compensation or had retired. Couples lived in both urban and rural settings, and their educational and occupational backgrounds varied widely. Among partners, employment situations varied: some worked throughout the study period, others were on sick leave, and others reduced their working hours without being paid to provide care.

## 9. Data analysis

Data were analysed using both quantitative and qualitative methods, with the choice of analysis for each study reflecting the theoretical perspective applied. Studies I and II adopt a system-world perspective, using statistical methods to examine associations and factors related to support provision based on registry data. Studies III and IV, based on interview data, draw on both the lifeworld and the system-world perspectives, as well as Neugarten's concept of off-time events, employing qualitative methods to explore how couples experienced and navigated support in their daily lives over time. In the qualitative studies, the dyad served as the unit of analysis, with both partners' perspectives considered together throughout the analysis.

### 9.1. Study I

Logistic regression is suitable for examining associations between a binary outcome and multiple predictor variables, as it estimates the probability of an outcome given a set of predictors (Bewick et al., 2005). Logistic regression models were conducted to investigate associations between participant characteristics and post-diagnostic support variables. Descriptive statistics were presented to describe participants' characteristics and support variables. Each model included one support variable as the outcome, with relevant background characteristics as predictors. Variables with more than two response options were dichotomised for regression: accommodation was recoded as either ordinary housing or a care facility, and daycare as yes/no. For the dementia nurse variable, 'no nurse available' was recoded as missing (n=24), and similarly, 'no relative available' for information and educational support for family members was recoded as missing (n=5). To ensure accurate coefficient estimates, collinear variables were omitted from three models. Goodness of fit was assessed using chi-square tests, and Nagelkerke's adjusted  $R^2$  indicated the proportion of variance explained by each model. A significance level of 0.05 was used in both Studies I and II.

## 9.2. Study II

Descriptive statistics were used to describe participants' characteristics and support variables. Cox proportional hazards regression was chosen as it accounts for censored observations and allows examination of multiple factors associated with the timing of an event (Bewick et al., 2004). This method was used to examine factors associated with delays in receiving support services. The outcome event was defined as the first recorded onset of support in SveDem. For each analysis, persons who had already received services at baseline were excluded from the models. If support was never recorded, the time of the last entry in the registry was used. Accommodation and daycare were dichotomised into binary variables due to inconsistencies in specific response options over the 13-year period. Accommodation was recoded as ordinary housing or care facility, and daycare as yes or no. Models were adjusted for age, sex, MMSE score, number of medications as a proxy for general health, living arrangement and care setting. The proportional hazard assumption was assessed using cumulative hazard plots, which did not indicate any violations.

For most support variables, baseline data were used. However, for counsellor contact, the baseline variable indicates only whether contact was offered. Therefore, the value from the first follow-up, which records established contacts, was used in place of the original value.

## 9.3. Study III

A meaning-oriented thematic approach informed by lifeworld theory (Lindberg et al., 2024) was used to analyse how couples experienced support in their daily lives. The phenomenon was defined as the support experienced by couples where one partner had young-onset dementia, which guided the focus of the analysis. The analytical process was iterative, and earlier steps were revisited throughout to ensure that the emerging interpretation was grounded in the material.

The interviews were first read several times to gain a sense of the material. After this, the transcripts were coded by identifying meaning units related to the phenomenon. Meaning units that expressed related meanings were

grouped into clusters, which helped organise the material and make recurring meanings more visible. The clusters were compared with the transcripts during analysis to ensure they remained close to the descriptions the couples gave.

As the analysis progressed, the clusters were developed into themes that described broader ways in which couples understood support in their daily lives. This process involved moving between detailed readings of the interviews and a more overarching view of how the different descriptions related to the phenomenon. The analysis was conducted by me and presented to the research team, where alternative interpretations were considered. Examples of the development of the themes are illustrated in Figure 2.

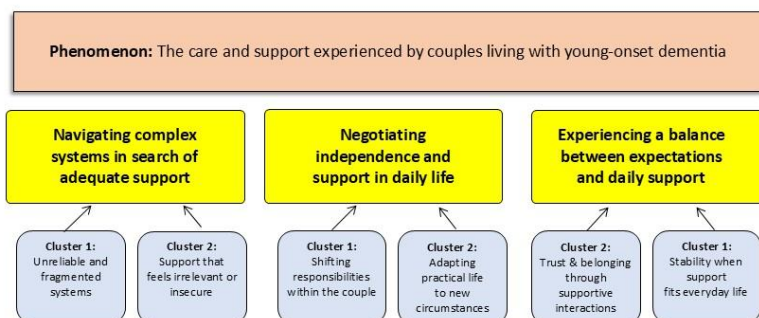


Figure 2. The three themes and selected clusters from Study III, describing care and support experienced by couples living with young-onset dementia

## 9.4. Study IV

A Pattern-Oriented Longitudinal Analysis [POLA] (Kneck & Auduly, 2019) was used to examine how couples' interactions with formal support developed over time. The analysis was conducted at both within- and across-couple levels. Each couple was treated as a case, which made it possible to follow

their trajectory across four interviews and analyse both the developments within each couple and the similarities and differences between couples. The analysis concentrated on how couples described their contact with formal support, how they responded to it, and how these interactions changed or remained stable over the 18-month period.

The analysis followed the two-stage structure outlined in the POLA approach. In the first stage, the material was organised to give an overview of each couple's trajectory. Each interview was coded according to the study's aims, focusing on descriptions of formal support, such as access to services, follow-up, decisions about applying for support, and reasons for accepting or declining what was offered. The coded material from each interview was then transferred to a chronological matrix for each couple, with one column per interview. For each case, the matrix was summarised with brief descriptive texts outlining how their interaction with formal support evolved over the four interviews. This enabled the identification of both continuity and change within each case, including periods when support remained largely consistent and moments that could be seen as turning points, such as the introduction of new services, the rejection of applications, or couples altering how they interacted with formal support.

In the second stage, the focus shifted to analysing variation and change across couples. The longitudinal summaries from the matrices were compared to identify similarities and differences in how couples interacted with formal support over time. Attention was directed towards recurring ways of relating to formal support, such as withdrawing after initial efforts or maintaining ongoing involvement. Based on these comparisons, preliminary patterns were identified and then repeatedly checked against the matrices and the original transcripts to ensure the material supported them. Through this iterative process, three distinct patterns of interaction with formal support were identified.

## 9.5. Reflexivity and researcher role

Reflexivity involves recognising how the researchers' position, background and assumptions shape the research process and its findings (Finlay, 2002).

My background as a nurse, with experience in healthcare, nursing homes, and home help services, meant that I entered this research with an established understanding of how care and support systems function and what dementia care and support look like in practice. However, my clinical experience was primarily with persons in more advanced stages of the condition, which may have shaped my expectations of what living with dementia looks like, expectations that were sometimes challenged when meeting couples at an earlier stage of the disease. But also, this familiarity facilitated sensitive communication during interviews and helped create a trusting environment with the couples. However, it also posed a risk of framing the couples' experiences within patterns I recognised from other contexts, for instance, interpreting descriptions of support in light of what I knew to be typical rather than staying close to what the couples described themselves. In addition, my background in gerontology may have shaped my preunderstanding in other ways. Familiarity with theories of ageing, the life course, and age-related norms meant that I entered the research with established frameworks for understanding how timing and social expectations influence personal experiences. While this theoretical base helped me identify patterns of life-course disruption and off-time events, it also risked viewing the couples' experiences through existing theoretical assumptions, particularly given that the couples were younger than those typically studied in ageing research.

Interviewers with limited experience may rely more heavily on prior knowledge when conducting interviews, which can unintentionally shape interpretation (Powell et al., 2012). To address this, the analysis was conducted with a continuous focus on openness. Meaning units, clusters, patterns, and themes were developed iteratively, with conscious reflection on how my pre-understandings might influence interpretations. Quotations were used to ensure that findings remained grounded in the couples' own words. The collaborative analysis within the research team also fostered reflexivity, enabling alternative interpretations of the data before a shared understanding was reached.

In the longitudinal interview study, an additional reflexive consideration occurred from the repeated contact with the same couples over time. The

relationship between the interviewer and interviewee may evolve over multiple interviews, affecting what participants decide to share on different occasions (Elliot & Bonsall, 2018). While growing familiarity can encourage openness, it also risked reinforcing my earlier interpretations rather than remaining open to change. This was mitigated by the pattern-oriented longitudinal analysis, which facilitated grounding results in data rather than assumptions.

In the registry studies, my role as a researcher was less visible during data collection, as analyses drew on pre-existing registry data. However, reflexivity remained relevant: decisions on how to select and categorise variables, model construction, and the interpretation of associations all involved my judgment and shaped the findings. Reflecting on such analytical decisions is an important aspect of reflexivity, also in quantitative research (Jamieson et al., 2023)

Taken together, reflexivity was present across all parts of the thesis, though in different forms, centred on interpersonal dynamics and interpretation in the qualitative studies, and on analytical choices and assumptions in the registry studies. Making these aspects visible enhances the thesis's credibility by presenting my role as a researcher transparently rather than in the background.

## 10. Ethical considerations

Research involving persons with dementia presents particular ethical challenges, as their ability to understand information and provide informed consent may change over time (Abbato, 2015). The Declaration of Helsinki emphasises that research with vulnerable groups should be conducted only if the potential benefits outweigh the risks and if the knowledge cannot be gained by studying non-vulnerable groups (World Medical Association, 2025). In this thesis, the risk of excluding persons with young-onset dementia was weighed against the importance of including them. To understand support needs in depth, relying solely on partners' accounts was not deemed sufficient. Furthermore, being interviewed can be a meaningful experience for the couple, supporting self-esteem and a sense of worth (Dewing, 2001). Excluding persons with dementia could also be seen as reducing their dignity (Hellström et al., 2007). The importance of including persons with dementia when their experiences are portrayed has been emphasised as a matter of respect, trust and dignity (Alzheimer Europe, 2022). Recent research has emphasised that the systematic exclusion of persons with dementia from research constitutes an epistemic injustice and that meaningful participation should be recognised as an ethical concern in its own right, rather than only a methodological choice (O'Shea et al., 2025). Earlier research has noted that persons with dementia may be motivated to participate due to altruism or perceived medical benefit (Howe, 2012). As the qualitative studies in this thesis do not involve direct medical benefits, altruistic reasons may have influenced participation.

Since understanding and decision-making may change over time, consent was revisited during the longitudinal interviews. Attention to consent as an ongoing process has been recognised as important for ensuring participation in dementia research is conducted safely and with respect (Hirt et al., 2024). Accordingly, informed consent was regarded as an ongoing process. Written consent was obtained at the initial meeting, and verbal consent was sought prior to each interview. Participants were also reminded that they could withdraw at any time without giving a reason, and they were reassured that neither the information they conveyed nor their decision to withdraw would

affect the care or support they received, nor would any formal care or support providers be informed of their decision.

The decision to use dyadic rather than individual interviews also had ethical implications. Interviewing couples together enables shared reflection and richer descriptions, but it also means that conversations may sometimes touch on sensitive aspects of the couple's relationship. Joint interviews involve dynamics where one person's account may dominate or limit the other (Polak & Green, 2016), but they can also open up interaction and shared memory that might not emerge in individual interviews (Morgan et al., 2016). I, therefore, carefully observed the interaction, offering breaks and ensuring that both voices were heard. I also looked for signs of discomfort or strain, allowed pauses when necessary, and drew on my professional experience in communicating with persons with dementia to foster a supportive interview environment. The expert group established for the project also contributed to the ethical soundness of the research, reflecting a broader movement towards participatory dementia research that highlights both ethical importance and the practical benefits of involving people with lived experience (Morbey et al., 2019).

For the registry studies, no individual consent was obtained as only de-identified data was received. Consent to be included in the SveDem registry is obtained at the point of registration. Patients are informed of their right to decline participation, to receive a free copy of their registry data once per year, and to withdraw from the registry at any time and that their information can be used for quality assurance, statistical production and research (SveDem, 2023). Using registry data also had ethical advantages, as the information was already collected as part of routine quality monitoring and did not place additional demands on persons with young-onset dementia or their families.

A data management plan was established in line with Jönköping University guidelines, which are based on the European Commission's recommendations for research data management (2016). An ethical application was submitted to the Swedish Ethical Review Authority on 26 January 2022 and was approved on 22 February 2022 (DNR 2022-00459-01). The ethical application covered the interview study, registry data, and the inclusion of persons with dementia in the expert group.

Taken together, these considerations show how ethical awareness was integrated throughout the thesis. In Studies I and II, using de-identified registry data reduced risks but limited participants' direct voice. In Studies III and IV, dyadic interviews maximised the chance to hear perspectives while requiring careful attention to consent and power dynamics. Across all studies, ethical considerations centred on enabling participation while remaining attentive to vulnerability, an approach that has been described as needing carefully considered ethical strategies in dementia research (Murphy et al., 2015).

# 11. Findings

## 11.1. Support at diagnosis (Study I)

At diagnosis, very few persons with young-onset dementia had formal support already in place. The large majority (94.4%) resided in ordinary housing, and only a small proportion had home help services (8.8%), day care (1.5%), or LSS-related services (2.2%). The registration unit offered several forms of support at the time of diagnosis. Most persons were offered information and educational support, both for themselves (90.1%) and their family members (78.9%). Contact with a dementia nurse, counsellor, or needs assessor was offered to approximately half of the sample (49.3%, 51.4%, and 47.9%, respectively), while cognitive aids were offered to less than a third (28.5%).

## 11.2. Factors influencing offered support at diagnosis (Study I)

Regression analysis (Table 5) showed that being diagnosed at a memory clinic, compared to primary care, was associated with a higher likelihood of being offered information and education for the person with young-onset dementia ( $B = -2.135$ ,  $p < .01$ ) and for family members ( $B = -1.567$ ,  $p < .01$ ), as well as being offered contact with a counsellor ( $B = -2.982$ ,  $p < .01$ ). Living with another adult similarly increased the odds of family members being offered information and educational support ( $B = -1.020$ ,  $p < .01$ ). Lower cognitive functioning ( $B = 0.075$ ,  $p < .05$ ) and already receiving home help ( $B = 1.466$ ,  $p < .05$ ) were each associated with a higher likelihood of being offered contact with a needs assessor. Age, sex, children living at home, accommodation, and number of medications did not significantly predict the offer of any support type.

**Table 5.**

*Predictors of offered support (Study I)*

<b>Variables</b>	<b>Support (person)</b>	<b>Support (family members)</b>	<b>Dementia Nurse</b>	<b>Needs assessor</b>	<b>Counsellor</b>	<b>Cognitive aids</b>
<b>Age</b>					+	
<b>Sex</b>					+	
<b>Children at home</b>	-- <sup>a</sup>				+	
<b>MMSE</b>				*		
<b>Medications</b>						
<b>Accommodation</b>					-- <sup>a</sup>	-- <sup>a</sup>
<b>Living with another adult</b>		**				
<b>Home help service</b>				*		
<b>Care setting</b>	**	**	-- <sup>a</sup>		**	+

<sup>a</sup> Predictor was collinear with the outcome, so it could not be included in the regression.

+  $p < .10$  \*  $p < .05$  \*\*  $p < .01$

### 11.3. Time to support (Study II)

At baseline (time of diagnosis), formal support was limited (Table 6). Only a small proportion already had home help services (7.7%), day care (2.3%), or resided in a care facility (4.6%). Contact with a counsellor had been offered to just under half of the sample (47.5%).

**Table 6.***Prevalence and timing of support services at baseline and follow-up (N=2592)*

	N	Valid per cent (%)	N	Valid per cent (%)	Mean days to first support
	Baseline		Follow-up		
<b>Counsellor</b>	1192	47.5	258	19.6	490
<b>Daycare</b>	59	2.3	653	26.5	775
<b>Home help service</b>	196	7.7	537	22.8	856
<b>Care facility</b>	118	4.6	280	11.3	996

*\* For counselling, the baseline variable only indicates whether contact was offered. Therefore, the value from the first follow-up, which records established contacts, was used in place of the baseline value.*

During follow-up, the proportion receiving support increased considerably across all support service types (Table 6). Home help services were obtained by a proportion of the sample (22.8%), as was day care (26.5%), counsellor contact (19.6%), and care facility (11.3%). Although substantial time passed from diagnosis to first support, once one service was initiated, others tended to follow within a relatively short period. Counselling was accessed earliest, followed by day care, home help, and care facility.

#### 11.4. Factors influencing time to support (Study II)

Cox proportional hazards regression (Table 7) showed that living with another adult was associated with later access to home help (HR = 0.689,  $p < .001$ ), day care (HR = 0.787,  $p = .010$ ), and care facilities (HR = 0.641,

p<.001), compared to living alone. Higher MMSE scores showed a similar pattern, with higher cognitive functioning associated with later access to home help (HR = 0.952, p <.001), day care (HR = 0.949, p <.001), and care facilities (HR = 0.946, p <.001). For day care specifically, older age (HR = 0.976, p=.023) and diagnosis in primary care (HR = 0.684, p=.016) were additionally associated with later access. Sex and medications were the only variables not significantly associated with the timing of any of the examined support services.

**Table 7.**

*Factors associated with time to support services (Study II)*

<b>Variables</b>	<b>Home help service</b>	<b>Care facility</b>	<b>Counsellor</b>	<b>Daycare</b>
<b>Older age</b>				Later*
<b>Female sex</b>				
<b>Higher MMSE score</b>	Later**	Later**		Later**
<b>Higher number of medications</b>				
<b>Living with another adult</b>	Later**	Later**		Later*
<b>Diagnosed at primary care</b>				Later*

*Later = associated with later access to support. \*p < .05 \*\*p < .01*

## 11.5. Negotiating independence and support in daily life (Study III)

Young-onset dementia deeply affected couples by forcing adjustments in routines and relationship dynamics. Partners gradually assumed greater responsibilities for daily tasks, reflecting shifts in roles within the relationship, while persons with young-onset dementia described wanting to remain active and contribute meaningfully. Although both partners shared the goal of preserving independence and balance in the relationship, navigating this shift was emotionally demanding for both. Partners worried about taking on too much, while persons with young-onset dementia sometimes felt their remaining abilities were underestimated, even when support was well-intentioned.

The tension between support needs and the desire to maintain independence also influenced major life decisions. Where couples chose to live or whether to proceed with a planned move was affected by the availability and reliability of support. Some relocated to access better services, while others postponed or cancelled plans due to uncertainty about the support available elsewhere. Employment was another area affected by the need to provide support. Partners described reducing work hours or leaving employment entirely to offer support without pay, which caused financial stress. Adjusting to a single or reduced income affected daily routines and decisions, negatively impacting household finances and increasing the strain of daily life.

Informal support from family was described as taking place within existing routines and relationships, rather than something additional or sought. Informal support was easier to integrate into daily life. At the same time, couples reflected on its limits. While it was often easier to integrate family support, relying on family members raised concerns about boundaries and created ambivalence in seeking help. Support from friends was described as both supportive and challenging in daily life. Staying in touch with friends helped preserve a sense of normalcy. At the same time, couples described how friendships could become strained when the changes related to the condition were hard to explain or understand, leading to feelings of distance or misunderstanding.

## 11.6. Navigating complex systems in search of adequate support (Study III)

Couples described navigating and using formal support in daily life as deliberate choices rather than the automatic uptake of available services. Support was evaluated based on how well it fit into their daily lives, including their mutual routines. When support was perceived as fitting in daily life, it was described as helping daily life function. When it felt intrusive or poorly aligned with daily life, support was limited or declined.

Navigating municipal support was challenging because there was limited information on how support was organised and how to access it. Access to support was also described as depending on knowing what to ask for and when, which was difficult given the couple's limited prior experience with formal support systems. The couples also reported being promised coordinated support but ultimately having to manage on their own. There was no clear contact person to turn to, and each new professional seemed to start from scratch without shared tools or guidelines.

Alongside navigating available support, couples explained that their use of formal support services depended on whether they felt these services were tailored to their needs. Day care and group activities were sometimes poorly suited to the couple's age or interests, particularly when they focused on low-energy activities or unstructured socialising. Couples favoured activities based on shared interests over those connected to a shared diagnosis. Encounters with more advanced stages of dementia in these settings also lessened their willingness to participate due to feelings of alienation.

## 11.7. Experiencing a balance between expectations and daily support (Study III)

While couples recognised challenges in navigating support systems, they also described a sense of balance when support aligned with their daily lives and current circumstances. It was not the amount of support that mattered most, but whether it matched their stage in the condition and their sense of

independence. For some, life felt stable and manageable to the point where further support seemed unnecessary or even abstract.

The quality of interactions within support contexts was sometimes more important than the practical support itself. Being treated with warmth and as part of a shared effort fostered trust and a sense of belonging. Especially, memory clinics were seen as stable, familiar contacts where couples felt comfortable asking questions about support. Reassurance also came from simply knowing that support would be available if needed - not from constant contact, but from a quiet confidence that support could be accessed if circumstances changed.

*Study IV* explored how couples with young-onset dementia interacted with formal support systems over 18 months through repeated dyadic interviews. The analysis identified three distinct patterns of engagement. Couples' interactions with support were not uniform but shifted over time as circumstances and needs changed. While couples maintained relatively consistent contact with memory clinics, which offered regular follow-up and ongoing support, their interactions with municipal support services were more varied.

### 11.8. *Keeping formal support at a distance (Study IV)*

This pattern describes couples who maintained a consistently low level of interaction with formal support systems throughout the study period. These couples did not pursue further services after their initial contact, either because the couples felt the support provided by the memory clinic was sufficient and they did not need additional services, or because they believed the existing services would not meet their needs. Others had been promised support that never materialised, and instead of following up themselves, the couples continued waiting for someone to make contact. Even when they were uncertain about future needs, they did not actively seek additional guidance. In either case, this led to a lack of further interaction with formal support.

Some couples also perceived the available services as unsuited to their life situation and believed that appropriate support would never be granted, which prevented them from exploring possible options. In other cases, when a contact person left, couples did not look for a replacement but instead waited to be approached, causing the process to stall.

### **11.9. *Trying to connect, but stepping back over time*** ***(Study IV)***

There were those couples who initially sought formal support but did not pursue further contact after their first attempt. Their early efforts to engage with support systems failed to provide meaningful support, and the services offered did not match their needs. For instance, couples tried home help but found that it did not fit their daily routines, or the person with young-onset dementia attended day care, which turned out to be designed for older adults and held little meaning for them. In one case, psychosocial support provided to the partner to reduce caregiving strain was discontinued because it became hard to prioritise alongside other responsibilities. When the support was insufficient or seemed irrelevant, couples decided not to pursue further contact, believing that the available resources could not meet their needs. This led to disengagement from ongoing support.

### **11.10. *Persisting in seeking support despite obstacles*** ***(Study IV)***

Couples who continued seeking formal support often found themselves navigating the system even when services seemed unavailable or insufficient. When one option was no longer available, they looked for alternatives to keep the process moving, driven by the need for practical solutions when service providers offered none. As the couple's need for support grew, access to support became more difficult; what had initially seemed simple requests turned into lengthy, confusing procedures with unclear responsibilities and slow decision-making. Couples frequently had to follow up with municipal services, only to experience slow or stalled progress. This lack of relevant support led them to explore different

approaches, even if it meant re-engaging with services they had previously tried, this time with an adapted approach, hoping for a different result. Despite these obstacles, couples continued interacting with formal support systems. Although they recognised the importance of staying involved, they also found it exhausting and challenging to maintain this level of engagement. Their ongoing efforts were not driven by choice but by the necessity to secure the support they urgently needed. Persistence could sometimes lead to change, such as when repeated requests eventually led municipalities to organise age-appropriate activities. Yet such outcomes required sustained advocacy over time, illustrating that while change was possible, the burden of making it happen fell on the couples themselves.

## 12. Discussion

This thesis aimed to explore and describe support for persons living with young-onset dementia and their partners, and to examine how this support is experienced and adapted over time. Drawing on findings from four studies, the discussion addresses what support is available, how couples navigate it, and how both provision and experiences change over time. Although the sections address distinct aspects of support, they are deeply interconnected in the everyday lives of couples living with young-onset dementia. Finally, methodological considerations are addressed.

### 12.1. Support as a relational and dyadic phenomenon

#### 12.1.1. *Shifting responsibilities and negotiating support*

While previous research has often focused on the person with young-onset dementia or the partner, the findings of this thesis highlight support as something continuously shaped within the couple relationship. The findings show how couples negotiate support and autonomy in daily life, how the

partner to the person with young-onset dementia risks becoming invisible to formal support services by taking on increasing responsibilities, and how family members beyond the household may also be overlooked.

Couples described how daily tasks became sites of negotiation between support and autonomy, reflecting a continuous effort to maintain their shared lifeworld while adapting to new circumstances. Persons with young-onset dementia sometimes felt their remaining abilities were underestimated, even when support was well-intentioned. This is consistent with Bannon et al. (2021), who found that perceived overprotective behaviours often created tension despite being intended positively. This resonates with the concept of couplehood described by Hellström et al. (2005), and aligns with previous research showing that balancing support and independence is a central challenge for couples living with young-onset dementia (Bannon et al., 2022; Wang et al., 2026). While couplehood as a relational dynamic may be universal across age groups living with dementia, the practical consequences of role shifts are likely more complex in young-onset dementia, where multiple ongoing responsibilities such as employment and parenting may still be present (Gelman & Rhames, 2020; Kokorelias et al., 2024). When couples negotiate whether one partner can handle finances, cook, or drive to appointments, these are not only matters of practical tasks but also negotiations embedded in the couple's lifeworld. In this space, shared meaning and identity are created, and daily activities within it hold emotional and relational significance beyond their practical function (Habermas, 1987).

Registry data showed that persons with young-onset dementia living with another adult accessed both home help services, day care, and care facilities later than those living alone. The qualitative findings shed light on why this might happen. Couples described how responsibilities had shifted within the relationship, with partners taking on practical tasks, and support was sometimes actively declined to maintain everyday routines and independence. In Sweden, spouses are also legally obligated to support one another (SFS 1987:230), which may further reinforce partners' tendency to absorb responsibilities before seeking formal support. Beyond legal obligations, research suggests that partners of persons with dementia often want to provide support themselves, motivated by love and commitment to the relationship (Shiff et al., 2025). This desire to support each other is a natural part of close

relationships and should be taken into account when interpreting patterns of delays in accessing support. When partners compensate for declining abilities in this way, the couple may seem to be coping from the outside, even when the caregiver burden is already significant. Family members of persons with young-onset dementia describe daily life as fundamentally disrupted and burdensome (Helvik et al., 2024). Family caregivers of persons with dementia have been described as “the invisible second patients” (Engel et al., 2022), and this dynamic may be particularly relevant here. The more a partner absorbs, the less visible the couple's actual situation becomes to a system that operates independently of their lived experience, potentially delaying support until the situation has reached a critical point.

### *12.1.2. Extending support beyond the couple*

The concept of the “invisible patient” may extend beyond the partner to include the family as a whole. Children living in the household represent an additional layer of responsibility and complexity for the family (Gelman & Rhames, 2018). Yet in the findings, their presence did not increase the likelihood of any type of support being offered, suggesting that formal support services do not systematically respond to the needs that children may represent. Like the co-residing partner, children may absorb responsibilities informally while remaining invisible to the support system, a pattern consistent with research showing that children of persons with young-onset dementia often take on informal caring roles without receiving adequate support (Groennestad & Malmedal, 2022). Although minor children were not the main focus of this thesis, these findings highlight a gap that warrants further research and targeted interventions, particularly given that professionals report limited preparedness to support them (Tyrrell et al., 2024). At a minimum, the presence of children in the household should be a signal to formal support services to proactively offer information and education to the family.

Persons living alone in Study I were also less likely to have information and education being offered to family members, suggesting that those without a co-residing partner may be at risk of their wider family network being overlooked. Family members not living with the person with young-onset dementia may still carry significant responsibilities while also feeling

powerless to influence the situation (Aspö et al., 2023). Care providers should therefore more often include family members beyond the household when offering information and education at diagnosis, especially if the person with young-onset dementia lives alone. This is important because family support was described in the interviews as a key factor in keeping daily life manageable. When the wider family is not reached with information and education, they may be less equipped to provide this support, and the responsibility may ultimately fall back on the co-residing partner. High caregiver burden has previously been linked to earlier institutionalisation (Bakker et al., 2013). Hence, when the wider family is included and supported, responsibility may be shared more evenly, helping the co-residing partner avoid becoming overwhelmed and supporting the person with young-onset dementia in remaining at home for longer.

These insights highlight the importance of providing support that recognises the couple as a shared unit while remaining attentive to each partner's individual needs and autonomy, as the couples may not always share the same perspective on the person with young-onset dementia's capacities. While role shifts within the couple may be an inevitable part of living with young-onset dementia, formal support can help by reducing the extent to which partners must shoulder responsibilities alone. For example, Larochette et al. (2020) developed a couple-focused programme for caregivers of persons with young-onset dementia addressing acceptance, role transitions, and couple dynamics, which showed positive effects on well-being, coping and communication. Future research should explore how such interventions can be further developed and tested, including how to more fully involve the person with young-onset dementia in the process.

## 12.2. Timing and trajectories in support use

### 12.2.1. *Patterns of engagement with formal support over time*

The findings suggest that couples follow different trajectories in their interactions with formal support, and that the timing and quality of support may shape these trajectories in important ways. Three distinct patterns were identified: some couples maintained minimal contact with formal support

throughout the 18-month period, others initially engaged with services but then withdrew, and a third group persisted in interacting with formal support despite obstacles. These categories are not fixed; they are fluid processes. A couple with little contact with formal support now might seek help later, and how the first encounter unfolds can determine whether they stay engaged or withdraw entirely from the system.

Neugartens (1970) concept of off-time events helps explain why timing is so central to these patterns. Young-onset dementia disrupts typical life stages, when dependency and formal support are not usually expected. Because the diagnosis occurs off-time, neither the couples nor support systems have a social clock that accounts for when support becomes relevant. Couples may not identify a need for formal support, and professionals may be unsure when to intervene. This may be reflected in the registry data. Once one support service was initiated, others tended to follow within a relatively short period, consistent with Cations et al.'s (2017) description of a snowball effect of service use, in which engagement with one service improved access to the next. Together, this suggests that the timing of the initial support might be a key threshold rather than a gradual progression.

### *12.2.2. Invisibility within the system*

For couples who initially sought support but gradually stepped back, early encounters with the system shaped what followed. What often appeared to trigger withdrawal was the system's difficulty in responding to the couple's life world. They withdrew not because they had no needs, but sometimes because what was offered did not fit their circumstances. Dementia research has found that first service encounters are crucial for ongoing engagement with support systems (Stephan et al., 2018), and research specifically on young-onset dementia shows that negative service experiences can reduce willingness to engage further (Cations et al., 2017). Therefore, reconnecting with these couples requires more than simply offering the same support. It requires understanding what went wrong in the first place.

Couples who maintained minimal contact were not necessarily struggling; some managed well and felt that support was not yet needed, trusting that help would be available if circumstances changed. Research highlights that this is

common, as persons with dementia and their families often do not seek help themselves, either because they are reluctant to bother professionals or because they do not recognise their own needs (Bamford et al., 2021).

Couples who withdrew after initial attempts to engage, as well as those who held back in the hope that the promised follow-up would materialise, risk becoming invisible to the system. Once they step back, without follow-up, the system has few ways to know whether their needs have changed. For those maintaining minimal contact, the risk is similar: when couples do not actively seek contact, the system may interpret this as a lack of need, further reinforcing their invisibility. When current support systems tend to be reactive in times of crisis rather than proactive in preventing them (Quinn et al., 2025), these couples may therefore drift out of the system's awareness until a crisis occurs.

Paradoxically, some might argue that the off-time nature of young-onset dementia justifies a cautious approach to early support. Accepting help too soon may itself reinforce the sense of being off-time, confirming that something is happening that should not yet be happening. However, it is precisely because young-onset dementia occurs off-time, for both couples and the municipal support system, that proactive contact is even more important, not less. Ideally, timing in support should align with the couple's life worlds, responding to needs as they emerge rather than following rigid administrative schedules. Since predicting when needs will shift for each couple is impossible and there are no clear reference points for when support becomes relevant, waiting can cause a gap between what the system offers and what couples actually need. Closing this gap requires rethinking what proactive support means in practice, not as imposing help but as establishing a connection before needs escalate. Developing instruments specifically designed to assess the support needs of persons with young-onset dementia may also help close this gap, as such tools are currently lacking (Kim et al., 2024). The Swedish standardised intervention pathway for dementia (the National Board of Health and Welfare, 2019) emphasises that the right support should be provided at the right time and that interventions should be adapted continuously throughout the course of the condition. Yet to provide support at the right time, the system needs to follow couples as their needs evolve, and to do that, a connection must first be established.

Low-threshold support accessible without a formal needs assessment (Hochgraeber et al., 2017) may offer a practical means of establishing such early connections, both as an entry point for couples who have not yet engaged in the support system and as a way to maintain contact with those who have stepped back from it. The new Swedish Social Services Act (SFS 2025:400) recognises such support by explicitly enabling municipalities to provide certain interventions without prior individual needs assessments, with the aim of reaching people earlier and preventing more extensive needs from developing. For persons with young-onset dementia, accessible and responsive services of this kind have been shown to be particularly valued (Stamou et al., 2022).

### *12.2.3. Gaps in follow-up and the burden of navigation*

For couples who persisted in navigating the system (IV), the challenge was different. Their persistence kept them visible to the system, but at a great personal cost. Those who persisted in seeking support over time often found the process difficult to navigate, particularly once responsibility shifted from memory clinics to municipal services. Securing relevant support remained fragmented and slow, leaving couples to maintain continuity largely on their own. Drawing on Habermas's (Habermas, 1987) distinction between the lifeworld and the system, this persistent navigation can be understood as a form of colonisation. Notably, it was not the support itself that colonised the couple's daily life, but the process of seeking it. The repeated explanations, stalled processes and unresolved responsibilities came to occupy the space that support was meant to free up.

A key question is whether current support systems provide sufficient regular contact to identify evolving needs before they escalate. Study II found that Swedish memory clinics generally maintained consistent follow-up, with an average of 14 months between contacts, aligning with international findings from specialised dementia settings (Loi et al., 2021). Sweden's standardised care pathway for dementia (The National Board of Health and Welfare, 2019) recommends continuous follow-up throughout the course of dementia, and the qualitative findings confirmed that couples experienced memory clinics as a source of regular contact, suggesting at least reasonable alignment with this recommendation. However, this consistency did not extend to municipal

services. Couples described being promised contact that never materialised, leaving them uncertain about whether to reach out themselves or keep waiting. Together, Neugarten's (1970) concept of off-time events and Habermas's (1987) distinction between the system-world and the lifeworld help explain this discrepancy. Both memory clinics and municipal services operate within system-world logic, following administrative timelines and standardised criteria for follow-up. The quantitative findings showed that the vast majority of persons with young-onset dementia were diagnosed within specialist care. Combined with qualitative findings showing that memory clinics provided regular follow-up, while municipal services often failed to make contact. Together, this suggests that memory clinics encounter younger persons with dementia far more frequently than municipal services, making young-onset dementia a more on-time event within their system. For municipal services, young-onset dementia represents a more off-time challenge, for which they are rarely structured or resourced for.

Without proactive follow-up, the system risks reinforcing the very things it should prevent. However, proactive follow-up and low-threshold support become insufficient if the support offered is unsuitable or inaccessible. A couple who are contacted multiple times but receive services not tailored to their needs have not truly been supported. They have simply been reminded that the system has nothing suitable for them. This brings us to a broader challenge: the system-level disparities and fragmentation within the Swedish support system.

## 12.3. System-level fragmentation and structural gaps

### 12.3.1. *The absence of tailored support*

Couples living with young-onset dementia may face several barriers when seeking formal support. Receiving support at a stage of life when dependency is not expected can in itself be threatening, as it may conflict with the person's sense of identity and social expectations of capability at midlife (Tang et al., 2023). Couples described how support was actively evaluated and sometimes declined when it felt intrusive or poorly aligned with their daily lives and sense of independence. If the support offered is also not tailored to their life

situation, these feelings may be further reinforced, making it even harder to engage with available services. When the system offers support that does not fit the couple's lifeworld, it risks doing two things at once: confirming that something is happening off-time, while failing to address what is actually needed. This may partly explain why, despite reporting high levels of burden, persons with young-onset dementia and their informal caregivers underuse formal community services, often because services do not meet their personal and psychological needs (Cations et al., 2017).

The findings of this thesis suggest that a key reason why services fail to meet the needs of couples living with young-onset dementia is that they are rarely designed with younger persons in mind. Although the findings showed that a large majority of both persons with young-onset dementia and their families were offered informational and educational support, the registry data do not reveal what this information included or if it was directed towards younger persons. Earlier studies indicate that information resources for persons with young-onset dementia tend to focus on older adults rather than on age-specific needs of younger persons, such as employment rights and financial benefits (Jones et al., 2018; Novek & Menec, 2023). It therefore remains unclear whether high rates of information provision translate into meaningful support for persons with young onset dementia and their families. This highlights the need to review existing information and educational resources to assess whether they meet the specific needs of persons with young-onset dementia and their families.

Another area where this thesis's findings point to shortcomings is daycare. According to Swedish national guidelines, day care should foster social interaction, structure, and meaningful activities during the day for the person with dementia, while simultaneously improving the situation of family members (The National Board of Health and Welfare, 2017). For couples living with young-onset dementia, day care serves a dual purpose. Meaningful activity outside the home helps the person with young-onset dementia feel useful, while simultaneously creating space for the partner to continue their own work and sustain their own identity (Roach et al., 2016). However, available day care was described as poorly suited to the person with young-onset dementia's interests, especially when focused on low-energy activities or unstructured socialising. Additionally, encounters with more advanced

stages of dementia in these settings further reduced willingness to participate. Similar findings have been reported internationally, with persons with young-onset dementia frequently encountering support services designed for older adults, leading to reluctance to participate (Giebel et al., 2020; Novek & Menec, 2023; Stamou et al., 2022; Wang et al., 2026). Meaningful activities should provide a sense of purpose and an opportunity to contribute, rather than passive participation (Stamou et al., 2024). Without age-appropriate alternatives, participation can become isolating and distressing (Quinn et al., 2025), yet despite national guidelines recommending age-appropriate day care services for persons with young-onset dementia, only 20% of municipalities in Sweden provide them (The National Board of Health and Welfare, 2020).

Couples described preferring activities based on shared interests rather than shared diagnoses, suggesting that peer support is not always what is valued the most. Even so, persons with young-onset dementia have previously described peer support as one of the few contexts where they can express themselves freely without fear of judgment, finding understanding and practical advice among others with similar diagnoses (Wang et al., 2026). Together, these findings underscore that support needs to be individually tailored rather than based on assumptions about what younger persons want. In practice, this could mean that, instead of expecting all municipalities to create separate young-onset support services, other approaches are necessary. These might include municipal collaboration, in which smaller municipalities jointly offer age-appropriate services for persons with young-onset dementia who want to meet peers. For others, to develop more flexible activity-based day care focused on life stage rather than diagnosis. For example, day care could be tailored to younger persons on leave from work, offering meaningful activities and enabling them to participate alongside others without requiring diagnosis-specific settings. Either way, developing tailored support services for persons with young-onset dementia does not necessarily require completely new structures. Approaches such as establishing informal specialist networks across existing services or building cross-sector collaborations have been identified as potential starting points (Oyebode et al., 2024). Civil society organisations, in particular, have been highlighted as well-positioned to develop and pilot new forms of support, given their greater flexibility compared with public-sector services.

In Habermas's (1987) terms, this represents a way of allowing the lifeworld to inform the design of formal services, rather than expecting persons to adapt to a system built around the needs of older adults. Research shows that such involvement can reframe priorities and generate approaches that standard service models have not considered (Mayrhofer, Shaheen, et al., 2021). How such approaches can be developed and sustained, including greater engagement of civil society, remains an important question for future research. Regardless of the approach taken, previous research has shown the value of actively involving persons with young-onset dementia and their partners in shaping the support intended for them (Hutchinson et al., 2020; Mayrhofer et al., 2020).

Neugarten's concept of off-time events (1970) helps explain these gaps. Support systems are built around an implicit social clock that assumes dementia belongs to old age, when retirement and reduced activity are already expected. When dementia occurs off-time, the system has no ready response because it was never designed with young-onset dementia in mind. This is not simply a gap in provision but a structural mismatch between the life situations of persons with young-onset dementia and the logic on which services are built. Support systems are, in other words, not poorly designed by accident. They reflect assumptions about when people become dependent, and young-onset dementia falls outside those assumptions entirely. This has concrete implications: if support systems continue to operate around an on-time logic, persons with young-onset dementia will remain structurally invisible, not because their needs are lesser, but because the system was not fully built to see them.

The off-time assumption of retirement also shapes the broader welfare system, with consequences that reach far beyond the provision of social services. Partners of persons with young-onset dementia often face an impossible dilemma: the need to reduce working hours for care conflicts directly with the financial pressure caused by the person's lost income. In the interviews, couples described how an already strained household economy worsened when partners also had to reduce or leave employment, yet no formal economic support was available to bridge this gap. This aligns with wider evidence indicating that persons with young-onset dementia and their families frequently identify the need for financial support but find it largely unavailable

(Wang et al., 2026). The result is a structural contradiction where those who need to work less feel compelled to work more, while the welfare system remains largely unresponsive to this dilemma. Addressing this gap is not primarily a matter of social services but of social insurance. Existing welfare benefits, such as the 'benefit for care of a close relative', are designed for short-term care and offer limited protection when partners of persons with young-onset dementia need to reduce working hours over extended periods. Expanding such provisions, or introducing new forms of financial support for partners, could help close this gap.

Offering support is only meaningful if there is actually something relevant to offer. Sweden's standardised intervention pathway for dementia (The National Board of Health and Welfare, 2019) emphasises that support should be tailored to individual needs (person-centred care). Yet, professionals can recognise needs, make contact, and encourage interaction, but if the available support does not address the specific challenges of young-onset dementia, the offer becomes hollow. The findings of this thesis showed that couples who declined services were not refusing support; they were simply declining support that did not fit their lifeworld. The responsibility, therefore, does not only lie with couples to interact or with professionals to offer. It also rests with the broader welfare system to ensure that there are offers that meet the couple's needs. Without tailored support, even the most well-intentioned efforts fall short, leaving couples to cope within a support system not designed for them.

### *12.3.2. From fragmentation towards coordinated support*

Beyond the challenges of proactive follow-up previously described, couples encountered a lack of an integrated support system. This was visible both between memory clinics and municipal services and within the municipal system itself, where different professionals were responsible for different types of support without consistent coordination. In Habermas's (1987) terms, healthcare and municipal support systems operate as separate systems within the system-world, each following its own procedures and budgets. Regions and municipalities are required by law to collaborate in matters concerning individuals who need services from both healthcare and social care (SFS 2001:453; SFS 2017:30). This structural fragmentation is not unique to Sweden. In Ireland and the UK, persons with young-onset dementia have

described how healthcare professionals failed to provide basic next steps or connect them to social support following diagnosis, causing confusion and making it difficult to access appropriate services (Wang et al., 2026). In Canada, families have similarly described navigating a fragmented support system in a continuous, demanding manner (Novek & Menec, 2023).

In the Swedish context, this fragmentation is visible at the system level. At the time of diagnosis, the link between memory clinics and municipal support is not always routinely established. Only half of the persons with young-onset dementia were offered contact with municipal professionals at the time of diagnosis, indicating that while memory clinics recognise persons with young-onset dementia as on-time within their own system, they do not consistently connect them to municipal services. This may partly reflect a reasonable assessment that municipal support is not yet needed at the time of diagnosis. However, it could also leave couples to navigate the transition to municipal services on their own once needs do increase, without clear guidance on how to access relevant support.

The qualitative findings revealed what this looks like in practice. Couples described having to navigate different support providers, with different professionals responsible for different types of support that were not always well coordinated with one another, and where even promised contacts or support never materialised, leaving them to piece together support on their own. This lack of coordination caused confusion, forcing couples to repeatedly explain their situation and needs to multiple providers. The result is a broken chain: healthcare settings do not consistently connect couples to municipal support early in the dementia trajectory, and even when connections are made, municipalities sometimes fail to follow through. Furthermore, couples were uncertain about who was responsible for each support type and which professional or service they should contact to advance the process. Sweden's national standardised intervention pathway for dementia (The National Board of Health and Welfare, 2019) was developed to address this problem precisely by providing a framework for coordinated support across healthcare and social services. However, the qualitative studies suggest that such frameworks are rarely experienced as consistently implemented in practice. This challenge is not unique to young-onset dementia. Studies on dementia more broadly show that poor coordination among care and support

providers is a persistent problem, and that unclear divisions of responsibility often hinder continuity of care (Österholm et al., 2023).

At its core, the problem is this: memory clinics offer structured follow-up, but cannot provide support, while municipalities are obligated to provide support but lack organised follow-up. Each operates within its own system-world logic, and neither has a social clock for young-onset dementia. It is this fragmentation that couples may encounter. Addressing this fragmentation requires not only better coordination but also rethinking how support is tailored and delivered.

Sweden is currently undergoing several policy developments relevant to the challenges identified in this thesis. The transition towards person-centred and integrated care aims to bring support closer to individuals through changed ways of working (2025:400), #687), implemented in July 2025, introduces a requirement for a designated contact person for those receiving home help services and strengthens the obligation to provide support to informal caregivers of long-term ill relatives. Together, these developments reflect a policy direction consistent with the needs identified in this thesis. Whether these policy developments will ultimately benefit couples living with young-onset dementia in practice remains to be seen.

Couples described clearer pathways and more consistent follow-up from memory clinics compared to municipal services. However, such reliance may risk creating a false sense of security. Couples felt reassured that the memory clinic would help them access other support when needed echoing international research showing a high trust in memory clinics. (Stamou et al., 2021). Even so, memory clinics are most often limited to medical follow-up and counselling. They cannot provide the formal support that becomes essential as dementia progresses. Such support, including daycare, home help and respite care, falls under municipal responsibility (SFS 2001:453). The findings therefore suggest that no single provider is currently well positioned to serve as a comprehensive coordinating hub. However, building on the trust relationships that memory clinics have already established with couples may offer a more realistic starting point than creating entirely new structures.

Like several other countries, Sweden has established extensive national frameworks for dementia care (Socialdepartementet, 2025; The National

Board of Health and Welfare, 2017, 2019). However, coordination challenges that undermine continuity and trust in dementia support systems have likewise been reported internationally (Abrams et al., 2024; Kern et al., 2024). An important difference is that countries such as the Netherlands (Bakker et al., 2022) and Australia (Cations et al., 2021) have developed specialised care pathways, including case management models for young-onset dementia, that Sweden currently lacks. Case management involves a dedicated professional who serves as a stable point of contact and coordinates support across providers. The findings of this thesis suggest that introducing coordinated support models, such as contact persons or case managers, could help ensure that couples receive timely and relevant support without having to navigate the system on their own. In Sweden, municipalities employ dementia nurses who could potentially serve this coordination function, provided they are given adequate resources and sufficient time.

## 12.4. Methodological considerations

### 12.4.1. *Validity and reliability in the registry studies*

Emilsson et al. (2015) define validity in quality registries as “the extent to which the registry reflects the real world of patients and healthcare in a given area” and emphasise the importance of completeness, coverage, timeliness, and comparability. The national registry SveDem covers all memory clinics and a majority of primary care units in Sweden (SveDem, 2024) and uses standardised data collection, ensuring consistency in data recording across the country. At the same time, not all persons with young-onset dementia are included in SveDem, as those diagnosed within primary care are less likely to be registered. Additionally, even when units participate in SveDem, it is not known to what extent all persons diagnosed with young-onset dementia at those units are actually registered. It is also worth noting that SveDem did not reach full coverage of memory clinics until 2014, meaning that registrations from the early years of Study II, which begins in 2009, may be less complete. Persons with young-onset dementia are mainly diagnosed in specialist care, and since SveDem covers all memory clinics in Sweden, this is a key strength of the registry data used in this thesis. Validity can therefore be considered strong within specialised dementia care, but more limited when applied to primary care centres. This is an important advantage over registry data on older persons with dementia, who are more often diagnosed in primary care, where registry coverage is less complete.

SveDem has been criticised for not including patient-reported outcome measures (PROMs) or patient-reported experience measures (PREMs), which means that persons’ own perspectives on support and care are not directly reflected in the registry (Religa et al., 2015). The lack of such measures further limits the validity of registry-based analyses when the research focus is on

experiences or perceived adequacy of support. This limitation is one reason why this thesis combines registry data with qualitative interviews, as these two approaches explore different aspects of support and complement each other by capturing both structural aspects and lived experiences.

Reliable registry data requires clear data definitions, standardised guidelines, and training (Arts, 2002). SveDem provides clear data definitions through predefined variables and a registration manual (SveDem, 2022) with standardised guidelines on when and how data should be entered. Training is offered to clinicians registering data, which supports reliability. Reliability was further supported by continuous communication with the registry administrator, providing a deep understanding of the dataset, including how variables were defined, adjusted over time, and used in practice. This informed the selection and interpretation of variables, thereby reducing the risk of misinterpreting registry data. However, missing data remain a limitation, and some variation in registration practices between clinics is also likely, which may partly reflect the time-consuming nature of registry work alongside other clinical duties (Lannering et al., 2017). This is particularly relevant in primary care, where SveDem is one of several competing registers used by clinicians, which may affect data entry consistency and completeness. In addition, several variables describing support were simplified, most often as dichotomous yes/no categories. The registry data indicate whether support was offered/provided, but not how extensive the support was or how it was experienced. This limits the level of detail that can be examined and needs to be considered when interpreting the findings.

Study I was further limited by its relatively small sample size, which reduced statistical power, whereas Study II benefited from a larger cohort and a longitudinal design. Right censoring is a characteristic limitation of survival analysis (Turkson et al., 2021). In study II, this means that persons who had not received support by their last registry entry may have received it later. Additionally, SveDem follow-ups may not capture the exact timing of support provision, which limits timeliness and constitutes interval censoring, making it difficult to determine exactly when support was received. Variables in SveDem change over time, which may improve data quality for clinical purposes but affects comparability, as data from different time periods cannot

always be compared in a straightforward way. This was particularly relevant in Study II, which spans 13 years. Across both registry-based studies, unmeasured factors such as socioeconomic resources or municipal differences in service provision may also have influenced the results. Unmeasured confounding is an important limitation in observational studies based on healthcare databases (Nørgaard et al., 2017), and should be considered when interpreting the findings. Despite these limitations, the registry-based studies provided a unique opportunity to examine support in a large, national cohort of persons diagnosed with young-onset dementia. The analyses were guided by supervisors with extensive experience in registry-based research and statistical methods, which strengthened the analyses approach and reduced the risk of systematic errors in data handling and interpretation.

#### *12.4.2. Trustworthiness of the qualitative studies*

Trustworthiness in the qualitative studies is addressed across four dimensions: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). The dyadic interview format strengthened credibility by capturing both partners' perspectives simultaneously. It also supported the person with young-onset dementia's memory and made communication easier than individual interviews would have. The repeated interviews over 18 months reflect prolonged engagement, a key strategy for credibility (Lincoln & Guba, 1985). This approach allowed for a deeper understanding of the couples' experiences over time and reduced the risk of superficial interpretations. At the same time, credibility was challenged by having both partners present, which may have prevented the discussion of sensitive topics. One partner dominating the conversation is also a known challenge in dyadic interviews (Szulc & King, 2022), and this occurred in some of the interviews. These dynamics may ultimately have influenced what was shared and what was left unsaid. Where one partner dominated, I directed questions to the other to ensure both perspectives were captured.

Thick descriptions of the research process and participants are considered a key strategy for supporting transferability (Lincoln & Guba, 1985). In the qualitative studies, participant descriptions were kept at a general level to protect confidentiality, which may limit readers' ability to fully assess the

transferability of the findings. Recruiting participants for the qualitative studies proved challenging, which affected the sample. Initially, inclusion required participants to have received their diagnosis within 3-6 months to capture early support experiences. However, due to recruitment difficulties, the criterion was later broadened, resulting in a sample with baseline time since diagnosis ranging from 6 months to 4 years. Consequently, interviews were conducted at various stages of dementia progression, as the initial interview did not provide a consistent starting point, with participants varying in both the time since diagnosis and cognitive functioning at recruitment. This may have affected participants' support experiences and should be taken into account when interpreting the results. The sample also consisted of couples willing to participate in joint interviews, which likely introduced self-selection bias. Couples with relational difficulties, language barriers or more advanced cognitive impairment may have been less likely to participate. This pattern is common in dementia research and is associated with an overrepresentation of resourceful or communicatively able participants (Bouranis et al., 2023). At the same time, the longitudinal design may have partially counteracted this bias. As the condition progressed, couples who remained in the study likely faced increasing challenges over time, meaning that the sample may have become more varied than it appeared at baseline. Persons without a co-resident partner were also excluded by design, as participation required that couples be living together. Together, these factors suggest that more vulnerable groups and situations where support is harder to access may be underrepresented in the sample. The sample was also drawn from a Swedish context, and the specific organisation of formal support in Sweden may limit the applicability of findings to other care and support systems. The findings should therefore be interpreted contextually, while still offering insights relevant to similar contexts.

Dependability refers to the consistency of the analytical process and ensuring it is in line with accepted standards for the research design (Lincoln & Guba, 1985). In the qualitative studies, dependability was maintained through a systematic and transparent analytical process. Transparency was supported by documenting each step of the analysis. In Study III, this process moved from meaning units through clusters to themes, illustrated through figures that allow readers to follow the analytical reasoning. In Study IV, the pattern-oriented

longitudinal approach (POLA) further supported dependability by allowing analysis of both within-case developments and cross-case similarities. Dependability was also enhanced by involving the research team in the analysis, where interpretations were discussed and refined throughout the process.

Confirmability was addressed through reflexive practices during the analysis, including conscious attention to how pre-understandings might influence interpretation. Quotations from the interviews were consistently used to anchor the findings in the couples' own words. The collaborative analytic discussions within the research team further enhanced confirmability, ensuring that results were not mainly based on the researchers' assumptions. Such reflexive engagement is considered essential for confirmability because it makes researchers' influence transparent and ensures that interpretations are anchored in the data. This was especially relevant in this thesis, as the first author's clinical background in dementia care provided valuable contextual understanding but also risked framing participants' experiences within familiar patterns rather than remaining true to what the couples themselves described (Berger, 2015).

# 13. Conclusion

This thesis aimed to explore and describe support for persons living with young-onset dementia and their partners, and to examine how this support is experienced and adapted over time. By combining registry studies with qualitative interviews and interpreting the results through Habermas's lifeworld-system-world distinction and Neugarten's concept of off-time events, the thesis offers both empirical insights and theoretical contributions to understanding support in young-onset dementia.

- Support is a relational and dyadic phenomenon, continuously shaped within the couple relationship. As partners assume greater responsibilities, couples may appear to be coping even when the caregiving burden is significant. Combined with a system that rarely reaches out proactively, this can create invisibility, with needs going unrecognised until they reach a critical point.
- How couples interact with formal support follows different trajectories over time. For some, an early encounter that does not meet their needs, or a promised contact that never materialises, can lead to withdrawal, which may be difficult to reverse, while those who persist in seeking support often do so at considerable personal cost.
- Available support is not always designed with younger persons in mind. Couples described declining services, not always because they rejected support as such, but because what was offered did not fit them, leading even well-intentioned support to fall short.
- Memory clinics provide trusted care and follow-up, but they cannot provide the practical support needed as dementia progresses. Meanwhile, municipal support lacks organised follow-up. This structural fragmentation causes couples to navigate the system without clear guidance, often uncertain who is responsible for what.
- Couples describe the financial consequences of young-onset dementia as inadequately supported by wider support systems. Partners who reduce or leave employment to provide care struggle to find a

financial safety net, adding financial strain to an already challenging period.

- These findings illustrate how Neugarten's concept of off-time events and Habermas's distinction between the lifeworld and the system world can deepen understanding of support for young-onset dementia. The off-time nature of young-onset dementia leaves both couples and support systems without a social clock to signal when support becomes relevant. At the same time, system-world logic often fails to respond to the couple's lifeworld, contributing to structural invisibility.

## 14. Implications and future research

The findings of this thesis indicate that the support system does not always take into account the needs of couples living with young-onset dementia. A need for change, therefore, emerges at multiple levels: in the conditions for practice, the organisation of support, and welfare policy priorities.

At the practice level, there appears to be a need for more structured ways to connect couples with municipal services at the time of diagnosis. Memory clinics often serve as a stable point of contact, yet this continuity does not necessarily extend to municipal support. Establishing clearer coordination routines may support a more consistent transition, though how best to achieve this remains to be investigated. One approach is the use of dedicated coordinators to support continuity both between and within services. In the Swedish context, this role could be integrated into existing professional functions. Exploring the organisation of support from a system perspective may be a first step towards identifying structural barriers and facilitators to such coordination.

Support systems need to recognise the couple living with young-onset dementia as a unit, as support directed to one partner also affects the other. Family members beyond the co-residing partner, including children, may also be at risk of being overlooked by formal support services. Further research is needed to better understand relational aspects and dynamics to inform the development of targeted support.

Available activities were not always experienced as meaningful for persons with young-onset dementia. This suggests a need to reconsider how such activities are organised, potentially through collaboration across municipalities or with civil society. Ways of organising activities that are not diagnosis-specific but instead built around shared interests and life situations could also provide a starting point for developing more relevant forms of engagement. Actively involving persons with young-onset dementia and their partners in the design of such services is likely to be central to ensuring that they meet the needs they are intended to address.

Low-threshold support emerges as a potential pathway into the support system, allowing couples to establish contact without undergoing a formal needs assessment. In light of recent policy developments, further research is needed to understand how such support is implemented and how it may influence access over time. Early encounters appear to play an important role in shaping following interactions with support, but there is a need to better understand how they can facilitate sustained access.

At the level of welfare policy, the findings draw attention to the financial consequences of young-onset dementia. Partners who reduce or leave employment to provide care currently have limited financial protection, pointing to a structural gap in existing systems. Addressing this requires greater policy attention, as well as research to understand the long-term economic impact on families and identify appropriate societal responses.

Finally, there is a need for longer longitudinal studies that follow couples beyond the 18-month period covered in this thesis. Such studies could deepen understanding of how support needs and interaction patterns develop as the condition progresses, and how the dynamics of both formal and informal support shift over time.

## 15. Svensk sammanfattning

Yngre personer med demenssjukdom är personer där symtom på demens debuterar innan 65 års ålder. Detta innebär ofta att diagnosen kommer i en livsfas som typiskt präglas av yrkesliv, familjeansvar och ett aktivt socialt liv, vilket skapar specifika behov och utmaningar som kan skilja sig från demens hos äldre personer. När en partner i en parrelation får en demensdiagnos påverkas båda och det gemensamma dagliga livet förändras i grunden. Trots ökande forskning inom området är kunskapen begränsad när det gäller hur stöd organiseras, erhålls och upplevs av par som lever med demenssjukdom i yngre ålder.

Det övergripande syftet med denna avhandling var att utforska och beskriva stöd för yngre personer med demenssjukdom och deras partners samt att undersöka hur detta stöd upplevs och anpassas över tid.

Avhandlingen bygger på fyra studier med både kvantitativa och kvalitativa metoder. Studie I och II använde data från SveDem, det svenska nationella kvalitetsregistret för demenssjukdomar. Studie I var en tvärsnittsstudie som undersökte vilket stöd som erbjöds vid diagnostillfället. Studie II var en longitudinell studie som undersökte faktorer som påverkar tiden till att få formellt stöd. Studie III och IV baserades på intervjuer med par där en partner hade fått en demensdiagnos innan 65 års ålder. Studie III undersökte hur par upplevde och använde stöd i det dagliga livet, medan Studie IV följde par under 18 månader för att undersöka hur deras erfarenheter av formellt stöd förändrades över tid.

Resultaten visade att de flesta yngre personer med demenssjukdom erbjöds information och utbildning vid diagnostillfället, medan ungefär hälften erbjöds kontakt med kurator, demenssjuksköterska eller biståndshandläggare. Att diagnostiseras vid en minnesmottagning, jämfört med på vårdcentral, var associerat med högre sannolikhet att erbjudas flera typer av stöd. Att bo tillsammans med en annan vuxen ökade sannolikheten att familjen erbjuds information och utbildning. Vidare visade resultaten att samboende och högre

kognitiv förmåga var förknippade med senare tillgång till hemtjänst, dagverksamhet och särskilt boende jämfört med de som bodde ensamma.

I parintervjuerna framkom att par som lever med demenssjukdom förhandlar balansen mellan stöd och självständighet i vardagen. Stöd uppfattades som mest meningsfullt när det passade in i parets dagliga liv och matchade deras aktuella behov. Att navigera det kommunala stödsystemet upplevdes som utmanande, med bristande information, otydlig ansvarsfördelning och avsaknad av en tydlig kontaktperson. Par beskrev hur de blivit lovade samordnat stöd, men i praktiken fick hantera mycket på egen hand. Dagverksamhet och gruppaktiviteter upplevdes ibland som dåligt anpassade till parets ålder och intressen. Minnesmottagningarna upplevdes däremot som trygga och pålitliga kontakter. Tre olika mönster av interaktion med formellt stöd över tid identifierades: att hålla formellt stöd på avstånd, att inledningsvis söka stöd men successivt dra sig tillbaka, samt att försöka fortsätta söka stöd trots hinder. För de par som drog sig tillbaka hade tidiga negativa erfarenheter av stödsystemet ofta varit avgörande, medan de par som fortsatte söka stöd beskrev det som utmattande att hålla processen i gång.

Sammantaget visar avhandlingen att stödet för yngre personer med demenssjukdom och deras partners i stor utsträckning är utformat utifrån äldre personers behov. När partners tar på sig ett allt större ansvar riskerar parets verkliga behov att osynliggöras. Fragmenteringen mellan minnesmottagningar och kommunala tjänster lämnar par att navigera i systemet utan tydlig vägledning, ofta osäkra på vem som ansvarar för vad. De ekonomiska konsekvenserna av demenssjukdom i yngre ålder är dessutom otillräckligt täckta, eftersom partners som minskar eller lämnar sitt arbete för att ge omsorg har begränsat ekonomiskt skydd. Fynden pekar på behovet av ett mer proaktivt, samordnat och individuellt anpassat stöd som erkänner paret som en gemensam enhet och som bättre möter deras behov.

# 16. Appendix 1 – interview guide

## **Interview 1**

Tell us what your daily life looks like.

Do you think that your daily life has changed since X was diagnosed?

Do you get any help or support from anyone else?

What healthcare contacts do you have?

What kind of health and social care do you receive? (Give examples, e.g. alarms, home help services, day activities, group meetings, counsellor support, etc.)

How are you involved in the care planning and delivery that is provided?

When in contact with healthcare professionals, what do you discuss?

Are you satisfied with the support you receive? Is that enough?

Have you received information about what support you can get? Have you received information about what support you are entitled to?

Do you lack support of any kind? What and why?

## **Interviews 2-4**

Tell us what your daily life looks like.

Do you think that your daily life has changed since we last met?

Do you get any help or support from anyone else?

Have you made any new healthcare contacts since we last met?

What kind of health and social care do you receive? (Give examples, e.g. alarms, home help services, day activities, group meetings, counsellor support, etc.)

How are you involved in the care planning and delivery that is provided?

When in contact with healthcare professionals, what do you discuss?

Are you satisfied with the support you receive? Is that enough?

Have you received information about what support you can get? Have you received information about what support you are entitled to?

Do you lack support of any kind? What and why?

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## Care and support for couples when one partner has young-onset dementia

Young-onset dementia refers to dementia with an onset before the age of 65, affecting people at a life stage when employment, parenting, and other responsibilities may still be central. This shapes the kinds of support that are needed. Formal care and support are often designed with older adults in mind, which can make it more difficult for younger persons and their families to find services that match their situation.

This thesis aimed to explore and describe support for persons living with young-onset dementia and their partners, and to examine how this support is experienced and adapted over time. It comprises four sub-studies that combine national registry data with dyadic interviews, including a longitudinal qualitative study that followed couples for 18 months.

The registry studies showed that most persons with young-onset dementia were offered information and education at diagnosis, while professional contacts were offered less consistently. Persons living with another adult accessed formal support later than those living alone. The interview studies showed how support was continuously shaped within the couple relationship, with partners gradually taking on greater responsibilities, and how couples actively navigated and evaluated support in daily life. Over time, couples followed different trajectories in their interactions with formal support, some withdrawing while others persisted despite obstacles. Together, the findings point to a need for coordinated, age-appropriate, and proactive support that recognises couples as a shared unit while remaining attentive to each partner's needs.



FANNY KÅRELIND has a bachelor's degree in nursing and a master's degree in gerontology, both from Jönköping University. Fanny Kårelind conducted her doctoral studies in health and care science at the Research School of Health and Welfare at Jönköping University. Her research focuses on care and support for persons with dementia, with a particular interest in formal and informal support for couples living with young-onset dementia.

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