A rapid review of models of care and pathways for people with young onset dementia

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Executive Summary

Background

Young-onset dementia (YOD), with symptom onset prior to age 65 years, affects 28,000 people and their families in Australia. Pathways to access services for diagnosis and after diagnosis of YOD are disparate because YOD sits at the intersection of health, disability, and aged sectors. People with YOD wait too long for support, are offered services which are not age-appropriate, and fall through the gaps of these services.

As part of a larger consortium project to address this problem, this rapid review identifies models of support and systems of care for people with YOD and their families that exist internationally.

The overall question for the rapid literature review was:

> *What models of support and systems of care can be identified in Australia and internationally for people living with young onset dementia and their families?*

Data will be used by the Joint Solutions consortium to inform development of a fully described system of care for young onset dementia from diagnosis through to palliative care, with a road map of responsibilities that outlines services that should be available at particular points along the disease pathway.

Included literature

Nineteen peer-reviewed research studies that described models of YOD care were identified from a literature search, and an additional eleven documents were identified from grey literature sources. Of these:

- Eleven articles described a model or system of YOD care without evaluating it
- Nineteen articles both described and reported results of an evaluation of a model or system of YOD care
- Six articles were Australian; most others were conducted in Europe

Key themes

Three core types of models of YOD care were described in the available literature, including: (a) systems-level models, including national frameworks, referral pathways, guidelines and funding models; (b) specialised services and memory clinic models, including those within-systems, integrated and collaborative care models and (d) supportive care models.

All identified models included more than one component, most commonly access to specialised assessment and diagnostic services (sometimes facilitated via clearly described referral pathways), targeted psychoeducation, structures or supports to promote collaboration or integration of care (including a key worker, care navigator, or care coordinator), care planning, and family support.

Importantly, none of the identified models included targeted care for the later or advanced stages of YOD. This includes no recent literature about models of care related to YOD residential respite, long-term care, palliative care, or end-of-life care. This is a major international research gap.

Key themes within the data include:

- System-level referral pathways, guidelines, or funding structures are essential for facilitating equitable access to best practice YOD assessment, diagnosis, and care. However, high-level structures are insufficient on their own and must be enacted via a competent workforce within local markets.
- Delivery of specialised, multi-disciplinary collaborative services can hasten and improve the quality of diagnosis and treatment of YOD. Their effectiveness is reduced when referrers do not know about them and are slow to refer. Most existing examples are run in collaboration with universities, raising the question of their feasibility without university support.
- Some research has identified that the delivery of a YOD-specific diagnosis service is not feasible across large geographical areas. In this case, equity of access to specialised support, education and diagnosis can be facilitated via ‘hub-and-spoke' models, in which specialist services in regional centres

(‘hubs’) provide consultation, resources and expertise to other non-specialist sites (‘spokes’). Telehealth resources can facilitate these models.

- Improvements to diagnostic services must be supplemented by simultaneous improvements to post-diagnostic treatment and care, to avoid people with YOD and families experiencing an abandonment after diagnosis.
- The available literature demonstrates that delivery of specialised services tends to be sporadic and reliant on 'champions’ within local areas. This limits equity of service access.
- Efforts to promote care integration and collaboration, including care coordination, are highly valued when provided. Equitable access to these services is affected by the issues mentioned above, but also by difficulty containing resources where a small number of individuals have high needs.
- Knowledge gaps exist across the health and social care workforces, and efforts to address these gaps can be challenging in the context of a relatively low prevalence disease. This can mean that having a general practitioner as the gateway to best-practice care can slow things down.
- Significantly more research is required about suitable models of residential respite and long-term care for people with YOD.
- Research has also not established models by which to deliver best-practice palliative and end-of-life care for people with YOD.

Research has identified that person-centeredness, functional consistency, and organisational coherence are the three pillars of best-practice YOD assessment, diagnosis, and care. The identified existing research demonstrates that these features can be achieved with dedicated effort and well-designed models of care. However, delivering cost-effectiveness and equity of access with these models remains a major challenge internationally.

Introduction

Young onset dementia (YOD) refers to any form of dementia with initial symptom onset before the age of 65 (Rosa-Neto, 2021; van de Veen et al., 2022) or below age 70 years in some instances (Draper et al., 2016; van de Veen et al., 2021; van Gils et al., 2023). The global prevalence of YOD is estimated to be 119 per 100,000 population aged 30 – 64 years (Hendriks et al., 2021). In Australia, it has been estimated that there are 29,000 people with YOD as of 2024, with a projected increase to 41,000 people with YOD by 2054 (Dementia Australia, 2023). Most people (95%) with YOD in Australia live in the community but are more likely to move to other settings including care homes as they get older (Australian Institute of Health and Welfare, 2024a). People with YOD have a longer average length of stay in hospital than all other age groups of people with Dementia in Australia (Australian Institute of Health and Welfare, 2024b).

Dementia is a syndrome characterised by progressive changes in cognitive function, and psychological and functional changes, with Alzheimer’s disease being the most common cause (Alzheimer's Association, 2024; Livingston et al., 2024). Symptoms typically worsen over time with advancement in dementia stage, resulting in an escalation in care needs. There is individual variability in the progression of symptoms and timing of transition between stages following diagnosis of YOD, with median survival times reported between six (Rhodius-Meester et al., 2019) and nine years (Gerritsen et al., 2019). Transition to residential care may be necessary with advancement in dementia stage, with a Norwegian study including 226 people with YOD revealing an average time from initial symptom onset to entry to residential or institutional care was nine years (Bakker et al., 2013).

Historically, the available pathways for dementia diagnosis and post-diagnostic care have been mainly focused on the needs of people with older-onset dementia, often caused by Alzheimer’s disease (AD) (Alzheimer's Association, 2024). Older-onset AD represents a substantial proportion of all dementia cases, and this is reflected in the nature of the dementia diagnostic services, care options available and the settings in which they are delivered. Clinically diagnosed AD also represents a sizable proportion of those with YOD (McMurtray et al., 2006). However, dementias attributed to frontotemporal degeneration, Lewy body disease, primary progressive aphasia, alcohol use and other rare forms of dementia, including those caused by genetic mutations, are more commonly diagnosed among younger people (McMurtray et al., 2006; Rosa-Neto, 2021). The specific diagnosis may have implications for disease progression, and care and support needs as clinical features may vary, including the presence and progression of neuropsychiatric symptoms (Heikkinen et al., 2024).

While there is no known cure for dementia, there are a range of care options that may improve quality of life, including early diagnosis, psychosocial support, and environmental modifications (Livingston et al., 2024). A diagnosis of YOD has implications for family relationships (Chirico et al., 2022; Grundberg et al., 2021; Wiggins et al., 2023), finances (Bayly et al., 2021; Mayrhofer et al., 2021), driving (Scott et al., 2023), and employment (Kilty et al., 2023; McCulloch et al., 2016; Nygard et al., 2023; Omote et al., 2023). These factors necessitate additional consideration beyond what is routinely considered when providing dementia care and locating suitable services for older people. People with YOD may experience a host of unmet needs, beginning with challenges associated with accessing diagnosis (Levine, 2013). To promote quality of life in people with YOD and their family members, care models that are appropriate for and meet the specific needs of this younger population are vital.

Dementia care models

Dementia care, like that for other progressive life-limiting conditions, can be conceptualised along a continuum encompassing pre-diagnosis, diagnosis, post-diagnostic care and end-of-life care. The delivery of appropriate care to people with dementia requires a comprehensive approach and typically spans different sectors, including the health care, aged care, and disability sectors. The term model of care has been defined as “the delivery of healthcare within the broader context of the health system” and includes the “overarching design for the provision of a particular type of health care service that is shaped by a theoretical basis, EBP [evidence-based practice] and defined standards” (Davidson et al., 2006, p49).

Best practice models of dementia care consider the needs of the person with dementia and their care partners or family members and may include multiple interventions or components to achieve these outcomes across health and social care systems. There are several broad types of dementia care models, systems, and frameworks. Common models of care include integrated care (Draper et al., 2018; Jones et al., 2022; Lee et al., 2019; Oostra et al., 2023; Organization, 2017; Valentijn et al., 2015; van der Feltz-Cornelis et al., 2023), collaborative care and care coordination (D’Cunha et al., 2023; Heintz et al., 2020; Lee et al., 2019), specialised care and memory clinics (Cahill et al., 2014; Naismith et al., 2022), dementia referral or care pathways (Begley et al., 2023; National Institute for Health and Care Excellence, 2018), and palliative care models (Lewis et al., 2023; Nishimura et al., 2024). Commonly, more than one care model may be delivered simultaneously to meet varied needs. Support services for care partners and family members are often included as a component of care models but may be available in the form of a standalone service or intervention. The principles of holistic, person-centred care, consumer-directed care, and relationship-centred care are often central to dementia care models.

An overview of common care models identified in the dementia literature is provided in Table 1.

Table 1. Overview of common models of dementia care in the literature

Model	Description
Care coordination model	A trained person (care navigator, key worker, or case coordinator) assists in managing, coordinating, or guiding a person through health and social care services consistent with care planning and individual needs.
Care pathway or referral pathway model	A structured approach to care in the form of guidelines, recommendations, or a protocol. Often includes a multidisciplinary team, stages or steps, and a timeline or milestones.

Integrated and collaborative care models	A collaborative approach, typically focused on the management of a health condition, using existing services across care settings. Emphasis on the use of existing resources, multidisciplinary and interdisciplinary approaches, care planning and continuity of care. Shared care approaches typically include a GP in central role.
Palliative care model	Care is focused on managing symptoms and enhancing quality of life. This includes providing comprehensive support for end-of-life care.
Specialised clinic and memory clinic models	Focused on comprehensive memory assessment and follow-up under the care including medical specialists, multidisciplinary teams and social care. May be restricted to diagnostic assessment alone. Often within integrated, collaborative or shared care models.
Supportive care models	Care is often focused on enhancing quality of life and may address psychosocial, social and practical aspects of care.

Systems and service settings

Service use and access may be affected by the location of services, with the location of care for YOD situated across sectors including health, aged care, social and community care (Day et al., 2022). The funding and policy contexts within a given location can have a significant impact on service provision and the setting in which care is provided and may contribute to differences in the accessibility of care.

Most dementia care services have been situated within older person's healthcare and aged care services and may have age-based eligibility criteria limiting access to diagnostic assessment and care for those under age 65 (Cations et al., 2022; Lai et al., 2023). While there have been efforts within some settings to remove age-related barriers, they remain in place within numerous health services in Australia and internationally. While the removal of age-based criteria could improve access to diagnostic services, it remains unclear whether these services would meet the comprehensive care needs of people with YOD and their family members (Cations et al., 2017).

Within the Australian care context, YOD care also spans the disability sector. People with dementia aged under 65 years may apply for support through the National Disability Insurance Scheme (NDIS), which aims to improve access to necessary care and support for people with a disability (Australian Institute of Health Welfare, 2024a). In the last quarter of 2023, almost 8,700 people with YOD were approved for NDIS funding which represented an increase of 600 people over the previous quarter (Australian Institute of Health Welfare, 2024a). The NDIS enables flexibility and control over service use, which can be managed by the individual, their carer or a private care coordinator who may be tasked with navigating care services (Foxe et al., 2024). This inclusion of components of dementia care in the disability sector is consistent with efforts by advocacy bodies, such as the Dementia Alliance International, to recognise dementia as a disability. Such recognition may promote greater focus on rehabilitative care and support and align with recommendations from international groups who have identified a need for greater access to rehabilitative services when a person’s functional capacity is reduced (World Health Organization, 2024). However, the delivery of services across health, disability, and aged care systems comes with a relative increase in the complexity of service delivery, integration, and navigation.

Dementia care can also encompass broader structures, such as community initiatives to promote dementia inclusivity, such as dementia-friendly city planning and the Dementia Friendly Communities initiatives (Hebert & Scales, 2019; Shannon et al., 2019).

Best practice in diagnosis and care

Diagnosis

The need for prompt diagnosis is not unique to YOD, but people with YOD often face additional challenges when accessing appropriate diagnostic services. Accurate and timely diagnosis has been identified as an important target within dementia care strategies on a global scale, including within the Australian National Framework for Action on Dementia 2015-2019 (Australian Department of Health, 2015). The absence of formal diagnosis and diagnostic delay is one of the key challenges and barriers to care provision for people with dementia across the disease trajectory (Foxe et al., 2024) and may result in greater excess disability, psychological and financial consequences (Burkinshaw et al., 2023; Davies-Abbott et al., 2024). By contrast, a timely diagnosis may enable a person with YOD to have greater participation in future planning and decision-making related to their health, care and finances (Gerritsen et al., 2019).

People with YOD are more likely to initially present with non-memory-related complaints and atypical presentations compared to those with older-onset dementia (O'Malley et al., 2019; Velayudhan & Mueller, 2024). This may contribute to delays in initial identification of symptoms and subsequent referral to a memory assessment service or appropriate specialist (Rossor et al., 2010). Inappropriate specialist referrals have been widely identified prior to diagnosis, which contributes to diagnostic delay and often comes at significant financial expense (Hussey & Butler, 2019). A clinical guideline for diagnosis of YOD by Queensland Health suggests referral to a medical specialist should follow where a possible diagnosis of dementia is considered by a GP (Queensland Health Clinical Excellence Division). Additional barriers to diagnosis can include potential knowledge gaps among health professionals and a reluctance to diagnose dementia owing to the perceived absence of treatment and care options following diagnosis (Perry et al., 2024).

The diagnosis of YOD typically involves a comprehensive assessment, including neurocognitive assessment, neuroimaging and fluid biomarkers (Konijnenberg et al., 2017; O’Malley et al., 2022; Young Dementia Network, 2024a). Time to diagnosis varies between studies and settings, with findings from an Australian study of 88 people with YOD revealing median time from initial symptom onset to dementia diagnosis was 3.2 years, with a total duration of 4.7 years from initial onset to a final diagnosis including dementia type (Draper et al., 2016), while a study from Norway identified time from symptom onset to diagnosis of young-onset AD at an average of 5.5 years (Kvello-Alme et al., 2021).

Guidelines for the diagnosis of dementia in memory clinics are increasingly common, including guidelines for diagnosis within Australian memory clinics established by ADNeT (Australian Dementia Network, 2024). While guidelines typically relate to dementia broadly, reference to YOD or specific practice guidelines for the delivery of services for younger people, such as prioritising assessment for people with YOD has been identified (Australian Dementia Network, 2024), and expert consensus outlines up to 47 elements to support the diagnosis of YOD (O'Malley et al., 2020). In a study of memory clinics in Australia, suspicion of YOD was provided as the reason for prioritising referrals in almost half the occasions where immediate assessment was noted (Naismith et al., 2022). The UK has both quality standards and an accreditation program for memory clinics, the UK Memory Services National Accreditation Program (MSNAP) which relate to dementia broadly, but include standards related to memory services for people with YOD (Royal College of Psychiatrists, 2022b). In an audit of memory programs using data from MSNAP, approximately half of the included memory clinics had a dedicated worker for YOD (Royal College of Psychiatrists, 2022a).

An absence of specialist services such as cognitive assessment or neuroimaging services, or extensive wait times for these services may also contribute to delay in diagnosis (O'Malley et al., 2021). These factors may be even more pronounced outside major cities, with differences in time to diagnosis and post-diagnostic support identified between metropolitan and regional areas of Australia (Pavković et al., 2023). Similarly, differences in time to diagnosis and subsequent post-diagnostic care were identified between rural and urban areas in the US (Xu et al., 2022).

The importance of improved recognition of YOD symptoms among primary care providers, coupled with knowledge about the clinical features of dementia in younger people, was considered very important by those with YOD (O'Malley et al., 2021). The way in which the diagnosis is communicated and the provision of support and information at this time is vital and should be individualised and appropriate to the needs of those diagnosed and their family members (Fox et al., 2023; O'Malley et al., 2021; Rabanal et al., 2018). People with YOD may have a greater awareness of the disease compared to those with older-onset dementia (Baptista et al., 2019), and improved disease awareness has been associated with higher psychological symptoms including distress and depressive symptoms (van Vliet et al., 2013b). A recent study identified a substantial increase in the risk of suicide within three months of YOD diagnosis (Alothman et al., 2022), which highlights the importance of skilled and sensitive disclosure practices together with defined pathways for post-diagnostic care, support and education.

Diagnosis has been identified as critical for subsequent care planning and intervention and which may be particularly important for a person with YOD. While diagnosis can occur at any stage of disease, it often takes place when severity is mild or moderate but can vary based on the type of dementia (Kvello-Alme et al., 2021; Loi et al., 2023). The tasks of diagnosis and the provision of post-diagnostic care differ and require a range of skills, resulting in services that may be fragmented or siloed for people with severe and advanced dementia. Care may be organised within services and settings to provide access to different levels of care corresponding with dementia stage, as care needs and functional capacity change with progression from mild to moderate stage dementia. While mild dementia is often managed within community care settings, including health and social care, moderate and severe dementia may necessitate the involvement of specialised services, including those equipped to provide residential care for people with severe behavioural and psychological symptoms of dementia.

Post-diagnostic dementia care

Guidelines for best practice dementia care have been described in various government policy documents, peak body, and organisational reports. This includes the National Institute for Health and Care Excellence (NICE) Dementia Guidelines (2018) and the Australian Clinical Practice Guidelines for Dementia Care (Guideline Adaptation Committee, 2016). Findings from a systematic review described the importance of care planning for people with dementia living in the community but determined that it should occur in combination with case management for implementation and potential refinement (Low et al., 2023). While guidelines for dementia typically encompass those with YOD, specific frameworks and clinical practice guidelines for YOD are less common. Best practice guidelines for YOD include core components to promote timely diagnosis and intervention, including age-appropriate services that address the specific needs of people with YOD and consider the vital role of family members in care planning and provision (Cations et al., 2017).

At a national level, Scotland's Pillar models offer frameworks for comprehensive post-diagnostic care and community-based care support for people with dementia at various stages of dementia severity, including advanced dementia care (Ahlzheimer's Scotland, 2015; Healthcare Improvement Scotland, 2023a). Ireland's model of dementia care including specific practice guidelines and a designated referral pathway for people with YOD (Begley et al., 2023). Other publications outline similar components of dementia care models (Hallberg et al., 2013).

Common components of quality post-diagnostic dementia care include timely access to appropriate interventions, the use of a multidisciplinary approach, person-centred care, psychosocial and emotional support, support and education for care partners (Butler et al., 2021; Livingston et al., 2024; National Institute for Health and Care Excellence, 2018; Scottish Intercollegiate Guidelines Network, 2023). The delivery of appropriate care requires models that address different domains of function, disease severity, individual preferences, and the available resources. Dementia care pathways and best practices were described in recent studies includes both pharmacological and non-pharmacological interventions, referrals to services (including allied health) and relevant organisations, information on financial and legal matters, and support and education for care partners (Dombrowski et al., 2024; Foxe et al., 2024).

Specific needs among those with YOD

An increase in research, particularly over the past ten years, has contributed to greater awareness of the care needs and experiences of those with YOD and their family members (Carter et al., 2018; Millenaar et al., 2016). People with YOD have different needs compared to those with older-onset dementia, owing in part to the economic burden associated with earlier disease onset and its potential impact on future income. Findings from a systematic review of direct and indirect costs associated with YOD, including two studies with cost-related outcomes, found costs were 39% higher in those with YOD compared to older-onset dementia (Ruiz-Adame, 2022).

A comprehensive review of the experiences and care needs of people with YOD by Sansoni (2016) highlighted the importance of improving access to timely diagnostic services and post-diagnostic support and the need for increased evaluation (including evaluation of costs) of existing services and programs. Efforts from the UK have been at the forefront (Carter et al., 2018).

The need for supportive and integrated post-diagnostic services, peer support, and age-appropriate care has been described by those with YOD, family members and care partners (Rabanal et al., 2018). The age-appropriateness of care is frequently described as a core care requirement and an element of positive post-diagnostic care (Stamou et al., 2021). This includes considering age-based requirements that may limit access to services, the service setting, the age of the peer group and the suitability of activities for those with YOD (Rabanal et al., 2018), including access to an age-appropriate peer group (Ottoboni et al., 2021). Care partners identified a need for education and support, with one study finding that the available services in Australia were not considered by care partners to fully address this need (Cadwallader et al., 2023).

Several reviews have examined specific interventions for people with YOD and their family members, demonstrating the effectiveness of peer support interventions, allied health interventions, and other interventions in promoting functional independence and quality of life (Aplaon et al., 2016; Cui et al., 2024; Fox et al., 2020; Kim et al., 2024; Richardson et al., 2016; Sullivan et al., 2022).

Despite this, Mayrhofer et al. (2018) noted limited evidence of service development or delivery for people with YOD. In this review, the authors emphasised the limitations of care delivery owing to funding constraints under project-based funding models or pilot studies (Mayrhofer et al., 2018). The limited availability of age-appropriate services for YOD is evident among support-based models, which have focused on services for those with older-onset dementia and may negatively affect perceptions of care and willingness to approach these services (Cations et al., 2017).

Finally, the number of people with YOD entering and living in residential aged care in Australia suggests that there continues to be an absence of suitable accommodation and long-term care options, despite the government targets which aim to ensure that no person under age 65 lives in residential care by 2025 outside “exceptional circumstances” (Australian Institute of Health and Welfare, 2024c). In the final Royal Commission into Aged Care Quality and Safety report, a recommendation that people aged under 65 years be provided with care that is considered more appropriate to their needs and moved from residential care is also made (Royal Commission into Aged Care, 2021). While NDIS funding for disability services and accommodation such as supported independent living is increasing the availability of these options, these services may not be universally appropriate or accessible and may not be inclusive for affected families.

Service and care needs of family members and care partners

Family members and care partners of people with YOD often have their own unique needs which may differ from those with older-onset dementia (Svanberg et al., 2011; Wong et al., 2020). Findings from a recent scoping review identified the impact of providing informal care on the carer's employment and education capabilities, with greater strain associated with dual caring and occupational roles, identity-related changes within the carer, and a need for greater support for care partners identified (Kokorelias et al., 2024). Similarly, the impact on care partners was described in a previous review by van Vliet et al. (2010), which showed that care partners of people with YOD experienced high levels of burden, stress, and depression. There is limited availability of suitable services that meet the diverse needs of family members of people with YOD. Family members of people with YOD are also likely to be younger and may have children or young people in their care. One Australian report described care partners of people with YOD ranging in age from teenagers to those over 75 age years (Westera et al., 2014). As such, they may occupy multiple care roles, including caring for children or ageing parents. The potential to deliver care for people with YOD within a family-based approach has been identified in one study of family members of people with YOD and health care providers (Hutchinson et al., 2020).

The diagnosis of a parent can be particularly disruptive for children and young people, and they may face changes in family roles and responsibilities, uncertainty and change in life circumstances (Chirico et al., 2021). Service needs among young children are also unique (Gelman & Greer, 2011). A thematic synthesis of qualitative literature identified four main themes among young people who had a parent with YOD: changing family dynamics, psychological strain, physical strain, and coping strategies (Blake & Hopper, 2022). One qualitative study of people under the age of 18 who had a parent with YOD identified themes related to change in multiple domains, including psychological and emotional impacts, an absence of relevant support or recognition and barriers to accessing systems of psychosocial support and education (Blake & Hopper, 2023). There have been several programs designed to address these needs including online-based education and support programs for young people (Cose & Dean, 2023b; Masterson-Algar et al., 2022). Further, resources have been developed for family members and children, including a guide for parents and professionals to support children and young people with a parent with YOD (Robyn & Jeneva, 2022).

The support and service needs of family members and care partners may be affected by neuropsychiatric symptoms or changed behaviours. Neuropsychiatric symptoms include behavioural and psychological symptoms of dementia and have been associated with poorer quality of life (Hartmann et al., 2021) and higher rates of cognitive decline (Gerritsen et al., 2018) among those with YOD. There are also differences observed in initial symptoms and the progression of symptoms compared to those with older-onset dementia (Gumus et al., 2021). Neuropsychiatric symptoms can be particularly challenging for family care partners and may contribute to an increase in carer burden (Chiari et al., 2021) and a greater need for support services. In the absence of suitable support services for YOD, demands may be placed on other services including those not equipped to provide suitable support, such as mental health triage services, as identified in one recent study by (Loi & Velakoulis, 2024). An increase in neuropsychiatric symptoms is a factor contributing to entry to residential care, and the prevalence of these symptoms was greater among those with YOD compared to people with older-onset dementia living in care (Hartmann et al., 2021; Mulders et al., 2016). There is also evidence that care staff distress is increased when caring for a person with YOD who experiences neuropsychiatric symptoms (van Duinen-van den Ijssel, Mulders, et al., 2018).

What does best-practice YOD care include?

The large-scale, UK-based Angela project identified elements of good practice and components of helpful post-diagnostic support from the perspective of those with YOD. The study identified person-centeredness, functional consistency and organisational coherence as the three core pillars of best practice YOD care (Stamou et al., 2022). Findings highlighted the importance of dedicated YOD care and the integration of care components for people with YOD and their families. Other identified features of best-practice YOD care included integration, availability of specialists, consistency in contact, age appropriateness, holistic care (capable of addressing the diverse needs of the family system), responsive and timely, accessible (affordable, local), and general themes of person-centeredness including positive and respectful communications, collaborative, flexible, in-person contact vs online, and provision of user-friendly material (Stamou et al., 2022). For people with YOD and their family members, timely access to dedicated YOD services with age-appropriate care, care coordination and specific care elements for family members and carers were identified as important factors (Stamou et al., 2022).

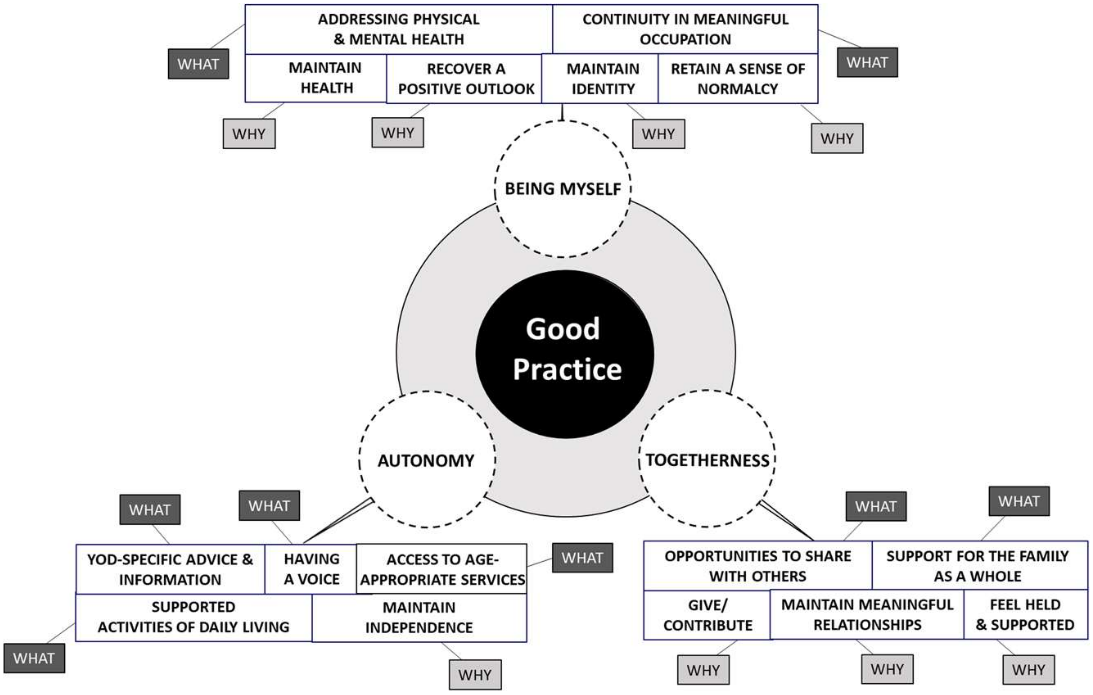

Figure 1. Good practice in post-diagnostic support for young onset dementia (reproduced under Creative Common License from Stamou et al., 2023)

Several themes associated with good practice within services for people with YOD were described, as depicted in Figure 1 (Stamou et al., 2023). This included promoting independence and autonomy by providing tailored and advice and services, the capacity to maintain a sense of individuality and “being myself” such as taking part in meaningful activity, and a sense of togetherness or supporting relationships in multiple domains including family relationships and community connections (Stamou et al., 2023). Other components of helpful care models include the availability of suitable psychosocial care for both the person with dementia and their family members, peer support, meaningful activities, financial and legal guidance and advanced care planning (Oyebode et al., 2023; Stamou et al., 2021; Stamou et al., 2022; Stamou et al., 2023).

Within the literature, there is a preference for clear care pathways (Rabanal et al., 2018), integrated care (Stamou et al., 2022), care planning, and care managed by specialists who are well-educated in matters related to YOD (O'Malley et al., 2021; Stamou et al., 2022). Relational aspects of care are also commonly described, including consistency with a single point of contact, empathy and understanding (Stamou et al., 2022). Services that were flexible and could adapt when needs change, along with in-person service provision, were preferred (Stamou et al., 2022).

The Australian Royal College of Psychiatrists recommended equitable access to a dedicated YOD service for assessment, diagnosis and care owing to the differences in clinical needs and expertise required to manage YOD effectively (RCPsych, 2018). In their view, dedicated YOD services should include access to a local clinical lead, a key worker, multidisciplinary care, a person-centred approach, networked services, continuity of care, long-term support and leadership from a manager of the service (RCPsych, 2018). Similar recommendations were made by the Royal College of Psychiatrists and the Alzheimer’s Society London more than a decade earlier (RCPsych & Alzheimer's Society London, 2006).

YOD in priority groups

For people with YOD needing diagnostic care and services, First Nations people, culturally and linguistically diverse groups, and people living in regional and remote areas are among the most marginalised (Burkinshaw et al., 2023).

There is a higher prevalence of YOD among First Nations people of Australia compared to non-Indigenous people (Sait & Brown, 2012). In the Northern Territory, the estimated prevalence of dementia in First Nations peoples aged between 45 and 64 years was 6.5% compared to 5.5% for non-indigenous people (Li et al., 2014). However, rates for First Nations peoples in remote regions in this age group have been estimated to be as high as 12.4%, five times greater than when compared to 2.4% in the general population (Smith et al., 2008) and 14.2% among Torres Strait Islanders between 45 and 93 years of age (Russell et al., 2021). By 2051, projections suggest the number of First Nations people with dementia in Australia is expected to substantially increase in people aged between 60 and 69 years (Temple et al., 2022).

In Australia in 2016, 21% of people with YOD were born in a non-English speaking country (Australian Institute of Health Welfare, 2022). People with YOD from culturally and linguistically diverse groups face barriers when accessing the NDIS due to a lack of interpreter services, access to documents in different languages, and challenges with using online applications (Dementia Australia, 2024). These challenges are more difficult to navigate in rural and regional areas, where long waiting times for medical appointments and a need to travel to major cities for specialist appointments are both common (Lai et al., 2023). Intersecting marginalisation presents additional barriers to the delivery of best-practice care for these priority groups.

Aims

Despite the extensive literature describing best practice in YOD assessment, diagnosis and care, the delivery of these principles within existing service systems is a global challenge. Identifying and reviewing existing YOD care models delivered within existing service systems can help inform efforts for implementation in Australia.

A rapid review was chosen to explore models of care for people with YOD, drawing upon evidence from within Australia and international approaches. The aim of this review was to identify examples of high-quality, integrated models of support and systems of care for people with YOD and their family members.

The research questions for this review were:

- Based on evidence from Australia and internationally, what models of support, systems of care, and care pathways have been developed or implemented for people with YOD and their family members?
- What are the outcomes of these models or systems of care?

Methods

Search Strategy

The search strategy was developed using keywords and relevant terms identified during an initial search of PubMed and Google Scholar, and the search strategy was reviewed in collaboration with a librarian. A comprehensive search of three electronic databases, PubMed, PsycINFO and CINAHL was conducted between January 2024 – April 2024 to identify relevant articles. The following search terms were included: dementia, Alzheimer* young onset, younger onset, early onset, care, care models, support, pathways, systems, primary care, integrated, outpatient, clinic*, rehabilitation, aged care, residential care, nursing home, community, respite, practice, multidisciplinary, interdisciplinary, allied health, guideline, health service, health care, healthcare, service, care navigator, care coordination, case manage*, care delivery, and peer support. Search strings were adapted for each database. The search was supplemented by citation searches, including manual screening of the reference lists of included studies.

Grey literature

A search of grey literature was also conducted using internet searches on Google and Google Scholar these search terms. A targeted search of Australian Government websites, including the Analysis and Policy Organisation, Australian Institute of Health and Welfare, international research, and government websites (Agency for Healthcare Research and Quality, NICE, Open Access Theses) and Dissertations, non-profit organisations (Dementia Australia, Young Dementia Network, Alzheimer's Disease International) websites was also conducted.

Focus

We included studies that focussed on models of care for people with YOD delivered within any healthcare or community setting. This includes people with YOD broadly, without differentiating between forms of dementia. For the purposes of this review, we define model of care for YOD as a model of care that:

- Comprised of more than one intervention or component
- Can be adopted at the systems level

Outside the scope of this review are matters associated with service provision primarily for conditions that may result in dementia or cognitive decline, but where YOD is not the primary condition, such as Down syndrome.

Inclusion Criteria

Studies or reports that were included if they met the following criteria:

1. Published in English.
2. Described or evaluated support models, models of care, care pathways, systems of care, service structures or multimodal interventions for people with YOD and/or their family members.
3. The study population or intended population is people with YOD or people diagnosed with dementia before the age of 70 and their family members or care partners.
4. Published in the last 15 years between January 2009 and January 2024.

While YOD is classified as people who are diagnosed with the type of dementia under the age of 65 years, we used a cut-off of 70 years for included studies, given people with YOD often experience diagnosis delay (van de Veen et al., 2021; van Gils et al., 2023). Diagnosis of YOD following presentation of symptoms has been demonstrated to take an average of 4.4 years in YOD compared to 2.8 years in people with older-onset dementia (van Vliet et al., 2013a), and 4.7 years to receive the diagnosis of type of dementia (Draper et al., 2016).

Exclusion criteria

Studies or reports were excluded if they:

1. Did not describe or evaluate a care model, support model or system of care for people with YOD and/or family members.

2. Described or evaluated a single therapeutic intervention, or a care or support component.
3. Did not specify YOD and/or family members as the target population, including where dementia was referred to, but age was not specified, or reference was made to YOD and older-onset dementia as single group.
4. Did not include a specific YOD component.
5. Did not focus on YOD as a primary condition, including where models of care designed primarily for a different condition, such as Down syndrome or intellectual disability.
6. Document was a review, abstract or conference proceeding.

Study selection

Studies were retrieved and citations imported to Endnote (Philadelphia, PA, USA) where duplicates were removed before being exported to Covidence (Veritas Health Innovation, Melbourne, Australia) for screening. An initial screening of title and abstract was completed by two reviewers working independently followed by full-text screening, with disagreement discussed with additional reviewers.

Data Extraction

Data were extracted from included studies using an extraction table including the following information (where available): author and year, country, sample, study design, study aims, service delivery model and setting, outcome measured and findings.

Quality Appraisal

The Mixed Methods Assessment Tool (MMAT) Version 2018 was selected to enable the appraisal of quantitative, qualitative, and mixed-methods studies (Hong et al., 2018). The MMAT tool is commonly used in reviews to appraise articles, where multiple different study designs and methodologies are expected to be used in the included studies. The articles were independently appraised by two authors (JN and SI) and discussed until consensus was reached or mediated by a third author

(NMD). The results of the quality appraisal are presented based on a star rating system. Studies that met 100% of quality criteria received five stars, 80% of quality criteria met received four stars, 60% of quality criteria met received three stars, 40% of quality criteria met received two stars, and 20% of quality criteria met received one star. No studies were excluded based on the quality appraisal.

Results

Article selection

A total of 2,419 citations were identified from database searches after the removal of duplicates. After title and abstract screening, 145 citations remained and were reviewed for eligibility. A final set of 19 studies were selected for inclusion in the review from the database searches. The PRISMA flowchart in Figure 2 provides an overview of this process. An additional eleven documents were identified from grey literature sources and included in the review. We also reviewed national policy documents on dementia from 14 OECD countries available in English to examine the inclusion of YOD recommendations at the national level.

The final selection of documents and published material included in this review were from a range of sources and included different study methods, including a randomised controlled trial (RCT), narrative reports, protocols, cross-sectional studies, service audits and evaluations, focus groups, reports, policy documents from government agencies and presentations.

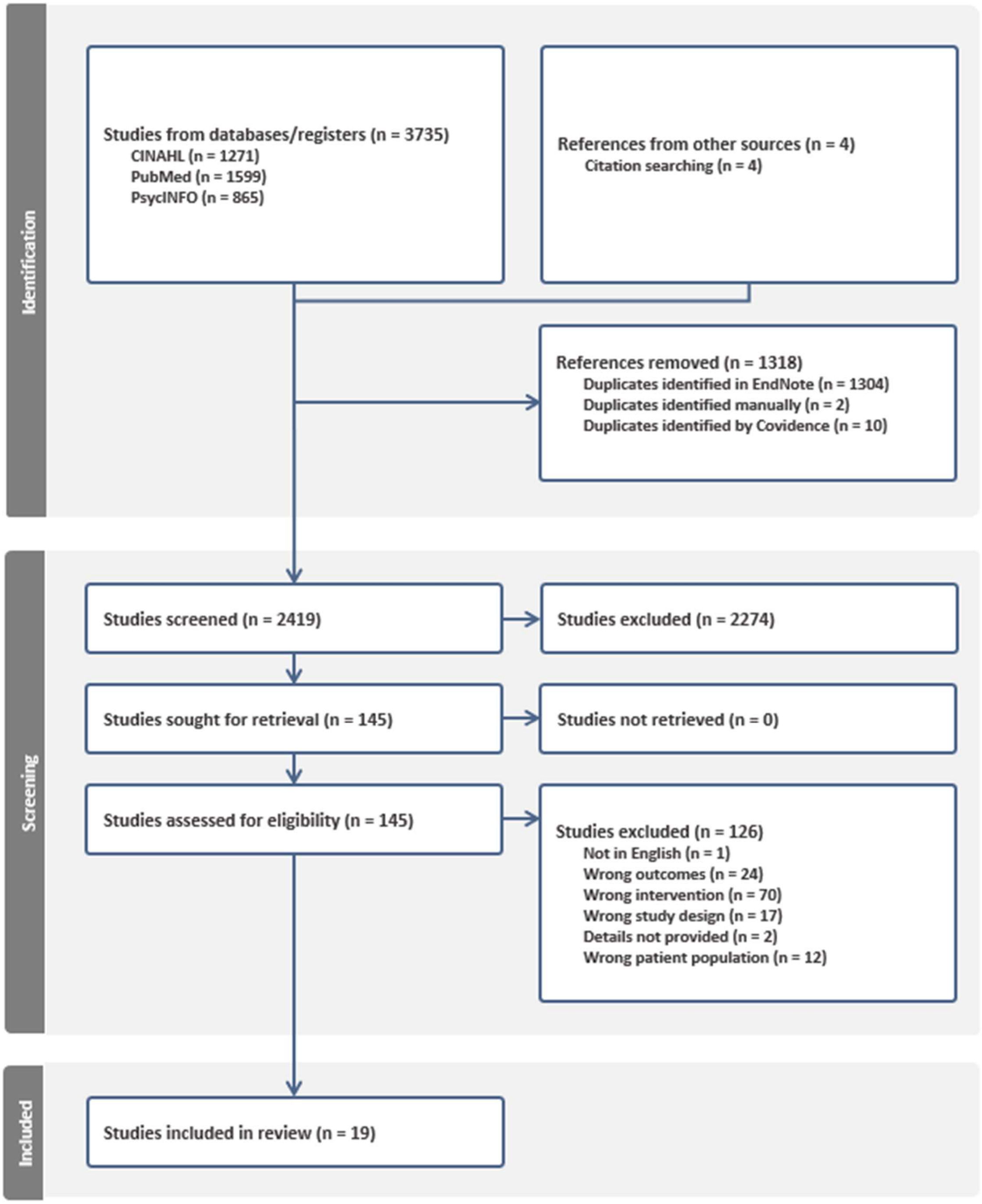

Figure 2. PRISMA flow chart of included studies

Study characteristics

The characteristics of the models of care identified in the included peer literature of the review are displayed in **Table 2.** Most included sources were narrative reports, cross-sectional studies, and qualitative studies. There were fewer sources that included an evaluation of the care model on quantifiable outcomes. The perspectives of staff or healthcare professionals were included in some studies. At the broader systems level, the unique needs of people with YOD were identified within 14 national dementia plans reviewed in **Table 3**. Eleven documents were identified from grey literature and are presented in **Table 4**. Eleven articles described a model or system of YOD care without evaluating it. Nineteen articles both described and reported results of an evaluation of a model or system of YOD care.

Features of identified care models

While most models shared one or more similar components, each included distinct features. No models included components of care across the care pathway from diagnosis to palliative and end-of-life care. Most models included a component focussed on assessment or diagnosis, often combined with one or more additional components of care (Bottomley, 2023; Brown et al., 2023; Chiari et al., 2022; Farrand et al., 2019; Giebel et al., 2020; Hussey & Butler, 2019; Jockey Club Centre for Positive Ageing, 2024; Loi, Goh, et al., 2022; Loi, Walterfang, et al., 2022; Morhardt et al., 2015; National Collaborating Centre for Mental Health, 2018; Ramluggun & Ogo, 2016; Tilki et al., 2023; Young Dementia Network, 2024b). Several models also incorporated principles of integrated care, coordinated care, and/or care planning (Brown et al., 2023; Chiari et al., 2022; Farrand et al., 2019; Giebel et al., 2020; Jockey Club Centre for Positive Ageing, 2024; Loi, Goh, et al., 2022; Loi, Walterfang, et al., 2022; Morhardt et al., 2015; National Collaborating Centre for Mental Health, 2018; Ramluggun & Ogo, 2016; Westera et al., 2014). Memory clinics and specialised services for were also identified (Giebel et al., 2020; Loi, Goh, et al., 2022). Supportive care models incorporated day respite and peer support with meaningful activity, physical activity, access to health or other referrals (Davies-Quarrell et al., 2010; Tilki et al., 2023; Wheeler et al., 2015). Where a care approach was described, person-centred and tailored care were the predominant approaches (Loi, Walterfang, et al., 2022; Ramluggun & Ogo, 2016; Tilki et al., 2023).

Most models included some service provision at the core of the model, often supplemented by a referral or coordination service to support needs outside the core scope of the model. There were several examples of models that included two or more services working in collaboration within and across sectors(Tilki et al., 2023; Wheeler et al., 2015) and one YOD pop-up clinic involving two NHS services (Young Dementia Network, 2024b). Most care models were in community-based settings, while one study was conducted within a specialised residential care unit for people with YOD (Appelhof et al., 2018; van Duinen-van den Ijssel, Appelhof, et al., 2018; van Duinen-van den Ijssel et al., 2020; van Duinen-van den Ijssel et al., 2019). Specialist clinics affiliated with a research or university setting were also described (Dulaney, 2022; Konijnenberg et al., 2017; Loi, Goh, et al., 2022; Loi, Walterfang, et al., 2022; Morhardt et al., 2015). One model was facilitated via telehealth (Brown et al., 2023). Other dementia care frameworks were described in sources, including the Senses Framework (Davies-Quarrell et al., 2010).

Outcomes reported

Several of the included studies described the model of care, YOD referral pathway or study protocol, but did not include or report on evaluation of the model. One study described components of a comprehensive intervention for neuropsychiatric symptoms for people with YOD living in residential care (van Duinen-van den Ijssel et al., 2018), while three sources evaluated outcomes of this model including implementation, feasibility and effectiveness in managing neuropsychiatric symptoms (Appelhof et al., 2018), staff outcomes such as burnout and absenteeism (van Duinen-van den Ijssel et al., 2019), and cost outcomes of implementing this model (van Duinen-van den Ijssel et al., 2020). Six sources evaluated time to diagnosis as an outcome of the care model. Factors associated with delayed diagnosis were examined in two sources (Chiari et al., 2022; Loi, Goh, et al., 2022). Other quality indicators were examined by Konijnenberg et al. (2017). One study evaluated care use and time following diagnosis to care access following GP referral for diagnosis (Hendriks, 2023). One study evaluated referral numbers, and differences between people with YOD and those with older-onset dementia in a general memory service (Yeung, 2021). One study described the NDIS funding model and reported on experiences and satisfaction among people with YOD (Cations et al., 2022). Six studies provided qualitative outcomes related to experiences, three studies described experiences of people with YOD participating in supportive care programs (Davies-Quarrell et al., 2010; Tilki et al., 2023; Wheeler et al., 2015), one described experiences of staff and people with YOD and their care partners who underwent diagnosis at a memory service (Giebel et al., 2020), one described challenges associated with accessing care (Ramluggun & Ogo, 2016), and one study described experiences of clinicians delivering a telehealth program for people with YOD (Brown et al., 2023). One study described themes of the content of calls made to a YOD helpline (Kogata et al., 2024)). One study described financial benefits (in local currency) for people with YOD and care partners as a result of program participation (Wheeler et al., 2015).

Quality Appraisal

As this review aims to identify models of care from different sources and outcome data for models are still emerging, the quality of evidence was expected to vary. The included peer-reviewed literature was assessed using the Mixed Methods Appraisal Tool (MMAT) where appropriate. Most studies were scored as five stars (Giebel et al., 2020; Hendriks et al., 2023; Kogata et al., 2024; Konijnenberg et al., 2017; Loi, Goh, et al., 2022; Yeung et al., 2021). Two studies scored four stars (Cations et al., 2022; Chiari et al., 2022). Of the included studies relating to the BEYOND-II study, they were scored with five stars for mixed methods (van Duinen-van den Ijssel et al., 2020) and two stars for quantitative RCT quality criteria (Appelhof et al., 2018). Several studies were scored with lower star ratings due to lack of detail in the qualitative methodology, with one study scoring three stars (Tilki et al., 2023), one study scoring two stars (Davies-Quarrell et al., 2010), and one study scoring zero stars (Wheeler et al., 2015). Three studies were not assessed as they were narrative or descriptive studies (Bakker et al., 2022; Morhardt et al., 2015; Ramluggun & Ogo, 2016) or a study protocol (van Duinen-van den Ijssel, Appelhof, et al., 2018).

Table 2. Studies identified in peer reviewed literature

Author (Year)	Sample	Country	Study design	Aims	Service delivery	Outcome Measured	Findings
Appelhof et al. (2018)	*n* = 13 YOD special care units	Netherlands	Process evaluation of intervention “Grip on Challenging Behavior”. Randomised controlled trial, stepped wedge design. Control = care as usual Duration 18 months	“a process evaluation was performed for an intervention aimed at improvement of the management of NPS in institutionalized people with YOD (1) to establish internal and external validity and (2) to provide information about the implementation strategy and factors affecting implementation.”	Residential care	Describes the components of the BEYOND-II project. Examines feasibility and staff satisfaction. Staff: workload, absenteeism, and job satisfaction. Describes other outcomes and barriers to implementation.	Staff: satisfied with program 74.6% not feasible 61.9% Barriers: rate of staff turnover, staff education or experience, deviation from intervention protocol, changes in environment or team approach. Facilitators: multidisciplinary meetings, limit involvement in other research projects, staff positive expectations, an ambassador who facilitated implementation, whole team involvement.
Bakker et al. (2022)	NA	Netherlands	Descriptive report with original research component	Explores barriers and facilitators for the development of post-diagnostic care	Multiple services	Describes key components of the Dutch Young Onset Dementia Care model.	Components include acknowledging unique needs, innovation, service development, provider education, continuity in care, access to care and support,

				and support in YOD		Barriers and facilitators to post-diagnostic care.	care coordination, age-appropriate services, use of quality indicators.
Brown et al. (2023)	*n* = 23 clinicians	Australia	Qualitative study	"The aim of this study was to investigate the experiences of clinicians involved in the implementation of a novel hub and spoke telehealth YOD service into rural settings. Specifically, we aimed to evaluate barriers and facilitators to successful implementation, across metropolitan (hub) clinicians who provided YOD telehealth services and rural (spoke) clinicians who facilitated service delivery at rural sites."	Community healthcare Specialised service Telehealth delivered through metropolitan clinicians remotely to rural locations, facilitated by rural clinicians.	Describes the components of the BRIGHT-YOD program, examines clinician experiences with implementation of statewide YOD telehealth service. Reflexive thematic analysis.	Five themes identified during the pre-implementation phase: clinical need, previous experiences and views, potential telehealth barriers, solutions to potential telehealth barriers, and potential clinical outcomes. Nine themes during the post-implementation phase: clinical need, clinical relationships, concerns about the future of rural healthcare, clinical practice and resourcing factors, patient suitability, difficulties with technology, service quality, the way forward, and the impact of COVID-19. Clinicians had positive views toward telehealth. Potential clinical outcomes improved quality of care, improved access to specialised care.

Cations et al. (2022)	*n* = 42 people with YOD, *n* = 109 informal care partners	Australia	Cross-sectional survey	"The aim of this study was to examine the experiences of people with YOD and their care partners with the NDIS, determine satisfaction with NDIS services and identify strategies for service and system improvement for this group"	Community care/funding	Describes experiences and satisfaction with the NDIS.	7% were too old to make a request for plan and 60% had approved NDIS plan. Time since request for plan was 3-6 months (38%); 1-3 months (30.4%); 6 – 12 months (18.5%); more than 12 months (8.7%). Common approved services on NDIS plan were in home support (e.g. cooking, cleaning) 63%; allied health 60.9%; transport 56.5%; social support 55.4%; exercise programs 25%; home modifications 23%; respite 23%; personal care 22.8%; counselling or psychology services 20.7%; residential aged care 16.3%; financial planning 1.1%. Fewer than 30% agreed that the NDIS understands dementia, particularly physical needs. 60% of those with a plan were satisfied with the plan. 87% would prefer to remain on the NDIS rather than move to aged care system when they reach 65 years old.

Chiari et al. (2022)	*n* = 95 people with YOD, *n* = 73 people with older-onset dementia	Italy	Cross-sectional cohort study	Primary aim “to compare time to diagnosis between YOD and older-onset dementia patients consecutively seen in the same specialist cognitive neurology service." Secondary aim to identify “clinical, demographic, and social factors mostly affect the time taken to reach a diagnosis.”	Specialist cognitive neurology clinic specialist (Centre for Dementia and Cognitive Disorders)	Describes the Centre for Dementia and Cognitive Disorders. Primary outcome: time to diagnosis (time between symptom onset and the diagnosis). Secondary outcome: clinical characteristics.	Time to dementia diagnosis 45.5 months. Factors contributing to delay – delay in appointment, depression, language difficulties.
Davies-Quarrell et al. (2010)	People with YOD	Wales	Service evaluation Qualitative study	“The primary aim of the evaluation was to help generate new insights into the meaning and functioning of the ACE club, as well as to provide pointers for practice	Community	Describes the ACE club and qualitative findings from a service evaluation.	Evaluated using Senses Framework: sense of achievement, belonging, continuity, purpose, security, and significance as key elements in their approach to care and support. Participation in program associated with greater wellbeing, subjective reported.

				drawn from such contributions.”			
Giebel et al. (2020)	*n* = 2 people with YOD, *n* = 5 care partners, *n* = 11 staff	England	Exploratory service evaluation	"The aim of this exploratory service evaluation was to assess the provision and experiences of providing post-diagnostic support to people with YOD and their caregivers, from the perspectives of staff and service users."	Community - Memory assessment service	Evaluation of Wigan Later Life and Memory Service (LLAMS). Focus groups with staff. Semi-structured interviews with people with YOD and care partners.	People with YOD: satisfied with the diagnostic process, expressed need for more post-diagnostic support, including peer support and meaningful activities tailored to needs.
Hendriks et al. (2023)	*n* = 75 people with YOD	Netherlands	Register-based study	“Provide insight in the care use of persons with YOD and identify factors influencing care use”	Community	Service use/care trajectory. Factors influencing decisions and care. Explorative descriptive analyses Qualitative content analysis	Data drawn from GP file database containing written notes. Carer concern was primary reason for GP referral for diagnosis. Mean age of person with YOD = 63.2 (range 32 – 69). 96% were referred to a specialist for diagnosis. Follow up time after diagnosis ranged from 1 year to 6 years. A case manager assigned to 72% of participants. Day respite was used by 42.7%. Other care services were used

							by 44%. Pharmacotherapy was used by 30%.
(Kogata et al., 2024)	*n* = 132 people with YOD or concerned about YOD	Japan	Cross-sectional study	"The study aimed to examine the connection between the content of first-time consultations and the profiles of clients using helplines for YOD."	Community healthcare	Themes of regional YOD helpline use Themes = consultations on medical matters, daily life, work, social resources, financial matters, and miscellaneous topics Association between initial consultations and client profile.	Theme medical matters more common in those who were employed with undiagnosed dementia. Other themes including daily life or work mainly involved individuals diagnosed with dementia.
Konijnenberg et al. (2017)	*n* = 1,325 people with YOD	Sweden Netherlands Denmark	Cohort study	"The aim of this study was to investigate quality-of-care indicators in subjects with EOD from 3 tertiary memory clinics in 3 European countries."	Community healthcare – specialised memory clinic	Quality of care indicators: time to diagnosis, diagnostic investigations undertaken (testing, neuroimaging, biomarkers), treatment (prescription medication), care Quantitative outcomes	Quality of care indicators varied by clinic. Time to diagnosis quality indicator was met by one of three centres (Amsterdam). Targets met for MMSE, neuroimaging and biomarker testing. Differences observed between centres in time to diagnosis between centres: Amsterdam median (IQR) = 3 days (2-4); Copenhagen median (IQR) = 50 (30-78) days; Stockholm median (IQR) = 69 days (19-117).

							Age at diagnosis, median = 60 years (all centres). MMSE median = 23 (all centres).
Loi, Goh, et al. (2022)	*n* = 242 people with YOD	Australia	Retrospective cross-sectional study	"To investigate predictors of diagnostic delay and the impact of a specialist YOD service on time to diagnosis."	Community healthcare – outpatient clinic - specialised service Melbourne Younger Onset Dementia Service (MYOD)	Describes components of the Melbourne Younger Onset Dementia Service (MYOD) services. Examines time to diagnosis and predictors of time to diagnosis.	Predictors of diagnostic delay: younger age at onset, increased number of services consulted prior to diagnosis, having a dementia type other than AD, behavioural-variant frontotemporal dementia. Average increase 20 days diagnostic delay with 1 year age younger. Increase of approximately 6 months in diagnostic delay for each prior service consulted.
Loi, Walterfang, et al. (2022)	N/A	Australia	Narrative	To describe the "components of a specialist younger-onset dementia service: a potential model for a dementia-specific service for younger people."	Community healthcare – outpatient clinic – specialised service.	Describes key components of the Melbourne Younger Onset Dementia Service (MYOD) service.	Service offers multidisciplinary assessment, follow-up, support, psychoeducation, referral to age-appropriate services, access to clinical trials. Neuropsychiatry: "tertiary specialist state-wide service located at the Royal Melbourne Hospital"

Morhardt et al. (2015)	N/A	USA	Narrative	"The goal of the Care Pathway Model for Dementia (CARE-D) is to improve quality of life and daily functioning both for individuals diagnosed with dementia and for their families or other caregivers." "This article describes the conceptual design and implementation of CARE-D".	Community, outpatient clinic Model focus on identifying care pathway to address the individuals' symptoms.	Describes the CARE-D model and implementation.	CARE-D has three components: assessment of neurocognitive profile, psychosocial assessment, specific strategies, and recommendations. Tailored care model with different pathways: memory care, language care, visuospatial care, behaviour care. Flexible and adaptive over time as needs change. Delivered by an interdisciplinary team of neuropsychologists, speech and occupational therapists.
Ramluggun and Ogo (2016)	N/A	England	Narrative	"This article critically explores the additional challenges faced by the younger population suffering from dementia, including the service provision,	Community - comprehensive specialist service model	Describes challenges faced in accessing care and provides an overview of the Young People with Dementia Service North Cambridgeshire.	Describes the challenges faced in accessing care and provides an overview of a comprehensive specialist service model.

				pathways, and delivery."			
Tilki et al. (2023)	*n* = 48 people with YOD	England	Qualitative	"This paper aims to showcase an innovative programme of physical activity and sport to enhance the health and well-being of people with Young Onset Dementia (YOD)."	Community collaboration .	Describes a collaborative model between Peaceful Place (day service for people with YOD) and Sport for Confidence in Essex, UK. Examines qualitative outcomes, subjective program benefits.	Subjective benefits included: increased fitness and mobility; reduction in depression and anxiety; fun, enjoyment, self-esteem; improvement in confidence; increased social interaction.
van Duinen-van den Ijssel et al. (2020)	*n* = 274 people with YOD	Netherlands	Cluster randomised controlled trial.	"The aim of this study was to compare the costs and the consequences of the intervention for the management of NPS with nursing home care as usual".	Residential care Specialised unit	Describes BEYOND-II program. Examines care cost: staff absence, psychotropic drug use, staff time. Cost-consequence analysis.	Care time: Change in care minutes with physician during intervention (52 minutes) compared to care as usual (79 minutes). Care costs: mean cost of physician decreased from €292.52 (SD €605.40) to €255.73 (SD €445.45) when the intervention was applied.
van Duinen-van den Ijssel, Appelhof, et al. (2018)	N/A	Netherlands	Protocol	"The Behavior and Evolution of Young ONset Dementia part 2 (BEYOND-II) study aims to	Residential care Specialised unit	Primary outcomes (people with YOD) Cohen-Mansfield Agitation Inventory (CMAI) score and the	Describes care program of educational program combined with an intervention to manage neuropsychiatric symptoms.

				improve the management of neuropsychiatric symptoms in institutionalized people with young onset dementia."		Neuropsychiatric Inventory-Nursing Home (NPI-NH) Secondary outcomes (staff) Quality of Life, burnout (UBOS), job satisfaction (LQWQ), and job demand (LQWQ)	Includes the evaluation of psychotropic drug prescription, detection, analysis. (including the detection of unmet needs), treatment and the evaluation of symptoms.
Wheeler (2015)	*n* = 178	England	Pilot study	To assess the effects and usefulness of a service partnership between Bermingham Working Age Dementia Service and Citizens Advice Bureau.	Community collaboration	Describes a collaboration between Birmingham Working Age Dementia Service (WADS) and the Citizens Advice Bureau (CAB) funded by Birmingham city council as a one year pilot. Quantitative (program evaluation) and qualitative (interviews) outcomes.	Financial outcomes: After 12 months program staff had assisted 96 people with YOD and 82 care partners Collectively, financial benefits totalling more than £196,210 were identified associated with service use. Service evaluation: A total of 23 people completed service evaluations. 91% stated that the advocate understood their problems very well and 87% stated that the advice was very useful, 74% stated that the advice had made ‘a lot of difference’ and 78% reported feeling very happy with the service. Interviews were conducted with 13 participants and positive

							comments about service use were received.
Yeung et al. (2021)	*n* = 173 YOD, *n* = 3553 older-onset dementia	England	Retrospective cross-sectional study	"In order to inform future service design, we therefore sought to evaluate our patients with established YOD and patients under 65 referred for memory assessment, in comparison with those with LOD."	Community – specialised memory service	Service evaluation of Older Persons Mental Health service Cambridgeshire. Retrospective review of records; detailed review of case notes. Health of the Nation Outcome Scales (HoNOS). Addenbrooke's Cognitive Examination (ACE).	Service model described. Outcomes: YOD was 2% of referrals and caseload. YOD compared to older-onset dementia: HoNOS scores on entry to the service: YOD higher scores for depression ($p < 0.001$), occupation ($p = 0.01$) and 'other' ($p < 0.001$).

Abbreviations: AD = Alzheimer's disease; BEYOND-II = Behaviour and Evolution of Young Onset Dementia part 2; BRIGHT-YOD: Bridging gaps in health using telepsychiatry for young onset dementia; CARE-D = Care Pathway Model for Dementia; EOD = Early onset dementia; GP = General Practitioner; LOD = late-onset dementia; NDIS: National Disability Insurance Scheme; NPS = Neuropsychiatric symptoms; YOD = younger onset dementia.

Description of identified models

This section describes the models identified in the review, grouped according to their shared features: (a) systems level models, including national frameworks, referral pathways, guidelines and funding models; (b) specialised services and memory clinic models, including those within-systems, integrated and collaborative care models and (d) supportive care models.

Systems-level models

Structures and systems level models were identified, including those at national and community levels to promote diagnosis and care for people with YOD. This included national frameworks, funding models referral pathways and guidelines.

The Dutch National YOD Model

The Dutch National YOD model includes components at the national, regional and local levels to improve YOD care and promote quality and consistency across regions (Bakker et al., 2022). This model is an example of a ‘hub and spoke’ system, including a national Knowledge Centre which acts as a “hub”. The Knowledge Centre has developed standards and guidelines for care delivery and provides education and training for healthcare professionals and others involved in YOD care. At the regional level (the “spokes”), there are dedicated YOD centres that coordinate delivery of specific services and care at local levels using case managers and primary care providers. While the model aims to provide greater consistency and access to care, geographical variability affects the availability of suitable services, with fewer services available in remote areas. Barriers were also identified in care integration and in accessing services.

The Dutch YOD model also includes a primary care component, in which a GP initiates referrals to diagnostic services and most participants (96%) are referred to a specialist. Pharmacotherapy for dementia was received by 30.6% of participants, and a case manager was assigned in 72% of cases. Of these, 57.1% received a case manager within the first year following diagnosis. Evaluation of this model component (Hendriks et al., 2023) demonstrated that a higher percentage of people without a case manager were admitted to long term care (63.6%) compared to those with a case manager (35.8%).

Japanese National Early Onset Dementia Support Centre

Similar to the Dutch model, the Japanese national dementia model operates at national, regional and local levels. At the national level, the National Dementia Care and Research Centre offers education and guidance on care practices. As part of the national framework, a dedicated telephone support and advice helpline for YOD is available (Kogata et al., 2024). The helpline is staffed by care coordinators and is available to people with YOD, family members, healthcare professionals, and those with concerns related to YOD. Care coordinators can offer personalised support, advice and information related to a range of concerns including diagnosis, medical management, social care, navigating daily activities, maintaining community engagement and employment-related issues. They may also help callers access locally available resources. The helpline may serve as a first point of contact for accessing services, including diagnostic services in the local community. An evaluation of the helpline by Kogata et al. (2024) used data from 132 people with or without a YOD diagnosis who accessed the helpline. The helpline consultations mostly involved consultations for people who were employed but without a dementia diagnosis and seeking information on receiving a diagnosis, and advice on daily life and work for people who did have a diagnosis. As the helpline is most often used for concerns relating to people with older-onset dementia, the authors suggest it was unique that people with YOD were using the helpline for concerns relating to themselves and their employment.

UK Young Dementia Network Young Onset Dementia pathway and recommendations

In the United Kingdom (UK), recommendations set forth by the Young Dementia Network for a national YOD dementia pathway (Young Dementia Network, 2024d) and guidance for people with YOD to support the implementation of NICE Dementia Guidelines have been proposed (Young Dementia Network, 2021). The Young Dementia Network is an online collaborative community, including people with dementia, professionals and organisations, with the aim of improving awareness, research and initiatives and improving the lives of people affected by YOD (Young Dementia Network, 2024c). The recommendations for a YOD pathway focus on the use and adaptation of existing services, coordination between providers, and emphasise the importance of practices to serve the specific needs of people with YOD and their family members. This includes a dedicated clinical lead for services for people with YOD. The recommendations also identify the importance of early assessment and comprehensive diagnosis delivered by those with expertise in YOD. Further, the use of a multidisciplinary approach, access to a care plan and post-diagnostic care, addressing changing needs over time, care navigation, legal and financial advice and planning. The extent to which the pathway recommendations have been implemented within organisations is unclear. However, a recent report by Dementia UK stated that there is “an urgent need for a mandated young onset dementia pathway” within every Integrated Care System to support diagnosis, post-diagnostic support and a coordinated care plan” (Dementia UK, 2024).

The recommendations provided by the Young Dementia Network to support the existing NICE Dementia guidelines (National Institute for Health and Care Excellence, 2018) highlight additional considerations to support people with YOD within a number of domains including diagnosis, care coordination, post-diagnostic care and support (Young Dementia Network, 2021). These recommendations include improving awareness of symptoms of YOD among GP’s, supporting access to specialist services, and the use of a comprehensive assessment process to improve timely and accurate dementia diagnosis. The inclusion of a dedicated care coordinator or key worker to support care planning across multiple domains, including those that may be unique to people with YOD such as navigating employment-related concerns, is recommended. While NICE guidelines include a person-centred approach and recognise the importance of including the person with dementia in decision-making and family members or care partners, the Young Dementia Network recommendations underscore the importance of considering family members and their needs. The importance of age-appropriate post-diagnostic interventions and care is also identified, along with a need for tailored information and support suitable for people with YOD and their family members.

YOD Referral Pathway Ireland

There is a dedicated referral pathway for YOD described within Ireland's dementia care model (Begley et al., 2023). The YOD referral pathway begins with GP assessment, referral for diagnostic assessment, and post-diagnostic support where appropriate (Begley et al., 2023). The pathway stipulates that post-diagnostic supports should include cognitive therapies and specific advice around employment and financial planning. The referral pathway also considers the potential for diagnosis of mild cognitive decline and provides recommended alternative approaches, such as referral to risk reduction programs involving lifestyle and behavioural support. All professionals having contact with people with YOD are expected to be aware of and follow recommended referral pathways.

NDIS support for YOD in Australia

In Australia, the NDIS is a funding model that provides individual support packages to people with YOD diagnosed before age 65. Eligible people can apply for funding after receiving a diagnosis and are allocated funds to access reasonable and necessary post-diagnostic care service. Importantly, current regulations prevent the use of NDIS funding for services or access to health care for care partners, except in relation to respite.

Cations et al. (2022) conducted a cross-sectional online survey of 151 people with YOD and care partners in Australia, 60% of whom had a NDIS plan. The findings suggest those with an NDIS plan were accessing a range of support services for in-home support, allied health, transport, and social support. A need for further knowledge and understanding about dementia within the NDIS system and disability workforce, particularly pertaining to physical needs, was identified. However, most people using NDIS indicated that the system was, for them, preferable to receiving care through the aged care funding system.

Care coordinator service via the Dementia Australia Young Onset Key Worker Program (Australia)

The Dementia Australia Key Worker Program (Westera et al., 2014) is a now-defunded national initiative to improve care and support for people with YOD and their family members or care partners by providing individualised support through a central point of contact. Trained key workers were assigned to people with YOD to coordinate and assist with identifying and accessing services health, social and community care settings. The key worker offered individualised support, liaise with local services, and provide referrals. Together with the key worker, people with YOD could explore goals in collaboration with the key worker to achieve goals in a range of domains including health-related goals, individual care and support, and activities. Counselling was also available to people with YOD and care partners. Findings from a survey of 94 participants found that most (91%) indicated their needs were met through this program (Westera et al., 2014). However, evaluation of the service did note that Key Workers faced difficulty with program scope and that a high level of time was required to support a relatively small number of people with YOD with high needs.

BEYOND-II (Netherlands)

The Behaviour and Evolution of Young Onset Dementia Part 2 (BEYOND-II) is a structured care model aimed to improve the identification and management of neuropsychiatric symptoms in people with YOD living in residential care settings in the Netherlands (Appelhof et al., 2018; van Duinen-van den Ijssel et al., 2020; van Duinen-van den Ijssel, Appelhof, et al., 2018; van Duinen-van den Ijssel et al., 2019). The protocol for the model was described in one source (van Duinen-van den Ijssel, Appelhof, et al., 2018). The program includes staff education and decision-making tools to improve the detection of neuropsychiatric symptoms through regular screening and considers potential causes including an assessment of unmet needs. A core element of the model is the use of a multidisciplinary approach to individual treatment planning and the evaluation of psychotropic medication use. Components of the model include staff training and modified treatment approaches for management of neuropsychiatric symptoms.

The BEYOND-II model was investigated within 13 specialised care units for people with YOD in a residential care setting in different locations within the Netherlands. The process of implementation and effectiveness in improving neuropsychiatric symptom management was examined in one included source (Appelhof et al., 2018).

The program evaluation demonstrated that staff satisfaction was high but implementing the model was generally considered unfeasible owing in part to time constraints. However, implementation and adherence to the program components varied across the included sites, with barriers including staff and organisational factors, while facilitations included strong multidisciplinary teams and leadership. A cost consequence analysis of BEYOND-II was conducted by van Duinen-van den Ijssel et al. (2020), who identified no significant difference in the costs between the care units delivering the intervention and those who provided care as usual. The time required by physicians decreased, while time required by psychologists increased. A study by (van Duinen-van den Ijssel et al., 2019) evaluated staff outcomes following implementation of BEYOND-II and found that the program was not associated with outcomes such as burnout, job satisfaction and demands. However, use of the model was associated with decreased job satisfaction and increased emotional exhaustion among registered nurses.

Young onset dementia in national dementia plans and strategies

In addition to the examples of systems level approaches described, several countries refer to YOD assessment, diagnosis and care within their national dementia plans as outlined in **Table 3**. Some plans describe people with YOD as having specific or unique needs. General recommendations for care or management of people with YOD were made within most national plans, through detailed and specific recommendations specific for YOD were not commonly included.

Table 3. Overview of components related to young onset dementia in a sample of national dementia plans and strategies

Country (Year) **Title**	**Recommendations**
Australia (2015) National Dementia Action Plan 2015 – 2019	The plan recognises that people with YOD require access to specific information, support, and counselling needs, and they may need to discuss their current situation in terms of their abilities, changing needs, and potentially their work conditions, with family, work, colleagues, community, and social groups. Improved support for people with YOD through the provision of a link or key worker is also recognised, as well as support to remain in employment for as long as possible and to maintain family and community participation. The development of flexible clinical referral and care pathways is recommended. Subsequently, new service models are recommended, supported by policy and practice. The preferences for respite and residential care for people with YOD need to be taken into consideration through a more person-centred approach with individualised funding options.
Canada (2019) A Dementia Strategy for Canada	The strategy states that all people with YOD should be referred to a memory clinic with access to genetic counselling and testing, and those with a rapidly progressing dementia should have access to consultation with a specialist. It is also acknowledged that improvement is needed for age-appropriate services to increase access to geriatricians with YOD-specific skills and knowledge.
Denmark (2017) National Action Plan on Dementia 2025	The plan aims for 80% of people with YOD to have a specific diagnosis. Increased quality and flexibility of daycare centres and relief care with a focus on specific problems faced by relatives of people with YOD is also stated. Access to counselling and activity centres for people with dementia and their relatives, including people with YOD is mentioned, and these centres should focus on support, counselling, social and physical activities.
England (2009) Living Well with Dementia: A National Dementia Strategy	The strategy states the need for public information campaigns and services with tailored approaches people with YOD, and a focus on supporting people to be supported to stay in their home. A trained and competent workforce with an understanding of the diversity of dementia (including YOD) is also required.
Germany (2020) National Dementia Strategy	The strategy states a need to extend counselling and support structures for people with early-onset dementia and their family members via 1) Expansion of information and continuing education resources; 2) Support of local support networks by integration offices; and 3) Moderated online groups.
Ireland (2014) The National Dementia Strategy	The strategy specifically includes people with YOD, noting that their difficulties are compounded by multiple responsibilities, including employment, financial, and parental and family responsibilities. In addition, the critical need for health professionals and service providers to be trained to meet the needs of people with YOD is recognised.

Japan (2019) The National Framework for Promotion of Dementia Policies	The framework promotes the creation of barrier-free spaces and services and opportunities for social participation for people with dementia, including YOD. Creating barrier-free spaces incorporates several dementia-friendly initiatives, including aspects of community engagement, transportation, housing security, reinforcing support systems, consumer, and financial protection, and reducing abuse.
Malta (2024) Reaching New Heights, National Dementia Strategy for the Maltese Islands 2024 – 2031	The strategy states that services must be aware of YOD-specific resources and service options.
Netherlands (2020) The National Dementia Strategy 2021 - 2030	The strategy acknowledges that people with YOD often have a different position in society and are in a better state of health and stronger physical condition than those who develop dementia at a later life stage. Therefore, their requirements for support are different and while their support can be included within regular dementia programs, collaboration with relevant parties such as the Knowledge Centre for Younger Persons with Dementia is recommended.
New Zealand (2020) New Zealand Framework for Dementia Care	District health boards are suggested to develop regional and local governance boards to ensure a consistent approach for complex dementia cases including YOD. Health services should ensure timely referral to a specialist team within a secondary health care service for people suspected of YOD following a cognitive assessment.
Norway (2020) Dementia Plan 2025	The plan recognises that it is essential to provide activity services that are an integrated part of the local community to meet the needs of people with YOD. Specialist health services for assessment and diagnostics are necessary to address YOD, and following diagnosis, increased competency in the workforce for nutrition, physical activity, and adaptation for groups with special needs are required, including for people with YOD.
South Korea (2020) National Dementia Plan (4th)	Strengthened support for YOD including daycare programs at local dementia centres, information websites and counselling services, and prioritisation of public works programs by local governments.
USA (2023) National Plan to Address Alzheimer's Disease Update	The plan states that timely and accurate diagnosis is particularly important in YOD and requires optimal assessment tools and technology to detect and monitor cognitive changes. Rebalancing Medicaid long-term services and supports towards home and community-based services for subpopulations with dementia, including YOD, is also mentioned.
Wales (2018) Dementia Action Plan for Wales 2018 - 2022	The plan acknowledges that services must address needs of people with YOD and their family members, so they are aware of the support available. Workforce should have access to appropriate information and demonstrate how they are providing meaningful, age-appropriate support in day, respite, or residential care.

Specialised services and memory clinic models

Specialised services and memory clinic models for people with YOD, including those that were within existing services and operated under principles of integrated or collaborative care, often involved medical specialists and multidisciplinary teams, care coordinators and care plans. Some services offer comprehensive assessment and post-diagnostic care, while others are limited to diagnosis of dementia and rely on principles of shared care involving a GP for ongoing management.

Melbourne Young Onset Dementia (MYOD) (Australia)

The Melbourne Young Onset Dementia (MYOD) program is a dedicated memory assessment and care service based at the Royal Melbourne Hospital tailored to the needs of people with YOD (Loi, Goh, et al., 2022; Loi, Walterfang, et al., 2022). The MYOD service is funded by the state health system, aiming to reduce diagnostic delay by providing rapid access to diagnostic services and post-diagnostic care. Two articles described the MYOD program and its outcomes (Loi, Goh, et al., 2022; Loi, Walterfang, et al., 2022). One study described the components of the service model, which features a multidisciplinary approach, comprehensive diagnostic service including neuropsychological testing, neuroimaging, and biomarker and genetic testing, and access to post-diagnostic care, education and support including referrals to allied health services (Loi, Walterfang, et al., 2022).

An evaluation study Loi, Goh, et al. (2022) described time to diagnosis and diagnostic accuracy in a sample of 242 people with YOD, with the mean time from symptom onset to diagnosis 3.4 years. Time to diagnosis for people with YOD before and after the service was established was compared. The MYOD service reduced the time to diagnosis to 2.8 years compared to 3.8 years pre-MYOD service ($p = .02$). The MYOD service also led to better recognition of YOD among community mental health, geriatric, and neurology services. Weekly case conferences and an eight-bed inpatient unit, which enabled comprehensive assessment during a two-week admission, also contributed to the reduced time to diagnosis. Interestingly, across the entire sample, an increase in the number of services that people consulted in effort to receive a diagnosis led to a decrease of 0.47 years in diagnostic delay on average.

Bridging Gaps in Health using Telepsychiatry for Young Onset Dementia (BRIGHT-YOD) (Australia)

The Bridging Gaps in Health using Telepsychiatry for Young Onset Dementia (BRIGHT-YOD) program is a model of service delivery to improve access to assessment and diagnosis services and support to people with YOD living in regional and rural Australian areas using telehealth in addition to existing resources (Brown et al., 2023; Farrand et al., 2019). The project was funded by a Better Care Victoria Innovation Fund Grant via a branch of the Victorian Department of Health, and a collaboration between Royal Melbourne Hospital, NorthWestern Mental Health and the MYOD service.

The model is described as a “hub-and-spoke" approach which includes collaborations between clinicians within a metropolitan specialist service, the Centre for Dementia and Cognitive Disorders, healthcare providers based in Melbourne, and locally based providers in rural and regional areas. The program includes comprehensive diagnostic assessment, delivered by neuropsychiatry and neuropsychology specialists, in addition to multidisciplinary care, and support and education for people with YOD and care partners. A further aim was to build capacity within teams of local healthcare providers by providing professional education opportunities and support (Farrand et al., 2019).

One qualitative study described the program components and explored the feasibility of the program from the perspectives of healthcare providers (Brown et al., 2023). The participants, who were clinicians at different sites, took part in interviews at both the pre-implementation and post-implementation phases. The use of telehealth was evaluated positively by most clinicians, and from their perspective, telehealth increased access diagnostic and post-diagnostic care in regional Victoria where services are otherwise limited (Brown et al., 2023). Clinicians reported access to local support as facilitators to telehealth delivery and identifying suitable patients. Barriers were also identified, including limited access to quality technology, a need for training for clinicians to use telehealth, lack of resources to reduce administrative and scheduling difficulties, and limitations of telehealth for conducting physical and neuropsychological assessments. According to Farrand et al. (2019), the program increased equity in access to and reduced travel time for people with YOD. A reduction in environmental impacts associated with reduced travel time were also highlighted, including lower carbon emissions.

Tertiary memory clinics in Sweden, the Netherlands and Denmark

Tertiary memory clinics in three major European cities were described in one study exploring diagnosis of YOD and quality-of-care indicators (Konijnenberg et al., 2017). The clinics were located at Karolinska University Hospital in Stockholm, Sweden, VU University Medical Center in Amsterdam, the Netherlands and the Rigshospitalet specialist hospital in Copenhagen, Denmark. The memory clinics provide comprehensive diagnostic assessment and care for dementia. Differences in quality indicators between the three centres were explored as a key outcome, although notably these indicators were developed for people with older-onset dementia.

There were differences in the proportion of YOD cases identified between the locations, with YOD diagnosed more frequently in Amsterdam (48% of cases), while both Copenhagen and Stockholm saw less than half (20% and 21%, respectively) this frequency of diagnosis. Time to diagnosis differed substantially between centres, with median time to diagnosis in Amsterdam three days, Copenhagen was 50 days and Stockholm was 69 days (Konijnenberg et al., 2017). While the entire diagnostic process, including neuroimaging, was described as occurring on a single visit in a ‘one-stop-shop' clinic model in Amsterdam, the process in Copenhagen and Stockholm took multiple visits, and the wait time for neuroimaging services alone was between two to three months. Overall, the quality indicators were not always met during the diagnosis of YOD, and the authors recommended the development of YOD-specific quality indicators to reduce diagnostic delay including reduced waiting times for neuroimaging and standardised procedures for diagnosing YOD.

NHS Young People with Dementia Service (YPWD) North Cambridgeshire (England)

The Young People with Dementia Service (YPWD) teams are available countrywide in England and operate in location-based teams. Specific services may differ based on individual locations. The components of the YPWD North Cambridgeshire service, a dedicated service for people with YOD, were described in one source (Ramluggun & Ogo, 2016). The service aims to provide comprehensive support services to people with YOD and their family members. This includes a holistic, interdisciplinary approach and collaboration with allied health, social and community care providers in addition to practical support.

NHS Young Onset Dementia Service (YODS) (England)

The NHS Young Onset Dementia Service is a specialised team for people with YOD and typically operates within local NHS Community Mental Health services in England. The YODS Doncaster service was described in detail in one source (Bottomley, 2023). This service includes a specialist multidisciplinary team including medical specialists and allied health professionals and offers diagnosis, treatment, and care. Comprehensive assessment and post-diagnostic care are provided, in addition to care planning, carer support and education. The service aims to provide people with access to YOD treatment within six weeks of referral and achieved this target for 85% of people (Bottomley, 2023).

NHS Memory Assessment Service – Wigan Later Life and Memory Service (England)

The Wigan Later Life and Memory Service provides comprehensive diagnostic and post-diagnostic services to people with dementia. While the service has included those with YOD, as described in a service evaluation by Giebel et al. (2020), it is not a dedicated service for YOD. This service was evaluated using focus groups with people with YOD, care partners and staff (Giebel et al., 2020). The service consists of a multidisciplinary team including a consultant psychiatrist, nursing staff and allied health professionals. Post-diagnostic support is available including support and education, medical management, and non-pharmacological interventions. Findings from the focus groups with staff and interviews with people with YOD and care partners suggest that both groups were satisfied with the diagnostic process but identified a lack of subsequent post-diagnostic support including peer support, meaningful activities and tailored information related to YOD. Within the education program, people with YOD often felt out of place and there was a preference for more tailored YOD information and support. People using the service are discharged to their GP for ongoing care.

NHS Old Age Psychiatry Service Berkshire – Wokingham Memory Assessment Service (England)

The Wokingham Memory Assessment Service operates within the Old Age Psychiatry Service in Berkshire, England and provides a dedicated care pathway for people with YOD. This service specialises in memory assessment, psychosocial interventions and support and education for people with dementia and has a dedicated pathway for people with YOD and care partners. Additional access to post-diagnostic support is provided through referral to a local charity service (Hussey & Butler, 2019). The diagnostic assessment includes referral to a consultant psychiatrist dedicated to YOD diagnosis and follow-up, nursing and allied health professionals, access to post-diagnostic support, counselling and education programs, and peer support groups. The service also provides access to legal advice and day respite services. Two sources described the Wokingham service. One source provided an overview of the model and staffing (National Collaborating Centre for Mental Health, 2018). One retrospective record review examined the time to diagnosis and time to post-diagnostic care (Hussey & Butler, 2019). The average time to diagnosis was 9.7 months. On average, people diagnosed within six months had two specialist consults, and those diagnosed in greater than six months had three consults. Receiving psychosocial intervention took an average of 10.9 weeks, but 65% were offered a referral to the local YOD charity service within eight weeks.

NHS Older Persons Mental Health Service Cambridgeshire (England)

The Older Person’s Mental Health Service (OPMHS) service in Cambridgeshire, England was described as providing diagnostic services to people with dementia and YOD (Yeung et al., 2021). The service includes a consultant psychiatrist and a multidisciplinary team including those who specialise in care for YOD. A study by M. Yeung et al. (2021) compared data between 173 people with YOD and 3,553 with older-onset dementia assessed and diagnosed within the service, concluding that a separate service for YOD was not warranted. However, this was attributed to the number of people with YOD in the large rural region they serve as it was said to not be practical to have a specialist team covering the area. Therefore, assessment by a consultant psychiatrist in consultation with a neurologist was deemed more suitable to address the needs of people with YOD for this service.

Leeds joint working model, collaboration between neurology and psychiatry services (England)

The Leeds joint working model is a collaboration between two specialised services, the psychiatry-led Leeds Young People with Dementia Service, and the neurology-led Leeds Neurology Cognitive Service. The joint working model operates as a monthly clinic (Young Dementia Network, 2024b). The service provides diagnostic assessment and care for people with YOD and offers access to a multidisciplinary team including medical doctors, nurses, a neuropsychologist, occupational therapist, and clinical team manager. There is a comprehensive diagnostic process including screening, neuropsychological assessment, and neuroimaging. As of June 2024, 131 people were reviewed, with 104 diagnosed and 42 given post-diagnostic support. The average time to diagnosis from referral was eight months. Post-diagnostic support includes medical management of symptoms. Post-diagnostic support and education may be offered. Further post-diagnostic support is provided through referral to the Leeds Dementia Hub or Leeds Adult Social Care service.

Centre for Cognitive Disorders and Dementia (Italy)

The Centre for Cognitive Disorders and Dementia is a specialised memory clinic providing diagnostic services for people with dementia, including those with suspected YOD, in Modena, Italy (Chiari et al., 2022). Access to the clinic is obtained through referral from a GP or other healthcare provider. The services include comprehensive diagnostic assessments, medical management and specialist referrals and are undertaken by a multidisciplinary team, including a neurologist, neuropsychologist, and other medical and allied health providers. The assessment includes complete clinical history, neuropsychological testing, neurological examination, neuroimaging, and assessment of fluid biomarkers and genetic testing if indicated.

Findings from one study described the mean time to dementia diagnosis for people with YOD (*n* = 95) was 45.5 months (Chiari et al., 2022). Compared to those diagnosed with older-onset dementia (*n* = 73), there was no significant difference in time to dementia diagnosis (*p* = .09). However, a disease-specific dementia diagnosis for people with YOD took 11.2 months longer than those with older-onset dementia, which represents a statistically significant difference (*p* = .022) in time to diagnosis. Delays in time to diagnosis were attributed to the length of time between referral and the first cognitive assessment and presence of language disturbances and coexisting depression. The authors concluded that more awareness and education on YOD are needed to address diagnostic delay.

Care Pathway Model for Dementia (US)

The Care Pathway Model for Dementia (CARE-D) is a comprehensive, specialised interdisciplinary care model tailored to the unique needs of people with YOD, established at the Alzheimer's Disease Centre at Northwestern University in the US (Morhardt et al., 2015). Access to the program is through referral from a healthcare provider. The care model includes comprehensive diagnostic evaluation, medical management, and psychosocial care. The post-diagnostic care program is personalised to the needs of the person with YOD and includes a detailed assessment process, psychosocial assessment and symptom profile which are used to develop a comprehensive care plan. There are five designated care pathways which reflect different domains, including memory, language, visuospatial, behaviour/comportment and psychiatric and neurologic symptoms. Each pathway includes general goals, strategies and supports which are tailored to the needs of the individual. The inclusion of specific care pathways and their sequence is determined by the assessment process, individual goals, and care plan. Treatment is delivered by a multidisciplinary team including neurologists, neuropsychiatrists, neuropsychologists, social workers, speech pathologists and occupational therapists. Support and education are available to family members and care partners.

Care Ecosystem Model (US)

The University of California San Francisco Care Ecosystem model is a comprehensive care model for dementia and includes a specific pathway that can be tailored to YOD. This includes assessment and diagnosis, individual care plans, a care navigator, access to a multidisciplinary team, support and education, counselling, peer support, day respite and legal and financial advice. The Care Ecosystem has a YOD protocol which includes age-appropriate advice relating to legal and financial implications, and information for children of people with YOD (Dulaney, 2022). Five key steps are described to assist people with YOD with their concerns: 1) consideration of capacity to manage their own affairs; 2) determining if the carer has legal authority to manage the persons financial affairs; 3) assessing the persons employment and income status; 4) considering their insurance options; and 5) providing education and referral to support services.

Jockey Club Early Onset Dementia Support Program (Hong Kong)

The Jockey Club Early Onset Dementia Support program (Jockey Club Centre for Positive Ageing, 2024) is a pilot program at the Jockey Club Centre for Positive Ageing in Hong Kong. The program incorporates diagnostic assessment, a case manager, referrals to allied health specialists and family therapy, post-diagnostic support and care for people with suspected or diagnosed YOD. The program aims to increase access to diagnostic services for people suspected of YOD, provide suitable post-diagnostic care, and improve outcomes for people with YOD and their family members. It was designed based on the Dementia Australia Young Onset Key Worker Program. Following diagnosis and enrolment in the program, a case manager is assigned, and the follow-up service provides a total of ten sessions for between three and six months. The follow-up service includes a half-day at a day care centre, education, and carer strategies to manage stress (including access to an online platform for care partners), life coaching for the person with YOD, a well-being action plan, and advice on community resources.

Supportive care models

ACE Club (Wales)

The ACE Club describes its YOD day program as a member-led group, aimed to promote peer support and meaningful activity for people with YOD and family members (Davies-Quarrell et al., 2010). The study describes qualitative findings from the ACE Club, a day respite service model with a relationship-centred approach that also includes referral pathways with local healthcare providers and other local agencies. Services delivery was described as a relationship-centred care approach with people with YOD central to the operation of the program. Family members and care partners are also welcome to participate in activities. A self-evaluation by Davies-Quarrell et al. (2010) reports a range of subjective benefits related to participation using the Sense Framework which is a theoretical framework for people with dementia staff, and family care partners comprising six senses: security, continuity, belonging, purpose, achievement, and significance. Members of the ACE Club reported an increase in self-esteem, companionship, improved insight, and acceptance of dementia, and regained their sense of self.

Peaceful Place Essex and Sport for Confidence Program (England)

The collaboration between two services, a day service for people with YOD, ‘Peaceful Place Essex’ and a community program called Sport for Confidence was described in one study (Tilki et al., 2023). This collaboration between services offers a model of care that provides day respite, meaningful activity, physical activity, and peer support for people with YOD. The study described qualitative findings and collated the experiences of 60 participants in the program, 48 of whom were people with YOD who took part in a range of activities. Feedback from staff was also obtained and subjective reports of outcomes were described. The program was described as having a range of physical, social, and emotional benefits for people with YOD. Staff also described positive experiences associated with program delivery.

Welfare advice and advocacy service (England)

A study by Wheeler et al. (2015) described a unique model involving a partnership between two services, the Birmingham Working Age Dementia Service which primarily delivers healthcare-related services, and the local Citizens Advice Bureau. The service aimed to provide individualised financial guidance and advocacy to people with YOD and their family members. Among the 96 participants with YOD and 82 care partners, there were significant financial benefits totalling more than £196,210 in benefits (Wheeler et al., 2015). The service evaluation including 23 participants revealed that 87% found the advice very useful and 74% indicated that the service had made a “a lot of difference” (Wheeler et al., 2015). Qualitative findings from 13 interviews revealed that beyond the financial benefits that were received, participants found that the service helped them to overcome barriers to accessing social welfare such as difficulty completing forms or otherwise navigating the application processes. Navigating debt reduction was also a theme identified in interviews, with one example of advocacy within the service contributing to reducing debt payments that allowed for improvements in the day-to-day financial situation. The access to personalised support and assistance was identified as key benefit by those who used the service. In addition, the service was family-inclusive, and one carer stated that if it were not for the staff advocate “... life would have been much more difficult” (Wheeler et a., 2015). Participants also expressed relief and hope after learning more about their rights, such as flexible working and care partners allowances.

Other

There are other examples of care models, but publications evaluating or describing the details of the services were not identified in searches. These include (among others):

- Young Onset Dementia Service (NHS Greater Glasgow & Clyde)
- Johns Hopkins FTD and Young-Onset Dementias Clinic, Johns Hopkins Medicine (Baltimore, US)
- Concord Early-onset Familial Dementia Clinic, Frontier Research Group and the University of Sydney (Sydney, Australia)
- Uniting War Memorial Hospital Younger Onset Dementia program (Sydney, Australia)
- Younger Onset Dementia Aotearoa Trust Day Service (Wellington, New Zealand)
- Young Onset Dementia Service offered by Cardiff and Vale University Health Board (Cardiff, UK)

- Florence Centre for Specialized Care in Early Onset Dementia (Mariahoeve, Netherlands)
- Croydon Memory Service (UK) (not YOD specific)
- Glasgow Younger Persons Support Service (GYPSS), Alzheimer Scotland
- Glasgow Younger Persons Support Service (Glasgow, Scotland)
- France National - Multisite reference centre (for YOD) linked with 26 Memory Resources and Research Centres (not YOD specific)
- Brightwater Younger Onset Dementia (Western Australia, Australia)
- Yooralla Young Onset Dementia care homes (Victoria, Australia)
- Community Home Australia (Australian Capital Territory & New South Wales, Australia)

Table 4: Models identified from grey literature

Author (Year)	Sample	Country	Study design	Aims	Outcome Measured	Findings
Bottomley (2023)	N/A	UK	Descriptive, presentation	Nil	Description of NHS Young Onset Dementia Service Doncaster.	Aims to conduct assessment within six weeks of referral.
Farrand et al. (2019)	N/A	Australia	Descriptive report	Nil Describes BRIGHT-YOD model, benefits and challenges of delivery.	Broad evaluation of the program and qualitative data on delivery.	Cost savings due to reduced travel Telehealth acceptable approach to delivery, with some challenges related to technology and internet. The importance of flexible delivery to individual by offering choice of telehealth or face to face delivery.
Hussey and Butler (2019)	N/A	UK	Retrospective audit of service records	The current study aims to explore the time to diagnosis for people with YOD within an Old Psychiatry Memory Clinic in Wokingham which offers YOD assessment and age-appropriate support.	Describes the Wokingham Memory Service Time to diagnosis Time to post-diagnostic care	Mean time to diagnosis 9.7 months. Mean time to psychological intervention 10.9 weeks.

Jockey Club Centre for Positive Ageing (2024)	N/A	Hong Kong	Descriptive	Nil	Describes the Jockey Club Younger Onset Dementia program.	A specialised program providing diagnosis, post-diagnostic care and support for people with YOD and family members or care partners.
National Collaborating Centre for Mental Health (2018)	N/A	UK	Descriptive	Nil	Describes the Wokingham Memory Service details.	N/A
The Royal College of Psychiatrists (2018)	n = 100 consultant old age psychiatrists	UK	Descriptive report Cross-sectional survey	Nil	Describes the service. Evaluates access to diagnostic assessment, post-diagnostic care, multidisciplinary care.	Diagnostic YOD assessment (100%) Multidisciplinary YOD service (29%) - “often limited to nursing staff without access to other healthcare professionals”. Post-diagnostic care (16%) “Integration within and between trusts appeared low and arguably not aligned with the needs of people with YOD.”
Westera et al. (2014)	N = 120 (included people with YOD and family	Australia	Descriptive report Cross-sectional survey	To evaluate the implementation of the key worker program; measure the impact on client access to services	Describes the national Younger Onset Dementia Key Worker Program. Outcomes	Positive impact on clients, assisted in meeting individual goals, high satisfaction.

	members or care partners; Alzheimer's Australia advisory committee; government and industry representatives; key worker program management, team leaders and key workers).			and capacity to maintain social engagement; assess impact on services and broader community.	Client impact, satisfaction, challenges	Key worker offered range of services: information and support; service liaison; referral; counselling. Challenges include delays in service delivery, limited availability, external demands limit referrals.
Young Dementia Network (2024b)	People with YOD	UK	Service evaluation	Nil	Service evaluation - Referral acceptance - Timeliness - Diagnosis - Post-diagnostic support	198 referrals initially accepted and 131 underwent reviews following triage. Of 131 assessments were conducted, 104 were diagnosed with YOD. 42 received post-diagnostic support. Time to first assessment mean = 4 months (range 3 – 498 days) Time to neuropsychology assessment mean = 8 months (range 34 – 334 days)

						Time to diagnosis mean = 8 months (range 3 – 559 days) Time to post-diagnostic support after diagnosis mean = 44 days (range 7 – 132) Service capacity is limited, this affected referral acceptance rate.
Young Dementia Network (2024d)	N/A	UK	Recommendations	Nil	Describes recommendations for pathway for YOD in UK Core components: specialist support following diagnosis, care plan, support for living with a diagnosis and end-of-life care.	N/A
Young Dementia Network (2021)	N/A	UK	Recommendations	Nil	Describes specific recommendations for YOD to accompany NICE guidelines for dementia.	N/A
Begley et al. (2023)	N/A	Ireland	Descriptive	Nil	Describes designated YOD referral pathway in Ireland. Core components: referral to specialist diagnostic assessment, care planning and follow-up, and post-diagnostic interventions.	N/A

Common components of care models for young onset dementia

In summary, common components of care models identified within documents included in this review included:

- Specialised assessment and diagnosis
- Medical management of symptoms
- Collaboration or integration of care, including a care coordinator or key worker
- Access to allied health services
- Care plan and monitoring
- Referrals to community providers
- Peer support
- Post-diagnostic care
- Education and resources
- Meaningful activity
- Day respite
- Long term care
- Financial and legal guidance or advocacy
- Advanced care planning and end of life care
- Family and carer inclusive services and dedicated supports
- Staff education, training or resources to support care

All studies described models of care that consisted of more than one component, with common components of care models outlined in **Table 5.**

Table 5. Model components identified within models described in this review

Model	Author (year)	Diagnosis	Integrated care or coordinated care or case manager	Care plan	Medical management	Access to allied health	Community referrals	Day Respite	Long term care	Psychosocial care	Family focused care	Peer support	Education	Financial/legal advice, support, advocacy	Advanced care planning and end of life care	Staff education or training program or tools
ACE Club	Davies-Quarrell (2010)						X	X		X						
BEYOND-II	Appelhoff (2018) Van Duinen-van den Ijssel (2018; 2019; 2020)			X	X	X			X							X
BRIGHT YOD	Farrand (2019) Brown (2023)	X	X	X	X	X	X			X			X			
Care Ecosystem	Dulaney (2022)		X	X	X	X	X			X	X	X	X	X	X	X

Care Pathway Model for Dementia (CARE-D)	Morhardt (2015)	X	X	X	X	X				X		X	X			
Centre for Dementia and Cognitive Disorders	Chiari (2022)	X		X				X								
Dementia Australia Key Worker Program	Westera (2014)		X	X	X		X					X	X	X	X	X
Jockey Club Early Onset Dementia Support Program	Jockey Club Centre for Positive Ageing (2024)	X	X	X	X	X	X	X			X		X	X		
Leeds Joint Clinic	Young Dementia Network UK (2024)	X		X	X	X	X			X					X	
MYOD	Loi (2022) Loi (2022)	X	X	X	X	X	X			X			X			
NHS Young Onset Dementia Service Doncaster	Bottomley (2023)	X			X	X	X			X	X	X				

NHS Young People with Dementia Service (YPDS)	Ramluggun (2016) National Collaborating Centre for Mental Health (2018)	X	X	X	X	X							X			
Peaceful Place Essex and Sport for Confidence program	Tilki (2023)					X		X		X						
Wigan Later Life and Memory Service (LLAMS)	Giebel and Eastham (2020)	X	X	X				X								
Wokingham Memory Service	Hussey and Butler (2019)	X					X			X	X					

Abbreviations: BEYOND-II = Behaviour and Evolution of Young Onset Dementia part 2; BRIGHT-YOD = Bridging Gaps in Health using Telepsychiatry for Young Onset Dementia; MYOD = Melbourne Younger Onset Dementia service.

*Does not include elements of models where service is partially described or part of larger national model (Kogata, 2022; Hendriks, 2023; Konijnenberg, 2017)

Discussion

People with YOD, together with their family members and care partners, have needs that are often not met by broad dementia-related services. This review explored models of care for people with YOD, which commonly included diagnostic components, post-diagnostic support, psychosocial care, and community support services. Several included reports were descriptive in nature or did not evaluate outcomes associated with the model. There were few models or pathways identified that addressed the needs of this population at the advanced and end stages of dementia. Efforts were made to identify examples of care models from international evidence, though substantial variation often exists even within similar geographical regions or countries.

Systems level approaches

Diagnosis, care and support for people with YOD often fall within the broader dementia care policy and planning strategy at national levels. Supporting evidence can be observed within dementia-related national plans and strategies from several OECD countries, including Australia, Ireland, Japan, and the Netherlands where there was acknowledgement of the specific needs of those with YOD and their family members or care partners, and recognition that this may fall outside of the scope of broad dementia-related services intended for older people. However, detailed recommendations and guidelines for these services were not often identified within national plans or policy documents, and the level of detail related varied substantially, from brief mention to detailed recommendations to guide service provision.

Specific referral and care pathways for YOD were identified in health policy documents in Ireland (Begley et al., 2023), while recommendations for a specific pathway were outlined by the Young Dementia Network (Young Dementia Network, 2024d). Other efforts to improve outcomes, such as an emphasis on improving community inclusivity for people with dementia and barrier-free spaces, were found in plans in countries such as Japan and the Netherlands.

Some countries have clearly defined systems level approaches to care for people with YOD, including networks of memory clinics, in countries such as Italy and the Netherlands. The Dutch National Infrastructure model for YOD is a framework with components at the national, regional, and local levels and includes a national knowledge centre, care standards, specialised memory clinics and care coordination (Bakker et al., 2022). While specialised care is provided through memory clinics in the Netherlands and provides diagnosis and care for people with YOD, significant regional variability in services remains a barrier to access even where practice guidelines and policies are in place. The Prevalence, Recognition, and Care pathways in young-onset Dementia (PRECODE-GP) study examines data from memory clinics in the Netherlands to understand care pathways for YOD, and the importance of specialised care pathways and a multidisciplinary care approach has been highlighted (van Gils et al., 2023).

Similarly, in Japan, dementia care (including YOD) is organised at national and local levels, with a National Early Onset Dementia Support Centre operating to provide training, education, awareness of YOD in addition to individual advice and support via a dedicated YOD helpline staffed by trained YOD support coordinators which has been well-accepted by users (Baba et al., 2024; Kogata et al., 2024). In addition, in Japan, there are targeted efforts to improve community-based care and integrated care for dementia and YOD (Ishihara et al., 2024). This level of integration may be critical to the success of telephone-based services as it facilitates connectivity between available services and those who require access to the services.

The funding models that support access to services also affect the availability of YOD-specific care. In Australia, services for dementia may be received under different funding models such as the NDIS and My Aged Care which determines the dollar amount and type of services available through these initiatives for YOD compared to those diagnosed with dementia over age 65. With recognition of YOD as a disability, there have been a greater number of services and supports accessible to people with YOD in community settings. While the NDIS has been well accepted by those with YOD and their family members, issues related to the limited availability of suitable service providers for this population and a perceived lack of knowledge and awareness specific to dementia and YOD have been identified (Cations et al., 2022). This suggests that while funding systems are essential to facilitating best-practice care, they are not alone sufficient to realise these goals.

Assessment and diagnosis

One of the core indicators of quality dementia care (National Institute for Health and Care Excellence, 2018) and a priority for improving YOD care (Cations et al., 2021) is that of timely diagnosis. Several models were identified which focused on providing comprehensive diagnostic assessment to people suspected of YOD, with some of these studies highlighting factors contributing to delayed diagnosis and access to care.

Most models of care examined in this review which included diagnosis as a component of the care model required referral from a general practitioner or healthcare provider to access the service which emphasises the use of integrated and shared care. As a result, the primary care setting was often identified as the gateway to diagnosis and additional services for people with suspected YOD, whereby GPs would initiate and provide a referral for diagnostic assessment, a memory clinic, or other medical specialists. Knowledge gaps related to YOD among GPs and healthcare providers, coupled with unclear guidance on available services and supports in the local region, may contribute to delay in the identification of symptoms, delay in referral for assessment and poorer care coordination following diagnosis. As the incidence of dementia among younger people is low, there may be reluctance among some GPs to pursue screening for YOD due to a perceived lack of available treatment and care options (Perry et al., 2024). However, GPs are uniquely placed to detect initial symptoms of YOD, and recent data suggest people with YOD in Australia have a greater use of GP services compared to those without dementia, with an average of 17 visits per year among people with YOD (Australian Institute of Health Welfare, 2024).

Some studies suggest that the responsibility to pursue further evaluation for YOD may fall largely on those affected, as opposed to healthcare providers. Findings from a UK study identified that among those with rare forms of dementia, including YOD, navigating the diagnostic pathway was associated with a range of emotional and practical consequences, including financial costs due to inappropriate referrals (Davies-Abbott et al., 2024). In a study examining the experiences of diagnosis among people with YOD in Australia, participants described “difficulty trying to convince their general practitioner that the symptoms warranted investigation” (Lai et al., 2023). Similarly, recognition that this task often requires significant self-advocacy is recognised by Alzheimer’s Canada who provide suggestions on how those concerned about YOD should self-advocate and even educate their healthcare providers about YOD (Alzheimer's Canada, 2024).

Following referral, other factors may contribute to diagnostic delay. Waitlists across services are not uncommon and have been identified as a factor contributing to delayed diagnosis, although several models described in this review had time-bound quality indicators and targets which were met. The name given to the service may also affect its use and GP referrals and those identified as general memory assessment services may be more accessible to people with YOD than those identified as dementia or older person specific (O'Kelly et al., 2015).

Access to a service for assessment and diagnosis may be further delayed for people living in regional and rural areas with limited access to medical specialists, healthcare providers and equipment typically used to diagnose rarer forms of dementia (Lai et al., 2023). Models such as the BRIGHT-YOD clinic, an example of a ‘hub-and-spoke' model which harnesses existing resources available in a major city and improves access to these services through telehealth in collaboration with local clinical staff. This model appears to be a novel and sustainable approach to addressing this need in a cost-effective and timely manner (Brown et al., 2023). Further, the use of telehealth in conjunction with existing services was received positively by staff and patients (Brown et al., 2023).

Given that most service models require a referral from a GP or healthcare provider to access diagnosis and assessment services, the delay in referral for assessment could play a pivotal role in the care trajectory of a person with YOD. For instance, a delay in diagnosis in Australia could have implications for eligibility for NDIS funding and may limit access to care and support services (Cations et al., 2022). There are differences in the average annual financial support for people with NDIS support, which is approximately $52,000 AUD compared to $17,000 AUD for a person in residential care (Spiers & Hicks, 2021). The possible implications of delayed diagnosis on subsequent care access and financial support highlight the importance of eliminating barriers to diagnostic and assessment services. One element of the national dementia care model in Japan may reduce such barriers, with individuals who are concerned about possible YOD having direct access to a trained care coordinator who can provide information without a referral through the national telephone helpline (Kogata et al., 2024). Direct access to support may improve the flow of information and access to diagnostic services and support, particularly where access to services is tightly controlled, or the initial demand for services exceeds provider capacity.

Improving diagnosis and care through education, guidelines and pathways

An expert panel developed consensus recommendations related to the knowledge that healthcare professionals working with people with YOD should possess (Couzner et al., 2022). This study highlighted the need for broad knowledge on diagnosing YOD, treatment, and post-diagnostic support delivered by a multidisciplinary team. Improving provider dementia-related knowledge has been described within NICE dementia guidelines (National Institute for Health and Care Excellence, 2018) and the Young Dementia Network accompanying guidelines for YOD (Young Dementia Network, 2021). In the absence of accessible and dedicated YOD teams, building knowledge and awareness of symptoms among primary care providers through training and education could be beneficial (Smith et al., 2017).

Findings from a recent study using an integrated cognitive assessment tool harnessing artificial intelligence within primary care could improve care pathways and reduce diagnostic delay among people aged 50 – 90 years (Modarres et al., 2023).

In the absence of clear pathways and guidelines for diagnosis and care for people with YOD, it may be critical to improve awareness and information related to suitable and accessible services. This may be in the form of a current directory, such as the directory of memory clinics and cognitive assessment services provided by the Australian Dementia Network. This may also include support and training for managing challenges faced by providers or enhancing specific knowledge.

One example of a service aiming to enhance access to knowledge of appropriate services among clinicians working with people with dementia is the Dementia Pathways Tool, established as part of the Dementia Pathways Project in the Grampians region (Ollerenshaw et al., 2018). Improvements in timely diagnosis and success in integrated care for YOD may be dependent on clear guidelines and pathways, such as those described in the referral pathways for YOD from Ireland (Begley et al., 2023) and the UK Young Dementia Network (Young Dementia Network, 2024d). This need has been identified elsewhere, with findings from a recent Scottish report describing a lack of appropriate diagnostic pathways and age-appropriate services for people with YOD (Healthcare Improvement Scotland, 2023a). Where pathways are unclear or undefined, people with YOD, and family members may be tasked with identifying suitable services and supports alone. Access to a care coordinator, key worker or other centralised source of support may be particularly important where service delivery is fragmented or there is limited access to specialised services.

Models of care and service settings

Access to diagnostic assessment and other components of care for those with YOD may take place in a range of healthcare settings. These services are typically located within community-based settings, and all models included in this review with a diagnostic component were community-based. Specialised services and memory clinics may be best placed to conduct comprehensive assessments and diagnose YOD in a timely manner.

Memory clinics and specialised services for people with YOD

While several countries have networks of memory clinics for people with dementia, such as those located in Italy, Norway and England, services dedicated to YOD were not commonly identified. Instead, specialised services for people with YOD often appear within existing memory or community mental health services or memory assessment services and often operate within an integrated or collaborative care model. Findings from a recent review in Scotland found that most dementia diagnostic assessments including those for people with YOD were undertaken within Older Adult Community Mental Health Services (Healthcare Improvement Scotland, 2023b).

The process of diagnosing YOD within memory clinics in three tertiary memory clinics located in Denmark, Sweden and the Netherlands, found substantial differences in time from referral to diagnosis, ranging from a median of three days in the Netherlands, where elements of the diagnostic process are completed on the same day, to 69 days in Sweden where the components may take multiple days, and there were lengthier wait times for neuroimaging services (Konijnenberg et al., 2017). A study of retrospective records from the Wokingham Memory Service, an NHS memory clinic with a dedicated YOD diagnostic and care pathway, found the average time to diagnosis was 9.7 months (Hussey & Butler, 2019).

While there is evidence that specialised service models and dedicated teams operate within larger health systems such as the NHS in England, there appears to be significant variation in the availability of these services and the available components of care based on location. A brief review of services within the UK for people with YOD noted that the available services had “wide regional variation” (Rayment & Kuruvilla, 2015). This may result in greater dependence on existing services within the community mental health system and old age psychiatry services, and fewer components of care. Consistent with this are findings by Yeung et al. (2021) indicating that people with YOD who accessed an NHS older person’s mental health service in Cambridgeshire, England, did so due to the lack of alternatives for YOD in the region. While dedicated YOD services have been described as offering the optimal approach, the authors conclude that the development of a YOD service would be impractical owing to the small number of people affected and the geographical dispersion within the serviced region (Yeung et al., 2021).

Specialised services for YOD are often considered optimal in providing clear care pathways from diagnosis through to post-diagnostic care (Royal College of Psychiatrists & Alzheimer’s Society London, 2006; The Royal College of Psychiatrists, 2018). While the benefits associated with diagnosis of YOD within specialised services have been described, including reduced diagnostic delay (Loi, Goh, et al., 2022) and improvements in post-diagnostic care and satisfaction by people using the service (Booth, 2022), they often require significant resources. The Leeds joint clinic serves as an example of innovation among practitioners who developed a joint working model between a psychiatry-led service and neurology services to improve diagnosis and care for people with YOD in the absence of other suitable specialised services in this location (Young Dementia Network, 2024b).

Specialised services for YOD may be best placed to support people following a diagnosis. When diagnosis and management are provided within a specialised service, it may be more likely to conform to the needs and preferences of those with YOD, with a clear pathway, seamless integration of care and accessible care identified as preferences (Stamou et al., 2022). Further, a specialised service may remove ambiguity about next steps and barriers to follow-up care, particularly where such follow-up care is not coordinated, and instead people are advised to self-refer to support services.

There were few examples of comprehensive care models designed specifically to address the needs of people with YOD within the literature. One example was the CARE-D model designed or affiliated with a university in the US (Morhardt et al., 2015). This may reflect the lack of feasibility outside the research setting. A second was operated by a charitable organisation in Hong Kong (Jockey Club).

Establishing sustainable care models that are accessible is also of foremost importance. Given that there are individual differences in needs for services, and needs change over time and may require a range of services across different sectors, access to a sustainable model that accounts for these differences appears critical. Several recent initiatives aimed to promote improved care provision can be seen within health systems at national levels. From the initial identification of possible dementia through to diagnosis and post-diagnostic care, integrated and collaborative models providing community-based care were identified. The importance of integrated care models that use existing community services and resources have been identified. This would also ensure that services can adapt to changes in needs at different stages of disease severity.

Internationally, efforts toward improvements in care integration and collaboration between services appears common. In the UK, within the NHS, the introduction of Integrated Care Systems aims to promote the delivery of care across sectors through partnerships between local NHS services, local authorities, and other organisations, including the non-profit sector (van der Feltz-Cornelis et al., 2023). In the Netherlands, efforts to improve care integration and interprofessional collaboration have been made through the DementiaNet system, where “each DementiaNet represents a local interprofessional team that includes healthcare professional from medical, care and social domains” (Nieuwboer et al., 2017). Findings from a long-term evaluation of the DementiaNet model demonstrate improvements in care integration associated with use of the model (Oostra et al., 2023). A recent review in Scotland found that most dementia diagnostic assessments, including those for people with YOD, were undertaken within Older Adult Community Mental Health Services (Healthcare Improvement Scotland, 2023b).

The US Centres for Medicare and Medicaid Services GUIDE model is a new nationwide voluntary collaborative care model for dementia care commencing in 2024 and will operate as a pilot for eight years (Centre for Medicare and Medicaid Services, 2024). The GUIDE model aims to improve care quality and access for people with dementia and care partners through improved access to funding for services and applies broadly to people with dementia (Alzheimer's Association, 2024; Centre for Medicare and Medicaid Services, 2024). Given that people with YOD often have needs that can be effectively managed within community care settings setting, the GUIDE model may have a considerable impact on access to services for people with YOD in the US.

Person-centred approach

Across all types of care models, the importance of person-centred care, relationship-centred care or individualised care approaches were described. The importance of relational elements of care received has been identified as a key component of care from the perspective of people with YOD, family members and care partners (O'Malley et al., 2021; Stamou et al., 2022). Provider and staff knowledge, education and training were also essential components. Age-appropriate peer support services and activities were another element of YOD care that differs from care provided in general dementia services, where age differences among service users may be less apparent.

Care coordination and care planning

The success of integrated and collaborative care models appears to rely on the capacity for services to communicate with ease and provide those who access services an individualised approach tailored to their care plan or needs. The importance of this element of seamlessness in care has been identified among people with YOD, family and care partners, and providers (Stamou et al., 2022; Stamou et al., 2023). However, not all services may be equipped to provide integrated services and structural barriers that hinder information sharing may make collaboration challenging.

Several challenges associated with the practical implementation of integrated care within the NHS system were identified in a study by (Chase et al., 2021). These challenges include resource limitations owing to a competitive commissioning of funds, an absence of systems that would enable seamless access to shared patient data, and interprofessional knowledge gaps including in relation to scope of practice and responsibility (Chase et al., 2021). The importance of collaborative care and an interagency model of care was also explored in a previous review (Beattie et al., 2002; Chase et al., 2021)

Multidisciplinary teams are often considered central to effective collaborative care models, and most comprehensive services include medical and allied health professionals. People with YOD have described the challenges of coping and adapting to these changes during the first year following diagnosis (Aspö et al., 2024). The loss of meaningful activities may further contribute to a sense of social isolation, and access to health professionals who have an awareness of the complexity of coping with YOD is important. Access to rehabilitation by people with YOD, which was evaluated in a recent review by (Suarez-Gonzalez et al., 2024), is central to person-centred care and is a basic human right. Rehabilitation for people with YOD needs to be age-appropriate, and staff providing interventions may require expertise on symptoms of different types of dementia which is not common across health services. However, collaboration between allied health professionals such as occupational therapists and speech pathologists can support sustainable participation in rehabilitation for people with YOD to meet their goals and prolong function and independence (Cations et al., 2017).

Care coordinators and key workers also play a significant role in supporting care delivery within different settings and services, including collaborative care and specialised clinics, and some services rely on this role as a central component of their care model. The inclusion of a key worker has been identified as a core feature of service that is suitable for people with YOD by the Royal College of Psychiatrists (The Royal College of Psychiatrists, 2018). Findings from a systematic review identified the benefits associated with a case manager approach in dementia care, finding improved care coordination between providers and settings, improved communication and greater ease in navigating healthcare systems (Khanassov & Vedel, 2016).

Previous findings from an evaluation of the Dementia Australia Key Worker program found that access to a key worker was considered helpful among those with YOD and care partners who identified the importance of having reliable support assistance available when needed (Westera et al., 2014). However, the cost-effectiveness of these services may be diminished where a small number of people with higher needs rely heavily on the service and reduce the capacity to provide care across the spectrum of needs. The involvement of a case manager was associated with substantial differences in outcomes for people with YOD in one study, with double the percentage of those without case managers admitted to long-term residential care compared to those who accessed a case manager (Hendriks et al., 2023). However, the direction of this association is unclear and some of those who did not access a care manager were already living in care homes or had greater symptom severity.

Care plans were also commonly featured in the identified care models. One example is the pathway from initial presentation within a primary care setting, a referral to a specialised clinic or service for memory assessment, and subsequent care or referrals provided at this point where indicated. Discharge to the GP may occur after diagnosis in some memory clinics, while other services offer more ongoing and holistic care. Care plans may be particularly important in these contexts, given the need to monitor and modify care over time. The importance of a care plan is emphasised within dementia care broadly within NICE Dementia Guidelines (NICE, 2018) and is one of the core components of recommendations proposed by the Young Dementia Network (Young Dementia Network, 2024d). A care plan promotes an individualised approach, as care needs are likely to change over time, with a preference among those with YOD for accessible services that can adapt when care needs change (Stamou et al., 2022).

Supportive care models

Supportive care models that address a range of needs beyond those tied to medical management, including those related to meaningful activity, peer support and access to day respite, were highlighted in supportive care models suitable for people with YOD and their families. Models that combined a number of interventions, such as meaningful activity, peer support and day respite were identified (Tilki et al., 2023 and Davies-Quarrel et al., 2010).

Needs of the family and carer partners

The unique impact that YOD can have on the family members of those diagnosed is well established, along with a need for inclusive service models that address the needs of the family unit. However, the availability of suitable support beyond dedicated and holistic YOD care models may be limited. The models that were identified as dedicated for people with YOD often described components of care for family members and care partners, providing education and counselling for care partners, including family members in care planning, and in providing guidance and advocacy related to financial matters.

It appears more common to find dedicated resources and programs for family members and care partners of people with YOD as stand-alone support models, such as online-based support programs (Daemen et al., 2022; Gerritzen et al., 2022; Gerritzen et al., 2024; Metcalfe et al., 2019). One example is the RHAPSODY-Plus online education and support program for care partners, which has demonstrated effectiveness (Perin et al., 2023). Such a program could be deployed widely to reach people within communities where support was not locally available or included as a component of care in locally available models.

While there appears to be greater efforts to consider family in YOD service provision, one study described a need for co-created family-focused model of care for YOD, though the specific elements of this model were not identified (Hutchinson et al., 2020). Resources specifically designed to assist children and young people who have a parent with YOD have also been developed (Robyn & Jeneva, 2022).

Providing family-focused care may also require additional training and support for staff. In one study, staff who provided care to people with YOD and their family members reflected on the challenges of providing support related to finances, education and physical well-being (Roach et al., 2012). They also described challenges related to advice, given the complexity of family dynamics. However, the authors recommended a family-centred approach involving getting to know the family members and plotting biographical information to inform clinical decision-making.

Employment and finances

People with YOD may face financial pressures due to unplanned retirement and accessing appropriate care and support. People with YOD are often engaged in the workforce at the time of symptom onset, and there is growing recognition of the issues related to participation in employment and financial security (McCulloch et al., 2016). One study found few people with YOD appear to remain at their place of employment for extended periods after their diagnosis, with unplanned early retirement or periods of extended leave or mandated leave commonly reported (Kilty et al., 2023). The Dutch Work and Dementia study aims to explore engagement in the workplace among people with YOD, with the initial study findings describing significant challenges continuing in their usual roles in the workplace with a diagnosis of YOD, while the benefits of supportive strategies and accommodations were also identified (De Vugt et al., 2023). However, findings from a study conducted in Japan described reluctance among employers to provide workplace accommodations for people with YOD (Omote et al., 2023).

There were few strategies or support models identified that aimed to address these complex issues. One model offered information and support to those with YOD related to finances and employment (Wheeler et al., 2015). However, models that include specific components related to finances and employment do not appear to be commonplace.

People with YOD may have access to their workplace sick leave entitlements where available and a person is unable to continue working. In Australia, people with YOD are eligible for disability support through NDIS funding which is consistent with the World Health Organization's definition of disability relating to reduced workforce and community participation (Cations et al., 2022). However, this approach is not common in other countries. Early access to superannuation is also possible for people with YOD in Australia.

Beyond the financial implications, unplanned retirement may have broader implications for individual well-being, daily life, and sense of purpose. Findings from a qualitative study of twelve people with YOD who retired following their diagnosis suggest a host of losses experienced, including a loss of meaningful activity, familiar routine and social contact (Issakainen et al., 2023). In the Netherlands, people with YOD strongly desired to continue working post-diagnosis to help preserve their confidence and self-identity (Smeets et al., 2024). There are several interventions aiming to promote social participation through voluntary or work-adjacent roles, which may address the losses in the sense of community and contribution with unemployment, although these programs often focus solely on social participation. One example is a volunteer program whereby people with YOD participated in voluntary work in a hardware store (Robertson et al., 2013), while in the Netherlands, there are numerous green care or farm work programs that may allow for continued participation in meaningful activity.

However, these programs do not address the financial aspects of early unemployment, which has been identified as a primary issue among those with YOD and family members. Further, ways to plan for and transition from work to retirement have not yet been explored. An article by Yaeda et al. (2022) discusses the importance of people with YOD remaining engaged in work and the benefits to the local community and family members in addition to the person themselves. Vocational rehabilitation includes assessment, personalised planning, counselling, training, age-appropriate job development, placement, and restructuring, as well as support for job retention. The authors note these practices should be considered immediately following a diagnosis both for the person and to foster support from co-workers. While reasonable accommodations are relatively commonplace for people with disabilities, there is limited evidence regarding YOD. Online guides such as those available on the Alzheimer’s Canada website links to resources and highlights that there is a “duty to accommodate” disability within Canadian workplace law (Alzheimer's Canada, 2024). Use of assistive technology to assist people with YOD, such as checklist applications or smart devices may also be useful to assist adjustments in work settings.

People with YOD may require care and support which is often costly, particularly over extended periods of time. Coupled with a loss of income from usual employment, this may impose significant financial strain on a person with YOD and their family while also experiencing care-related costs (Mayrhofer et al., 2021). The costs associated with care and support are also likely to be substantial and unplanned. In Australia, YOD is recognised as a disability, and this enables access to funding through the NDIS. Internationally, in countries such as the UK, the Netherlands and Canada, dementia is also recognised as a disability. Funding models to enable payment for care and support for those with disability are available internationally, although program eligibility requirements may differ substantially within and between countries, and the funding levels are often determined individually. In England, a ‘Personal Budget’ may be available to support payment of care needs (Alzheimer's Society UK, 2022), while the Adult Disability Payment in Scotland provides a payment to support access to social and care services in the community.

Palliative care, advanced directives, and end of life care

Care models with education components often include topics related to advance care planning, though there were none describing specific models or practices related to end-of-life care specifically for people with YOD. There has been increased attention on palliative care models and end of life care practices for dementia broadly, focused on quality of life and symptom management and inclusive of end-of-life care practices (Mamun et al., 2023; Nishimura et al., 2024) and barriers to access (Erel et al., 2017). Palliative care for dementia typically takes place when dementia is advanced and focuses on end-of-life care, but given that dementia is often caused by a life-limiting disease, these care practices could commence following diagnosis (Lewis et al., 2023).

There is a lack of palliative and end-of-life care practices for people with YOD (Koopmans et al., 2015) and this has been identified as an issue requiring further attention. While Scotland has detailed practice models for end-of-life care in people with dementia, a need for further recommendations for people with YOD at the advanced stages of dementia has been identified (Healthcare Improvement Scotland 2023a; Ahlzheimer's Scotland, 2015). A recent study described the advanced care practices in residential care homes in the Netherlands from 185 people with YOD living in specialised residential aged care units with a mean age of 63.9 years and found that only 5.4% of people with YOD had a written advance directive (Maters et al., 2024). The EPYLOGE study from Germany was designed to examine issues related to palliative care and advanced dementia care and included those with YOD, and differences in needs between people with YOD and those with older-onset dementia at advanced stages of dementia were hypothesised (Diehl-Schmid et al., 2018). The perspectives of people with YOD and care partners on advance care planning and voluntary assisted dying support greater involvement in decision-making and enabling choice among people with YOD (Van Rickstal et al., 2019; Van Rickstal et al., 2023). Although, some of the potential ethical issues related to advanced directives and the provision of end of life care for people with YOD have been identified (Fischer et al., 2023).

Accommodation and Respite

None of the identified articles included discussion or model components related to residential respite or long-term care. Between 2011 and 2017, 25% of people with YOD accessed respite care in Australia and 35% of these stays transitioned into a permanent RAC placement (Australian Institute of Health Welfare, 2022). In a survey of day respite services in the US, just under half (44%) indicated that they provided programming for people with YOD, though the nature of these services was not described in detail (Silverstein et al., 2010). Through the NDIS in Australia, people with YOD may have access to housing that is better suited to their needs. Under the NDIS Supported Independent Living funding model, providers such as Yooralla in Victoria (Yooralla, 2024) and Community Home Australia in NSW and ACT have commenced offering dedicated YOD accommodation options in small-scale home settings. In homes of six to seven people, people with YOD are provided relationship-centred care with a minimum two to six care staff ratios, with the ability for one-to-one staffing if the person's NDIS funding allows (D'Cunha et al., 2023). These housing options may be more appropriate for people with YOD than specialist disability accommodation, which are often designed for people with physical disabilities and not cognitive disabilities (Cations et al., 2021).

People with YOD are often left with minimal options if they have complex care needs and changed behaviours and are often cared for within geriatric wards in hospitals. Small-scale home settings may better meet their needs; however, NDIS providers have different levels of expertise in providing dementia care and not all settings suit this population. As the Australian government set a goal of no younger people living in residential care by 2025, more community-based care settings are needed to accommodate people with YOD.

Support and education

Most care models include components of support and education which are considered important components of comprehensive care. The delivery of support or peer groups may be online or in person and may include education alone, education with or without peer support and self-management strategies. The provision of support and education is also available through not-for-profit organisations and peak charity bodies who provide YOD-specific online education modules, brochures and local handbooks in Australia, the UK, Canada, and others such as Dementia Australia, Dementia UK, and Alzheimer's Society Canada. Peer support is also available through these providers. However, in a study of several European countries, the availability of information for people with YOD and their family members was found to vary significantly by country, with some countries having little to no dedicated YOD-related educational resources (Jones et al., 2018).

In Australia, dementia-related support and education through telephone and web services are also available, including telephone helplines for care partners and dementia-related service wayfinding. However, the availability of these services alone may not be sufficient, particularly when there are behavioural concerns or challenges, and there may be a need for guidelines to streamline access to support services, particularly for behavioural changes associated with dementia (Cadwallader et al., 2023). Findings from one Australian study suggested that accessing formal support navigating behavioural changes associated with YOD was difficult to navigate and took too long to receive the help that was needed (Cadwallader et al., 2023).

There are several examples of carer-only education and support programs, including the RHAPSODY program which has been investigated in different countries (Daemen et al., 2022; Perin et al., 2023). The inclusion of online peer support may be particularly useful for those living in rural areas where access to peer groups may not be feasible, and there are international organizations, such as Lorenzo’s House, provide a community of support for care partners of a person with YOD (Cose & Dean, 2023a). There were benefits associated with participation in a telehealth-based peer support group for rural spouses of people with rare dementia and YOD (O'Connell et al., 2014). A support group for care partners developed in the United States through the Rush Alzheimer's Disease Centre “Without Warning” has been long running and the service has developed a toolkit to support the formation of other groups (Arends & Frick, 2009). There are several examples of peer-led peer support and education groups and organisations, such as “YES!” an organisation (https://yessupport.org/) that provides peer support and education for partners, spouses, children, teenagers and adult children of people with young-onset dementia.

Implications

These findings provide insights into a range of service models and approaches to care that could be used to guide the development or improvement of services for people with YOD and their family members. The importance of location-specific factors can be seen throughout these findings, including those related to different geographical locations, funding, and staffing. Comprehensive diagnostic services were typically located in major cities. Moreover, dedicated YOD care models and clinics appeared almost exclusively in collaboration with a university or specialist hospital (Dulaney, 2022; Loi, Goh, et al., 2022; Loi, Walterfang, et al., 2022; Morhardt et al., 2015), which means expansion may not be widely feasible beyond these contexts. This may also reflect the economic, staffing and infrastructure-related challenges associated with care provision and delivery of specialised and comprehensive care models within the broader community. There may be unique barriers for specific populations which requires a personalised approach, adapting materials and improving accessibility. Further, the importance of including people with YOD and their families or care partners is well recognised.

Progress toward implementation likely requires a comprehensive understanding of the priorities and needs of people with YOD and in a given location, along with a shared understanding of these factors among services and providers within and across the health, social, and disability sectors. This includes limitations associated with funding structures. Progress may be further supported through improved YOD care guidelines and an increase in the evidence base related to best practice care models for this population. To ensure care models are appropriate and sustainable over time, the feasibility of care models under the available funding approaches may require further evaluation.

The sustainability of the models described owing to their grounds in temporary funding or research project funding is noteworthy. This was identified both within larger scale models, such as the BRIGHT-YOD model (Farrand et al., 2019) and in community initiatives, such as the collaboration between a dementia and financial advisory service (Wheeler et al., 2015) or respite and activity program (Tilki et al., 2023).

Existing services may draw upon models within similar settings and delivery frameworks. The inclusion of a key worker, case manager or coordinator appears to be a critical component of care and has been associated with improved satisfaction and health outcomes for people with YOD and care partners.

Further evaluation of services is needed to move toward high-quality care for people with YOD and their family members. Further efforts toward improving dementia inclusivity within communities at large may be beneficial. Additional guidelines and structures, such as detailed referral pathways to help facilitate quality care, in addition to education and training of relevant care providers, also appear to be increasingly adopted.

Limitations

There are several limitations in this review. While efforts were made to identify suitable studies or other sources describing models of care for people with YOD and their family members or care partners, the models described in these findings should be considered as examples of models described in this literature and not an exhaustive list. There may be studies that were not identified in these searches or those that were not available in English or did not describe the model. Several services were identified that did not have associated reports or publications describing or evaluating the care model. Thus, both availability and publication biases are likely to affect these results. Moreover, some of the models and services identified may not be current. Limited data was available from the included studies reporting quantifiable outcomes related to effectiveness. There is also a scarcity of robust use of outcome measures and cost-related outcomes, limiting the conclusions that can be drawn. There may be substantial differences in funding models by setting and region, and funding of services was not a focus of this review. As this review focused on models of care and support at the systems level, we did not examine single therapeutic interventions or support-only models of care for people with YOD and family members. Several reviews have assessed standalone interventions and specific services (Aplaon et al., 2016; Cui et al., 2024; Kim et al., 2024; Richardson et al., 2016). This highlights an urgent need for rigorous studies to evaluate outcomes associated with new and existing care models for YOD.

Conclusion

There is a need for comprehensive models of care for people with YOD and their families or care partners. There are some examples of these models at national and international levels, and several appear compatible with the expressed preferences and service needs. This includes models with clear referral pathways, memory assessment services that enable prompt diagnosis, and age-appropriate post-diagnostic support, which provide peer support, day respite, meaningful activity, and education. Missing from some of these models, and often expressed among preferences, is an emphasis on the relational element of care, such as consistency in care providers and access to support when needed. The fundamental role of the

GP and the primary care setting was identified in several studies, with GPs often being the first point of contact, source of information, support, and referral for assessment. This highlights the importance of awareness of symptoms of YOD among healthcare providers and GPs.

Further, the importance of flexibility and choice when approaching services was also identified among some models. Most care models considered were largely delivered in person, consistent with the preferences for in-person delivery. One model combined in-person and Telehealth components to enhance access to care. The inclusion of this face-to-face local healthcare support offers a novel approach to delivering suitable comprehensive care when resources may not permit this to occur entirely within an in-person delivery setting. There was a preference for seamless and cohesive care experiences, and this was not largely identified beyond memory clinics or specialised clinics where services were typically only offered at a single location. In practice, integrated and collaborative care models may effectively deliver a seamless care approach, provided the infrastructure enables this and providers are well informed of the process and role they play.

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