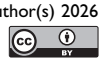
Check for updates

UK/Europe and the rest of the world

dementia

Dementia
2026, Vol. 0(0) 1–22
© The Author(s) 2026

Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/14713012261500879
journals.sagepub.com/home/dem
Sage

Content Analysis of Free Online Information and Support Available to Young Dementia Carers Across Europe

Patricia Masterson-Algar[1], Greg Flynn[1], Christian Bakker[2], Hanna Bodde[3], Rabih Chattat[4], Ilaria Chirico[5], Åsa Craftman[6], Rickie Duijvestijn[3], Lia Fernandes[7,8], Ana Rita Ferreira[7], Manuel A. Franco[9], Vaitsa Giannouli[10], Ragnhild Hedman[6,11], Louise Hopper[12], Esther Loseto-Gerritzen[13], Ana Meireles[14], Ana Belen Navarro[9], Janne M. Papma[3], Martina Quartarone[4], Destiny Snow[1], Catherine Talbot[15], Soraia Teles[7], Sara Trolese[4], Marie Tyrrell[6], Ziyue Wang[16] and Amber Watters[12] in collaboration with the INTERDEM Young Onset Dementia Taskforce*

[1]School of Health Sciences, Bangor University, Bangor, UK
[2]Department of Primary and Community Care, Radboudumc Alzheimer Center, Radboud University Medical Center, Nijmegen, the Netherlands
[3]Department of Neurology, Alzheimer Center Erasmus MC University Medical Center, Rotterdam, The Netherlands
[4]Department of Psychology, University of Bologna, Bologna, Italy
[5]Department of Human Sciences for Education Riccardo Massa, University of Milano-Bicocca, Milan, Italy
[6]Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden
[7]RISE-Health, Department of Clinical Neurosciences and Mental Health, Faculty of Medicine University of Porto, Porto, Portugal
[8]Psychiatry Service, São João University Hospital, Porto, Portugal
[9]School of Psychology, University of Salamanca, Salamanca, Spain
[10]Department of Psychology, Democritus University of Thrace, Didymoteicho, Greece
[11]Stockholm Gerontology Research Center, Stockholm, Sweden
[12]School of Psychology, Dublin City University, Dublin, Ireland
[13]Institute of Mental Health, School of Medicine, University of Nottingham, UK
[14]Institute of Psychology and Education Sciences, Psychology for Development Research Center, Lusíada University, Porto, Portugal
[15]School of Psychology, Bournemouth University, UK
[16]School of Nursing and Midwifery, University of Galway, Galway, Ireland

*INTERDEM Young Onset Dementia Taskforce.

Corresponding Author:
Patricia Masterson-Algar, School of Health Sciences, Fron Heulog, Bangor University, Bangor LL57 2EF, UK.
Email: p.m.algar@bangor.ac.uk

Abstract

The aim of this study was to gain insight into young dementia carer-specific content provided on the websites of dementia and (young) carers organizations in seven European countries including: the UK, the Netherlands, Italy, Greece, Portugal, Ireland and Sweden. Research questions were: 1). What types of young dementia carer-specific content are available on national websites of dementia and (young) carers organizations across Europe? and 2). How does the content address the complex impact that dementia can have on young dementia carers? The identification of websites was informed by the contextual characteristics of each country in relation to dementia and young carers support and services. A standard protocol describing the website inclusion and exclusion criteria, data extraction and content analysis using a categorical coding framework was followed. Descriptive statistics were calculated to summarize data within and across countries. A total of 312 organizations with active websites meeting the eligibility criteria across countries were identified, and their websites reviewed. Content relevant to young dementia carers was identified in 28% (n = 86) of the websites, with uneven availability of resources across Europe and very limited resources in some countries. Most contents addressed five categories: Diagnosis & symptoms, Uncertainty & family distress, Changes in roles, Stigma & isolation and Identifying need for support. A lack of tailored resources to support young dementia carers was identified, particularly in relation to two categories: Grief & loss and Education & life planning. Only a minority of websites included young dementia carer-specific content. These websites primarily focused on general support needs and explanations of dementia, while key areas such as guidance on school, career, and life planning remain underdeveloped. There is a need for greater recognition of young dementia carers, clearer terminology, and more developmentally appropriate and practically oriented resources to strengthen online support for these carers across Europe.

Keywords

young dementia carer, young carer, website content analysis, dementia, online resources

Introduction

There are approximately 20 million people currently living with dementia in Europe (Alzheimer Europe, 2025). Sustaining the health and capabilities of those who provide unpaid care to people living with dementia is therefore a global public health priority (World Health Organization [WHO], 2017). Among unpaid carers are children and young people, often referred to as young carers (under the age of 16/18 depending on the definition adopted) or young adult carers (up to the age of 25) who undertake regular and significant caring responsibilities for family members who have chronic physical and mental illnesses or disabilities, including helping with personal hygiene, meal preparation, medication and finance management, domestic tasks, and providing emotional support (Grundberg et al., 2021; Lacey et al., 2022; Masterson-Algar et al., 2023; Nichols et al., 2013). Reliable dementia-specific prevalence data of young carers remain limited. However broader estimates of unpaid care in Europe indicate that between 2% and 8% of children and adolescents will assume caring roles (Leu & Becker, 2017; Leu et al., 2023).

Children and young people who live in families affected by dementia can be referred to as young dementia carers. They often face distinct challenges as the impact of the illness and associated caring responsibilities occur during critical developmental periods (Gelman & Greer, 2011; Masterson-Algar et al., 2023). While some young dementia carers report strengthened family

bonds, enhanced maturity and resilience (Grundberg et al., 2021; Masterson-Algar & Williams, 2020), the caring role can compromise wellbeing and disrupt multiple domains of life, including education, family roles, social relationships and future opportunities (Blake & Hopper, 2022; Cartwright et al., 2021). For example, when the person living with dementia is a parent, young dementia carers report challenges associated with changing parent-child roles, financial concerns, developmental incongruence between age and responsibilities, fear and emotional distress related to changes in their parent's behavior, and exclusion from health and social care systems (Grundberg et al., 2021; Millenaar et al., 2014). Recent reviews similarly conclude that young dementia carers experience psychological and psychosocial difficulties, physical strain, and social isolation, linked to uncertainty around dementia progression, changing family dynamics, dissonance between societal expectations and personal experiences, anticipatory grief, and stigma (Blake & Hopper, 2022; Cartwright et al., 2021; Chirico et al., 2021; Poole & Patterson, 2022). An additional recurring concern is limited awareness of young dementia carers among professionals and the general public, making needs assessment and support provision extremely challenging, as well as a scarcity of developmentally appropriate, tailored support to help young people navigate caring responsibilities, understand dementia and its implications for the family, and protect their health and wellbeing (Chirico et al., 2026; Masterson-Algar et al., 2023; Tyrrell et al., 2024). Research shows that families, particularly those affected by young onset dementia, also have to contend with delays to diagnosis and difficulty navigating the complex health, aged and disability care systems (Loi et al., 2022, 2023). Existing health and social care structures for dementia are often designed for older adults, leaving them less able to meet the needs of people with young onset dementia and their families, while specialized services are often difficult to access due to geographical barriers. During this time and also in the period following diagnosis the internet often becomes a significant source of information for families. Young dementia carers and their parents express specific need for education about dementia and for proactive professional support and guidance in accessing resources (Ritzen et al., 2025).

Accessible and accurate information plays a key role in supporting carers of people living with dementia. Family carers consistently identify disease-specific information, guidance on caring, and knowledge about available services as important for managing the practical and emotional demands of care (Soong et al., 2020). The internet has become a highly utilized source of information for people living with dementia and carers, with websites and online platforms frequently used to access information about symptoms, practical guidance, service navigation, and peer support (Coulson & Talbot, 2025; Efthymiou et al., 2020; Teles et al., 2022). However, concerns have been raised about the accuracy and appropriateness of online information, as misleading content may contribute to misunderstanding dementia symptoms, unrealistic expectations about treatments, and heightened anxiety about disease progression (Dixon et al., 2022; Talbot et al., 2024). For young dementia carers, the availability of online information may be especially important because many families lack effective frameworks for discussing these topics and younger people routinely turn to online spaces for health information and support (EuroStat, 2025; Stifjell et al., 2025). There are additional risks that young dementia carers, as a low-recognized group, may encounter, including content designed primarily for adult carers that is not developmentally appropriate or tailored to their unique experiences. To date, no studies have evaluated content specific to young dementia carers available on the (national) websites of dementia or young carer organizations. This study aims to examine whether online resources targeted at young dementia carers exist, to what extent they adequately address their specific needs and what the variability is across European countries. We also aim to investigate content types, target audiences, and which aspects of dementia and the care pathway are addressed.

Methods

Websites dedicated to dementia or (young) carers were identified in seven European countries, including the UK, the Netherlands, Italy, Greece, Portugal, Ireland, and Sweden (for full details on each country's national policy context please see Supplemental file 1). In order to reflect the variability across the selected countries, in this study children were considered young carers up to the age of 16 or 18 and young adult carers if they were between the ages of 16 or 18 and 25 yrs. Both categories were included in who we define as young dementia carers. Selected websites were screened for content relevant to young dementia carers which was categorized.

No ethical approval was required, as the study used data available in the public domain and did not involve the collection or processing of personal data.

Website Identification and Eligibility

Relevant websites of organizations were selected following standard inclusion and exclusion criteria outlined below. However, due to the multi-country nature of this study, the identification and selection of websites of organizations was adapted to reflect each country's context and differences in the way that services for people living with dementia and/or carers are provided and set up. This minimized the chances of missing relevant websites and organizations during the screening process. Two distinct approaches to purposive screening were adopted across participating countries: Type A - in countries with existing umbrella networks for dementia or young carers (e.g. UK) the screening was informed by these and only organizations included within these networks were reviewed; This approach allowed for the work to be targeted and manageable within the available resources. This was very relevant for example in the case of the UK, which has thousands of young carers charities across the country. Type B - in countries without relevant umbrella networks (e.g. Portugal, Greece) the identification of organizations and websites was carried out mainly via internet searches. Some countries used a combination of Type A and Type B strategies (e.g. the Netherlands). For full details on country specific approaches used to identify relevant organizations and their websites please see Supplemental file 2.

Websites were included if: (1) they had dedicated pages on young carers or young adult carers, or dementia. In countries where no young carer–specific websites were identified, broader carer websites were considered eligible (e.g., Portugal, Ireland, Greece and Italy); and (2) they belonged to nonprofit organizations, networks, or government-based organizations (e.g. local council).

Websites were excluded if: (1) they belonged to organizations that were a school or university; (2) they were under construction or did not work at the time of the search; or (3) they belonged to organizations that were not based in the target country.

Website Review and Data Extraction

A bespoke template for data extraction was prepared in consultation with all team members. Methodological adjustments were addressed via regular online team meetings. Each website was given a unique identification number. The data extraction was piloted by the UK team on 15 of the identified websites to ensure consistency and that relevant information was captured. In countries with a high number of websites (more than 50) one reviewer extracted the content from all the included websites and a second reviewer completed the extraction process in a 10% randomly selected sample of the websites. In countries with a small number of websites and organizations,

two reviewers independently extracted the data. Information was extracted on the type of organization, web link, its main focus, the date accessed and whether a direct definition of young dementia carers was provided.

Young dementia carers relevant content was extracted from each website, given a unique ID, downloaded/copied and labelled depending on whether it was: (1) text directly copied from website; (2) downloadable PDF; (3) video; (4) game; (5) PowerPoint presentation; (6) audio file, or (7) other.

Content Analysis

The extracted materials were analyzed using categorical content analysis, following the approach described by Bengtsson (2016) and Monnet et al. (2023). A coding framework (Table 1) was developed by synthesizing the information in published reviews on the impact of parental/grandparental dementia on young dementia carers. The coding framework was further validated with input from four professionals in the field of dementia care and people with lived experience including two mothers of young dementia carers and a young adult who cared for his mother living with young onset dementia.

In each country, two researchers reviewed the extracted documents independently (or a 10% sample if the number of documents was significant as in the case of the UK) using the categorical coding framework. Content that did not fit within any of the categories could be labelled as a new category following an inductive approach, however, no new categories were identified. Disagreements were resolved via discussion until consensus was reached.

Table 1. Categorical Coding

Area	Categories	Brief description of the area
Making sense of dementia	C1 diagnosis & symptoms	- Understanding the dementia diagnosis and physical and behavioral symptoms.
	C2 uncertainty & family distress	- Impact of the uncertain nature of dementia and its trajectory on family's wellbeing.
Dealing with changes in relationships and roles	C3 changes in roles	- Information on how family members' roles might change as the condition progresses. Taking up caring responsibilities.
	C4 grief and loss	- Impact on the young dementia carers relationship with their family member with dementia but also with others (e.g. siblings, healthy parent) and the need for readjustment.
	C5 stigma & isolation	- Feelings of grief and loss as well as fear of stigma as a consequence of changes in roles and responsibilities.
Adapting to the new caring role and responsibilities	C6 identifying the need for support	- Dealing with caring responsibilities and the importance of asking for help and identifying sources of support (how and where to find it).
	C7 education & life planning	- Information which supports young dementia carers in education (e.g. school and university) and also with life planning decision making

Synthesis Across Countries

Results were first presented descriptively within the research team using tables and diagrams to show the types of content and their coded categories (including examples) across websites in each country. Results from all countries were then collated by the first author (PM-A). To complete the data synthesis, an online workshop was organized and delivered by PM-A and attended by all members of the research team (co-authors). Prior to the workshop, PM-A shared a detailed summary of the results across countries, mapping key findings, gaps and priorities, conclusions and recommendations. During the workshop all team members discussed the findings and resolved conflicts following a collective iterative process. As a result, a series of recommendations closely linked to needs identified from the literature were generated providing an in-depth understanding of the current state of support for young dementia carers across the seven European countries.

Results

The results are presented in three subsections. First, the characteristics of the websites identified are described, followed by an overview of the extracted content included in the study. The final subsection presents the content analysis findings, outlining the main themes identified in the data.

Characteristics of Included Websites and Their Organizations

A total of 312 organizations with active websites across all seven participating countries were identified and reviewed (Table 2 for a full list per country please see Supplemental file 3). Of those, 87 (28%) organizations had website content considered relevant to young dementia carers. The number of websites reviewed varied significantly across countries, with the UK contributing the largest number (n = 213), while Greece and Italy identified the least (n = 7 each).

Across countries, websites with relevant content varied widely in the amount, and detail of content provided: some contained a single webpage with relevant information (e.g., in Italy, Alzheimer Italia nonprofit organization), while others provided a much larger variety and range of content over several webpages (e.g., in Portugal, Associação Alzheimer Portugal).

A similar pattern emerged across countries, where the majority of relevant content was identified from a small number of organization websites. For the UK, while 41 websites had relevant content, the majority (61%) was identified from just four organization websites: Young Dementia Network, Dementia UK, Alzheimer's Society and Alzheimer's Research UK. For the Netherlands, relevant content was identified from six organization websites, with two of the organizations (Breinspoken and Dementie. nl, a website by Alzheimer Nederland) responsible for most (91%) of the content relevant to young dementia carers. For Portugal, one organization provided most (69%) of the relevant content (Associação Alzheimer Portugal). For Sweden, while 17 out of the 18 identified organizations had relevant content, three organizations (Ung Anhörig, Svenskt demenscentrum and YTAN: Digitalt stöd för unga anhöriga) were responsible for more than half of it (55%).

Across the 87 organization websites with relevant content, 64 (74%) were nonprofit organizations, 12 (14%) were government entities and 11 (13%) were categorized as "other" (e.g., networks, Limited Companies) (Table 2). In Italy (67% n = 2), Portugal (67% n = 2), Greece (100% n = 1) and the Netherlands (83% n = 5), most of the young dementia carer-relevant content were identified from dementia-focused organizations (Table 2). In the UK, Ireland and Sweden, relevant content was identified across all types of organizations.

Table 2. Website and Content Characteristics by Country

	Websites reviewed				Characteristics of content		
Country	Total n	With relevant content n (%)	N (%) main focus	N (%) type	Testimonies (e.g. blogs)	Support for YDCs (e.g. summer camps)	Information on dementia (e.g. books, games)
UK	213	41 (19)	14 (34) Dementia 7 (17) Carers 11 (27) YC/YAC 9 (22) Other	32 (78) NPO 5 (12) GOV 4 (10) other	✔	✔	✔
IT	7	3 (43)	2 (67) Dementia 1 (33) Darers 0 (0) YC/YAC 0 (0) Other	3 (100) NPO 0 (0) GOV 0 (0) other	✔		✔
PT	27	3 (11)	2 (67) Dementia 1 (33) Carers 0 (0) YC/YAC 0 (0) Other	3 (100) NPO 0 (0) GOV 0 (0) other			✔
EL	7	1 (14)	1 (100) Dementia 0 (0) Carers 0 (0) YC/YAC 0 (0) Other	1 (100) NPO 0 (0) GOV 0 (0) Other		✔	
NL	24	6 (25)	5 (83) Dementia 0 (0) Carers 1 (17) YC/YAC 0 (0) Other	6 (100) NPO 0 (0) GOV 0 (0) other	✔	✔	✔
IE	16	16 (100)	4 (25) Dementia 5 (31) Carers 7 (44) YC/YAC 0 (0) Other	8 (50) NPO 2 (13) GOV 6 (38) Other	✔		✔
SE	18	17 (94)	6 (35) Dementia 3 (18) Carers 3 (18) YC/YAC 5 (29) Other	11 (65) NPO 5 (29) GOV 1 (6) other	✔	✔	✔
Total	312	87 (28)	34 (39) Dementia 17 (20) Carers 22 (25) YC/YAC 14 (16) Other	64 (74) NPO 12 (14) GOV 11 (13) Other			

NPO: Nonprofit Organization; GOV: Government; YDCs: Young Dementia Carers; YC: Young Carer; YAC: Young Adult Carer.

Characteristics of Extracted Content

In total, 482 documents for analysis were extracted from 87 websites. For the UK, 246 documents were extracted from 41 websites. This was followed by Sweden (127 from 17), the Netherlands (46 from 6) and Ireland (30 from 16). For Italy, Portugal and Greece combined, 33 documents were extracted from seven websites. Across all countries, most of the content extracted was in the form of

text directly copied from websites (60%), followed by downloadable PDFs (20%) and videos (11%).

The type and extent of the content directly targeted to young dementia carers varied across countries in depth and detail (see Table 2). In the Netherlands (e.g., Nonprofit organization Breinspoken), Sweden (e.g., Ung Anhörig) and the UK (e.g., Dementia UK, Young Dementia Support) the content was diverse and provided in the form of information sheets (e.g., on behaviors, diagnosis and treatment), Q&A documents, podcasts and real life stories (e.g., in Sweeden - YTAN: Digitalt stöd för unga anhöriga), videos (e.g. in Netherlands – Breinspoken), and games (e.g., in UK – Alzheimer's Research UK). In the Netherlands, a dedicated organization specifically focused on young dementia carers was identified (Breinspoken), which provided content tailored to different age groups (4-7, 7-10, 10-12, and 12-18 years). Additionally, content linked to peer support initiatives was identified in three countries (Netherlands, Sweden and the UK). In the Netherlands and Sweden website content provided information on an annual summer camp for young dementia carers (e.g., Svenskt demenscentrum in Sweden and Breinspoken in the Netherlands) and in these countries two nonprofit organization's websites included information on monthly online meetings (Svenskt demenscentrum in Sweden and dementie. nl by Alzheimer Nederland in the Netherlands). Similarly, one of the dementia UK nonprofit organizations (Dementia Adventure) provided in its website information on supported holidays for families affected by dementia. The only online psychosocial education program specifically tailored to young dementia carers (iSupport for Young People) was identified in the UK (Dementia Community website). Across all websites, only one in the UK (Dementia UK) included details for a specialist nursing support service for young dementia carers in the form of a Consultant Admiral Nurse for Children and Young People. In Italy, searches identified content directly relevant to young dementia carers within a platform linked to a research study (DemCareAll). This platform included different activities (e.g., crafts, comics) aimed at young dementia carers. Personal stories were identified in most countries. In the UK, Sweden and the Netherlands, these were often shared as podcasts and short videos, whilst in the remaining four countries, content remained mostly text-based (e.g., written blogs).

In several countries (e.g., Associação Alzheimer Portugal in Portugal and Alzheimer's Research UK in the UK) content was provided via activities and information to explain dementia and the brain to the general population of young people. Although this content was not specifically targeted at young dementia carers (young people in general could benefit) it was identified as highly relevant.

Content Analysis Results

Content analysis revealed high variability in terms of how the extracted content addressed the seven categories of analysis across countries (Table 3). Most content was classified as addressing more than one category. For example, 16% of the extracted content (n = 75) was considered to cover five categories and 18% (n = 85) covered three categories out of the seven. Overall, content that addressed three or more of the categories were personal stories from young dementia carers and their families which were conveyed in a variety of formats across countries. For example, the UK nonprofit organizations Dementia UK and Alzheimer's Society and Breinspoken in the Netherlands included in their websites testimonies from families affected by different types of dementia (e.g., young onset dementia, frontotemporal, vascular, Alzheimer's). In some cases, the young dementia carer, cares for a parent or grandparent and is the one relating the story in the first person but in other cases it is the adult unpaid carer who explains how dementia has impacted all aspects of family life. However, other types of content that was classed as addressing three or more categories were books,

Table 3. Documents Extracted per Country and per Category Addressed

	UK		IT		PT		EL		NL		IE		SE	
Total number	246	%	19	%	13	%	1	%	46	%	30	%	127	%
C1. Diagnosis & symptoms	85	35	10	53	10	77	1	100	17	37	3	10	48	38
C2. Uncertainty & family distress	86	35	9	47	9	69	1	100	25	54	3	10	72	57
C3. Changes in roles	97	39	8	42	5	38	1	100	21	46	7	23	55	43
C4. Grief & loss	48	20	0	0	3	23	1	100	12	26	3	10	49	39
C5. Stigma & isolation	68	28	16	84	5	38	1	100	17	37	6	20	49	39
C6. Identifying need for support	101	41	19	100	2	15	1	100	19	41	23	77	106	83
C7. Education & life planning	28	11	1	5	2	15	0	0	1	2	4	13	20	16

Note. The total number of documents across categories may exceed the overall total, as individual documents can be classified into more than one category.

games and videos for children in different ages groups (e.g., 4-7yrs and 12-18yrs) to help them understand emotions and the illness (e.g., Breinspoken - https://breinspoken.nl/4-7/boeken-en-films).

Content analyzed across countries gave substantial attention to categories C1: Dementia diagnosis & symptoms (36% n = 174), C2: Uncertainty & family distress (43% n = 205), C3: Changes in roles (40% n = 194) (Table 3). Content coded as C1 was presented in different formats, however, there was consistency with most countries' organizations offering information within a specific section of their website often labelled as 'understanding dementia' or 'understanding the brain' (or similar) which in some cases included the option to download further information (e.g., YTAN: Digitalt stöd för unga anhöriga in Sweden) and interactive activities. For example, Alzheimer's Research UK included a quiz and a crossword explaining dementia and its symptoms. Two websites, the Young Dementia Network in the UK and the Associação Alzheimer Portugal in Portugal signposted users to resources created by an Australian nonprofit organization (Dementia Australia). In the UK, this signposting was done simply providing the link, whilst Portugal translated the Australian resources explaining dementia and the brain into Portuguese and embedded its content in the webpages of the Associação Alzheimer Portugal.

All categories were addressed at least once in content found for all countries with one exception: In Italy, there was no content that explicitly addressed C4 (Grief and loss). Notably, this category was available but often limited in the other countries. In the UK and Sweden for instance, most content in this category reported on grief and loss indirectly through case studies or personal experiences from people in the form of blogs (e.g., Alzheimer Research UK - https://www.alzheimersresearchuk.org/news/meet-one-of-britains-youngest-dementia-carers/) or podcasts (e.g., Svenskt demenscentrum podcast series, episodes 43, 45, 46 which includes interviews with young dementia carers and families living with young onset dementia https://demenscentrum.se/Publicerat/poddradio).

Across all countries, content focused on supporting young dementia carers to identify the need for help (C6) was identified (Table 3). In Sweden and Ireland, 83% and 77% of the content respectively, addressed this category. For example, the Swedish nonprofit Ung Anhörig provided a webpage with different sources of support for young dementia carers depending on need (https://www.unganhorig.se/om-du-vill-veta-mer). In Italy, the organization supporting people with Frontotemporal dementia (Associazione Italiana Malattia Frontotemporale – AIMFT) includes

personal stories of young dementia carers explaining how peer support is a valuable source of support (e.g., https://frontotemporale.it/2017/12/21/storie-fronto-temporale-3/).

Across countries, variability was identified in relation to C7 (Education & life planning) where a lack of content was the norm (e.g., Italy (5%)) even in countries with more established dementia networks (e.g., Netherlands (2%)). This suggests that across Europe, resources currently provide limited guidance on how young dementia carers (and education staff) can navigate school systems and decisions on their education and future planning alongside their caregiving responsibilities. In Sweden 16% of the content identified was classed as addressing C7. This content was often targeted mostly at schools and staff, for example, the organization Anhörigas riksförbund provided a guide for teachers on supporting young dementia carers (and young carers) in education (https://anhorigasriksforbund.se/barnsomanhoriga/).

Discussion

Our content analysis has shed light on current support that young dementia carers can access from websites across seven European countries. We identified great variability in both availability and type of content addressed across these countries. A significant geographical concentration of organizations and identified content was in the UK. However, this can be also explained by the presence of an umbrella network (Young Carers Alliance), which includes more than 200 member organizations all focused on support for young carers and One Dementia Voice (see Supplemental file 3). None of the other countries included in this study identified a similar type of network encompassing a wide diversity of organizations working towards a common goal.

Most of the young dementia carer-targeted support is available on a small number of websites for each country. This suggests an overall lack of awareness about young dementia carers, their limited visibility within formal service systems and society, and a lack of recognition of their roles. The policy and service context across the seven countries (Supplemental file 1) may be linked to the level of targeted support identified. In countries such as the UK, the Netherlands and Sweden, positive steps have been made to start to recognize young dementia carers as a distinct group. For example, in the Netherlands, the Dementia Care Standard (Dutch Government, 2026) has been instrumental in drawing attention to the needs of young dementia carers. In the UK, the draft Wales National Strategy for Unpaid carers (Welsh Government, 2026a) and the draft Dementia Strategy for Wales (Welsh Government, 2026b) identify the needs of young people explicitly. This aligns closely with the work that these three countries are developing to increase awareness and improve diagnostic and support pathways for people with dementia, particularly for families affected by young onset dementia (defined by a symptom onset <65 years (van de Veen et al., 2022)), that are more likely to include young dementia carers. This, for example, is demonstrated through the resources and activities developed by the Young Dementia Network in the UK. Similarly, in the Netherlands the Young-onset Dementia Knowledge Centre has been instrumental in the development of resources, specifically targeted to people living with young-onset dementia, and (young) carers (Bakker et al., 2022). When looking at the international context, our findings show that some young dementia carer-specific support originated in Australia (DementiaAustralia), a country where evidence has shown improved diagnosis of young onset dementia in recent years (Loi et al., 2022; Tjokrowijoto et al., 2025).

On the other hand, in countries such as Greece, Portugal and Italy we found significant lack of information on young dementia carers which may reflect young carers and young people not being included within current government strategies for dementia and unpaid carers (see Supplemental file 1).

Our findings also highlight the importance of terminology in determining the pathway to access support that young dementia carers follow. The term 'young dementia carer' is very rarely used, even within dementia-focused organizations, and there was a lack of consistency across countries in relation to the terms 'young carer' and 'young adult carer'. Whilst in some countries these terms are widely used (e.g. UK, the Netherlands), in other countries they are not. For example, in Sweden, the term 'young dementia carer' was not used in any of the websites and the term 'young carer' (unga omsorgsgivare) occurred sparsely, instead the term 'unga anhöriga' (young next-of-kin) was widely used. Evidence shows that, as with young carers, young dementia carers often do not see themselves in this role, and even actively avoid being identified as a carer for fear of discrimination, stigma and possibly consequences for their families (e.g., involvement of child protection services) (Masterson-Algar & Williams, 2020; Pakenham & Cox, 2018; Saragosa et al., 2022). Additionally, society itself does not recognize them as carers and there is a tendency to view the 'healthy' parent as the carer, underestimating the caring roles these children are adopting in their everyday lives (Masterson-Algar et al., 2023).

It is important to note that as well as available support, terminology can also be driven by the policy context. For example, in Sweden, the welfare system reflects the belief that care is the responsibility of the state, not of family members, especially not children. As such, the Swedish health and social care legislation emphasizes children's right to be protected from caregiving and supported in their upgrowing process (Hedman et al., 2026; Leu et al., 2023). Hence, the term 'young carer' is not widely used. On the other hand, countries like the UK and Ireland embrace the term 'young carer', which is explicitly used in dementia, caring and children-specific policies (see Table 1 (Carers Trust, 2026)). In Italy, Portugal and Greece, young dementia carer visibility is reduced, with this term being rarely used in information embedded in analyzed websites and not linked to an institutionally created policy structure which currently does not include strategies to support young carers (Supplemental file 1). In line with what others have suggested (Fives et al., 2013; Masterson-Algar et al., 2023), we believe that terminology can play a significant role in defining successful pathways young dementia carers and their families can use to access support. This is particularly important in societies heavily reliant on the internet to access and find information. We agree with Watson et al. (Watson et al., 2025) that greater awareness and clear presence of a defining term can potentially facilitate identification of young carers (and young dementia carers), development of dedicated support services and greater social recognition of the caregiving role.

Our results also highlight the heavy reliance, across all seven countries, on nonprofit organizations for support. Beyond direct service provision, nonprofit organizations address socioeconomic disparities in the health and social care sector and advocate for the voice of the persons living with dementia (Bowles et al., 2023). As these roles require positive and efficient communication between sectors, evaluating their impact can be difficult due to system complexity. Evidence has repeatedly shown that health and social care professionals across Europe experience shortages of available support pathways that they can refer young dementia carers to (Hedman et al., 2026; Poole & Patterson, 2022; Sobers et al., 2026; Tyrrell et al., 2024). This is in line with evidence published in a review (Sobers et al., 2026) that highlighted a lack of cohesive and clear links between different sectors to support young dementia carers and their families. Our results show that, particularly in countries such as the UK, the Netherlands and Sweden support is improving, and positive initiatives are underway. Hence, more effort needs to be made to make this support known and trusted by the health and social care sector.

The findings identified that current content available across countries is often poorly targeted and not tailored to young dementia carers (e.g. not age-specific, role-related, nor adapted to

developmental needs). Less than half of the websites' content was directly targeted at young carers, content related to school or career planning was scarce, and content was predominantly text-based rather than delivered through video, audio, or gamified modalities, which may be more engaging for younger populations. This lack of tailoring can potentially drive young dementia carers and their families away (Masterson-Algar et al., 2023). Additionally, identified content was often not specific to young dementia carers actual needs, their preferences and circumstances. When it was young dementia carer-specific, the content rarely offered tangible support or specific strategies to cope with and deal with the multifaceted impacts of having a parent with dementia and providing care for someone with dementia. Hence, our study adds to the body of knowledge advocating for more research that aims to unpick this impact and also work with young people and their families to co-develop and evaluate tailored support, as previous research has highlighted (Masterson-Algar et al., 2023).

Results from this study indicated that a significant proportion of young dementia carer-specific content takes a narrative form of real stories or testimonies from families or individuals. This type of narrative has been shown to be highly valued by family members including children (Bruinsma et al., 2021). Similarly, the relatability of narratives can be described as a form of peer support. Evidence shows that peer support has been found to improve mental health (Gillard et al., 2017) and increase self-esteem and reduce anxiety in young people by helping them use adaptive coping strategies (Simmons et al., 2023). This is underpinned by the notion that there is an 'exchange' between peers, which provides reciprocal benefits. The content we identified in our study in the form of narratives (e.g. blogs, testimonies) will resonate with young dementia carers and can potentially bring positive impacts, however, little evidence is available, and more research needs to be underway in order to unpick the multifaceted aspects of this impact.

Our findings indicate that most identified content is primarily informational and rarely directs young dementia carers toward psychosocial interventions, either in person or online. Psychosocial interventions are those centred around changing cognitive and behavioral characteristics through the development of skills, such as rational/optimistic thinking, problem-solving and coping skills. They have shown promising results in reducing and preventing symptoms of depression, social, emotional, and behavioral problems for adolescents (Duagi et al., 2023). Our study identified a small number of examples of these types of interventions which are more likely to provide tangible support and coping strategies. For example, a self-directed online psychosocial program, iSupport for Young People (Masterson-Algar et al., 2022) and summer camps for young dementia carers (in services in Sweden and the Netherlands). Psychosocial interventions have shown positive impacts on wellbeing and resilience building in young dementia carers (Cunningham et al., 2017). Our findings identified an innovative nurse-led service provided by Dementia UK's Consultant Admiral Nurse for Children and Young People. This role was recently developed informed by the results of a systematic review that identified the needs of young dementia carers (Sobers et al., 2026). While our study focused on examining website content for young dementia carers, support for these carers requires a multifaceted approach, grounded in the recognition that 'one size doesn't fit all'. It also needs to extend beyond websites to include coordinated initiatives across multiple contexts, such as schools and community-based services. We have identified examples of organizations that include in their websites content of different types which we hope can be explored, adapted and replicated by other countries in Europe or internationally in order to avoid duplication and in turn save public spending. In this study we also found content addressing schooling and education; however, medium to long term life planning remained largely underrepresented across all countries, with low focus on the cumulative impact of caregiving on young people's developmental trajectories and life opportunities. Evidence shows that educational attainment (Joseph et al., 2020; Lacey et al., 2022)

and work prospects (Cheesbrough et al., 2016) are heavily impacted by caring responsibilities when you are young (Carers Trust, 2026, 2025). Conditions like dementia can affect a family for many years, meaning the impact on young people can be particularly significant (Masterson-Algar & Williams, 2020). Our findings add to the body of knowledge in the field of young carers (Stevens et al., 2024) advocating for the development of school-based support that can be clearly linked to other services and settings (e.g. higher education) to assist young dementia carers in decision-making and planning.

From our findings, we propose a series of recommendations for future research and practice:

(1) Countries should build on positive initiatives and examples of support content to avoid replication and safeguard the use of public resources. This content should be adapted to different contexts and cultures, evaluated and evidence based and generated by working with young dementia carers, families and health professionals to ensure it is grounded in real experiences.
(2) Young dementia carers should be recognized as a distinct group. Clear and consistent terminology can help achieve this aim and should facilitate the design and access to suitable resources for this group.
(3) There is a need to develop, via robust co-design-based research, tailored and targeted support that leads to sustained improvement in the lives of young dementia carers. Co-design will ensure that resources will align to the preferences and developmental stage of young carers, identifying choices on the way written content, visuals, and information are presented (e.g., through video, text, or gamified formats). This in turn will make online information attractive and accessible to young carers.
(4) There is a need to develop effective signposting to organizations with more comprehensive content and to share practices and outcomes widely, via joint working between nonprofit organizations and health and social care sectors to avoid duplication and promote effective usage of public funds. This will, in turn to enhance future access and impact on young dementia carers and their families.
(5) There should be more emphasis on support in decision-making around schooling and life planning leading to young dementia carers joining the workforce.

Limitations

The results of this study should be interpreted in light of its limitations. While the inclusion of heterogeneous countries at different policy and statutory stages in terms of dementia and young carers' support pathways is a strength of the study, it also presents methodological challenges, necessitating adaptations to website identification procedures. Our screening and extraction methods were adapted accordingly to allow for flexibility and tailoring. Furthermore, heterogeneity can be seen as a strength, as the differing contexts helped identify examples of support that other countries could reference or adapt when developing their own services. Secondly, as with any study involving a diverse group of researchers and contexts, fidelity to protocol was challenging. To minimize this challenge, regular meetings were held during the process to allow for clear communication pathways and rigorous documentation of procedures and challenges. Thirdly, our content analysis was focused on organizations that had a working website. It is likely that there is support for young dementia carers delivered by organizations that do not have a web presence, meaning our results will underestimate the scale of available content. Also, in countries where web searches are used to identify relevant organizations (e.g., Portugal, Greece and Italy), the

traceability and search engine optimisation of websites can influence the results retrieved, as organizations which are better indexed are more likely to be identified. However, this also corresponds to what a typical internet user would experience when conducting a web search. Fourth, our study focused on the availability and characteristics of online content, but did not assess whether, how often, or by whom these resources are actually accessed, or how they are perceived or used by young dementia carers. Consequently, we are unable to draw conclusions about the usability or impact of the identified content. Similarly, our study did not assess the quality and rigour of the identified content. Understanding how young dementia carers engage with online information, its quality and whether it meets their needs at different stages, is a crucial next step for future research. Furthermore, in this study we focussed on young dementia carers, and this included young and young adult carers. We acknowledge that more research is needed to identify differences in need and support across these two groups.

Finally, and similar to our third limitation, our searches followed a subjective process to select organizations for analysis and did not include stand-alone social media content (e.g. Facebook groups and TikTok creators). We are aware that social media platforms and more recently artificial intelligence (AI) chatbots are increasingly used as a primary information source, particularly among young people (Stifjell et al., 2025), and that this trend is likely to increase over time. Future work will need to account for this type of content which is highly diverse, ever changing, and variable in credibility. Whilst we acknowledge these limitations, we are confident that our findings provide relevant evidence to support decision-making of European and international organizations on the next steps in the development of support pathways for young dementia carers.

Conclusions

Our content analysis has identified current support available in websites across Europe which young dementia carers can access. Our findings advocate for increased recognition of young dementia carers as a distinct group of carers (using consistent terminology) and for tailored information and support. Although we have identified content available to young dementia carers, this rarely translates into clear, structured and young dementia carer-specific pathways for support. The evidence here presented should contribute to raise awareness to advocate for joint working between nonprofit organizations and the health and social sectors to lead research that focusses on adapting and co-developing tailored content and resources across Europe but also worldwide.

Acknowledgments

INTERDEM Young Onset Dementia Taskforce (for more information or to join INTERDEM, please visit the website - https://www.interdem.org/).

ORCID iDs

Patricia Masterson-Algar https://orcid.org/0000-0001-6344-1346
Åsa Craftman https://orcid.org/0000-0002-0553-199X
Manuel A. Franco https://orcid.org/0000-0002-3639-2523
Ragnhild Hedman https://orcid.org/0000-0003-0103-8994
Louise Hopper https://orcid.org/0000-0002-9382-5241
Ana Belen Navarro https://orcid.org/0000-0003-1931-4619
Catherine Talbot https://orcid.org/0000-0001-9353-8990

Marie Tyrrell https://orcid.org/0000-0001-6405-2326
Ziyue Wang https://orcid.org/0009-0002-7041-0913

Author Contributions

P Masterson-Algar: Writing – original draft, Writing – review & editing, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **A Watters, A Meireles, Z Wang, H Bodde, R Hedman, S Teles, AR Ferreira, Å Craftman, G Flynn, V Giannouli, M Quartarone, M Tyrrell:** Writing – review & editing, Methodology, Investigation, Formal analysis, Data curation. **L Hopper, C Bakker, JM Papma, L Fernandes, R Chattat, C Talbot, S Trolese, I Chirico:** Writing – review & editing, Methodology. **D Snow, R Duijvestijn:** Investigation, Data curation. **E Loseto-Gerritzen, MA Franco, AB Navarro:** Writing – review & editing.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

The datasets generated and analyzed during the study are available upon request. All data requests should be submitted to the corresponding author for consideration. Access to data may be granted following review.

Supplemental Material

Supplemental material for this article is available online.

References

Alzheimer Europe. (2025). Prevalence of Dementia in Europe. https://www.alzheimer-europe.org/dementia/prevalence-dementia-europe?language_content_entity=en

Bakker, C., Verboom, M., & Koopmans, R. (2022). Reimagining postdiagnostic care and support in young-onset dementia. *Journal of the American Medical Directors Association*, *23*(2), 261–265. https://doi.org/10.1016/j.jamda.2021.12.008

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *Nursing Open*, *2*, 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Blake, C., & Hopper, L. (2022). Childhood perspectives of parental young onset dementia: A qualitative data synthesis. *Dementia*, *21*(4), 1304–1313. https://doi.org/10.1177/14713012221077531

Bowles, J., Clifford, D., & Mohan, J. (2023). The place of charity in a public health service: Inequality and persistence in charitable support for NHS trusts in England. *Social Science & Medicine*, *322*(April 2023), 115805. https://doi.org/10.1016/j.socscimed.2023.115805

Bruinsma, J., Peetoom, K., Bakker, C., Boots, L., Millenaar, J., Verhey, F., & de Vugt, M. (2021). Tailoring and evaluating the web-based 'Partner in Balance' intervention for family caregivers of persons with young-onset dementia. *Internet Interventions*, *25*(September 2021), 100390. https://doi.org/10.1016/j.invent.2021.100390

Carers Trust (2025).*Caring and classes 2025 – Young carers and attainment inequalities*. https://carers.org/downloads/caring-and-classes-2025—attainment-report.pdf

Carers Trust.(2026). Caring and classes: The education gap for young carers. Retrieved March 9, 2026, from. https://carers.org/downloads/young-carers-in-education-reportfinal.pdf

Cartwright, A. V., Stoner, C. R., Pione, R. D., & Spector, A. (2021). The experiences of those affected by parental young onset dementia: A qualitative systematic literature review. *Dementia*, *20*(7), 2618–2639. https://doi.org/10.1177/1471301220988231

Cheesbrough, S., Harding, C., Taylor, L., Public, K., Jo, W., & Young, A. (2016). The lives of young carers in England. Retrieved March 24, 2026 from. https://assets.publishing.service.gov.uk/media/5a80eaec40f0b62305b8de15/DFE-RR499_The_lives_of_young_carers_in_England.pdf

Chirico, I., Ottoboni, G., Valente, M., & Chattat, R. (2021). Children and young people's experience of parental dementia: A systematic review. *International Journal of Geriatric Psychiatry*, *36*(7), 975–992. https://doi.org/10.1002/gps.5542

Chirico, I., Trolese, S., Esposti, V. D., Veronese, G., Cavazzoni, F., & Chattat, R. (2026). Psychosocial interventions, programs and support to promote young caregivers' well-being: An integrative review. *Current Psychology*, *45*(3), 273–281. https://doi.org/10.1007/s12144-025-08781-0

Coulson, N. S., & Talbot, C. V. (2025). Examining support marshalling within an asynchronous online peer support forum for individuals affected by dementia. *Journal of Health Psychology*, *30*(8), 1795–1808. https://doi.org/10.1177/13591053241287029

Cunningham, L. C., Shochet, I. M., Smith, C. L., & Wurfl, A. (2017). A qualitative evaluation of an innovative resilience-building camp for young carers. *Child & Family Social Work*, *22*(2), 700–710. https://doi.org/10.1111/cfs.12286

Dixon, E., Anderson, J., Blackwelder, D., L Radnofsky, M., & Lazar, A. (2022). Barriers to online dementia information and mitigation. In: *Proceedings of the 2022 CHI conference on human factors in computing systems* (pp. 1–14). CHI.

Duagi, D., Carter, B., Farrelly, M., Lisk, S., Shearer, J., Byford, S., James, K., & Brown, J. S. L. (2023). Long-term effects of psychosocial interventions for adolescents on depression and anxiety: A systematic review and meta-analysis. *Clinical Medicine*, *68*(February 2024), 102382. https://doi.org/10.1016/j.eclinm.2023.102382

Dutch Government (2026). *Dementia care standard*. Retrieved February 15, 2026 from. https://www.zorgstandaarddementie.nl/zorgstandaard

Efthymiou, A., Papastavrou, E., Middleton, N., Markatou, A., & Sakka, P. (2020). How caregivers of people with dementia search for dementia-specific information on the internet: Survey study. *JMIR Aging*, *3*(1), e15480. https://doi.org/10.2196/15480

EuroStat. (2025). Young people: Digital world. Retrieved April 3, 2026 from. https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Young_people_-_digital_world

Fives, A., Kennan, D., Canavan, J., & Brady, B. (2013). Why we still need the term 'young carer': Findings from an exploratory study of young carers in Ireland. *Critical Social Work*, *14*(1), 49–61. https://doi.org/10.22329/csw.v14i1.5872

Gelman, C. R., & Greer, C. (2011). Young children in early-onset Alzheimer's disease families: Research gaps and emerging service needs. *Am J Alzheimers Dis Other Demen*, *26*(1), 29–39. https://doi.org/10.1177/1533317510391241

Gillard, S., Foster, R., White, S., Bhattacharya, R., Binfield, P., & Eborall, R. (2017). Describing a principles-based approach to developing and evaluating peer worker roles as peer support moves into mainstream mental health services. *Mental Health and Social Inclusion*, *21*(3), 133–143. https://doi.org/10.1108/mhsi-03-2017-0016

Grundberg, Å., Sandberg, J., & Craftman, Å. G. (2021). Children's and young adults' perspectives of having a parent with dementia diagnosis: A scoping review. *Dementia*, *20*(8), 2933–2956. https://doi.org/10.1177/14713012211023653

Hedman, R., Tyrrell, M., Jönsson, A., Södergren, U., Sandberg, J., & Craftman, Å. G. (2026). Professionals' prerequisites and preparedness for supporting young people living with a parent with dementia. *European Journal of Social Work*, *29*(4), 1–13. https://doi.org/10.1080/13691457.2025.2599088

Joseph, S., Sempik, J., Leu, A., & Becker, S. (2020). Young carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolesc Res Rev*, *5*(1), 77–89. https://doi.org/10.1007/s40894-019-00119-9

Lacey, R. E., Xue, B., & McMunn, A. (2022). The mental and physical health of young carers: A systematic review. *The Lancet Public Health*, *7*(9), e787–e796. https://doi.org/10.1016/S2468-2667(22)00161-X

Leu, A., & Becker, S. (2017). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers. *Journal of Youth Studies*, *20*(6), 750–762. https://doi.org/10.1080/13676261.2016.1260698

Leu, A., Berger, F. M. P., Heino, M., Nap, H. H., Untas, A., Boccaletti, L., Lewis, F., Phelps, D., Santini, S., D'Amen, B., Socci, M., Hlebec, V., Rakar, T., Magnusson, L., Hanson, E., & Becker, S. (2023). The 2021 cross-national and comparative classification of in-country awareness and policy responses to 'young carers. *Journal of Youth Studies*, *26*(5), 619–636. https://doi.org/10.1080/13676261.2022.2027899

Loi, S. M., Cations, M., & Velakoulis, D. (2023). Young-onset dementia diagnosis, management and care: A narrative review. *Medical Journal of Australia*, *218*(4), 182–189. https://doi.org/10.5694/mja2.51849

Loi, S. M., Goh, A. M. Y., Mocellin, R., Malpas, C. B., Parker, S., Eratne, D., Farrand, S., Kelso, W., Evans, A., Walterfang, M., & Velakoulis, D. (2022). Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. *International Psychogeriatrics*, *34*(4), 367–375. https://doi.org/10.1017/S1041610220001489

Masterson-Algar, P., Egan, K., Flynn, G., Hughes, G., Spector, A., Stott, J., & Windle, G. (2022). iSupport for young carers: An adaptation of an e-Health intervention for young dementia carers. *International Journal of Environmental Research and Public Health*, *20*(1), 127–136. https://doi.org/10.3390/ijerph20010127

Masterson-Algar, P., Egan, K., Flynn, G., Hughes, G., Spector, A., Stott, J., & Windle, G. (2023). Hard to reach and hidden: Improving the identification of young dementia carers. *International Journal of Environmental Research and Public Health*, *20*(23), 7103-7113. https://doi.org/10.3390/ijerph20237103

Masterson-Algar, P., & Williams, S. (2020). "Thrown into the deep end": Mapping the experiences of young people living in a family affected by a neurological condition. *Qualitative Health Research*, *30*(5), 717–729. https://doi.org/10.1177/1049732319900498

Millenaar, J. K., van Vliet, D., Bakker, C., Vernooij-Dassen, M. J., Koopmans, R. T., Verhey, F. R., & de Vugt, M. E. (2014). The experiences and needs of children living with a parent with young onset dementia: Results from the NeedYD study. *International Psychogeriatrics*, *26*(12), 2001–2010. https://doi.org/10.1017/S1041610213001890

Monnet, F., Pivodic, L., Dupont, C., Dröes, R. M., & Van den Block, L. (2023). Information on advance care planning on websites of dementia associations in Europe: A content analysis. *Aging & Mental Health*, *27*(9), 1821–1831. https://doi.org/10.1080/13607863.2022.2146051

Nichols, K. R., Fam, D., Cook, C., Pearce, M., Elliot, G., Baago, S., Rockwood, K., & Chow, T. W. (2013). When dementia is in the house: Needs assessment survey for young caregivers. *Can J Neurol Sci*, *40*(1), 21–28. https://doi.org/10.1017/s0317167100012907

Pakenham, K. I., & Cox, S. (2018). Effects of benefit finding, social support and caregiving on youth adjustment in a parental illness context. *Journal of Child and Family Studies*, *27*(8), 2491–2506. https://doi.org/10.1007/s10826-018-1088-2

Poole, C., & Patterson, T. G. (2022). Experiences and needs of children who have a parent with young onset dementia: A Meta-ethnographic Review. *Clinical Gerontologist*, *45*(4), 750–762. https://doi.org/10.1080/07317115.2020.1765933

Ritzen, M., Peetoom, K., Bartels, S. L., Bakker, C., de Vugt, M., & YOD-included consortium #. (2025). Needs of people living with young-onset dementia and family carers, explored by dementia subtype, phase in the disease process, and living setting: A scoping review. *Journal of Alzheimer's Disease*, *107*(4), 1340–1363. https://doi.org/10.1177/13872877251372148

Saragosa, M., Frew, M., Hahn-Goldberg, S., Orchanian-Cheff, A., Abrams, H., & Okrainec, K. (2022). The young carers' journey: A systematic review and Meta ethnography. *International Journal of Environmental Research and Public Health*, *9*(10), 5826–5837. https://doi.org/10.3390/ijerph19105826

Simmons, M. B., Cartner, S., MacDonald, R., Whitson, S., Bailey, A., & Brown, E. (2023). The effectiveness of peer support from a person with lived experience of mental health challenges for young people with anxiety and depression: A systematic review. *BMC Psychiatry*, *23*(1), 194–203. https://doi.org/10.1186/s12888-023-04578-2

Sobers, T., Wolverson, E., Gardner, H., Joddrell, P., Walpert, M., Pepper, A., & Harrison Dening, K. A. (2026). Systematic review of the needs of children and young people of a parent diagnosed with young-onset-dementia: Informing a nursing intervention. *Journal of Advanced Nursing*, *82*(5), 4733–4749. https://doi.org/10.1111/jan.70205

Soong, A., Au, S. T., Kyaw, B. M., Theng, Y. L., & Tudor Car, L. (2020). Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: A scoping review. *BMC Geriatrics*, *20*(1), 1–17. https://doi.org/10.1186/s12877-020-1454-y

Stevens, M., Brimblecombe, N., Gowen, S., Skyer, R., & Moriarty, J. (2024). Young carers' experiences of services and support: What is helpful and how can support be improved? *PLoS One*, *19*(3), e0300551. https://doi.org/10.1371/journal.pone.0300551

Stifjell, K., Sandanger, T. M., & Wien, C. (2025). Exploring online health information–seeking behavior among young adults: Scoping review. *Journal of Medical Internet Research*, *27*, e70379. https://doi.org/10.2196/70379

Talbot, C. V., Roe, D., Anderson, J. G., Donnellan, W. J., Wilson, S. A., & O'Dwyer, S. T. (2024). Unpaid carers' experiences of supporting people with dementia to use social media. *Aging & Mental Health*, *28*(7), 977–984. https://doi.org/10.1080/13607863.2024.2301725

Teles, S., Paúl, C., Costa-Santos, C., & Ferreira, A. (2022). Use of dementia and caregiving-related internet resources by informal caregivers: A cross-sectional study. *Frontiers in Medicine*, *9*, 978635. https://doi.org/10.3389/fmed.2022.978635

Tjokrowijoto, P., Beard, C., Stange, D., D'Cunha, N. M., Cartwright, J., Moylan, N., Withall, A., Draper, B., Scott, T., Irish, M., Lewis, R., Atkins, K., Goodlet, C., Burton, E., Cvejic, R., Glennen, K., Schweitzer, D., Cations, M., & Loi, S. M. (2025). The road to young-onset dementia diagnosis: Findings from the joint solutions Project. *Alzheimer's & Dementia*, *21*(8), e70538. https://doi.org/10.1002/alz.70538

Tyrrell, M., Jönsson, A., Södergren, U., Hedman, R., Sandberg, J., & Gransjön, C. Å. (2024). Insights from health and social care professionals supporting children and young adults with a parent diagnosed with dementia: An interview study. *Health and Social Care in the Community*, *2024*, Article 8886299. https://doi.org/10.1155/2024/8886299

van de Veen, D., Bakker, C., Peetoom, K., Pijnenburg, Y., Papma, J., & PRECODE study group. de Vugt, M., & Koopmans, R. (2022). Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study. *Int J Geriatr Psychiatry*, *37*(3), 1–10. https://doi.org/10.1002/gps.5691

Watson, M. C., Neil, K. E., & DJ Donnelly. (2025). *IHPE position statement: Young carers and young adult carers (UK)*: Institute of Health Promotion and Education.

Welsh Government. (2026a). Draft dementia strategy for Wales (2026-2036). Retrieved February 23, 2026 from. https://www.gov.wales/draft-dementia-strategy-wales-2026-2036

Welsh Government. (2026b). *Draft national strategy for unpaid carers 2026*. Retrieved February 23, 2026 from. https://www.gov.wales/draft-national-strategy-unpaid-carers-2026

World Health Organization. (2017). Global action plan on the public health response to dementia. Retrieved February 15, 2026 from. https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017—2025

Author Biographies

Dr. Patricia Masterson-Algar is a health researcher and lecturer at Bangor University. Her research explores the impact that dementia can have not only on the lives of those affected by it but also on the family as a whole, including young members. Patricia works at the Dementia Services Development Centre where her research focusses on designing and evaluating interventions tailored to support young carers of people living with dementia. She is a member of the INTERDEM network.

Greg Flynn has contributed to research projects examining clinical and personal experiences of individuals and families affected by long-term health conditions. His main research interest is around improving quality of life for people living with dementia and informal carers, and he has supported several UK-wide programmes which evaluated perspectives and available support for these groups.

Prof. Christian Bakker is a healthcare psychologist and lead of the dementia research program at UKON, Radboud university medical center. His research course and care needs, development of post-diagnostic care and support and palliative care. He is involved as a psychologist and program manager at the Center for Specialized care in Young-onset Dementia at Groenhuysen care group in the Netherlands. He is also board member of the Dutch Young-onset Dementia Knowledge Center and chair of Center's scientific board.

Hanna Bodde is a PhD candidate at the Alzheimer Center Erasmus MC. She has a background in medicine and neuroscience. Her research focuses on improving care for people with young-onset dementia. Specifically, her PhD project examines how post-diagnostic care can be improved in the period immediately following diagnosis, from the perspective of memory clinics, to better support patients and their families.

Rabih Chattat is a Professor of Clinical Psychology of Aging at the University of Bologna and a board member of INTERDEM. His research and teaching focus on dementia care, social health, stigma, young-onset dementia, and family caregiving. He has participated in and coordinated numerous national and European research projects aimed at improving the quality of life and care of people living with dementia and their families.

Dr. Ilaria Chirico is a clinical psychologist and psychotherapist. She holds a PhD in Psychology and currently works as Associate Professor of Clinical Psychology at the University of Milano-Bicocca (Italy). Her main research interests include young carers, young dementia carers and youth vulnerability within contemporary society. She is a member of the INTERDEM network.

Dr. Åsa Craftman, RN, is a researcher with a background in social services and nursing. Her research focuses on health and social care for older adults, particularly those living with dementia and cognitive impairment. She also examines the experiences of children and young people with a

parent affected by dementia, as well as family caregivers. Her work aims to improve quality of life, well-being, and care for individuals with dementia and their families. She is also a nurse educator.

Rickie Duijvestijn is a master's student in Neuropsychology at the Vrije Universiteit Amsterdam. She has a background in research on genetic variants associated with frontotemporal dementia (FTD), as well as clinical experience in specialized child and adolescent psychiatry. Her interests lie at the intersection of neuropsychology, neurodegenerative disorders, and mental health care, with a particular focus on translating scientific knowledge into meaningful clinical support.

Lia Fernandes is a Full Professor at the Faculty of Medicine of the University of Porto and the Director of the Department of Clinical Neurosciences and Mental Health at the same institution. She is also a Senior Graduate Psychiatrist at the Psychiatry Service of São João University Hospital in Porto and a certified Family Therapist. She currently chairs the Board of the Geriatrics Competence College of the Portuguese Medical Association, and is also a member of INTERDEM and integrates the board of directors of EAGP.

Ana Rita Ferreira is an Assistant Professor at the Department of Clinical Neurosciences and Mental Health of the Faculty of Medicine, University of Porto and a certified specialist in Clinical and Health Psychology and in Neuropsychology. She holds a PhD in Clinical and Health Services Research and a Master's degree in Clinical Psychology with specialization in Clinical Psychogerontology. She is a member of the INTERDEM network.

Manuel Franco-Martin is a full professor at Salamanca University (Spain) and the Head of Psychiatry Department of Complejo Asistencial de Zamora (Zamora Hospital, Spain). He is Director of the Psychosciences Research Group of the Biomedicine Research Institute of Salamanca. He is a Board Member of the European Association of Geriatric Psychiatry and the INTERDEM network (founder member). His expertise is on neuropsychology and psychosocial care in dementia as well as geriatric psychiatry.

Dr. Vaitsa Giannouli is a researcher and assistant professor interested in psychological assessment and interventions for those affected by dementia. Her research explores cognitive deficits in patients with neurocognitive disorders and their impact on families and caregivers as well as how these findings shape public health policies. Vaitsa works at the Department of Psychology, Democritus University of Thrace.

Ragnhild Hedman, RN, PhD, is a researcher and investigator at the Stockholm Gerontology Research Center and an associated researcher at the Department Neurobiology, Care Sciences and Society at Karolinska Institutet, Stockholm Sweden. She has a background in geriatric and gerontological nursing and teaching. Her research is mainly focused on care and support of older people living with frailty and cognitive impairment and their families.

Dr. Louise Hopper is a psychologist and dementia researcher focused on enhancing quality of life for people living with cognitive impairment. Her work examines how dementia affects individuals, families, and wider care networks, with a particular interest in digital supports and inclusive care models. Louise is based at Dublin City University, where she leads research on dementia interventions and technology-enabled supports designed to empower carers and improve wellbeing across the dementia journey.

Dr. Esther Loseto-Gerritzen is a postdoctoral researcher at the Institute of Mental Health, University of Nottingham, UK. Her research focusses on post-diagnostic support for people with

Young Onset Dementia and their families, and digital inequalities and access to digital care and support services for people with dementia and carers.

Dr. Ana Meireles is a psychologist and Professor of Psychology at the Instituto de Psicologia e Ciências da Educação of Universidade Lusíada and a researcher at the CIPD, Research Centre in Psychology for Development, Portugal. Her work focuses on mental health, wellbeing, caregiving, and vulnerable populations across the lifespan. Ana coordinates and collaborates on projects related to young carers, higher education mental health, and community-based psychosocial interventions, with particular interests in inclusion, prevention, and family and community wellbeing.

Dr. Ana Belén Navarro is Full Professor and researcher at the Faculty of Psychology of the University of Salamanca. Her research explores psychological resilience and satisfactory aging, focusing on how very old individuals thrive. Additionally, she works closely with the Psychosocial Unit for the Elderly (UMAPS), where her work focuses on designing and evaluating interventions to support dementia caregivers, while also advancing early Alzheimer's diagnosis through emotional speech analysis.

Dr. Janne Papma, PhD, is an associate professor and head of the Alzheimer Center at Erasmus MC. With a background in psychology and neuroscience, she studies how to personalize dementia diagnostics and post-diagnostic care. Her work includes culture-sensitive assessment, tailored pathways for young-onset dementia, and early detection of behavioral symptoms. She is committed to improving timely diagnosis and ensuring dementia care meets the needs of diverse patient groups.

Martina Quartarone is a psychologist and researcher interested in improving the lives of people affected by dementia. Her research focuses on understanding the experiences and support needs of people living with young-onset dementia and their families. Martina works at the University of Bologna, where she is involved in developing and evaluating psychosocial and non-pharmacological interventions aimed at promoting participation, wellbeing, and quality of life for people living with dementia.

Destiny Snow has recently completed an undergraduate degree in Psychological and Behavioural Sciences at Cambridge University. She is interested in health research and has supported research initiatives in the area of dementia.

Dr. Catherine Talbot is a Senior Lecturer in Psychology and member of the Ageing and Dementia Research Centre (ADRC) at Bournemouth University, UK. Her research focuses on how digital technologies can be harnessed to support the wellbeing, identities, and social inclusion of people living with dementia, while also addressing issues of digital inequality.

Soraia Teles is an Assistant Researcher at the Department of Clinical Neurosciences and Mental Health, Faculty of Medicine, University of Porto, and at the RISE-Health R&D Unit. She holds a PhD in Clinical and Health Services Research, a degree and master's in Clinical and Health Psychology, and a master's in Social Economics. Her main research interests include aging in place, dementia, informal care, eHealth, and Ambient Assisted Living solutions. She is a member of the iSupport Network and the INTERDEM network.

Sara Trolese is a researcher interested in improving the lives of young carers affected by dementia. Her research explores the impact that dementia can have on children and young people who support a family member living with the condition. Sara has worked with young carers and families across research and community-based projects. She works at the University of Bologna, where her

research focuses on identifying the needs of young carers and developing tailored interventions to support their wellbeing, participation, and quality of life.

Marie Tyrrell is a RGN, RPN, MSc., and lecturer at Sophiahemmet University, Stockholm, Sweden. She holds a PhD in medicine from Karolinska Institutet and has over 30 years of experience in the field of older adult care. Dr. Tyrrell's research focuses on persons' and family members' experiences of living with dementia in a community setting. She is currently involved in the implementation of iSupport (World Health Organization, 2017) inspired programmes. She is also a nurse educator in both graduate and post-graduate levels.

Ziyue Wang is a PhD candidate in the School of Nursing and Midwifery at the University of Galway, Ireland. Her topic focuses on social health in people living with young-onset dementia. Ziyue is a member of the INTERDEM Academy that has members across Europe, and a member of Psychosocial Dementia Research Group based at the University of Galway. In addition to her PhD project, Ziyue actively contributes to research on dementia care, dementia inequalities, young dementia carers and frailty.

Amber Watters is a graduate member of the Psychological Society of Ireland and recently completed a Masters Degree in Psychology. Her research interests include mental health and wellbeing in the workplace. She has presented her work at the Psychological Society of Ireland, Early Graduate Group Conference. She has contributed to research on young dementia carers. Amber also volunteers in workshops that support young people aged between 12-17. She is interested in psychological research and advocacy.