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REVIEW ARTICLE

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Housing needs for people with multiple sclerosis: a rapid review

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ABSTRACT

The impact of Multiple Sclerosis (MS) on mobility and other functions varies considerably and the trajectory of the disease is unpredictable. People often need timely funding for home modifications, with some needing specialist disability housing and support. This rapid review examined existing literature on the housing needs of people with MS. A representative reference group guided our process. Concentrating on the home environment, we systematically searched peer-reviewed literature through three databases and grey literature using a focused web-based process. The inclusion of 19 peer-reviewed articles and 13 grey literature documents revealed the need for accessible housing, affordable in-home assistive technology, and proximity to the community. A lack of timely funding was a primary barrier to independence in the home, resulting in calls for financial aid that is responsive to the progressive nature of MS. People with MS need comprehensive support, including timely access to information, affordable and accessible housing, and funding for necessary home modifications. These resources are crucial to promote independence at home, reduce hospitalisations, and prevent early admission to residential aged care. Further research is needed to capture the unique barriers people with MS face in their local context as a precursor to developing participant-led recommendations.

➢ IMPLICATIONS FOR REHABILITATION

- Improved availability of housing built to accessibility and usability design standards is required.
- Equitable, responsive funding should be available to meet the progressive needs of people with Multiple Sclerosis.
- Expert coordination and collaboration across sectors are necessary for sustainable housing solutions.

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Multiple sclerosis; housing modifications; Universal design; funding schemes; community integration; cross-sector collaboration; assistive technology

Introduction

Multiple Sclerosis (MS) is an autoimmune disease that progressively affects the central nervous system [1] and can lead to motor impairment, cognitive impairment, vision loss, poor balance, fatigue, and other physical symptoms [2]. An estimated 2.8 million people worldwide are affected by MS [3], with a greater incidence of the disease in countries further from the equator [4]. The most common type of MS is relapsing-remitting MS (RRMS), which impacts approximately 87% [1] of people with MS and is characterised by episodes of exacerbated symptoms followed by periods of partial or full recovery [5]. Progressive symptoms, without periods of remission, can signal the transition from RRMS to secondary progressive MS (SPMS) which typically involves acute exacerbations of symptoms without the recovery seen in RRMS [6]. It is estimated that 50–60% of people with RRMS eventually progress to having SPMS [7]. Other subtypes of MS include Primary Progressive MS (PPMS), where disability progressively worsens without distinct relapses or remissions [7], and Clinically Isolated Syndrome (CIS), where symptoms first present in an isolated episode but do not yet meet the criteria for a full MS diagnosis [6]. The impact of MS is highly variable [8], and its course can alter considerably, often without the ability to predict changes [6].

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Some people with MS may experience a gradual functional decline over time [9], while others are adversely impacted by multiple or severe episodes early on [6] and can experience rapid disease progression [10]. Consequently, this variability, unpredictability, and potential for rapid change can make future planning difficult [11].

Support needs can fluctuate significantly during relapses and can increase quickly as the disease progresses, leaving people in a situation where they require complex and expensive home modifications [12] or need to move into a more accessible home [13]. Consequently, younger people with MS (aged under 65 years) can face long hospitalisations [14], respite, which is in short supply and often age-inappropriate [12], or placement in residential aged care (RAC) which is designed for older people [15] and is associated with poorer outcomes and quality of life [15,16].

The cost of modifications or increased care, combined with the loss of income if a person can no longer work, makes MS an expensive disease to manage [17]. Campbell et al. [18, p.6] reported that in 2021, annual costs of living with MS in Australia were, on average, $73,457 per person, which includes direct costs, such as medical expenses, and indirect costs through lost wages and productivity. The costs varied significantly depending on the level of disability: those with no disability incurred average annual costs of $32,829, while those with severe disability faced average costs of $123,333 per year [18, p.6]. Calculations from 2017 revealed that people with MS themselves assume 22% of direct costs [18, p.11]. Ahmad et al. [19] provided a breakdown of direct costs for people with MS in Australia from 2017. Home and vehicle modifications were the second largest cost after prescription medication. People with severe disability spent $6,026 on home and vehicle modifications and $2,356 on specialist equipment (e.g. mobility aids and equipment for the kitchen, bedroom and bathroom) per annum, compared to people with mild disability who spent $1,456 and $319 respectively [19, p.8].

In 2013, the National Disability Insurance Scheme (NDIS) was introduced in Australia to support people with disability aged under 65 years. People who receive funding through the NDIS are known as 'participants,' and their allocated budget for a specified duration is called a 'plan'. Funding under the NDIS covers three broad categories: 'core funding' is for disability supports and social and community participation; 'capacity building' funds are for therapies that enhance a participant's independence and skills; and 'capital funding' finances assistive technology (AT) and home modifications [20]. To address the need for accessible housing for people with high support needs (approximately 6% of NDIS participants), a separate stated support known as Specialist Disability Accommodation (SDA) incorporates accessible features to help people live more independently and enable disability supports to be delivered efficiently [21]. As of June 2024, there were 661,267 active NDIS participants, of whom 20,663 received SDA funding [22,23], representing three percent. By the end of the fourth quarter in 2022, of the 9,938 active NDIS participants with MS, 441 received funding for SDA, accounting for four percent [24,25].

Incorporating minimum accessibility standards in housing may allow people to remain living in their homes for as long as possible if they acquire a disability and as they age. This supports the concept of 'aging in place' whereby people, regardless of ability, can safely maintain their independence in their own homes [26]. In Australia, the National Construction Code (NCC) incorporates the silver level of the *Livable Housing Design Guidelines* [27]. All new Class 1a dwellings, including housing, townhouses and units and Class 2, apartment buildings, must comply with the silver standards [28]. These include key structural features like step-free entry, wide internal doors, and corridors for easier movement. It also incorporates a ground-floor toilet, a hobless, slip-resistant shower, and reinforced walls for future grab rails [28]. Stairways are designed for safety and future adaptability. These elements enhance accessibility and adaptability, making homes safer for a diverse range of occupants and may reduce the costs of modifications if needed. This initiative aligns with the 'Australia's Disability Strategy 2012–2031,' further demonstrating a commitment to inclusive design [29]. Although the silver level guidelines support the needs of people with mobility limitations, including, for example, older people and some people with disability, people with severe disability will require housing with more specialised features. Investment in accessible housing can have positive outcomes for people's quality of life, reduce support costs [30], and facilitate activities of daily living (ADLs) [31].

Given that only three percent of NDIS participants in Australia receive SDA payments for disability-specific housing [22,23], most people with MS are dependent on mainstream private, social and public housing.

This underscores the need to evaluate whether the Australian housing and funding systems, including private, community, social and NDIS-funded housing, are sufficiently responsive to meet their increasing support needs and to understand the barriers and facilitators to live independently in the community. To bridge this knowledge gap, a comprehensive review of contemporary published and grey literature on the housing needs of people with MS is essential. The resultant research questions guided our research:

1. What are the housing needs for people with MS?
2. Do existing housing and funding systems adequately support people with MS to live independently?
3. What are the implications and recommendations for improving housing outcomes for people with MS?

This rapid review consolidated existing global findings to determine barriers to independent living and collated best practice recommendations for housing design, home modifications and AT as well as recommendations for future planning and funding.

Materials and methods

The rapid review drew from Garritty et al.'s [32] framework and was structured to align with Arksey and O'Malley's [33] scoping review stages and included Levac et al.'s [34] enhancements. This resulted in an accelerated approach, and unlike a scoping review [35], fewer databases were searched and the analysis was conducted in a concentrated timeframe [32]. Given that the research was on a health-related issue requiring a rapid turnaround, the rapid result methodology proved valid without compromising quality or standards [32,35]. Tricco et al.'s [36] guide for scoping reviews (PRISMA-ScR) was adapted to present results.

The value of a reduced timeframe was crucial to ensure we could present our findings to our knowledge users within their set deadline [32]. At the commencement of our research, the authors assembled a new reference group with representatives offering varying perspectives. The combination of members included people with MS, close others, researchers in the MS field and MS-related health professionals. We met the reference group at key stages. Within the first four months, they participated in refining the research focus, setting eligibility criteria, recommending sources, and providing feedback on our initial analysis. Our progress was reported at six months, and our final analysis was ratified 10 months before we presented our unpublished findings to the funding body, MS Australia, within their 12-month deadline. Our searches were repeated in August 2024 to capture the most recent literature.

Identifying relevant studies

We aimed to improve the understanding of the housing needs of people with MS by extracting and integrating data from peer-reviewed articles and grey literature. In consultation with a research librarian and our reference group, we developed a list of search terms that captured the population, setting and desired outcomes (see Appendix A). It was important to capture the period pre-, during and post-major disability sector reform in Australia; hence the time period for peer-reviewed literature was set to 2010 – 2024. This timeframe also accounts for disability housing reforms in other countries and captures changes influenced by the United Nations Convention on the Rights of Persons with Disabilities [37]. All ages and only articles in English were included.

In our peer-reviewed literature search process, we initially tested terms on MEDLINE (Ovid), adjusting based on accuracy, and applied them to Embase (Ovid) and PsycINFO (Ovid). We incorporated MeSH terms, truncation and proximity searching to enhance our search process. Boolean operators were used to link population, concept, outcomes, and context across the three databases in January 2023 and updated in August 2024. For citation and reference searching, we manually examined all included peer-reviewed articles, using Scopus and Google Scholar to identify citations and retrieve potentially relevant articles. Google Scholar was also independently searched as a supplementary source [38] using

condensed search terms, and results were limited to the first 50 [39] per search string (see Table 1). Prominent journals were hand-searched, and content experts provided guidance on additional sources.

Our grey literature search adapted the approach outlined by Adams et al. [40] from the inclusion of purposeful grey literature to the application of relevant findings. Jenkins et al.'s [41] advice refined our search process, incorporating incognito mode to mitigate Google search history bias, tailored search strings, location filters, and targeting specialist websites. Guided by Cullerton et al.'s [39] process, our search was limited to the first 50 Google Advanced Search results in PDF format. For websites with limited search functionality, we used a combination of site filters and manual searching. The Google Advanced Search and targeted website searches were employed to locate documentation, including industry reports, submissions to governments, and resource guides that were authored or commissioned by MS-specific organisations and affiliates stating MS-specific recommendations. The grey literature search was conducted in April 2023 and updated in August 2024.

Study selection

Inclusion criteria (see Table 2) targeted the population of people with MS and incorporated multiple perspectives. Discussion with the reference group resulted in the inclusion of the domains of housing, home modifications, and AT. We included peer-reviewed studies that reported primary data related to the home environment, including AT in the home, and home design. Articles required outcomes, thereby providing data that would advance our knowledge of what might improve the housing situation of people with MS. No age, geographic, or methodological restrictions were applied. Exclusions included studies where the MS population was not clearly defined, or the focus was on support needs in other contexts such as hospitals or rehabilitation centres. Conference papers, books and book chapters, trade journals, or opinion pieces were excluded, and grey literature was sourced in a separate search.

The database search resulted in 1214 papers identified and, using Covidence, 148 duplicates were automatically removed (see Figure 1). Two reviewers independently screened the titles and abstracts of 1066 articles. Where the two reviewers could not resolve conflicts, a third independent reviewer made a decision. A total of 171 articles advanced to a full-text review. An additional 150 articles located through additional search techniques were included at the full-text review stage. The review team assigned reasons for exclusion, and 19 articles remained. All inclusions were screened using an adaption of the Mixed

Table 1. Search terms and strings used for Google Scholar, Google Advanced Search, and website searches.

Search strings
1. 'multiple sclerosis' AND*
2. 'home' OR 'support' OR 'housing' OR 'assistive technology'*
3. 'residential' OR 'aged care' OR 'group home' OR 'home care services'
4. 'NDIS' OR 'independent living' OR 'assisted living' OR 'transitional care'
5. 'home modification' OR 'equipment' OR 'home design' OR 'in-patient care'

*Grey literature search strings.

Table 2. Database inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
1. Published since Jan 2010	1. Published before 2010
2. Published in English	2. Published in a language other than English
3. Peer-reviewed journals	3. Conference papers, book chapters, books, trade journals.
4. All ages	4. Focus of the article is not on people with Multiple Sclerosis or close others
5. Full text only	5. People without Multiple Sclerosis (or their close others)
6. Must include primary data	6. Undefined grey literature
7. Focuses on people with Multiple Sclerosis or their close others (with 1 or more of the following)	7. Scoping or systematic reviews
6. Includes people with MS, healthcare or close others perspectives.	
AND	
8. Focus on Housing and/or in-home support	
OR	
9. Focuses on hospital discharge	
OR	
10. Focuses on NDIS	
AND	
11. (OUTCOME) e.g. Focuses on the wellbeing of people with MS	

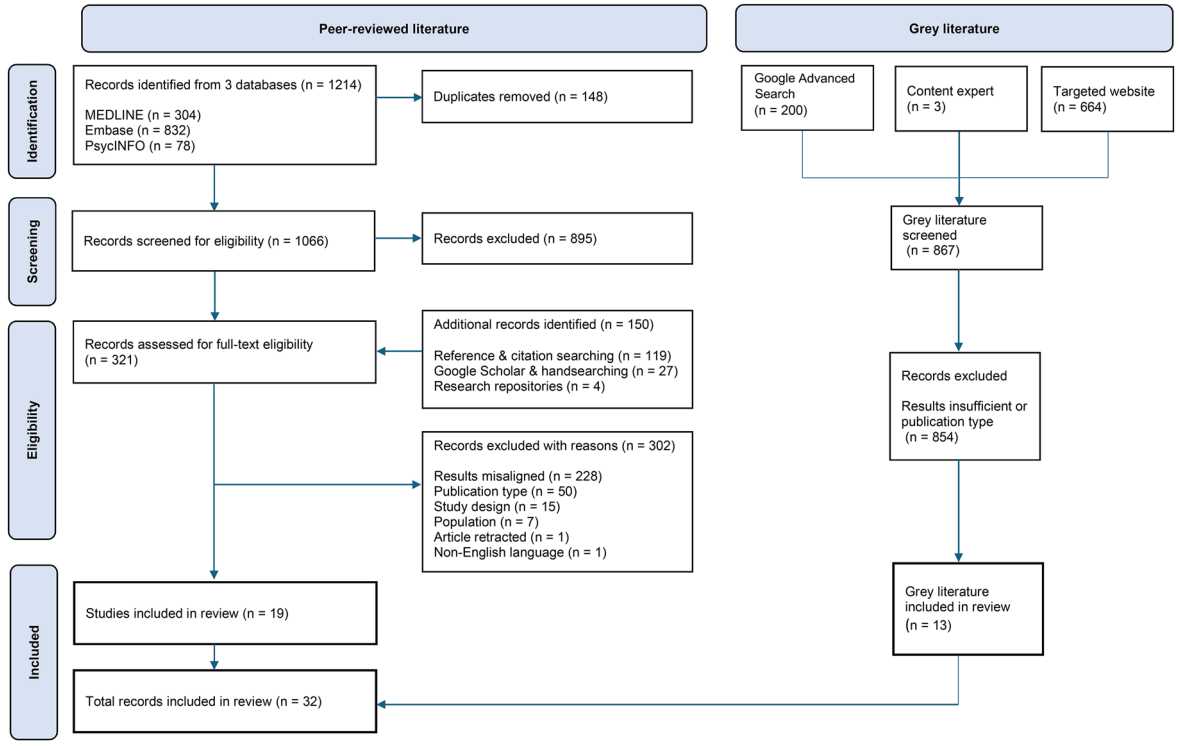

Figure 1. Screening process for grey and peer-reviewed literature.
Adapted from the template provided by Tricco et al. [36].

Methods Appraisal Tool (MMAT) [42]. Three key elements of the MMAT tool were applied as a consistent measure of quality: 1) Is the study aim clear and MS-specific? 2) Has primary data been collected using a valid and reliable method? 3) Is there potential for the results to be transferable or universally applied?

Our grey literature search revealed 867 potential documents using Google Advanced Search, a targeted website search, and advice from content experts (see Figure 1). One reviewer inputted the search terms and file type into Google Advanced Search. Location filters limited the results to 50 documents from Australia. We extended our search to incorporate results from the United Kingdom (UK) and the United States (US), which were selected because, like Australia, they have a high prevalence of MS [43] and individualised government funding schemes for people with disability. Disability laws and policies across countries are accessible via the United Nations Department of Economic and Social Affairs website [44]. The UK and US search added 50 documents for scanning. We applied 'fit-for-purpose quality criteria' [40, p.448], prioritising authoritative sources with direct experience with the MS population, including MS-specific organisations and their affiliations. To be included, documents had to provide MS-specific recommendations that either supported or extended the peer-reviewed findings. A total of 13 grey documents were included and confirmed by a second reviewer. Figure 1 provides a representation of the search process.

Charting the data

Using Microsoft Excel, we categorised the peer-reviewed data according to study features, which included the author(s), year of publication, geographical location, aims, method utilised, main findings and limitations. Participant characteristics documented sample size, perspective, demographic details, MS classification and current housing. One reviewer extracted the data and recorded it in a table, which a second reviewer then cross-checked for accuracy.

Collating, summarising, and reporting the results

A 'descriptive-analytical' framework was uniformly applied to all peer-reviewed studies per Arksey and O'Malley's [33, p.27] advice. The data were tabulated according to the key study characteristics, including

the study's focus or aim, the sample size, the participant perspective measured, the data collection method used, and where the study took place (see Table 3). Per each paper's conclusions, a summary of relevant findings is also presented in Table 3. NVivo20 was used to store and code articles. Qualitative data followed Bengtsson's [45] qualitative content analysis guidelines whereby reviewers independently inductively coded data and reached a consensus on emerging descriptors and eventual themes. Grey documentation followed a similar process with recommendations grouped under themes. The resultant compilation of housing and AT needs data were analysed according to ADLs and instrumental activities of daily living (iADLs) [31].

Results

Peer-reviewed literature

The following results contain an analysis of the peer-reviewed literature which includes 19 studies. Among these, the journals can be divided into four general disciplines: rehabilitation-focused ($n=7$), health-focused ($n=6$), MS-specific ($n=3$), policy-oriented ($n=2$), and built design ($n=1$).

Study characteristics

Of the 19 peer-reviewed studies, 10 had a quantitative design, four used qualitative methods, and five used a mixed-methods approach (Table 3). The countries represented included the US (6), Australia (4), the UK (2), and Canada (2) as well as one study each from Brazil, Iran, Italy, Poland, and Turkey.

Participant characteristics

Seventeen studies utilised the perspective of people with MS; two also included health professionals. One study focused on specialised housing experts, professionals with MS expertise and family members of people with MS. The remaining study focused solely on the views of health professionals. The aggregate count of individuals with MS across the studies is 9182, encompassing sample sizes ranging from 5082, where identical national data were utilised in four separate studies, to a single case study participant. It is important to note that this total figure accounts for unique individuals and does not involve duplications from papers using the same participant cohorts, as indicated by asterisks in Table 3. Among the studies reporting the course of the disease, the dominant diagnoses for participants were RRMS (59.7%) and SPMS (22.3%). Studies documenting gender revealed that females represented 77% of all participants with MS. Where reported, the age range across studies extended from 20 – 91 years (see Table 3).

Current housing or living arrangements were documented in four studies [47,49,52,57]. The US National survey [47,49] reported that 77% of respondents owned their own home and 15.5% rented; 17.2% lived alone. A study from Canada ($n=18$) reported that 77.7% lived in a private residence [58]. One Australian study ($n=51$) [52] indicated occupancy preference, with 61% of participants indicating they would prefer to live alone.

Housing design, home modification and assistive technology

Concentrating on the housing requirements for people with MS, we developed a theme encompassing housing design, home modifications, and the integration of AT within the home. Within this theme, several studies collectively highlighted various aspects of mobility aids used in and around the home. Although mobility aids do not constitute housing design or modifications, they are crucial for facilitating safe and independent navigation within the home for people with MS and, hence, play a significant role in achieving the goals of accessible housing. Therefore, examining mobility aids alongside housing design provides a more comprehensive understanding of the environmental needs of individuals with MS.

Across the studies, the most common mobility aids for people with MS included canes, crutches, walkers, and manual and electric wheelchairs [53,56,57,59]. These aids were consistently identified as essential for assisting with daily activities and navigating the home safely, with some individuals also employing compensatory strategies, such as holding onto furniture or walls for support [59].

Table 3. Study and participant characteristics.

Authors (year)	Country	Focus (Aim)	N	Perspective	Participant demographics Gender (n =) Age = mean (M) & range (R)	MS-related characteristics Relapsing-remitting (RR) Secondary progressive (SP) Primary progressive (PP) Progressive relapsing (PR)	Method	Relevant findings
Barnett et al. (2024) [46]	UK	To explore the acceptability and usability of assistive equipment and technology (AE&T) by people with MS from the perspective of occupational therapists [46, p.1].	5	Health professionals	Not reported	Not reported	Qualitative: Semi-structured interviews Reflexive thematic analysis	Transitions related to the nature of MS, such as changes in cognition, and adaptive skills, were seen as factors related to the acceptance and usability of AE&T. The meaning of technology was discussed as another influential element with multiple layers representing disability, losing abilities and deterioration; however, turning points in life and the need for occupational participation also appeared to influence technology acceptance and usability [46, p.9].
Bishop et al. (2013) [47]	US	To comprehensively evaluate the specialised housing situation for US adults with MS, and specifically, to identify the most pressing needs and most frequently identified barriers to achieving safe and accessible housing [47, p.111].	5082*	People with Multiple Sclerosis (PwMS)	Female: n = 3919 Male: n = 1117 M = 54.11 years R = 20–91 years	RR = 57.8% SP = 22.1% PP = 7.9% PR = 4.3% Unknown = 7.3%	Quantitative: Survey; cross-sectional Perceived Deficits Questionnaire-5-Item Version (PDQ-5), MSIS-29, Home functioning scale, MS Symptom Scale, MS severity scale Descriptive and inferential statistics	Residential accessibility was limited for almost 20% of the participants. A large percentage of people with MS reported that they do not have accessible bathroom/bathing facilities, an accessible kitchen, or a needed wheelchair accessible exterior entrance or ramp to their entrance. Awareness of specialized housing resources was very limited. Particularly at risk for requiring specialized housing were adults over age 50 [47, p.111].
Bishop et al. (2013) [48]	US	To explore the extent to which housing accessibility variables add to the prediction of employment status among a large sample of Americans with MS [48, p.4].	4201*	PwMS	Female: n = 3331 Male: n = 870 M = 52.02 years	RR = 61.1% SP = 20.8% PP = 6.7% PR = 5.1% Unknown = 6.4%	Quantitative: Survey; cross-sectional PDQ-5, MSIS-29, Home functioning scale Descriptive statistics, bivariate and multivariate analyses, cross-tabulation analyses, independent samples t-tests, backward stepwise logistic regression analysis	The findings emphasize the importance of including housing accessibility assessment in the vocational rehabilitation services provided to adults with MS [48, p.4].
Bishop et al. (2015) [49]	US	To provide information on the prevalence and characteristics of modified or adapted housing and assistive devices among Americans with MS [49, p.155].	5082*	PwMS	Female: n = 3919 Male: n = 1117 M = 54.10 years R = 20–91 years	RR = 57.8% SP = 22.1% PP = 7.9% PR = 4.3% Unknown = 7.3%	Quantitative: Survey; cross-sectional Multiple Sclerosis Impact Scale-29 (MSIS-29) Backward logistic regression analysis	The most prevalent modifications involved the bathroom. People who reported greater degrees of mobility limitations had an increased likelihood of having housing modifications [49, p.153].
Bo et al. (2018) [50]	Italy	To estimate the likelihood of receiving social security benefits for Italian MS patients [50, p.107].	297	PwMS	Female: n = 212 Male: n = 85 M = 49.5 years R = 26–78 years	RR= 73% SP or PP = 27%	Quantitative: Cross-sectional - Survey Semi-structured interviews to validate survey Descriptive statistics, Univariate and multivariable analyses, logistic regression analysis	The Expanded Disability Status Scale (EDSS) score is the strongest predictor of the probability of receiving all the benefits. Only a small proportion of patients received care allowance and working permits, probably because such benefits are only granted to people with a high level of disability. On the other hand, the low proportion of patients who enjoyed fiscal benefits for home and car adaptations could have been influenced by the way such benefits are granted in our country [50, p.107].

(*Continued*)

Table 3. Continued.

Authors (year)	Country	Focus (Aim)	N	Perspective	Participant demographics Gender (n =) Age = mean (M) & range (R)	MS-related characteristics Relapsing-remitting (RR) Secondary progressive (SP) Primary progressive (PP) Progressive relapsing (PR)	Method	Relevant findings
Çakır & Tosun (2022) [51]	Turkey	To identify the problems encountered by people with MS in their residence, and evaluate these within the framework of Universal Design principles, and state design recommendations [51, p.284].	1	PwMS	Gender not reported 43 years	PP = 100%	Mixed method: Case study - In-depth interview Spatial analysis Body and function (impairment) assessment, Activities (disability) assessment, Life health (emotional role restriction, mental health, vital and social function) assessment	Home design solutions associated with Universal Design principles were represented so that the users with MS have safe and accessible housing regarding their physiological and psychological conditions [51, p.284].
Cubis et al. (2024) [52]	Australia	To examine housing and support needs and preferences of people with MS with the intention to inform the planning of a co-designed intervention based on the study's findings [52, p.1].	84	PwMS	Female: n = 60 Male: n = 20 Unknown: n = 4	Not reported	Mixed method: Semi-structured interviews Survey Secondary analysis Application of the Knowledge to Action framework	People with MS have support needs that require proactive and responsive funding arrangements, housing design and support provision. In line with the Knowledge to Action framework, findings will inform the planning of a co-designed intervention that involves people with lived experience of MS and other stakeholders to influence policy and improve home and living outcomes for this population [52, p.1].
Franco et al. (2022) [53]	Brazil	To understand the difficulties and contextual factors (environmental and personal) that act in the daily activities of people with MS [53, p.1].	8	PwMS	Female: n = 6 Male: n = 2 M = 47 years	Not reported	Mixed method: Cross-sectional - Semi-structured interviews Survey – 36-item World Health Organization Disability Assessment Schedule (WHODAS 2.0)	The most used assistive technology resources are wheelchairs, canes and walkers. The installations of grab bars, handrails and ramps were described as modifications made to the environment [53, p.1].
Korchut et al. (2022) [54]	Poland	To explore the needs and acceptance of patients with MS for assistive technology using material from the research project 'RAMCIP' (Robotic Assistant for Mild Cognitive Impairment Patients at Home) [54, p.2].	307	PwMS, Health professionals	PwMS (n = 176) Female: n = 132 Male: n = 44 R = 90% were 21–60 years Health professionals (n = 131) Female: n = 86 Male: n = 45 M = 38 years	RR = 64.77% SP = 17.05% PP = 14.20% PR = 3.98%	Quantitative: Workshops to inform survey Survey - open-ended & closed questions Beck Depression Inventory, EDSS Descriptive statistics Spearman's rank correlation coefficient and Pearson correlation coefficient	Robotic assistance is designed to improve functioning, enable successful living at home and in the community, and enhance independence [54, p.14].
Lechner-Scott et al. (2021) [55]	Australia	To provide information of the cost of disability for patients with MS by assessing the relationship between EDSS and NDIS package value [55, p.746].	156	PwMS	Female: n = 117 Male: n = 39 M = 51.4 years	RR = 60% SP = 29% PP = 11%	Quantitative: Survey; single-point cohort study EDSS Audio Recorded Cognitive Score (ARCS), MSIS-29, five-level EuroQoL (EQ-5D-5 L) questionnaire, Work Productivity and Activity Impairment General Health (WPAI-GH) questionnaire25, Client Services Receipt Inventory (CSRI) Statistical analysis	The NDIS provides a vital infrastructure for people with multiple sclerosis. The NDIS support was correlated with disability measured by EDSS steps and cognition, but not psychological impact of the disease. More can be done to improve a more individual disability-related value of packages [55, p.751].

(*Continued*)

Table 3. Continued.

Authors (year)	Country	Focus (Aim)	N	Perspective	Participant demographics Gender (n =) Age = mean (M) & range (R)	MS-related characteristics Relapsing-remitting (RR) Secondary progressive (SP) Primary progressive (PP) Progressive relapsing (PR)	Method	Relevant findings
Lezzoni et al. (2010) [56]	US	To examine patterns of mobility aid ownership and use among working-age United States residents with multiple sclerosis [56, p.1010].	703	PwMS	Female: n = 545 M = 51.6 years R = 23–67 years	RR = 68.6% SP = 20.8% Unknown = 10.6%	Quantitative: Survey; cross-sectional Focus group interview to inform survey. Telephone survey Descriptive statistics, multivariable logistic regressions	Persons with multiple sclerosis own many mobility aids but can confront substantial barriers to their use, especially within homes. Consultations with physiatrists and home evaluations by physical or occupational therapists before purchasing equipment could provide practical suggestions for addressing barriers [56, p.1010].
Patten et al. (2012) [57]	Canada	To examine the health status, use of aids and supports, perceived unmet needs, and participation in society by people with MS in Canada [57, p.3].	245	PwMS	Female: n = 174 M = 50.5 years	Not reported	Quantitative: Survey; cross-sectional Canadian post-census survey: Participation and Activity Limitation Survey (PALS) including Comprehensive Health Status Measurement System (CHSMS) Descriptive statistics, Statistical analyses	The domains with the greatest unmet needs are meal preparation, housework, shopping, and chores. Innovative strategies are needed to deliver required supportive services in these areas. Despite their relatively high level of impairment, people with MS maintain a strong level of participation in society [57, p.7].
Ploughman et al. (2012) [58]	Canada	To describe the factors influencing healthy aging from the perspective of the older person with MS [58, p.27].	18	PwMS	Female: n = 14 Male: n = 4 M = 66.5 years R = 56–80 years	RR = 16.6% SP = 55.5% PP = 11.1% Benign = 5.5% Unknown = 11.1%	Mixed method: Semi-structured interviews Thematic content analysis Simple Lifestyle Indicator Questionnaire (SLIQ) EQ-5D health-related quality of life instrument	Independence and mobility at home were highly valued amongst participants. Many participants used either personal savings or health insurance to complete required home modifications (e.g. widened doorways and access ramps) and obtain equipment (e.g. mechanical lifts, bathroom equipment, wheelchairs) [58, p.30].
Roessler et al. (2013) [13]	US	To identify the (a) barriers to obtaining specialized housing and adapted transportation for individuals with MS, (b) factors contributing to maintenance of an independent lifestyle, and (c) information and referral resources pertinent to obtaining specialized housing and adapted transport [13, p.223].	5082*	PwMS	Not reported	Not reported	Qualitative: Survey - open-ended questions Content analysis	The results underscore the need for increased access to professional consultation, financial resources, and housing modification information and resources to enable persons with MS to obtain the specialized housing needed to maintain maximal independent lifestyles [13, p.223].
Saadati Qamsari et al. (2023) [59]	Iran	To discover the compensatory strategies that patients with MS use to overcome their mobility limitations [59, p.5].	13	PwMS	Female: n = 7 Male: n = 6 M = 43 years R = 30–65 years	RR = 69.2% SP = 7.7% PP = 15.4% PR = 7.7%	Qualitative: Semi-structured interviews Content analysis	Although families play a major role in compensating for the mobility problems of these patients, it is necessary for health providers to reduce the burden placed on their families, and to educate MS people on self-care and adjust their living environment. Furthermore, providing mobility assistive devices for the patients should be done according to their differences and their environment [59, p.1].

(*Continued*)

Table 3. Continued.

Authors (year)	Country	Focus (Aim)	N	Perspective	Participant demographics Gender (n =) Age = mean (M) & range (R)	MS-related characteristics Relapsing-remitting (RR) Secondary progressive (SP) Primary progressive (PP) Progressive relapsing (PR)	Method	Relevant findings
Sheppard-Jones et al. (2013) [26]	US	To present recommendations for rehabilitation professionals concerning specialised housing policies, resources, and services for people with MS [26, p.15].	12	Housing experts, MS experts, Family of PwMS	Not reported	Not reported	Mixed method: Delphi method - Three rounds commencing with open-ended & closed questions and concluding with consensus and convergence of opinion Descriptive statistics, statistical analyses - mean, median, and mode. measure of dispersion, standard deviation	Information development, advocacy and policy recommendations provided a comprehensive national agenda for rehabilitation specialists to address 'the specialized housing needs of people with MS and other conditions that may impact mobility and functional capacity' [26, p.15].
Squires et al. (2019) [60]	UK	To explore the experiences and perceptions AT use in the self-management of MS symptoms held by those involved in the AT process, from needs assessment and AT provision, through to use and support of use: PwMS, carers and OTs [60, p.482].	23	PwMS, Carers, Health professionals	PwMS (n = 14) Female: n = 10 Male: n = 4 M = 58 R = 43–74 years Carers: (n = 5) Female: n = 3 Male: n = 2 M = 68 R = 66–69 years OTs (n = 4) Female: n = 4 M = 52 R = 49– 57 years	RR = 14.28% SP = 42.85% PP = 21.42% Unknown = 21.42%	Qualitative: Semi-structured focus groups Experiential thematic analysis	The most common devices used by PwMS for mobility and the home environment were manual wheelchairs, grab bars and shower seats. Other common devices included continence aids, personal alarms, adapted toilets, specialised cooking equipment and walkers. Other mobility devices (e.g. walking sticks and scooters), computer access aids, vehicle adaptations, transfer and memory aids were also reported [60, p.483]. Personal and external influences, impact and acceptance of AT are key issues [60, p.492].
Summers et al. (2012) [61]	Australia	To investigate the home cooling needs of Australians with MS [61, p.2].	2385**	PwMS	Female: n = 1884 M = 52 years R = 25–83 years	Not reported	Quantitative: The Keeping Cool Survey (KCS) Demographic data from Australian MS Longitudinal Study (AMSLS) Climate data from Australian Bureau of Meteorology (BoM) Nonparametric tests were used to test categorical variables (Chi-square) and ordinal data (Kruskal-Wallis and Mann-Whitney), economic modelling and associated sensitivity analysis	The economic costs of extensive air conditioner use to regulate MS symptoms are increasingly problematic for low income households, and the research results have been essential in demonstrating the need for government assistance to these households. This includes financial assistance, replacing old air conditioners and plans to minimise heat exposure if blackouts occur [61, p.5].
Verikios et al. (2013) [62]	Australia	To investigate the current degree of economic disadvantage in trying to keep cool for people with MS [62, p.45].	2385**	PwMS	Female: n = 1884 M = 52 years R = 25–83 years	Not reported	Quantitative: KCS Demographic data from AMSLS Descriptive statistics, regression modelling, economic modelling, and associated sensitivity analysis	The economic disadvantage that is suffered by people with MS in trying to keep cool raises the policy challenge of ensuring that community service obligations to people who are heat-intolerant are met in a way that is effective. Concessions must be set at meaningful levels and be regularly adjusted to take into account changes in relative electricity price [62, p.56].

Several studies contained data outlining useful home modifications and home design principles [13,45–48,50–52,58,59,61,62]. In a national analysis of 5,082 people with MS in the US [47], 17.4% lived in a residence that did not meet their accessibility needs. Financial constraints prevented some people from modifying their homes (26.3%), and approximately 10% were not confident they could live independently in their current residence [47, pp.118–119]. With close to one-fifth of the sample living in homes with poor accessibility, Bishop et al.'s [47] research and a subsequent 2015 study [49], specified the most prominent modifications for an accessible home. Within the home, the most prevalent modifications were required in the bathroom [47,49], predominantly installing grab-bars, benches, and adaptations to the shower and toilet [49]. The improvement of entrances was highlighted as a common need. Changes to the external entrances to the home were primarily related to planning for wheelchair access. Ramps and widened doorways were other common housing modifications [46–48]. For housing with stairs, stair lifts were recommended [49].

Using the qualitative responses from the large US sample [47], Roessler et al. [13] elaborated on these findings with home modifications needed in the bathroom, doorways and hallways that can accommodate wheelchairs and hard floors. For those living in multi-level housing, recommendations included installing an elevator or stair lift or utilising a room on the ground floor as a bedroom for the person with MS. Given the breadth of modifications required, Roessler et al. [13] recommended integrating accessible design features in housing, such as one-level layouts, wider doors, wheelchair accessible showers, and ramps, to reduce future modification needs.

Studies with smaller sample sizes focused on barriers faced by people with disability and the home modifications made. In Franco et al.'s [53] study of eight people with MS, five participants installed grab bars and handrails on stairs, ramps, and elevated toilet seats. Home modifications in Ploughman et al.'s [58] study ($n = 13$) included widened doorways, ramps and elevators. A single case study of a 43-year-old person with MS in Turkey assessed their residence against the framework of universal design principles [51]. Çakir and Tosun [51] reference Mace et al.'s [64] explanation of Universal Design, which involves creating products, buildings, and outdoor spaces that are accessible and functional for everyone without the need for specialised adaptations or custom designs. Rooms such as the bathroom, kitchen and bedroom, did not have the required manoeuvring space to complete daily tasks for wheelchair users. Lezzoni et al.'s [56] study supported this, noting the absence of an entrance ramp or a residence with stairs, impeded indoor manoeuvrability. Occupational therapists in Barnett et al.'s [46] study ($n = 5$) prescribed ground floor extensions, elevators and stairlifts. Participants in Saadati Qamsari et al.'s [59] study ($n = 13$) utilised occupational therapists' advice to improve bathroom safety by installing multiple handles.

Several studies reinforced the importance of climate control in the home, recommending the installation of underfloor heating, climatisation systems [46,51], and air conditioning [52,61,62]. Summers et al. [61] reported thermal efficiency can be obtained by installing external and internal window coverings, ceiling and wall insulation and roof vents.

Interlinked with home modifications, Çakir and Tosun [51] proposed the use of smart technology for home automation, highlighting its ability to control interconnected and interactive home features. Çakir and Tosun's [51] participant sought accessible features such as sensor-activated faucets, motion light detectors, and other appliances that can be controlled by smartphones or voice assistants such as Google Home or Amazon Alexa. Although marketed for general use, the application of these tools in a disability context transforms them into AT.

AT use and perceptions were measured through focus groups by Squires et al. [60] They found AT supported people with MS to live autonomous lives by helping with daily functioning, such as household duties and daily living activities (e.g. using the bathroom, walking, and domestic tasks). The authors highlighted that AT needs often follow a hierarchy, transitioning from basic equipment towards specialised electronics as symptoms progress. Regular reassessment of symptoms and available AT ensured that current needs were met [60].

Accepting an MS diagnosis and integrating AT to support daily living are interlinked. Occupational therapists in Barnett et al.'s [46, p.5] study revealed that people with MS may reach a point where they 'are forced' to use AT as their symptoms worsen. While there can be reluctance and hesitancy towards

accepting and using AT [46,56,60], some people with MS report positive benefits when trialling new forms of AT [54].

In evaluating the needs and potential acceptance of a new form of technological support, Korchut et al. [54, p.2] sought the views of people with MS and medical personnel on the 'Robotic Assistant for Mild Cognitive Impairment Patients at Home' (RAMCIP) prototype. The robot can detect falls, send assistance alerts, offer reminders, automate lights and appliances, etc. Specifically, their study sought to understand if the robot would meet the needs of people with MS at home and any additional features they would require. Overall, 90% agreed it would enhance 'security, and 83% agreed that it would benefit their quality of life' [54, p.10]. In terms of acceptance and readiness to adopt this solution, 66% of people with MS would embrace the opportunity to learn new technologies, and although only 19% felt they would be ready to adopt this immediately, 70% hoped the technology would be available when they began to lose independence [54, p.10].

The perceived value of substituting human caregiving with AT was endorsed by 66% of people with MS and 80% of health professionals in Korchut et al.'s [54] study. Not everyone agreed, with nurses expressing the most doubts [54]. Carers being replaced by AT was also a concern articulated in Squires et al.'s [60] study, with some carers expressing opposition and discouraging the integration of AT into their homes. Informal caregivers (e.g. family and friends) sometimes *'feared being displaced'*; their concerns highlighting how central their caregiver role was to their personal identity [60, p.488]. Despite this, it was generally accepted that AT benefits people with MS by increasing their independence [60]. This notion was further reinforced by people with MS, who suggested that AT would provide them with a *"further lease of life"* and restore *'normality'* [60, p.489].

Funding and assistance schemes for accessible lifestyles

Financial issues and funding schemes for housing modifications, AT, or in-home assistance were important considerations in multiple countries across several studies [13,26,47,50,55,57,58,61,62].

Given heat can exacerbate symptoms of MS, people in Australia with MS use their air conditioning at a rate approximately 15 times the average household [62], increasing their electricity costs by over 20% [61,62]. Summers et al. [61, p.3] reported that 9.6% of their study participants ($n = 2385$) were unable to afford an air conditioner. Although Australia's state and federal governments fund concessions or rebates for electricity costs for people with MS, Verikios et al. [62] highlighted the need for additional funding.

Examining the NDIS in Australia more broadly, Lechner-Scott et al. [55] revealed that funding amounts increased in accordance with the level of disability. The average allocations were AU$34,224 for mild, AU$40,342 for moderate, and AU$114,585 for those with severe disability, showing that higher Expanded Disability Status Scale (EDSS) scores were associated with increased funding [55, p.748].

In Lechner-Scott et al.'s [55] study, NDIS packages were largely spent on core funding, including in-home domestic and daily support needs. However, several international studies [26,47,57,58] identified in-home assistance as an unmet need. For instance, Bishop et al. [47] and Sheppard-Jones et al.'s [26] analysis of US data found that 62% of participants requiring in-home care ($n = 315$) could not afford it, and 20% were unable to access or afford assistance. Similarly, people with MS in Patten et al.'s [57] Canadian study reported having either no support or inadequate support for chores, housework and meal preparation. Another Canadian study by Ploughman et al. [58, p.30] linked financial stability to early-life planning, finding that those who were more financially secure expressed fewer concerns about the affordability of home modifications and support. It is noteworthy that these support services included personal assistants or housekeepers to help with domestic daily tasks and did not explicitly refer to personal care or nursing services. Conversely, inadequate personal funds and insufficient government assistance reduce the ability to pay for in-home care and compelled participants to leave their homes and enter a publicly funded RAC or assisted living complex [58, p.31].

Without financial assistance from governments or health systems, people with MS requiring AT or home modifications either utilise their personal funds or, as Bo et al. [50] concluded, go without. Bo et al. [50] sought to determine the proportion of people with MS in Italy who have access to full or partial financial assistance. They discovered that around 75% ($n = 297$) received full financial assistance for their AT requirements. The likelihood of receiving these benefits was significantly correlated with age and

disease characteristics, aligning with Lechner-Scott et al. [55]. Bo et al. [50] found that care allowances for assistance in the home were only available to 12.8% of their study participants; however, 45% received funds for vehicle and home modifications.

Details emerging from the large US studies [13,47] found different outcomes for economically advantaged people with MS compared to those with limited finances. While some renters may be unable to afford to renovate their rented homes independently, others found property owners and managers unwilling to approve modifications [13]. Ten-percent of participants in Bishop et al.'s [47] survey were not confident they could afford to continue living in their current housing. A lack of financial confidence was associated with increased medical costs, low income, no Social Security benefits, and no assets [13].

In Bishop et al.'s [47] study, 10.6% reported experiencing discrimination in the forms of renting, modifications and purchasing housing. There was low awareness of schemes to support low-income earners with affordable housing, available funding for home modifications or 'legal protections provided by the Fair Housing Act and the Fair Housing Amendments Act' [47, p.120]. While some people in this US study could afford to own their own home or make modifications [47], others had to consider refinancing, seeking help from family, or moving [13]. Those relying on public housing often experienced long delays or waitlists before a house becomes available; Roessler et al. [13] reported that one participant waited 11 years. One person with MS in Roessler et al.'s study stated, *'I live in a low income housing apartment with my children but was forced to leave when rent went from $200 to $500 overnight'* [13, p.234].

The US study by Sheppard-Jones et al. [26] highlighted the need to bridge knowledge gaps regarding options for accessible housing, available financial assistance for home modifications, potential funding for buying or renting homes, and understanding legal rights and protections. Furthermore, they suggested providing subsidies or programs to assist those currently ineligible for home and vehicle modifications and provide affordable housing in more locations. Although poor awareness of funding for modifications can result in low uptake, the stage of the disease can also be a predictor. Bo et al. [50] similarly reported higher use of available funding with disease progression.

Grey literature

Thirteen documents provided important recommendations with implications for practice (see Table 4). The recommendations or guidelines in the grey literature complemented the two key themes that emerged from the peer-reviewed literature and incorporated the need for intentional housing design and proximity considerations and the need to reassess funding models. This section also highlighted the importance of acknowledging and incorporating the strengths of the nonprofit sector through cross-sector collaboration.

Encourage considered housing design and proximity

Grey literature data asserted that key considerations could be made in the early stages of MS. A process of planning for the future may facilitate the opportunity to live at home for as long as possible. Hopper stated, 'Nine out of ten people with MS live at home and want to stay there as long as possible' [68, p.8]. Despite this preference, housing purchase decisions made early in the disease trajectory may not be suitable once symptoms advance. Planning in advance, coinciding with early education could reduce the likelihood of people with MS purchasing homes that may become inaccessible in the future [12]. This point was raised by a staff participant in McCabe et al.'s research:

> *'They [individual's with MS] may go and buy a house with stairs, but not realise that as the disease progresses in two years time those stairs are going to be a problem, whereas if they had of planned for the future or at least had some education around possible future encounters before this, they would have been more prepared.' (staff).* [italics in original]. [12, pp.14–15]

The Multiple Sclerosis Society (UK) [72] also highlighted the need to plan ahead. In their advice provided directly to people with MS, they recommended compromise: 'It is impossible to predict exactly how MS will affect you, but sometimes there is a choice that allows for future possibilities without making things inconvenient right now' [72, p.2]. The National Multiple Sclerosis Society (US) [76] proposes a series of questions to aid in housing selection based on current and future accessibility needs. For those

Table 4. Professional associations and research Centre recommendations.

Country	Author(s) (year)	Affiliation	Document purpose	Recommendation(s)
Australia	Bowman (2012) [65]	MS Tasmania	Community consultation response calling for the Tasmanian Government to provide financial subsidies for people with MS.	Recommendations on financial subsidies for electricity costs, specifically, home cooling.
	Greenland (2022) [66]	MS Australia	MS Australia provides a pre-budget submission to the Australian Government consultation for the 2022–2023 Budget, highlighting key areas directly impacting people affected by MS.	Recommendations to provide more SDA, a funded National Assistive Technology Program and Home Care Packages that facilitates independence and remaining home.
	Graham & Greenland (2023) [67]	MS Australia	MS Australia provides recommendations for the National Housing and Homelessness Plan, outlining housing barriers faced by people with MS.	Recommendations to improve accessible housing stock, proximity to community and home modifications.
	Hopper (2019) [68]	MS Queensland	MS Queensland provides a response to the Joint Standing Committee on the National Disability Insurance Scheme regarding accommodation for people with MS.	'Accommodation that addresses possible solutions, innovations, pilot programs and possible funding models' [68, p.1].
	McCabe et al. (2012) [12]	Deakin University in collaboration with MS Research Australia	Professional research report presenting findings of a needs analysis for people with MS.	Recommendations include increased financial assistance, meeting information needs and improvements to services for those in rural and remote areas.
	McClay (2019) [69]	Multiple Sclerosis Limited	Multiple Sclerosis Limited provides a response to the Joint Standing Committee on the National Disability Insurance Scheme highlighting issues of the scheme.	Recommendations include the timely provision of AT and home modifications, plus the value in utilising knowledge provided by MS associations.
	Mackechnie (2019) [70]	MS Australia	Royal Commission submission into Aged Care Quality and Safety presenting key areas that impact people with MS.	Recommendations include equitable provision of AT, financial assistance to improve accessible accommodation options and greater collaboration between the sectors.
Global	Trisolini et al. (2014) [71]	MS International Federation	Professional report presenting principles to improve the quality of life for people with MS.	Recommendations to promote the quality of life for people with MS including improved financial assistance and to improve availability of accessible accommodation.
UK	Multiple Sclerosis Society (2014) [72]	Multiple Sclerosis Society (UK)	Resource guide for people with MS presenting a listing of home modification recommendations.	Advice for adaptations to the home, room by room and in the garden. Plus, potential funding sources.
	Multiple Sclerosis Society (2023) [73]	Multiple Sclerosis Society (UK)	Resource guide for carers of people with advanced MS providing AT options and home modification suggestions.	A comprehensive listing of AT options and home modifications.
USA	Frankel & Schneider (2019) [74]	National Multiple Sclerosis Society (US)	Resource guide for people with MS to reduce their risk of falling.	Home modification advice is provided for each room in the home.
	National Multiple Sclerosis Society (2014) [75]	National Multiple Sclerosis Society (US)	The National Multiple Sclerosis Society provides guidance on how to improve the safety of the home environment.	Home modification advice is provided for each room in the home.
	National Multiple Sclerosis Society (2023) [76]	National Multiple Sclerosis Society (US)	Resource guide for people with MS outlining housing options and home modifications.	A directory of organisations that can assist in locating housing, financing and home modifications. Guides people with MS through future scenarios.

needing to make modifications to existing homes, several MS organisations provided recommendations to reduce hazards and improve accessibility [71–75].

There is a need for an increased supply of new housing built with accessible features [66,68,71]. As such, it is essential that there is national and consistent implementation of the minimum accessible standards in the NCC initially outlined in '2010–2020 National Disability Strategy' [68] and updated with the 'Australia's Disability Strategy 2012–2031' [29].

Proximity to family, friends, community amenities, and health services are core considerations when choosing housing, however, a lack of housing options and health services in rural and remote locations creates a challenge [67]. With limited options, people with MS frequently move to metropolitan areas that are better equipped to meet their needs, but this relocation often brings

challenges such as adjusting to unfamiliar environments, experiencing social isolation, and managing the higher cost of living [67]. To address the issue of limited health service provision, McCabe et al. [12] recommend developing strategies aimed at improving services for people with MS located in remote or rural areas.

Extend financial assistance and eligibility

Recommendations for funding highlighted the need for concessions to offset costs associated with climate control [65,70], improved information provision about funding schemes [12], incentives to stimulate accessible housing supply [68], and unrestricted loan provision [71]. Two reports highlighted the need for people with MS to receive improved funding enabling home modifications [12] or to purchase AT [70].

The need to fund additional home-care packages for people with MS was highlighted by Mackechnie [70] and Greenland [66]. Mackechnie, in their submission to the Royal Commission into Aged Care Quality and Safety, highlighted the importance of accurate evaluation of functional limitations by qualified healthcare professionals, providing appropriate recommendations for care and support, and investment in additional new home care packages [70]. Greenland [66] reinforced the need for such investment, emphasising that additional home care packages would enable people with MS to remain at home longer and maintain connections to their community.

McCabe et al. [12] identified a perceived information gap related to funding. They recommended creating a centralised repository to provide information and education that helps people with MS better understand welfare, entitlements, and available financial assistance for which they may qualify [12, p.122]. Eligibility is raised by Trisolini et al. who recommend that means-testing should be fair yet 'high enough for people with MS to have an adequate standard of living' [71, p.36]. The Multiple Sclerosis Society [72] discussed the potential for equipment loans, hires, or low-cost trials. In their guidance for people with MS, the Multiple Sclerosis Society [72] recommends various government-funded schemes in the UK for home modifications. A recent Multiple Sclerosis Society [73] publication outlines the 'Disabled Facilities Grant', whereby local councils in England, Wales and Northern Ireland can assist with the costs of home modifications. They also provide links to several organisations that can provide comprehensive advice on funding.

Harness the knowledge and skills of the nonprofit sector

To improve efficiencies in the supply of housing, equipment, support, and other health needs for people with MS, Hopper [68] suggested the need for greater collaboration among stakeholders. Hopper [68, p.2] envisioned achieving 'a new paradigm of housing solutions' through cross-sector collaboration. Hopper [68, p.2] advocated for the involvement of 'all levels of Government inclusive of Health, Disability, Housing and Aged Care together with consumers, not-for-profits, builders, developers and corporations' in this unified approach. A submission to the joint standing committee on the NDIS suggested that the NDIA should work closely with the peak body for MS in Australia to build a better understanding of MS amongst their staff and partner agencies [69]. As capacity is built in the disability sector, ongoing acknowledgement of nonprofit-sector and peak body expertise and contributions to its development and maintenance is crucial [68]. This may address the siloed approach, fostering a unified network that empowers people with MS to access innovative housing solutions [68].

Discussion

This study aimed to explore the current literature on housing and AT requirements for people with MS, as reported through peer-reviewed studies and grey literature. The 19 peer-reviewed studies identified a combination of built design, home modifications, and AT people with MS currently have, as well as features or equipment they need. However, the features and equipment reported by research participants may not fully capture their latent needs, as they may be unaware of potential solutions. Moreover, the AT and home modifications currently in use may not adequately meet their current or evolving needs.

Addressing unmet needs was contingent on a funding scheme that is fit-for-purpose for people with a progressive neurological disability. Additional facilitators included early education and planning, responsive and timely funding and standardised inclusive housing design. Combined with insights from grey literature, these findings reveal the importance of a collaborative, inclusive approach to addressing housing needs for this population.

A detailed inventory of housing design, home modifications, and AT needs for people with MS was developed by synthesising peer-reviewed and grey literature. Table 5 presents a comprehensive overview of the diverse requirements identified to support people with MS in their homes. Housing design, home modifications, and AT features are classified according to their general function or the room in which they apply.

Given the progressive and variable nature of MS, some of the listed features may be especially relevant at a particular stage of the trajectory of living with MS. Each feature was assessed based on its potential to facilitate basic and instrumental activities of daily living using Edemekong et al.'s [31] definitions. Some features that did not align with the ADL or IADL categories but were still critical to managing the impacts of MS were categorised under two new domains: *environmental support* (E) and *technology-enabled independence* (Tch) (see Table 5). These domains reflected the unique concerns regarding thermoregulation for people with MS, and some ways that technology enhances independence beyond ADLs and iADLs.

Ambulation emerged as the most frequently supported ADL, whereby specific housing features and AT enable independent movement and access around the home (see Table 5). In many cases, support for ambulation facilitated additional ADLs. For example, bathroom grab bars not only aided mobility but also aided dressing, personal hygiene, and using the toilet. Similarly, specific AT solutions, such as head and side supports for seats or wheelchairs, enabled multiple ADLs and iADLs by providing postural stability that allowed people to prepare meals, eat, and clean independently.

Room-specific design, along with specialised equipment, has the potential to enhance or sustain independence. For instance, accessible kitchens with lowered bench and sink heights, sensor-activated tapware, and specialised cooking equipment increase opportunities to prepare meals and eat with a level of independence. Storage design features in kitchens and bathrooms also facilitate the accessible placement of household items like cleaning products and assistive equipment, enabling home cleaning. In addition to indoor spaces, accessible outdoor areas with features such as raised garden beds and paving or decking can improve engagement in activities like garden maintenance.

This comprehensive listing of housing and AT needs directly addresses our first research question regarding housing requirements among people with MS. The application of the ADL/iADL classification strengthens the rationale for each feature or piece of equipment by highlighting its potential to promote independence in the home.

People with MS typically prefer to remain living in their own homes for as long as possible [68]. To achieve this, housing should be designed to facilitate an individual's ability to remain living at home for as long as possible. Housing built according to universal design principles [13,51,64], or the silver level of the *Livable Housing Design Guidelines,* can reduce the need for future extensive modifications. Australia has made significant progress with a building code change incorporating minimum accessible standards [27]. Without these standards, people often required expensive modifications, such as widened doorways or the installation of elevators, to maintain independence at home. While most jurisdictions in Australia have committed to implementing these new standards, New South Wales and Western Australia have yet to adopt them [77]. However, changing the building code is just the first step. We need consistent national adoption, and it is critical that the implementation of these standards is monitored nationally to ensure compliance and minimise exemptions. Based on the comprehensive list of home design considerations, home modifications and AT suggestions presented in Table 5, it is evident that while the silver level standards of construction meet some of the housing design needs of people with MS, additional specialised features are required. Recognising that people with MS early in their diagnosis may not require the advanced features immediately supports the need for future needs planning.

People with MS are encouraged to plan ahead [12,52,72]. In Korchut et al.'s [54] and Squires et al.'s [60] discussion of AT, there were some indications that people with MS acknowledge the prospect of symptom progression and, as a result, will rely on more sophisticated AT to aid independence over time.

Table 5. Housing design, home modifications and assistive technology to support the ADL/iADL classification.

Housing and AT needs	Source	Classification
Built design		
Accessible electrical outlets & thermostats	[51,73,76]	H
Accessible parking	[13,47,48,52]	A
Impact-resistant walls	[68,76]	A, H
Outdoor area	[52,68]	A
Single-level homes	[13]	A
Skylights & wide-span windows	[51]	A
Wide hallways	[12,13,49,51]	A
General home modifications		
Accessible balconies	[51,68]	A
Accessible laundry facilities	[49]	A, H
Automated or power door openers	[46,47,49,52,68,72,73]	A, Tch
Ceiling & wall insulation	[61]	E
Ceiling-mounted hoist	[12,49,52,60,68,73]	A, D, P, T
Colour contrast between walls, floors & doors	[51,74,75]	A
Contrasting or reflective strips on stairs	[75]	A
Custom storage	[68]	A, H
Door handle height, shape &/or levers	[47,49,51,72,73–75]	A, T, P
Double glazed windows	[51]	E
Elevator/Lift	[12,13,45–49,52,58,72,73]	A
Environmental control system	[12,46,49,51,52,59–61,67,68,70,73]	E, Tch
External and internal window coverings	[61]	E
Grab bars/rails or handrails	[12,13,49,51,53,57,67,74,75]	A
Ground floor extension or garage conversion	[46,72,73]	A, P, T, M
Hard floors, fixed flooring or non-slip backing for rugs	[13,46,49,51,59,68,74,75]	A, D, H, P, T
Increased or modified lighting	[49,51,74,75]	A, D, F, H, M, P, T
Internal ramps	[48–50,53]	A
Levelled entryway	[49]	A
Modified light switches	[49,51,75]	A, Tch
Monitored alarm	[72,73]	A, C
Motion sensor lights	[51,74,75]	A, P, T, Tch
Raised (or custom height) furniture	[68,74,75]	A, F, T, P
Ramp to access house	[12,13,46–48,52,56,58,69,71–75]	A
Remote controlled/smart curtains or blinds	[51,68]	Tch
Removing or replacing doors	[49,75]	A
Roof vents	[61]	E
Stair lift	[13,45–48,71–73]	A, H
Swing away/offset door hinges	[75]	A
Therapy and exercise room	[13]	A
Underfloor heating	[51]	E
Widened doorways	[13,47,49,51,58,67,68,71–75]	A
Bathroom modifications and AT		
Accessible bathroom	[13,47,48,68]	A, P, T
Additional bathroom	[49,52]	A, P, T
Additional downstairs toilet	[72]	A, P, T
Freestanding toilet frame	[46]	T
Grab bars/rails	[13,47,49,51,59,60,71–75]	A, D, P, T
Handheld shower	[47,49,51,71–74]	P
Lever faucets/taps	[51,72,74,75]	P, T
Modified sink and cabinets	[49]	P
Motion sensor lighting	[75]	A, P, Tch
Non-slip flooring or non-skid mats	[49,74,75]	A, D, P
Remove bathtub	[49,73]	A, P, T
Sensor-activated faucets/taps	[51,72]	H, P, T, Tch
Shower board	[46]	A, P
Shower seat or bench	[13,46,49,51,59,60,71–74]	A, P
Slings	[73]	D, P, T
Step-free shower (level-access)	[13,49,51,72]	A, P
Toilet adaptation (e.g. elevation)	[13,46,47,49,51,53,60,71–74]	T
Wash and dry toilets	[46]	T, Tch
Wet room	[73]	A, D, P
Bedroom modifications and AT		
Accessible bedroom	[46–48,51]	A
Adjustable or hospital bed	[12,46,47,49,73]	A, D
Bed lift or bed raiser	[57,72,73]	A
Bed rails or bed hand blocks	[49,73]	A
Floor to ceiling pole	[49]	A
Ground floor bedroom	[13,49]	A
Modified closet access & shelf height	[49,51]	A, D
Floor to ceiling pole	[49]	A
Pressure-relieving air mattresses	[46]	P
Wall-mounted swing-arm lamps	[51]	Tch

(*Continued*)

Table 5. Continued.

Housing and AT needs	Source	Classification
Kitchen modifications and AT		
Accessible kitchen	[13,47,48,51,68]	A, F, M
Accessible storage cabinets	[49,51]	F, H, M
Adaptive cutlery	[46,72,73]	F
Kitchen trolley	[46,60,74]	F, M
Lever faucets/taps	[47,49,72]	F, M, P
Lowered countertops	[49,51]	F, M
Lowered or modified sink	[49]	F, M, P
Roll out shelves	[13,75]	F, H, M
Sensor-activated faucets/taps	[72]	F, H, M, Tch
Specialised cooking equipment	[60,72,73]	F, M
Under-cabinet lighting	[51,75]	F, H, M, Tch
Garden		
Automatic watering system	[72]	H, Tch
Long-handled tools	[72]	H
Outdoor paving or decking	[49,72]	A
Raised garden beds	[72]	H
General AT		
Chair raisers	[72,73]	A, D, F, T
Commodes	[72,73]	T, P
Fall detector	[60]	A, C, Tch
Head and side supports	[73]	C, D, F, H, M, P, T
Hoist (unspecified)	[46,72,73]	A, P, T
Leg lifter	[73]	D
Long-handled reacher (grab stick)	[74,75]	D, H, M, P
Perching stool	[46,72,73]	H, M
Portable wheelchair ramp	[73]	A
Positioning aids	[73]	A, D, F, H, M, P
Pressure relieving cushions	[73]	P
Robotic assistance	[54]	A, C, D, F, H, M, P, Tch
Sit-to-stand aids	[46]	A, D, P, T
Smartphone or remote-controlled appliances	[12,51]	C, H, M, Tch
Transfer boards	[46,73]	A, P, T
Transfer or handling belt	[73]	A, P, T
Video doorbell	[72]	C, Tch

Classification.
ADLs: Ambulating (A); Dressing (D); Feeding (F); Personal hygiene (P); Toileting (T).
IADLs: Housecleaning and home maintenance (H); Managing communication with others (C); Shopping and meal preparation (M) [31].
Other: Environmental support (E); Technology-enabled independence (Tch).

However, future planning was not the focal point of these studies or, indeed, any of the included peer-reviewed studies. This is despite it being well-established that many people with MS face varying levels of disability throughout the course of living with the disease [6,7]. Future research should focus on the changing needs of people with MS over time, and across the different types of MS.

Conversations about long-term housing considerations should begin early, ideally at the time of diagnosis, before functional impairments increase [12,52]. Health professionals [73], housing consultants [13], and MS peak bodies [71–75] can offer housing and AT planning advice towards maximising independence. However, a barrier to these conversations may be the person's readiness to consider a future with significant functional impairments. The unpredictable nature of the course of MS means that many people may not require accessible housing, thus complicating decisions. Future research should explore the experiences of people with MS and their readiness to engage in such conversations throughout their disease trajectory.

The location of housing, particularly its proximity to community infrastructure, is another significant factor [67,68,72]. Pre-established social connections contribute to positive wellbeing outcomes, underscoring the importance of remaining engaged in the community [78]. Consequently, access to community amenities becomes an important consideration when planning specialist disability housing [67] or when individuals with MS decide where to purchase or lease a property [76]. However, people in regional areas often face more significant challenges in accessing services and infrastructure than those in metropolitan areas [12]. In rural or remote locations, the lack of available, accessible housing and services sometimes results in displacement to metropolitan locations [67]. The research by McCabe [12], and Graham and Greenland [67] underscores geographic disparities and provides an essential precursor to generating greater knowledge and understanding of unique barriers and expressed needs for people with MS in regional, rural and remote locations. Further research is necessary to assess the impact of inadequate services and accessible housing availability in these locations.

Process-related factors inhibiting access to essential housing, home modifications and AT can be largely attributed to the application of government-assisted funding rules. The financial impact of MS emerged across several studies, with implications for people's ability to fund modifications or purchase or lease accessible housing. For people with MS to receive home modifications, accessible housing, or AT to maintain independence in the home, there is a need for government funding to provide these at the appropriate level. Given the progressive and unpredictable nature of MS [60], funding schemes need to be responsive to match funded support with current needs, as well as anticipating sudden increases in housing and AT needs. However, many people with MS encounter insufficient or inconsistent funding, limiting their ability to secure the necessary housing, home modifications or AT to maintain independence [13,47]. Although people with MS in Australia who had more severe disability tended to receive higher levels of NDIS funding, considerable variability in funding amounts was reported [55]. Further, there were more people with moderate disability rejected for entry into the scheme than those with mild disability [55], indicating inconsistency in how access decisions are made. Stringent or inconsistent rulings regarding funding can inhibit the ability of people with MS to plan for future support needs. A properly administered assessment, undertaken by somebody with the requisite expertise, is critical to ensure a fair and equitable budget for people with MS.

In Australia, budgets for NDIS-funded supports are typically reviewed annually or every two years. Currently, if an individual receiving NDIS supports experiences an increase in their disability-related housing or AT needs, they must apply to the NDIA for a review of their funding [79]. If the application is approved, they meet with an NDIA representative to discuss their needs and must provide evidence of these new requirements from an allied health professional. After this, the individual is given a new budget for the following year or longer. Each step of this process can take several weeks or even months to complete, with the entire process likely to take several months [79]. If the individual's needs change again due to further disease progression, they must repeat this process. Feedback from the reference group indicated that this is a frequent issue for people with MS in Australia, and further complicating factors include the limited expertise of community allied health professionals in working with people with MS and long wait times for assessments. These difficulties with NDIS planning and coordination were echoed by Mackechnie's [70] submission to the Royal Commission into Aged Care Quality and Safety. A process whereby people with progressive conditions are identified and have changing needs responded to in a timely manner would mitigate these challenges with NDIS planning and coordination for people with MS. Addressing our second research question, people with MS experience inconsistent decisions, long wait times, and a scheme that does not adequately support progressive conditions.

A synthesis of needs and barriers is presented in Table 6, accompanied by preliminary recommendations aimed at improving the home and living journey of people with MS while supporting long-term solutions. Collectively, MS specialist organisations (see Table 4), combined with peer-reviewed literature, provided valuable insights that shaped our proposed recommendations, thereby addressing our third research question.

Our preliminary recommendations target multiple stakeholders. Those in construction must continuously advance accessible housing design to ensure long-term viability. Funding decision-makers should acknowledge and respond to the progressive and unpredictable nature of MS by making evidence-based, 'fast-tracked' decisions supported by delegates with expert knowledge. Health professionals and MS-specialist organisations play a critical role in helping people with MS plan for the future, offering guidance on home modifications, AT, and home care supports, while also advocating for systemic improvements. A collaborative approach is essential, placing people with MS at the core of this intersection of stakeholders. Such an approach would enhance the effectiveness of support systems, enabling those with mobility impairments to remain in their homes for as long as possible. Ultimately, increasing the availability of affordable, accessible, and energy-efficient housing stock presents a sustainable, long-term solution to meet the evolving needs of people with MS.

Limitations

When conducting rapid reviews, certain limitations are inevitable, potentially leading to omissions or reviewer bias. We recognise the limitations of our process, including searching fewer databases than

Table 6. A summary of needs, barriers and preliminary recommendations for people with MS.

	Housing needs	Assistive technology	Funding
Needs	Major in-home modifications In-home minor modifications Accessible, affordable housing Proximity to accessible community amenities	Equipment New technology – robotic aids Smart technology for home automation	Expansion of existing schemes to include more PwMS Flexible, proactive and responsive funding scheme Funding access for all people with disability
Barriers	Financial constraints Inaccessible design Underserviced locations Property managers denying modifications Lack of regional and rural services and amenities	Homes that do not accommodate mobility aids and equipment Financial constraints	Financial constraints Means testing Stringent and inconsistent rules for accessing funding Time delays and discrimination Lack of consideration for progressive neurological disability
Recommendations	⇒ Education on long-term housing needs early in diagnosis ⇒ Ongoing case assessment and home modification recommendations from health professionals ⇒ Houses built to design standards that improve usability and accessibility ⇒ Accessible housing availability and supply close to services ⇒ Cross-sector collaboration for housing solutions ⇒ Equipment loans, hires or low-cost trials ⇒ Improved information provision about funding schemes ⇒ Cooling concessions and improving insulation reducing bills through passive design ⇒ Incentives to stimulate accessible housing supply ⇒ Improved funding for home modifications		

systematic reviews, focusing narrowly on housing and AT, which may have resulted in the potential omission of alternate search terms, and restricting our results to English-only studies. Although we recorded the country of origin, we did not account for cultural context or location-specific government funding, which may affect the generalisability of our findings.

Our grey literature process applied a limited set of search terms and, due to time constraints, was focused on just eight websites, five of which were Australian, introducing potential location-based bias. The use of location, file format, and English-language filters when using Google Advanced Search may have further contributed to bias in our results.

Our preliminary recommendations were derived from synthesising the 19 peer-reviewed studies and 13 grey literature documents. Given the size and time limitations consistent with rapid reviews, a complete systematic review could expand on the rapid review findings and may lead to more nuanced recommendations.

While the majority of studies included in this review were based on the perspectives of people with MS, there was limited data on their personal housing journeys that could improve our understanding of how people with MS negotiate this process as their disease progresses. Data on current housing or living arrangements were also limited, with few studies providing information pertaining to home occupancy or ownership [12,47,49]. Further investigation is needed to understand the specific housing needs and preferences of people with MS, including who they prefer to live with as their level of function changes. In addition, an exploration of preferences, facilitators and barriers to home ownership or renting accessible housing may prove valuable.

Our selection process prioritised peer-reviewed papers that directly addressed our research question concerning housing needs for people with MS. We intentionally included papers where aims and results demonstrated a clear connection to housing and in-home support. It is important to note that while other peer-reviewed papers may discuss community inaccessibility and environmental barriers, we limited our scope to those that directly contributed to our understanding of housing-related challenges for people with MS. However, we acknowledge the potential for future research to explore community accessibility independently of its connection to housing. Although this review recognised the financing of home care, a more in-depth analysis of the role and functions of paid caregivers could be conducted. Separate research concentrating on supports could further expand our understanding of the challenges faced by people with MS who aim to live independently in housing of their choice. Consequently, a review of the support needs and preferences of people with MS forms the basis of a subsequent study conducted by this study's authors.

Conclusions

People with MS have heterogeneous needs across housing (e.g. accessibility), home modifications (e.g. ramps, accessible showers) and AT (e.g. robotic assistants, smart technology and equipment). To avoid hospitalisation or admission to RAC following disease progression, people with MS should be supported to plan for potential future accessibility needs. A funding scheme that is flexible, proactive and responsive is needed so that unexpected changes to functioning can be managed without a need for lengthy review processes. Expert coordination with collaboration across sectors is necessary to ensure the correct and timely match between a person's needs and what they receive in terms of housing, modifications or AT. Future research should explore the support needs and preferences of people with MS, and engage people with MS, close others, hospitals, allied health professionals, and funders to provide recommendations based on lived experience and professional expertise.

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