

Disaster Preparation for People With Multiple Sclerosis: A Scoping Review of Resources

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CE INFORMATION

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TARGET AUDIENCE: The target audience for this activity is physicians, advanced practice clinicians, nursing professionals, rehabilitation professionals, mental health professionals, social workers, and other health care providers involved in the treatment of patients with multiple sclerosis (MS).

LEARNING OBJECTIVES:

1. Articulate why people with MS are vulnerable during disasters and relate these vulnerabilities to the specific needs of people in their care.
2. Identify crisis planning activities and evaluate disaster preparedness resources for comprehensiveness and suitability for people with MS.

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ABSTRACT

BACKGROUND: People with multiple sclerosis (MS) have unique needs during a disaster, increasing preparation requirements. The content and patient-level suitability of disaster preparation tools is unknown. This scoping review aimed to determine the range and content of disaster preparation resources that are freely available online and suitable to assist people with MS.

METHODS: Resources were identified via the Turning Research Into Practice medical database, Google, and disability-related websites. The included resources were disability specific and have been published since 2017. Resources were inductively analyzed and presented according to the target audience and themes. Findings were compared with stakeholder preferences.

RESULTS: Fifty-nine resources were identified, targeting carers (27.1%), health care professionals (10.2%), and people with disabilities (89.8%). Resource content themes were advanced planning, informing others, practical preparations, and review. Consumer involvement was reported in 2 resources. Stakeholder preferences for disaster preparedness content were not well reflected in the resources.

CONCLUSIONS: The review identified online disaster preparedness resources suitable for people with MS and highlighted important gaps. More inclusive resources can be created with consumer involvement in design. Identified themes inform professionals about resources to recommend to patients based on their needs. Health care professionals can aid preparation by addressing resource gaps, particularly regarding health condition management.

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and disaster plan creation, may improve postdisaster outcomes for people with disabilities⁶ and the general population.^{7,8} However, it is currently unclear whether existing disaster preparedness resources suit the specific needs of people with MS.

Individual disaster preparedness is low in the general population^{8,9} and among people with disabilities.¹⁰ Within Australia, there is a requirement for organizations providing support and services to people with disability via the government-funded National Disability Insurance Scheme (NDIS) to have a disaster preparedness resource.¹¹ These resources, however, do not always capture individual needs and may not be of assistance to individuals. Additionally, many people with mild to moderate disability do not have an NDIS plan, including approximately 50% of people with MS.¹²

Individuals preparing for a disaster, particularly people with MS, have been shown to prefer the internet for locating evidence-based information.^{8,13,14} Online sources (called *grey literature*) can be crucial in centralized disaster preparation resources and guidance. However, we know of no attempt to identify the availability, content, and/or target audience of grey literature focused on disaster preparation for persons with MS and related disabilities. As people with disability are rarely included in community disaster planning,¹⁵ it is not yet established the extent to which people with disability are included in disaster preparation resources. Consequently, the degree to which disaster preparation tools accurately capture their needs is questionable. As the next step in a larger program of work^{14,16,17} toward more inclusive disaster management policies, we identified freely available resources for people with MS and associated impairments and reviewed these with the anticipated end users.

The objective of this scoping review is to identify freely available resources to assist people with MS in preparing for a natural disaster and to develop a recommendation regarding necessary content for a valuable disaster preparedness resource for people with MS. This includes the consideration of the role of non-MS-specific resources due to the overlap of MS impairments and symptoms with other conditions.

METHODS

This scoping review used methodology recommendations from JBI¹⁸ and the Preferred Reporting Items for Systematic reviews and Meta-Analyses reporting¹⁹ with adaptations to reflect the inclusion of resources rather than academic literature.

Resources included in this review met the criteria of grey literature and grey data as defined by Adams et al.²⁰ They define grey literature as published work not controlled by commercial publishing organizations that is of sufficient quality to be preserved in library holdings. They define grey data as user-generated web-based resources. We included resources

People with disability have additional challenges during disasters, evident in an increased risk of mortality, development of comorbidity, and advancing impairment.^{1,2} For example, findings from studies have shown that people with disability evacuate less frequently and at a later time point than those without disability, losing medication and assistive devices during the process.³ The risk for people with multiple sclerosis (MS) may be further increased due to specific MS symptoms or symptom combinations. Although some symptoms (eg, mobility limitations or cognitive deficits) are similar to those in other conditions, MS-specific limitations such as altered depth perception, heat sensitivity, or somatosensory dysfunction⁴ are unlikely to be covered in non-MS-specific disaster preparedness resources. Additionally, the aftermath is likely to be more difficult for people with MS, as symptoms may increase post disaster and access to medical care, on which many people with MS are reliant, is likely to be disrupted.⁵ Disaster preparation, including hazard assessment

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if they were available in an English online format, were aimed at people with a physical or mental disability and/or the carer or health care provider (HCP) of such a person, and contained recommendations or strategies for disaster preparation. This approach was used as peer-reviewed scientific articles are not commonly used by the target population of people with MS, their carers, or HCPs.²¹ Resources were excluded if they were aimed at pediatric populations, adults with symptoms unrelated to MS, or context-specific responses to crises (eg, emergency department) or if they promoted marketing or commercial ventures. Digital applications were excluded due to varying accessibility across countries and mobile device operating systems. We searched from 2017 onward to capture current resources.

Our search used 3 complementary strategies recommended in the systematic review methodology literature (Godin et al²²). These were (1) a search of the Turning Research Into Practice (TRIP) medical database, (2) a customized search of Google using numerous search permutations until saturation, and (3) a search of targeted general and professional websites. Backward citation searching was conducted for identified resources. Searches were conducted in November 2022 and then updated in April 2023.

Google and TRIP were searched using the formula A + B, where A was a disaster term and B was a disability term, as seen in **TABLE 1** (full search history in **TABLE S1**).

To identify targeted websites to be searched, we performed a targeted Google search using the terms (multiple sclerosis OR neurological) AND (association OR support OR network); identified health services or health information sites were then searched individually. Identified sites included resources that could be classified as grey literature and/or grey data.

Information about all relevant sites, including the URL, was manually copied into a Microsoft Excel sheet. Two authors independently reviewed the sites in full for inclusion and exclusion criteria (P.M.L., Y.L.). Disagreements were resolved by discussion, with third-party adjudication occurring as needed. Excluded resources are reported in **TABLE S2**.

Data were extracted on the tool’s digital origin, location-specific advice, funding sources, evidence base, intended audience, mode of delivery, whether the recommendations were for self-action or action on behalf of another, disaster type, and the recommendations’ disability focus. Data extraction was performed by 2 reviewers working independently (P.M.L., Y.L.) and cross-checked by a third reviewer (J.T.). Following initial extraction, 2 reviewers (P.M.L., Y.L.) conducted the-

matic analysis to determine themes, or categories, of disaster preparedness recommendations.

Following the JBI methodology for scoping reviews, we did not perform a quality appraisal.

Reviewers read resource content for inductive analysis and qualitative synthesis. Content relating to disaster preparation was used to produce a codebook of common ideas within summarized content. These codes were synthesized into 7 subthemes and 4 overarching themes. A descriptive qualitative analysis was performed per the identified content themes. Findings are described in a narrative summary and tables.

Following the initial analysis, we hosted 2 online stakeholder workshops for 13 stakeholders (10 women) from all Australian states and 1 territory. The workshops were identical in content and were part of ongoing stakeholder engagement for the “Crisis Resilience in Persons with MS” study.²³ The stakeholder group, described in Learmonth et al,¹⁶ included 6 people with MS, 2 carers of people with MS, 2 HCPs experienced in working with people with MS, 2 MS advocates, and 1 person with MS who was also an HCP.

Prior to the workshop, participants were given 5 preparedness resources chosen to illustrate different formats.²⁴⁻²⁸ Workshop attendees discussed what types of resources would be helpful for people with MS, including content and mode of delivery, and their opinions of the provided resources. The workshops lasted 60 to 75 minutes and were audio-recorded and transcribed.

RESULTS

Our search yielded 515 resources, with 9.5% (n = 53) identified via backward citation search. The top 2 reasons for exclusion were an absence of recommendations or strategies (n = 163) and a lack of disability focus (n = 138). Thirty-five resources were excluded as they duplicated information from other sources. Six documents were excluded when the search was updated in 2023 due to pages no longer being active or resources being unavailable. The identification process is detailed in **FIGURE 1**, with exclusion reasons listed in full in Table S2.

Fifty-nine disaster preparedness resources specific to people with disability were identified (**TABLE 2**). Resources were information only (written, video, audio; 62.7%, n = 37) or information and a fillable form (37.2%, n = 22); they were either website-based (61.0%, n = 36) or a downloadable PDF (39%, n = 23), both editable and noneditable.

Resources were from the United States (55.9%, n = 33), Australia (27.1%, n = 16), the Philippines and Indonesia

TABLE 1. Terms Used Within the Search for Evidence on Disaster Preparedness Resources

Search parameters	Search terms
Disaster management	crisis OR crisis management OR crisis planning OR crisis mitigation OR crisis preparedness OR crisis intervention OR disaster preparedness OR disaster mitigation OR emergency planning OR emergency preparedness
Disability term	multiple sclerosis OR disability OR chronic illness OR vulnerable people OR neurological condition

TABLE 2. Characteristics of the Identified Resources (N = 59)

	n	%
Per year		
2017	1	1.6
2018	2	3.3
2021	6	10.2
2023	8	13.6
2020	12	20.3
2019	15	25.4
2022	15	25.4
Country		
United Kingdom	1	1.7
Canada	4	6.8
Philippines and Indonesia	5	8.5
Australia	16	27.1
United States	33	55.9
Disaster		
Heat wave	1	1.7
Bushfires/wildfire	4	6.8
Earthquake or volcanic eruption	4	6.8
Floods	5	8.5
Other weather event	6	10.2
General	43	72.9
Audience		
Carers only	1	1.6
People with disability and HCPs	1	1.7
People with disability, carers, and HCPs	1	1.7
HCPs only	4	6.8
People with disability and carers	14	23.7
People with disability only	37	62.7
Focus		
Action for patient	19	32.2
Action for self	59	100.0
Mode		
Video	5	8.5
PDF	22	37.3
Written text on website	36	61.0

HCPs, health care providers.

Note: Resources can be in multiple categories.

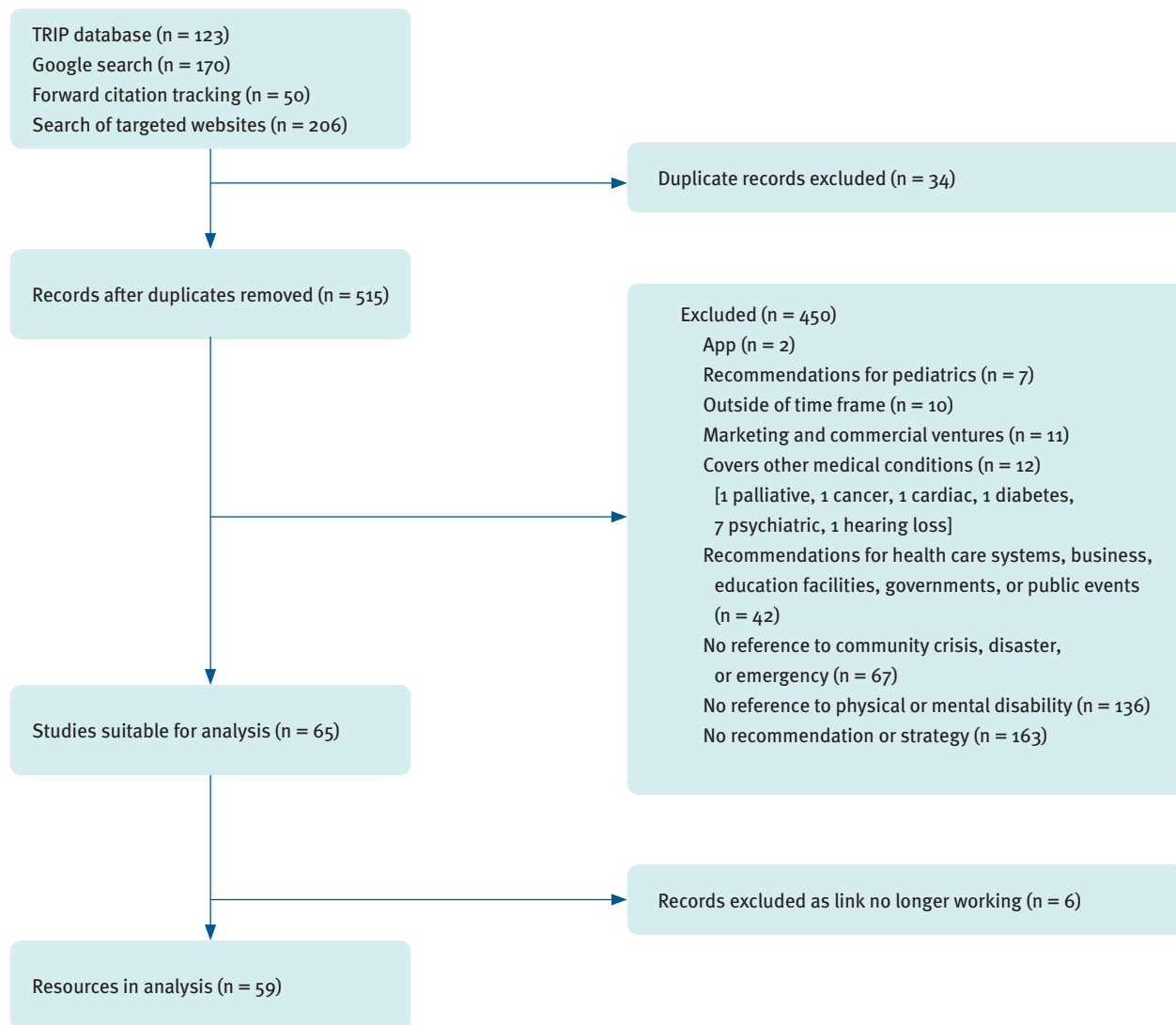
(8.5%, n = 5), Canada (6.8%, n = 4), and the United Kingdom (1.6%, n = 1). Most were applicable globally (55.9%, n = 33), with 22.0% (n = 13) specific to a local geographic region. Some resources contained region-specific information (18.6%, n = 11) or phone numbers (8.5%, n = 5) but were otherwise globally applicable. Most resources contained broad disaster preparedness advice (72.8%, n = 43). Resources that were specific to a disaster type came from Australia (bushfire: 18.8%, n = 3; flood: 6.3%, n = 1; heat wave: 6.3%, n = 1; storm: 6.3%, n = 1), Philippines and Indonesia (flood: 80.0%, n = 4; volcanic eruption: 80.0%, n = 4; tsunamis: 40.0%, n = 2; cyclone: 60.0%, n = 3), and the US (wildfire: 3.0%, n = 1).

Only 3 resources (5.1%) reported how the resource was derived, and 4 (6.7%) resources were adaptations of existing information. Two resources were informed by advice on disaster management from emergency agencies and disability needs from public health and disability organizations.^{29,30} Two resources stated their design approach and indicated they were created collaboratively. One used a committee design approach involving the disability network, disability advocates, and disaster management personnel to develop the tool.³¹ The other reported a codesign process with people with disability, disability advocates, and disaster management personnel.³² Only 1 resource conducted implementation testing with people with disabilities.³² Resources that reported on design were all published in the past 2 years.

As indicated in Table 2, 53 resources were primarily targeted at people with disability (89.8%), with 7 (11.9%) specific to HCPs and 16 (27.1%) to carers of persons with disability. Nine additional resources (15.3%) stated they were targeted at carers but were then addressed to people with disability in their entirety. Most resources were general in disability focus, with 8 (13.5%) specific to 1 disability or condition (TABLE S3). This included visual impairments (n = 2, 25.0%), paralysis or mobility impairments (n = 3, 37.5%), MS (n = 2, 25.0%), and cognitive impairments (n = 1, 12.5%). Content included disability-specific strategies for most aspects of disaster preparedness, including mobility restrictions (22.0%, 13 resources) and visual disturbances (11.9%, 7 resources).

Resource information was categorized into 16 separate categories with 4 overarching themes: (1)

FIGURE 1. Selection Process Flowchart



TRIP, Turning Research Into Practice.

the need to plan, (2) informing others about preparedness plans and disability needs, (3) practical preparations for disaster, and (4) plan review (TABLE S4). Practical preparations (96.6%, n = 57) and planning (91.5%, n = 54) were most frequent, and plan review was least frequent (28.8%, n = 17). Only 23.7% of resources (n = 14) had content across all themes. Resources that reported on design had more representation across all themes.

Resources generally contained disability-specific information for all themes except registering for prior assistance, as shown in FIGURE 2. Within each theme, there were between 1 and 14 specific recommendations. The most common recommendation was to prepare an emergency kit (45 resources, 84.9%) followed by planning for evacuation and shelter (42 resources, 79.2%). Themes that were more specific to disability included planning for emergency care (29 resources,

49.2%), care contingences (26 resources, 44.1%), logistic contingencies for assistance equipment and power disruptions (33 resources, 55.9%), and preparing others to be able to assist you (24 resources, 40.7%). Resources that reported on their design contained more frequent information on emergency care (85.7%, n = 6), logistic contingencies (71.4%, n = 5), and preparing others (85.7%, n = 6). Individual resources differed in content and level of detail.

The stakeholder group discussion emphasized the importance of including information on continued care and health management, with assessment of individual needs being particularly important. Stakeholders were concerned about how they would manage their health during and after a disaster; this was the focus of much of their desired content. The main themes from the stakeholder discussion are illustrated in

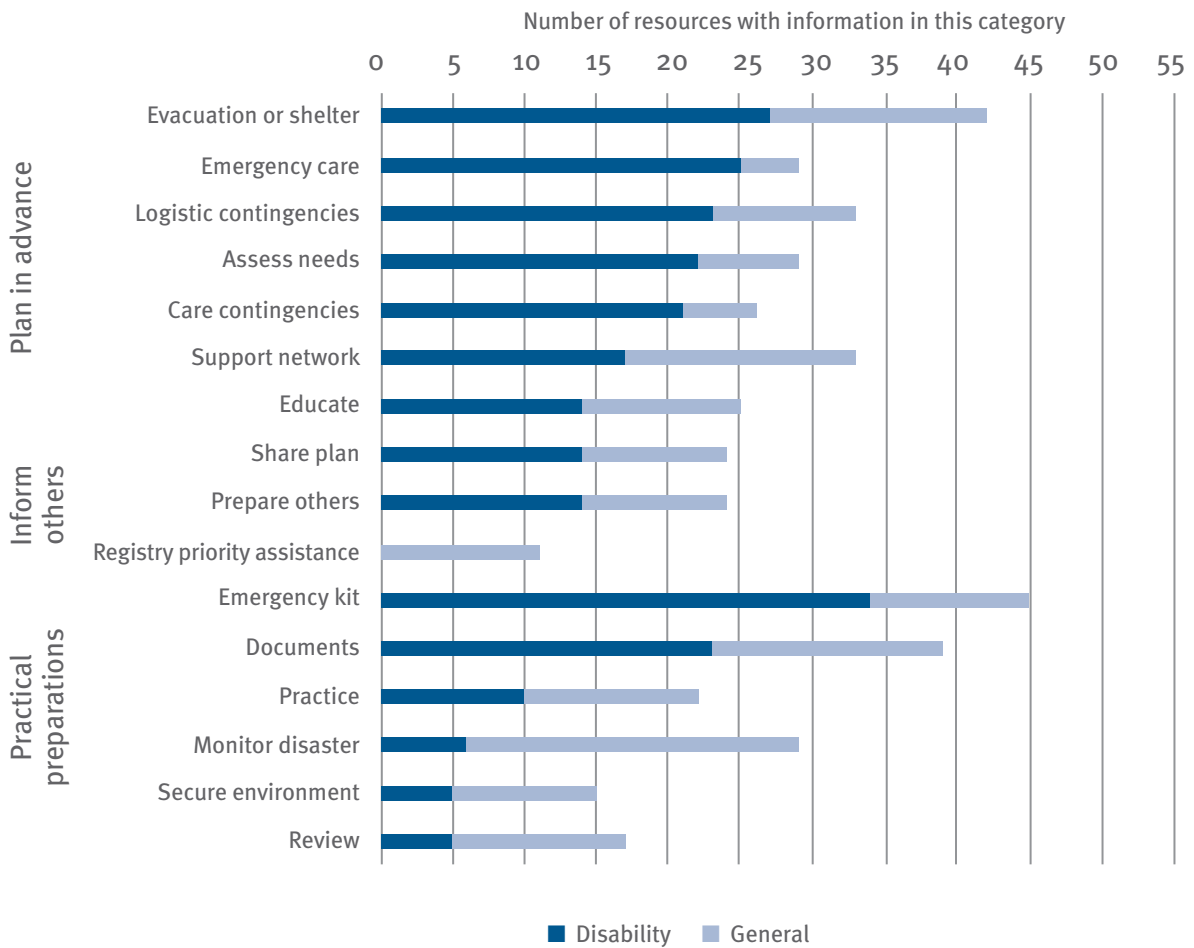
FIGURE 2. Resources Addressing Disaster Preparedness Activities Across the Recommendation Categories

FIGURE 3. Stakeholders indicated that they preferred shorter resources with prescriptive instructions and checklists. They indicated that resources should be able to be used independently by people with MS and that resource access was needed for carers and HCPs. Results from a poll of preferred items indicated that user friendliness and perceived effectiveness were the most important aspects predicting the acceptability of a tool (79% each), followed by suitability for universal usage (64%).

In contrast to the stakeholder group's expressed needs, a minority of resources contained content regarding managing and improving health throughout a disaster^{29,33-35} and no resources discussed planning for long-term disruption of care. Additionally, in contrast with stakeholders' indication that a checklist or action plan template was most appropriate given issues with fatigue experienced by people with MS, most resources were information only.

DISCUSSION

Our review aimed to identify online disaster preparedness resources accessible to persons with MS. Previous literature

has indicated that location-specific resources are most useful in the community.³⁶ Less than a quarter of the resources we identified were location specific, indicating a need to create country- or region-specific resources for people with MS.

Resources most commonly referred to impairments of particular concern during emergencies, such as mobility and vision impairments.^{2,9,37} Cognitive impairments were addressed less frequently. The lack of resources highlights the need for longer-term planning in resource creation. Consumer involvement is critical for development. It is emphasized within the international Sendai Framework, endorsed by most member states of the United Nations, to reduce and prevent disaster risks.³⁸ The role of engaging across stakeholder groups while preparing people with MS, care providers, and health organizations for disasters has previously been emphasized.^{4,16} As 96.6% of the identified resources in this review did not report consumer engagement during creation and did not report an evaluation process, whether the available resources are acceptable or usable by people with MS, their carers, or HCPs during a disaster remains unknown. Notably, resources



PRACTICE POINTS

Disaster events disproportionately affect persons with disabilities; as there is an increasing likelihood of disasters globally, clinicians should consider identifying resources to prepare patients for disasters.

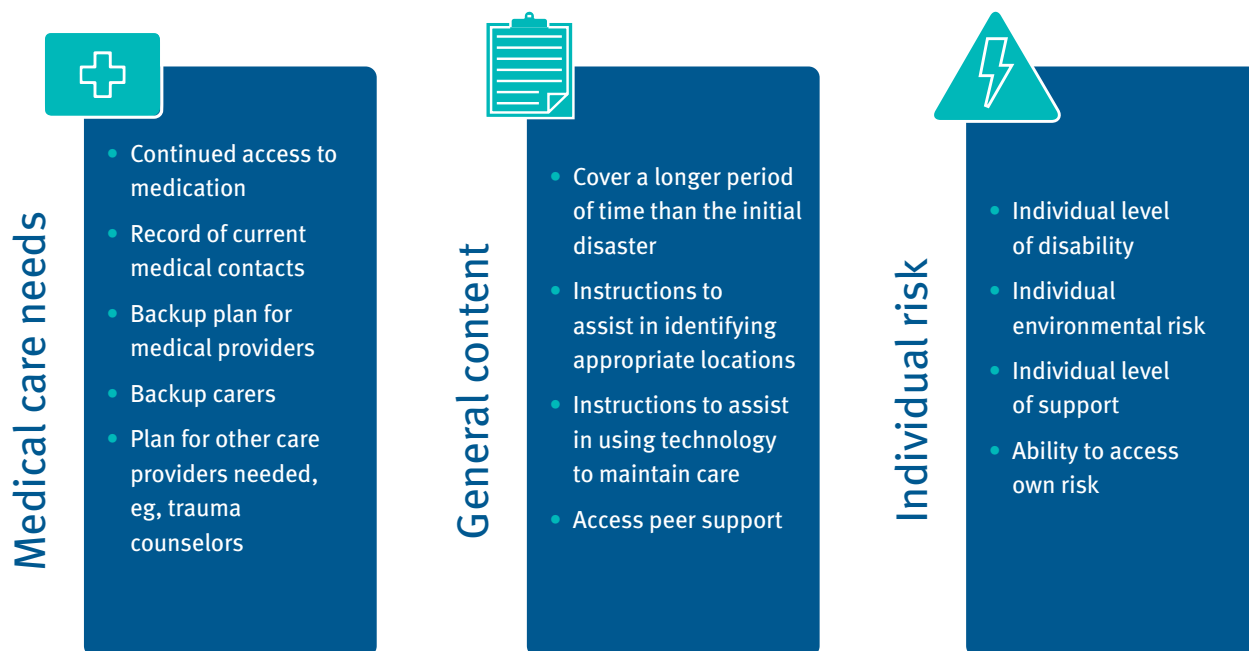
Clinicians can access online resources focusing on disaster preparedness for individuals with disability, preferably resources presenting region-specific information.

Clinicians should also discuss content that is missing across most disaster preparedness resources, such as maintenance of health care and positive health behaviors. ■

reported to have been developed with consumer engagement had a higher proportion of content relating to care arrangements. This finding aligns with our stakeholders' priority content. For example, emergency care, care contingencies, logistic contingencies, and preparing others to care and assist were less represented themes despite being recognized areas in which people with disability need assistance.^{17,39,40} Consultation with the MS community may enhance the relevance of disaster preparedness resources and improve preparedness within the community as well.

Resources specifically targeting information or recommendations to carers were scarce. For people with MS, the relational network is particularly important for the management of the condition,⁴¹ as reinforced by our stakeholder group. Up to 58% of people with MS receive informal care, indicating that there are more than 1.5 million MS caregivers globally.⁴² Carers are centrally involved in managing health through disaster⁴¹ and actively seek information on disaster preparation,⁴³ yet they are underrepresented in disaster preparation planning and recovery.^{39,43} Discussions with stakeholders indicated that targeting carers would facilitate assistance during a disaster. The same dearth of resources was seen for HCPs, despite their important role in assisting people with disability with disaster preparation.⁴³ However, this gap may be partially remedied by the presence of published literature with checklists to assist

FIGURE 3. Factors That Stakeholders Identified as Important in Disaster Preparedness Resources



patients in crisis preparation.^{4,44} By not targeting carers or HCPs as resource recipients, the onus is placed upon the person with the disability to locate the necessary information. This additional burden is particularly problematic as limited time and emotional energy have been identified as barriers to disaster preparedness in carers of individuals with disability.⁴³ The effects of cognitive fatigue in deterring disaster preparation were reinforced by our stakeholder group. This may be worsened by the complexity of navigating online resources.^{13,45} Locating resources in a convenient way, such as on the front page of disability sites or through health services, could help reduce access barriers.

This review was limited to online resources published in English from 2017 onward. We may not have captured relevant resources published before 2017 or in different languages. Despite attempts to limit the effect of algorithm bias on Google's search engine, algorithm effects may limit search results. The limitation of search time strengthens the applicability of this study's findings, as it only reflects resources that people with disability most frequently utilized. Additionally, excluding published literature limited the review by omitting resources that can only be located via medical databases. Although the inclusion of published literature is beyond the scope of the review, a preliminary PubMed search using our terms located 7 relevant resources from nearly 5 thousand results^{4,44,46-50}; however, resources solely located within the research literature may not be readily accessible to those who are not HCPs.

CONCLUSIONS

This review of publicly available online disaster preparedness resources found a range of disaster resources in different formats suitable for people with MS. Resources contained disability-specific information across 5 themes (plan in advance, inform, practical preparation, and review). However, few resources covered a full range of strategies, were available for carers or HCPs, or reported consumer engagement or cocreation. Information on aspects of health identified to be important for people with MS, such as managing long-term care disruptions, was unavailable, indicating the need for codesigned disaster preparedness resources for people with MS to address these content gaps.

To determine whether the identified gaps within publicly available resources are problematic for people with disability, their carers, and HCPs, further research is needed. Although there is evidence for the effectiveness of community-based engagement programs,³⁶ there is little evidence as to whether disaster preparedness resources improve outcomes during a disaster. Most of the resources included in this review were not evaluated for effectiveness or acceptability by people with disability, which is required. Further, specific attention should be paid to effective tools to help people manage their health through a prolonged disaster, given recent evidence of the long-term effects of the COVID-19 pandemic on health care disruption.^{14,51} There is also the opportunity to investigate the necessity of tailored disaster information for carers, HCPs, and people with specific disabilities. ■

Conflicts of Interest: Authors have disclosed no conflicts of interest.

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