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Supporting Informal Caregivers of Patients Diagnosed with Amyotrophic Lateral Sclerosis (ALS): The Development of A Comprehensive Resource Website

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SUPPORTING INFORMAL CAREGIVERS OF PATIENTS DIAGNOSED WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS):

THE DEVELOPMENT OF A COMPREHENSIVE RESOURCE WEBSITE

by

Makayla Matson

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The Capstone Final Paper is the final product that the OTD students need to complete to report his/her Capstone Project and his/her Capstone Experience.

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We, the undersigned, recommend that the Capstone Final Paper completed by the student listed above, in partial fulfillment of the degree requirements, be accepted by the Georgia State University.

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This project was inspired by and is dedicated to the memory of my grandmother, Mema, whose battle with ALS profoundly affected our family. Mema's strength, courage, and ability to find joy in the face of ALS will inspire me for the rest of my life. It is in her honor that I began this endeavor, and I am hoping to help provide the support and understanding that my family so desperately needed during her care. If you or a loved one is dealing with an ALS diagnosis, you are not alone.

ABSTRACT

Purpose: This capstone project addresses caregivers to patients diagnosed with Amyotrophic Lateral Sclerosis (ALS)'s overwhelming need for support. The purpose of this project is to fulfill this need by creating an easy-to-access website specific to ALS caregivers that provides comprehensive online educational materials and training videos.

Methods: An extensive literature review and needs assessment were used to identify significant gaps in current caregiver support efforts to guide the project's focus and determine the main topics of the website. This project also received guidance from an occupational therapist at the Emory ALS Clinic in Atlanta, Georgia to ensure the content's relevance and accuracy.

Output: The final website (www.knowals.com) provides instructional materials on three identified topics: techniques for safely performing transfers, the commonly used assistive devices in ALS care, and how to manage the financial costs of an ALS diagnosis. Each topic of the website, including video demonstrations and written guides, was developed to increase caregiver confidence and competence.

Impact: The launch of website is expected to have a profoundly positive impact on the ALS caregiving community. The website offers both immediate and practical support to caregivers by granting easy access to valuable caregiving information and resources. The website also aims to reduce caregiver stress and improve the quality of life for those affected by ALS. In the long term, it seeks to establish itself as a pillar in the ALS community that reflects the latest and best practices in ALS care.

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Introduction

The need this project is proposing to address is the demand for thorough educational resources for caregivers of individuals diagnosed with Amyotrophic Lateral Sclerosis (ALS). Many caregivers of patients with ALS experience low caregiver confidence and feel that they are under an overwhelming amount of stress (Bassola et al., 2020). The overall aim of this project is to increase caregivers' overall confidence in providing proper care and mitigate their stress levels. ALS is a complex progressive illness that many people do not have a full grasp on before experiencing it either themselves or watching a loved one progress through it, which contributes to its difficult navigation. The PICO question addressed in this project is: Does **(I)** providing caregiver education through a comprehensive singular website, including both training videos and written materials, lead to a higher **(O)** improvement in caregiver confidence when compared to **(C)** receiving only written educational materials from multiple sources in **(P)** caregivers of patients diagnosed with amyotrophic lateral sclerosis (ALS)?

A key factor that contributes to low caregiver confidence in caregivers to patients with ALS is that often only written materials on providing care are provided. These materials are also often provided from multiple sources and are easily lost or difficult to quickly access. As the disease progresses, ALS patients require increasing hands-on assistance with Activities of Daily Living (ADLs). Caregivers have reported not feeling safe and prepared to offer this type of care, especially related to transfers due to a lack of training (O'Brien et al., 2012). Overall, written materials can explain these skills and serve as a resource for quick reference, but they do not provide the seemingly necessary in-depth explanations and visual aids that videos provide.

Another key factor that contributes to low caregiver confidence is that many caregivers do not feel that they have the time or means to attain additional caregiving information. Many ALS patients, especially in the later stages, require 24-hour care. Due to the high demand, caregivers feel that they have little time for themselves, so they take advantage of any extra time they do find to care for their own needs. This leaves little time for extra caregiving classes and seeking out additional information even if it is useful.

The purpose of this project is to address these major concerns by creating easy-to-follow written educational materials and training videos for caregivers and patients to be able to easily access online from a single user-friendly website for 24/7 reference. The intended overall outcome is for caregivers of ALS patients to feel supported, to be able to anticipate the progression of the disease and their loved one's changing needs, and to feel confident with their caregiving skill set.

Methods/Results

To complete this project, a comprehensive literature review will be completed. Topics researched will include any similar programs and resources and examine their effect on caregiver confidence and factors that lead to low caregiver confidence. Articles will be broken down into study design, outcome measures, major findings, and weaknesses. The results of the literature review will determine the current need for further educational development. Once the current needs are determined, online educational materials aimed at increasing caregiver confidence in these needed areas will be developed.

Output

The final output of this project will be in the form of an easy-to-access, comprehensive website for ALS patients and their caregivers to use as an all-inclusive educational resource. The website will include written educational materials and training videos to provide easy-to-follow visuals and explanations on how to perform hands-on caregiving skills. Topics covered will be determined based on the results of the needs assessment conducted through the literature review.

Outcome

Caregivers feeling confident and informed is not only important to the well-being of the ALS patient being cared for but also to the caregivers themselves. Studies have shown that as the patient exhibits greater functional decline, the caregiver subsequently experiences increased feelings of depression, anxiety, loneliness, and helplessness (Schischlevskij et al., 2021) (De Wit et al., 2019). This project will provide much-needed education to ALS patients and their respective caregivers in enhancing their understanding of ALS as well as enhancing their caregiving performance. As a result, it is expected that ALS patients will receive the best possible care from their loved ones and that the caregivers will notice improved quality of life, increased confidence, and improved overall well-being in themselves. This project will not only be important to the ALS community, but to informal caregivers to patients of all diseases as many caregivers face similar challenges.

CHAPTER 1

Literature Review

Amyotrophic Lateral Sclerosis (ALS) is a fatal and progressive motor neuron disease, characterized by the progressive loss of muscle control throughout the entire body (Centers for Disease Control, 2022). According to the Centers for Disease Control (CDC), ALS has a prevalence of 9.1 per 100,000 U.S. population (Centers for Disease Control, 2022). The disease typically presents initially in a subtle manner with early symptoms often including noticeable muscle weakness, slurred speech, and/or sudden difficulty in performing once routine tasks (Foster & Salajegheh, 2019). The progression of ALS can vary significantly among individuals. Those affected may experience a rapid decline resulting in only 3-5 years of life following the initial diagnosis, while others live with the condition for many years (Foster & Salajegheh, 2019). Over time, individuals may experience increasing difficulties in speaking, swallowing, and breathing with respiratory complications ultimately leading to death (Valadi, 2015). Despite the rate of progression varying, ALS always eventually results in significant physical disability, which creates the need for comprehensive care and support (Valadi, 2015).

Overwhelming Nature of ALS Caregiving

Navigating the journey of ALS is profoundly challenging. The initial diagnosis often distresses patients and their families, who are typically the caregivers (informal or unpaid caregivers) (Aoun et al., 2012), and follows with the need of caregivers to conduct complex care planning and rapid acquisition of skills related to equipment and caregiving (Bassola & Lusignani, 2017). The overwhelming nature of ALS caregiving is often rooted in the patient's rapid deterioration in their performance of activities of daily living (Bassola & Lusignani, 2017). The decline ultimately leads to the placement of ever-increasing physical and emotional demands on caregivers. A recent qualitative survey also revealed that caregivers may experience greater stress levels than the ALS patients themselves, and the high stress leads to the deterioration of caregivers' own health (Brizzi et al., 2020). Caregiving can significantly impact personal health, leading to increased stress levels, higher incidences of physical ailments, and mental health challenges such as depression and anxiety (Brizzi et al., 2020). The constant demands and responsibilities often result in caregivers neglecting their own health needs, exacerbating existing health issues, or leading to new ones (Brizzi et al., 2020). Additionally, the emotional strain of caregiving can contribute to feelings of isolation and burnout, further compromising overall well-being (Bassola & Lusignani, 2017).

Lack of Knowledge in Skills Training for Caregivers

The care stress could be greatly contributed by the low confidence of caregivers of patients with ALS (Bassola et al., 2020). Low caregiver confidence, especially among family or informal caregivers, often originates from a combination of factors, such as a lack of formal training, insufficient knowledge about the care recipient's condition, the emotional, financial, and physical burdens of caregiving, and limited access to supportive resources and networks (Bassola & Lusignani, 2017; Brizzi et al., 2020; Bergin & Mockford, 2016).

The primary factor is the lack of formal training or preparedness in managing the intricate physical needs of a care recipient, which leads to the uncertainty of their ability to provide sufficient care (Bassola et al., 2020; O'Brien et al., 2012; Gillespie et al., 2021). A recent scoping review (Gillespie et al., 2021) also addressed the crucial need for skills training for caregivers, given the complexity of caregiving roles for chronic and progressive conditions like ALS. Informal caregivers commonly take the career role without preparation but with the urgent need to develop skills in managing medication, assisting with personal hygiene and transfers, and operating specialized medical equipment (e.g., cough assist and suction machines) (O'Brien et al., 2012). Another recent study showed consistent findings that not only were caretakers of ALS patients unsure of how to physically assist with transfers, but they also lacked the knowledge of how to complete transfers safely with proper body mechanics, which results in physical strain on the caregivers' bodies and increased stress (Schischlevskij et al., 2021).

Lack of Knowledge in Assistive Technology for Caregivers

Informal caregivers of ALS patients often face a significant need for more information regarding future assistive technology needs as the disease progresses (De Wit et al., 2019). As ALS advances, patients experience varying degrees of physical impairment, requiring different types of assistive devices for personal care, mobility, and daily activities (Bassola & Lusignani, 2017). Caregivers need to be informed about the available technologies, their appropriate usage, and adaptation over time.

Additionally, informal caregivers can benefit from guidance on accessing these technologies, including information on ordering and training on their usage and maintenance. Caregivers have expressed concerns that they were not given any information on the process of acquiring assistive devices and how to utilize them (Bassola et al., 2020). Studies also found that once caregivers found a device that would be helpful, it was usually too late to order it because it would no longer be useful by the time it was received (De Wit et al., 2019). This knowledge is essential in maintaining the patient's quality of life and ensuring safe, effective care throughout the disease. Access to detailed, accurate information empowers caregivers to provide better care, manage their expectations, and adapt to the evolving nature of ALS.

Lack of Knowledge of Financial Support Sources for Caregivers

Furthermore, many caregivers require additional information focusing on financial options to afford to purchase, for example, the needed assistive technology (De Wit et al., 2019). The financial burden of caregiving can be substantial due to the cost of medical expenses, assistive technologies, home modifications, and potential loss of income due to reduced work hours or quitting a job to provide care (Galvin et al., 2018). In a case study, a patient diagnosed with ALS located in the United States was followed over ten years, and all costs related to care were documented. The results showed that the total costs across ten years were $1,433,992, where the out-of-pocket cost was $215,098.08 (e.g., paid by family) (Obermann & Lyon, 2015). Without sufficient guidance, families may also miss out on charitable contributions (e.g., $86,039 documented in Obermann & Lyon, 2015), causing them to be liable for all out-of-pocket expenses.

The highest costs were for in-home caregivers, ventilation, and hospital care, which cost $669,150, $212,430, and $114,558, respectively (Obermann & Lyon, 2015). Caregivers require increased guidance on navigating insurance coverages, understanding entitlements to government aid and grants, and accessing community charity programs (Galvin et al., 2018). Adequate financial resources and knowledge alleviate the financial burden on caregivers and contribute significantly to the quality of care and the overall well-being of both the caregiver and the patient (Brizzi et al., 2020).

Current Gaps in the Literature

The results of the literature review bring to light the critical need for support for ALS caregivers, focusing not just on patient care but also on the caregivers' health and well-being (Brizzi et al., 2020). The need for support and resources for these caregivers is essential, as their role is critical in the management and quality of life of individuals living with ALS. The stress placed on caregivers is substantial and low caregiver confidence is common, which significantly contributes to this stress (Bassola & Lusignani, 2017). Low confidence largely stems from the need for resources that encompass skills training, assistive device information, and financial guidance. Without comprehensive, easy-to-access resources, caregivers feel a major burden to acquire all this valuable information themselves, which can potentially further increase their stress levels and decrease their perceived quality of life (Bergin & Mockford, 2016). Overall, the literature indicates a need for an all-inclusive resource geared specifically towards ALS that covers the practicalities of caregiving, provides information on assistive technology, and provides financial guidance.

Therefore, the purpose of this project is to create an easy-to-access website specific to ALS caregivers that provides online educational materials and training videos. The website will provide information on the techniques of safely performing transfers, the commonly used assistive devices in ALS care, and how to manage the financial costs of an ALS diagnosis. Also, because the website is focused on the most pressing issues according to the literature rather than briefly touching on a wide array of topics like in current programs, the information provided will be in-depth and all-encompassing enough to meet the unique needs of ALS caregivers. Because training videos will be provided, the need for visual demonstrations will be fulfilled without the requirement of in-person commitments. The overall outcome is for caregivers of ALS patients to feel supported, to be able to adapt to the progression of the disease and their loved one’s changing needs, and to feel confident with their caregiving skill set.

CHAPTER 2

Needs Assessment

A thorough needs assessment was carried out to closely examine two of the largest existing programs focused on increasing support and the confidence of caregivers. This needs assessment aimed to gauge how well these existing programs are equipping caregivers with essential knowledge, skills, and the emotional support they need to deliver high-quality care.

Existing Program 1

One specific program that has targeted increasing informal caregiver confidence is the Powerful Tools for Caregivers (PTC) program. PTC is a structured, evidence-based training program that is designed to support informal caregivers of individuals with chronic conditions, including ALS (Kim et al., 2022). It typically consists of six weekly sessions. Each section covers key areas such as self-care, emotional management, effective communication strategies, and handling challenging caregiving situations (Kim et al., 2022). Evaluations of PTC have shown its effectiveness. Caregivers have reported improvements in self-efficacy, reduced depression, and lower levels of stress (Rosney et al., 2017). Additionally, participants reported feeling more equipped to manage caregiving responsibilities. Therefore, the program has shown success in expanding caregivers' skill sets and providing emotional support (Rosney et al., 2017).

However, while the PTC program has shown a positive impact on caregiver confidence and well-being, there are potential drawbacks to the program. One limitation is the program's accessibility. The structured format of six weekly sessions may not be feasible for all caregivers, especially those managing significant time constraints or those who live in areas where the program is not offered. Additionally, the effectiveness of PTC could potentially vary from caregiver to caregiver depending on their learning style and the specific challenges faced by each caregiver. This means it might not address all the unique needs of every participant. There is also the issue of the program's scalability and the resources required to deliver it widely, which may limit its reach to a broader audience of caregivers. Finally, because PTC focuses on emotional management and communication strategies, caregivers might also find themselves needing more direct, practical training in physical care techniques.

Existing Program 2

Another program that has been created to improve low confidence in informal caregivers is the Family Caregiver Training Program (FCTP). The program is set up as a series of comprehensive modules and training sessions that cover a wide range of topics such as communication, feeding, transferring, toileting, dressing, and bathing. The program also covers emotional support and self-care (DiZazzo et al., 2017). These sessions are conducted in a workshop-style format, which allows for hands-on learning and personal interaction. Participants attend a two-hour PowerPoint presentation followed by a one-hour demonstration and hands-on training session (DiZazzo et al., 2017). When examining the effectiveness of the FCTP, both caregiver confidence and perceived quality of life increased when compared to solely being provided with printed information packets alone (DiZazzo et al., 2017).

While the FCTP takes a comprehensive approach to improving caregiver confidence by combining educational materials with practical training, it does come with possible setbacks. For instance, the workshop-style format requires physical attendance at a specific location. This requirement may limit access for caregivers with demanding schedules or those living in remote areas. Additionally, the program's delivery of information hinges on a structured schedule of presentations and demonstrations, which may not address the personalized needs of every caregiver. The materials may also not accommodate the highly complex nature of conditions like ALS as it is a generalized program. The effectiveness of FCTP could also potentially vary on the program facilitator's expertise and the ability to engage participants. This variability has the potential to affect the consistency of the results across different sessions. Furthermore, while hands-on training and demonstrations are critical, the workshops are greatly constricted by time and may not provide enough in-depth knowledge of each topic for some caregivers. Lastly, the time and financial commitments needed to participate in FCTP may also place a significant barrier for some individuals.

Project Purpose

After examining current initiatives, it is clear that multiple programs have attempted to meet informal caregivers' need for training and support, but all leave more to be desired. Current programs are generalized and meant to cater to all informal caregivers who provide hands-on care. While these programs are evidenced-based and effective in increasing overall caregiver confidence, there is little evidence showing they adequately support the specific needs of caregivers dealing with highly complex medical conditions like ALS (Pinho & Gonçalves, 2016). These programs are also mostly workshop style, which requires in-person attendance. While this in-person component is beneficial because it provides the opportunity for visual demonstrations and personal interactions, many ALS patients require 24-hour care (Valadi, 2015). This means caregivers may not have the time or means to attend, which ultimately severely limits their opportunities to enhance their skill set and caregiving knowledge. Also, there is potential for inadequate follow-up support or resources following the completion of the training. This may leave caregivers without resources as they face new problems.

Through this detailed examination, specific areas were determined to be lacking sufficient resources or needing more focused support. Overall, this assessment highlighted the strengths of current efforts but also revealed the areas needing further development to meet the many needs of informal caregivers. The insights gained from this needs assessment were used to determine the structure of the website and justify the need for this project.

CHAPTER 3

Capstone Plan and Process

Methods

The website includes three topics, using videos and written materials to provide instructional information to ALS caregivers on each topic. Each video provides visual demonstrations of either how to safely perform a transfer technique or use a specific assistive device. All videos are paired with supplemental written information to further explain each topic. These materials include detailed summaries of each transfer technique and assistive device, key step outlines, and “dos and don’ts” lists for safety. Written materials are also provided for each financial resource listed to outline the respective program’s most important factors such as the possible benefits, application process, and eligibility criteria.

Content Creation

Video Content. For video content production, an initial storyboard was developed for each video. The storyboard outlined the key concepts and visuals that were required to effectively relay the video’s specific learning objectives. Scripts were written to present the information simply and clearly, making sure to use language for a general audience to understand. Existing instructional videos sourced from YouTube were integrated to provide real-life examples and demonstrations with the narrator providing detailed descriptions of the videos and further tips to enhance performance. The information included relied on the knowledge and expertise of the occupational therapy doctoral student creating the project.

Finally, each video was edited using both iMovie and Fliki.ai software. The instructional video clips were edited using iMovie to cut the clips in order to focus on the most important aspects. Fliki.ai was used to create the narrations, provide the avatar character explaining the videos, and seamlessly integrate all images, videos, and text included. All videos and images utilized were given credit on the image credits page of the website. The goal of the editing process was to ensure an effective flow of information. The final videos were reviewed by an occupational therapist at Emory ALS Center for accuracy and effectiveness. All feedback was integrated before the videos were made available to the public.

Witten Content. For written content creation, an outline was created for each piece of written content. The outline included the main points to effectively relay the topic learning objectives. The materials were written in clear, concise, and jargon-free language so that all materials could be easily read and understood. Visual aids such as pictures, charts, and checklists were incorporated to further encourage understanding and carryover. The draft materials underwent a review process with Emory ALS Center staff to ensure the content was both medically accurate and matched their perceived understanding of the caregiver's experience. Revisions were made based on the feedback before publishing to the website.

Website Design and Development

This project aimed to design and launch a fully functional website. The development of the website was performed in several stages including server setup, Content Management System (CMS) installation, theme customization, video hosting, and content integration. Each stage was carefully completed with attention to detail to ensure a seamless and user-friendly website experience.

The initial phase involved setting up a hosting server for the website. A hosting plan was purchased from GoDaddy, which is a reputable web hosting company. This was done to ensure reliable uptime and support for the website. After securing the server space, WordPress was installed. WordPress is a leading CMS and was selected for its flexibility and user-friendly interface. Following the CMS setup, a custom WordPress theme was selected and installed to define the website's aesthetic and functional layout. The chosen theme was further customized to the project's specific needs. These customizations included design elements such as color schemes, fonts, and layout structures to enhance the visual appeal and navigation efficiency of the website. The website is also usable on any type of device such as laptops, tablets, and phones to ensure its availability to all caregivers.

The videos created for the website were uploaded to a third-party platform, YouTube, due to file size and bandwidth considerations. YouTube was chosen because it offers user-friendly and efficient video hosting. YouTube also provides free captioning for videos, which is beneficial in delivering information to a wide audience of caregivers with varying needs. To integrate the hosted videos into the website, embed codes provided by YouTube were used. This approach allows videos to be seamlessly displayed within the site's content.

Before the website's public launch, a testing phase was conducted. This phase aimed to both identify and correct any functional issues such as broken links, mistyped information, and design inconsistencies. This step was vital in determining the readiness of the website. The website was presented to staff members at the Emory ALS Center during this stage to gather feedback on usability, content relevance, and overall experience. The feedback from Emory staff was considered and adjustments were made before making the website public. Moving forward, feedback from users will be used to make any necessary, ongoing adjustments to the website's design and content.

Site Description

The Emory ALS Clinic, situated in Atlanta, Georgia is dedicated to advancing the knowledge of ALS, enhancing care, and helping patients and their loved ones. They take a holistic approach that caters to the needs of ALS patients by covering physical, emotional, and psychological aspects. The clinic's objectives include delivering top-notch clinical care to individuals with ALS, educating healthcare professionals and the community about the disease, and advocating for patients and their families to ensure they have access to all necessary support services.

At the Emory ALS Clinic, a range of individuals seek assistance, including ALS patients and their families. To provide care for these individuals, the clinic offers a variety of treatment services. Throughout their time at the clinic, clients receive education and resources to navigate the challenges associated with ALS. Furthermore, they offer support services such as counseling referrals and support groups to address both the practical and emotional hurdles faced by those affected by ALS.

The dedicated team at the Emory ALS Clinic consists of professionals known for their expertise and compassionate care. This team is comprised of neurologists, therapists, nurses, and social workers who work together seamlessly to provide care. Neurologists play a role in diagnosing and managing ALS by focusing on the neurological aspects of the disease. They develop treatment plans, oversee medication regimens, and closely track how the disease progresses. By ensuring that all healthcare professionals involved are aligned and working together harmoniously, neurologists help maintain coordination within the clinic.

The therapy team, which includes occupational therapists, physical therapists, and speech therapists strives to uphold the quality of life for patients. Physical therapists concentrate on exercises and mobility aids to retain functional mobility as long as possible. Occupational therapists assist individuals with adapting everyday tasks, modifying living spaces for accessibility, and providing wrist/finger splints to maintain hand dexterity. Speech therapists support patients in addressing communication and swallowing challenges to help them communicate effectively and consume food or beverages safely.

Social workers and counselors address the social and practical needs of both ALS patients and their families. Counselors primarily offer support by creating an environment for individuals to share their feelings at the clinic – from grief to anxiety to depression. Additionally, they organize support groups outside clinic hours where patients and families can connect with others facing challenges. These groups serve as sources of solidarity by reminding everyone that they are not alone in their journey. Social workers play a role in helping individuals navigate the healthcare system by offering guidance on healthcare policies. They support families by explaining the ins and outs of healthcare, insurance, and social services to ensure that patients have access to resources. They also assist in advocating for patients' rights.

Nurses and support staff handle day-to-day clinic operations, serving as points of contact for patients. Their dedication to providing comfort and assistance throughout the clinic experience, along with their help in appointment scheduling and care coordination, plays a role in ensuring smooth clinic functioning amidst its many components.

The Emory ALS Clinic's comprehensive approach to ALS care makes it an ideal location for developing this website. Known for its excellence in services and support for those impacted by ALS, the clinic's multidisciplinary team offers expertise that will guide the creation of content on the website. By providing recommendations on devices and insights into the needs of ALS patients and their caregivers, the website is set to deliver relevant, effective resources based on sound evidence. Collaborating with the Emory ALS Clinic to develop the website enhances its credibility and ensures that the information mirrors current ALS care standards, which will establish it as a reliable source for caregivers looking to enhance their caregiving abilities and their loved one's well-being.

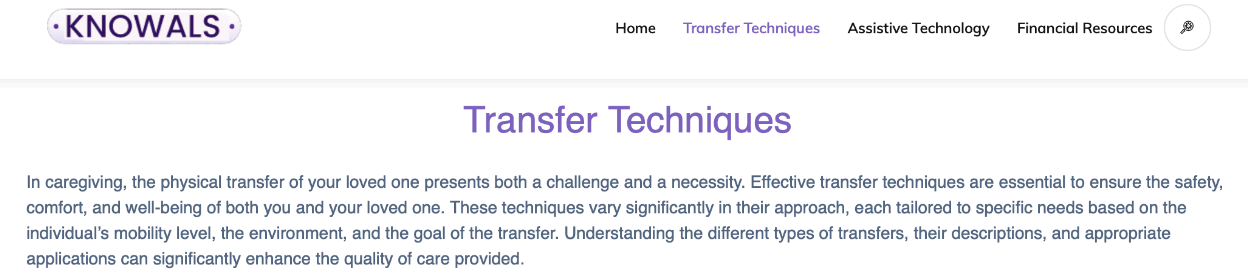
CHAPTER 4

Output

The final website is www.knowals.com. This platform is a specialized online resource that supports caregivers of individuals diagnosed with ALS. It is designed to provide caregivers with an exhaustive set of information, tools, and support mechanisms to manage the high demands of caregiving effectively. The primary objective is to increase caregiver confidence through educational content, focusing on transfer techniques, the application of assistive technology, and accessing financial assistance.

Transfer Techniques

Under the transfer technique page on the website menu (see Figure 1 for example), caregivers will find a detailed compilation of instructional materials on various transfer techniques critical for ensuring the safety and comfort of both the caregiver and the person being assisted.



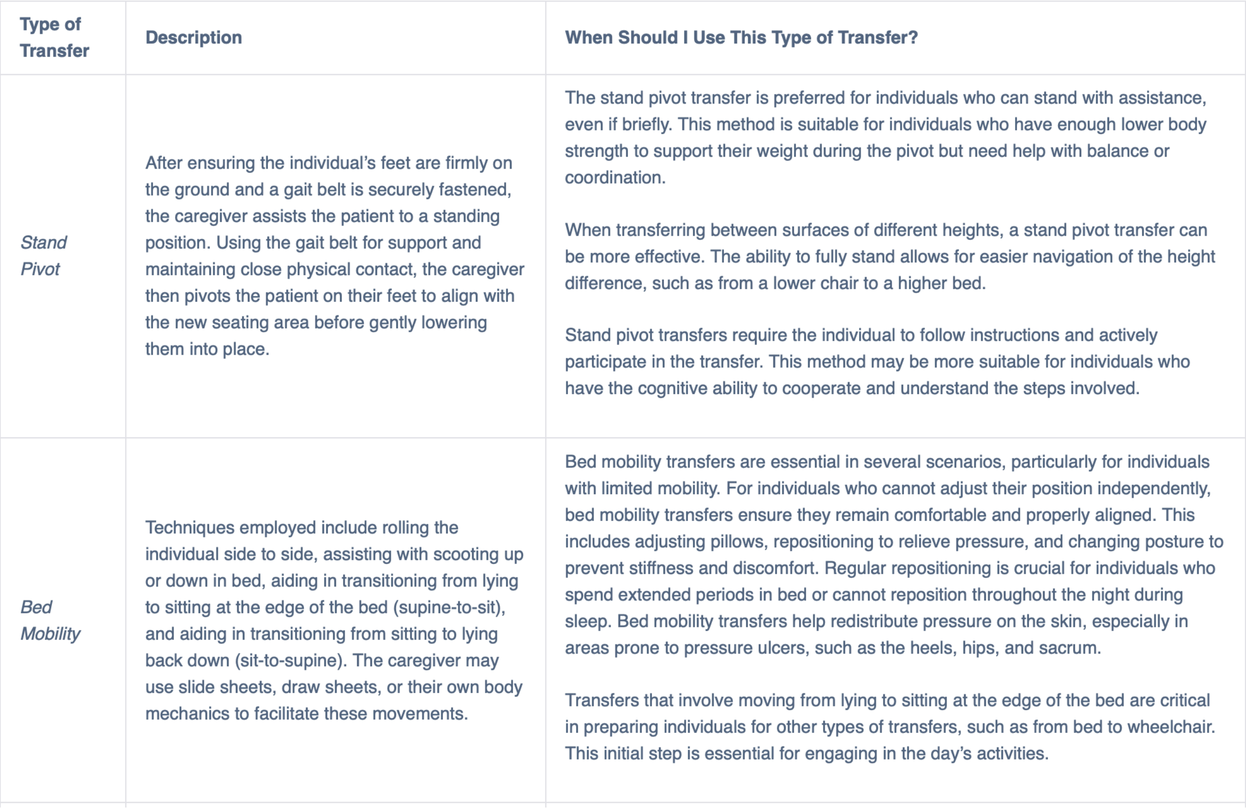
Transfer Techniques

In caregiving, the physical transfer of your loved one presents both a challenge and a necessity. Effective transfer techniques are essential to ensure the safety, comfort, and well-being of both you and your loved one. These techniques vary significantly in their approach, each tailored to specific needs based on the individual's mobility level, the environment, and the goal of the transfer. Understanding the different types of transfers, their descriptions, and appropriate applications can significantly enhance the quality of care provided.

Figure 1. *Website Menu Highlighting Transfer Techniques Section*

These resources include video demonstrations, written guides, and tips from an occupational therapy point of view on seamlessly executing each type of transfer. The transfers highlighted on the page include stand-pivot transfers, squat-pivot transfers, dependent-pivot transfers, transfers with a rolling walker (sit-to-stand and stand-to-sit), and bed mobility transfers (supine-to-sit, sit-to-supine, and rolling).

At the top of the transfer technique page, users can browse through a comprehensive table (Figure 2) that outlines each type of transfer by describing the steps involved in the technique and when the type of transfer would be most appropriate. This information includes the physical capabilities required by both the caregiver and the person being assisted, the ideal environment, and possible risk factors. With the help of the table, caregivers can feel confident in choosing which transfer will work best for them and create a starting point for deciding which instructional videos to focus on.

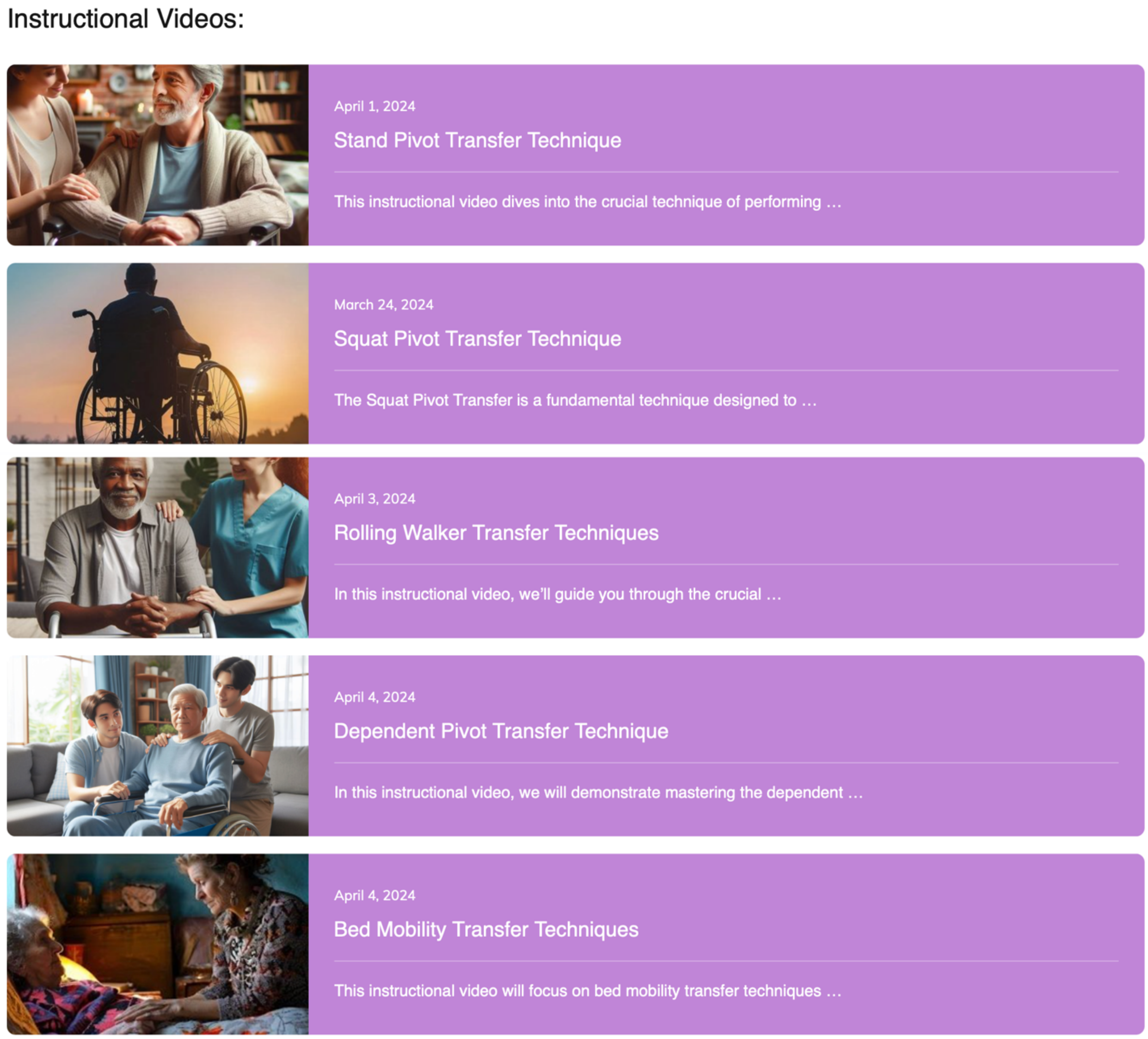


Type of Transfer	**Description**	**When Should I Use This Type of Transfer?**
Stand Pivot	After ensuring the individual's feet are firmly on the ground and a gait belt is securely fastened, the caregiver assists the patient to a standing position. Using the gait belt for support and maintaining close physical contact, the caregiver then pivots the patient on their feet to align with the new seating area before gently lowering them into place.	The stand pivot transfer is preferred for individuals who can stand with assistance, even if briefly. This method is suitable for individuals who have enough lower body strength to support their weight during the pivot but need help with balance or coordination. When transferring between surfaces of different heights, a stand pivot transfer can be more effective. The ability to fully stand allows for easier navigation of the height difference, such as from a lower chair to a higher bed. Stand pivot transfers require the individual to follow instructions and actively participate in the transfer. This method may be more suitable for individuals who have the cognitive ability to cooperate and understand the steps involved.
Bed Mobility	Techniques employed include rolling the individual side to side, assisting with scooting up or down in bed, aiding in transitioning from lying to sitting at the edge of the bed (supine-to-sit), and aiding in transitioning from sitting to lying back down (sit-to-supine). The caregiver may use slide sheets, draw sheets, or their own body mechanics to facilitate these movements.	Bed mobility transfers are essential in several scenarios, particularly for individuals with limited mobility. For individuals who cannot adjust their position independently, bed mobility transfers ensure they remain comfortable and properly aligned. This includes adjusting pillows, repositioning to relieve pressure, and changing posture to prevent stiffness and discomfort. Regular repositioning is crucial for individuals who spend extended periods in bed or cannot reposition throughout the night during sleep. Bed mobility transfers help redistribute pressure on the skin, especially in areas prone to pressure ulcers, such as the heels, hips, and sacrum. Transfers that involve moving from lying to sitting at the edge of the bed are critical in preparing individuals for other types of transfers, such as from bed to wheelchair. This initial step is essential for engaging in the day's activities.

Squat Pivot	This technique requires the patient to lean forward and push off from the seated surface with the caregiver's assistance, engaging in a semi-squat position. The caregiver supports the patient's weight through the transition as both pivot towards the target surface, where the patient is then lowered back into a seated position.	Use a squat pivot transfer when the individual has some ability to bear weight on their legs but may not have the strength or balance to fully stand. Also, if the individual tires easily or cannot sustain a standing position for the duration required for a stand pivot transfer, the squat pivot may be preferred. It minimizes the time the individual needs to bear weight and can be completed more quickly. The squat pivot is preferred in situations where controlled, gradual movement is necessary. It allows for a more paced transfer, which can be crucial for individuals who are at risk of losing balance or becoming dizzy during a full stand. In environments where space is tight and maneuverability is limited, a squat pivot transfer can be more practical. It requires less space to perform compared to a stand pivot, as the individual does not need to fully stand and turn.
Dependent Pivot	This method entails the caregiver performing most of the lifting and moving effort, supporting the individual who is unable to contribute to the transfer. The caregiver will need to employ a squatting position to safely lift the individual, pivot on their feet, and lower them to the target surface.	This approach is necessary for individuals with very limited or no mobility and strength, requiring full support to move. It's applicable in scenarios where the individual needs to be moved between different surfaces of similar heights like from a wheelchair to a toilet or from a chair to a bed, and cannot assist in their transfer. If the transfer requires moving the individual to a surface of a different height, the use of a Hoyer lift may be more appropriate. This type of transfer is also more appropriate when space is limited, such as in spaces like the bathroom, where it is not safe or practical to use a lift.
Rolling Walker	A sit-to-stand transfer to a rolling walker is a method used to assist individuals with mobility challenges in moving from a seated position to standing and walking with the aid of a rolling walker. This transfer is especially beneficial for individuals who have weight-bearing capacity but require additional support for balance and stability during the transition to standing and initiating walking. A stand-to-sit transfer from a rolling walker is a common method used to safely assist individuals with mobility challenges in transitioning from standing to a seated position, such as moving from a walker to a chair, bed, or toilet. This type of transfer is designed to ensure safety, maintain balance, and control the lowering motion to minimize the risk of falls.	Use a sit-to-stand transfer when an individual is transitioning from a seated position (e.g., from a chair, toilet, or edge of the bed) and preparing to walk or move to another location. This transfer is vital for starting any movement or activity. Standing also encourages regular changes in position for individuals who spend extended periods sitting, helping to redistribute pressure and prevent the development of pressure sores. Use a stand-to-sit transfer when an individual needs to safely move from a standing position back to a seated position, whether returning to a chair after a walk or activity, or sitting on a bed or toilet. Performing this transition safely is especially important for individuals who may experience fatigue, weakness, or balance issues while standing, ensuring they can sit down safely without risking a fall. It is also useful for those who need to manage their energy levels due to fatigue associated with ALS. Transitioning safely to a seated position helps in managing exertion.

Figure 2. *Transfer Techniques Guide*

Towards the bottom of the transfer technique page, an instructional video for each type of transfer included in the table is provided (Figure 3).



Instructional Videos:

April 1, 2024

Stand Pivot Transfer Technique

This instructional video dives into the crucial technique of performing …

March 24, 2024

Squat Pivot Transfer Technique

The Squat Pivot Transfer is a fundamental technique designed to …

April 3, 2024

Rolling Walker Transfer Techniques

In this instructional video, we'll guide you through the crucial …

April 4, 2024

Dependent Pivot Transfer Technique

In this instructional video, we will demonstrate mastering the dependent …

April 4, 2024

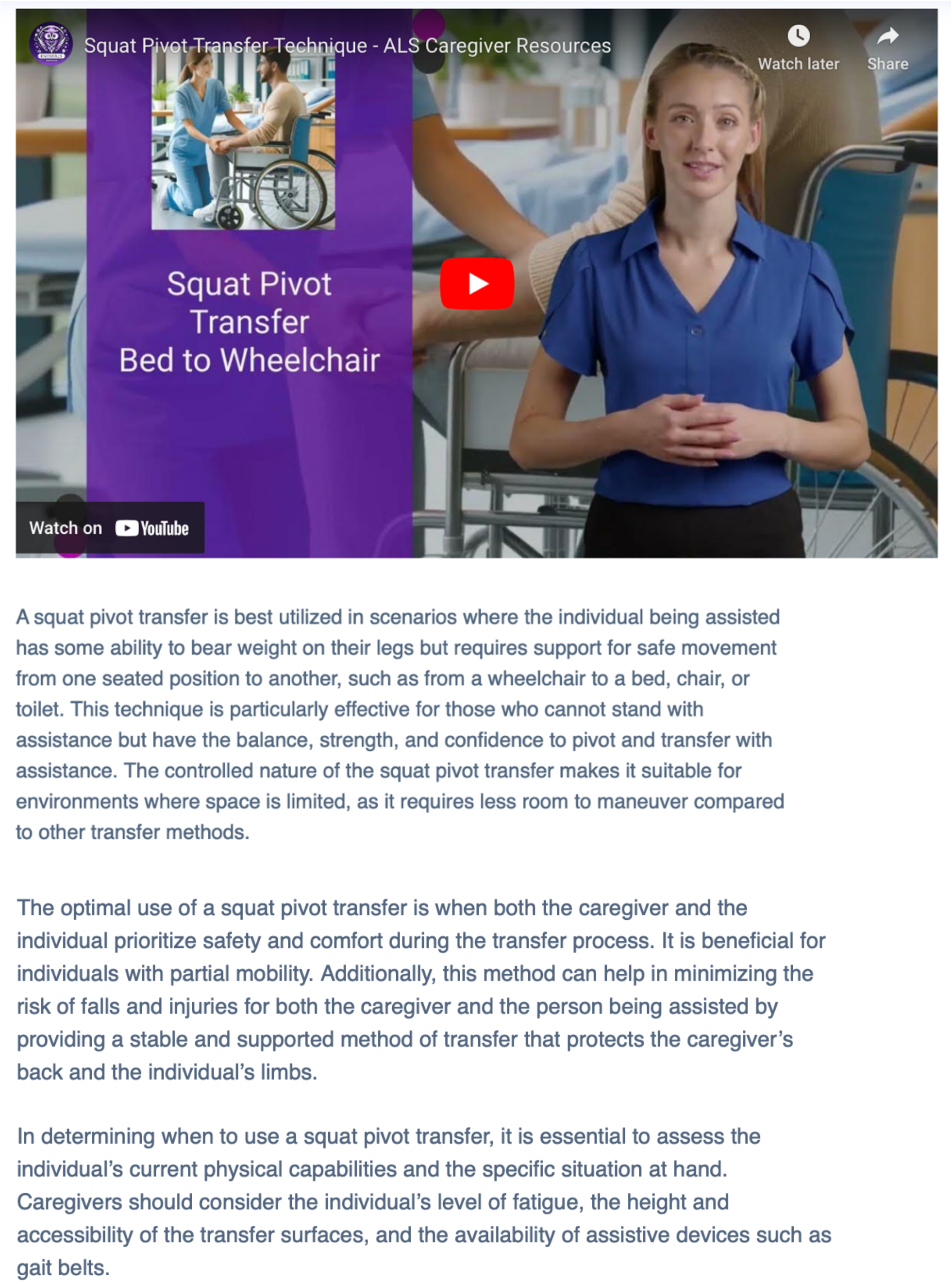
Bed Mobility Transfer Techniques

This instructional video will focus on bed mobility transfer techniques …

Figure 3. *List of Transfer Technique Instructional Videos*

Each video begins by detailing how to safely set up the environment and any equipment for the transfer. Initial safety pointers are also provided before diving into the detailed steps of the transfer. Then the video flows into a visual demonstration of the technique with a synced voice-over to narrate the actions being shown and provide additional commentary and tips through an occupational therapy lens. Each video ends by walking the caregiver through ensuring their loved one is properly and comfortably positioned in the target destination. All videos also highlight the importance of practicing to ensure the caregiver feels confident and empowered.

Along with each transfer technique video, an additional summary (Figure 4) is provided on the type of individual and the environment the technique is best suited. This information is more detailed than what is provided in the comprehensive table.



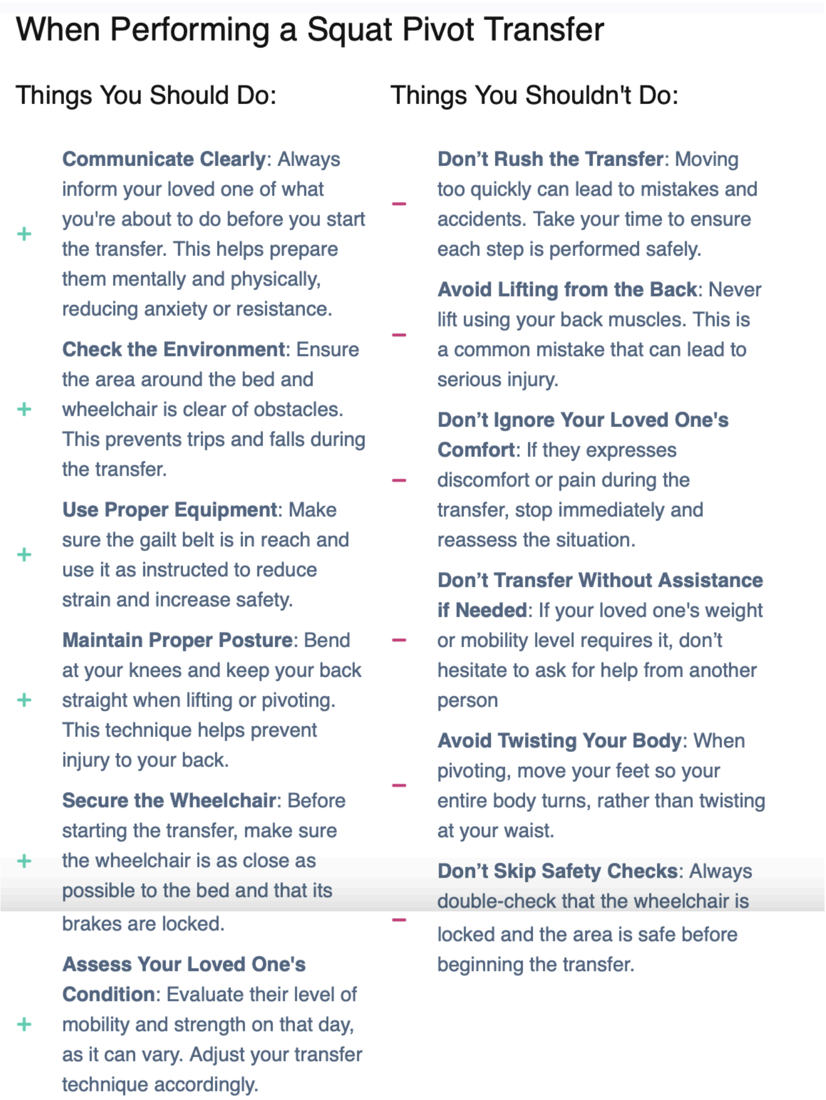
A squat pivot transfer is best utilized in scenarios where the individual being assisted has some ability to bear weight on their legs but requires support for safe movement from one seated position to another, such as from a wheelchair to a bed, chair, or toilet. This technique is particularly effective for those who cannot stand with assistance but have the balance, strength, and confidence to pivot and transfer with assistance. The controlled nature of the squat pivot transfer makes it suitable for environments where space is limited, as it requires less room to maneuver compared to other transfer methods.

The optimal use of a squat pivot transfer is when both the caregiver and the individual prioritize safety and comfort during the transfer process. It is beneficial for individuals with partial mobility. Additionally, this method can help in minimizing the risk of falls and injuries for both the caregiver and the person being assisted by providing a stable and supported method of transfer that protects the caregiver’s back and the individual’s limbs.

In determining when to use a squat pivot transfer, it is essential to assess the individual’s current physical capabilities and the specific situation at hand. Caregivers should consider the individual’s level of fatigue, the height and accessibility of the transfer surfaces, and the availability of assistive devices such as gait belts.

Figure 4. *Squat Pivot Transfer Technique Video and Summary Example*

A written outline of the key steps of the transfer is also included with each video for users who learn the best through reading. The written outline also serves as a quick reference when a refresher is needed, and the user does not want to rewatch the entire video. Finally, each video page contains a written list of the "dos and don'ts" of each technique (Figure 5). This section highlights important safety information, equipment information, and overall tips to ensure a smooth transfer process.



When Performing a Squat Pivot Transfer

Things You Should Do:

+ **Communicate Clearly**: Always inform your loved one of what you're about to do before you start the transfer. This helps prepare them mentally and physically, reducing anxiety or resistance.
+ **Check the Environment**: Ensure the area around the bed and wheelchair is clear of obstacles. This prevents trips and falls during the transfer.
+ **Use Proper Equipment**: Make sure the gailt belt is in reach and use it as instructed to reduce strain and increase safety.
+ **Maintain Proper Posture**: Bend at your knees and keep your back straight when lifting or pivoting. This technique helps prevent injury to your back.
+ **Secure the Wheelchair**: Before starting the transfer, make sure the wheelchair is as close as possible to the bed and that its brakes are locked.
+ **Assess Your Loved One's Condition**: Evaluate their level of mobility and strength on that day, as it can vary. Adjust your transfer technique accordingly.

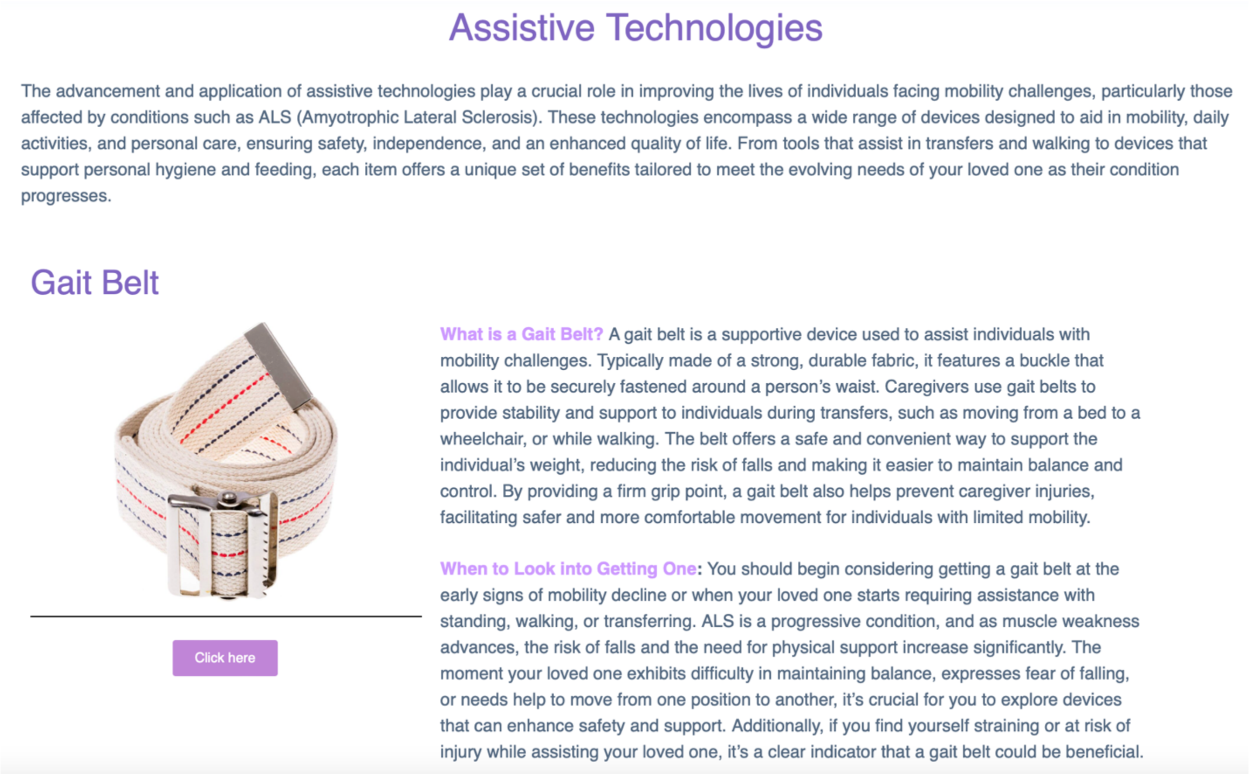
Things You Shouldn't Do:

− **Don't Rush the Transfer**: Moving too quickly can lead to mistakes and accidents. Take your time to ensure each step is performed safely.
− **Avoid Lifting from the Back**: Never lift using your back muscles. This is a common mistake that can lead to serious injury.
− **Don't Ignore Your Loved One's Comfort**: If they expresses discomfort or pain during the transfer, stop immediately and reassess the situation.
− **Don't Transfer Without Assistance if Needed**: If your loved one's weight or mobility level requires it, don't hesitate to ask for help from another person
− **Avoid Twisting Your Body**: When pivoting, move your feet so your entire body turns, rather than twisting at your waist.
− **Don't Skip Safety Checks**: Always double-check that the wheelchair is locked and the area is safe before beginning the transfer.

Figure 5. *Squat Pivot Transfer "Dos and Don'ts" Checklist Example*

Assistive Technology

Regarding assistive technology, the site acts as an extensive catalog showcasing current devices and tools designed to improve the quality of life for ALS patients and caregivers (Figure 6). Under the assistive technology page on the website menu, a detailed breakdown of ten unique assistive technologies is found. These technologies include a gait belt, Hoyer lift, Sara Stedy, GivMohr sling, universal cuff, built-up foam, tub-transfer bench, bidet, pressure relief cushion, and leg lifters.



Assistive Technologies

The advancement and application of assistive technologies play a crucial role in improving the lives of individuals facing mobility challenges, particularly those affected by conditions such as ALS (Amyotrophic Lateral Sclerosis). These technologies encompass a wide range of devices designed to aid in mobility, daily activities, and personal care, ensuring safety, independence, and an enhanced quality of life. From tools that assist in transfers and walking to devices that support personal hygiene and feeding, each item offers a unique set of benefits tailored to meet the evolving needs of your loved one as their condition progresses.

Gait Belt

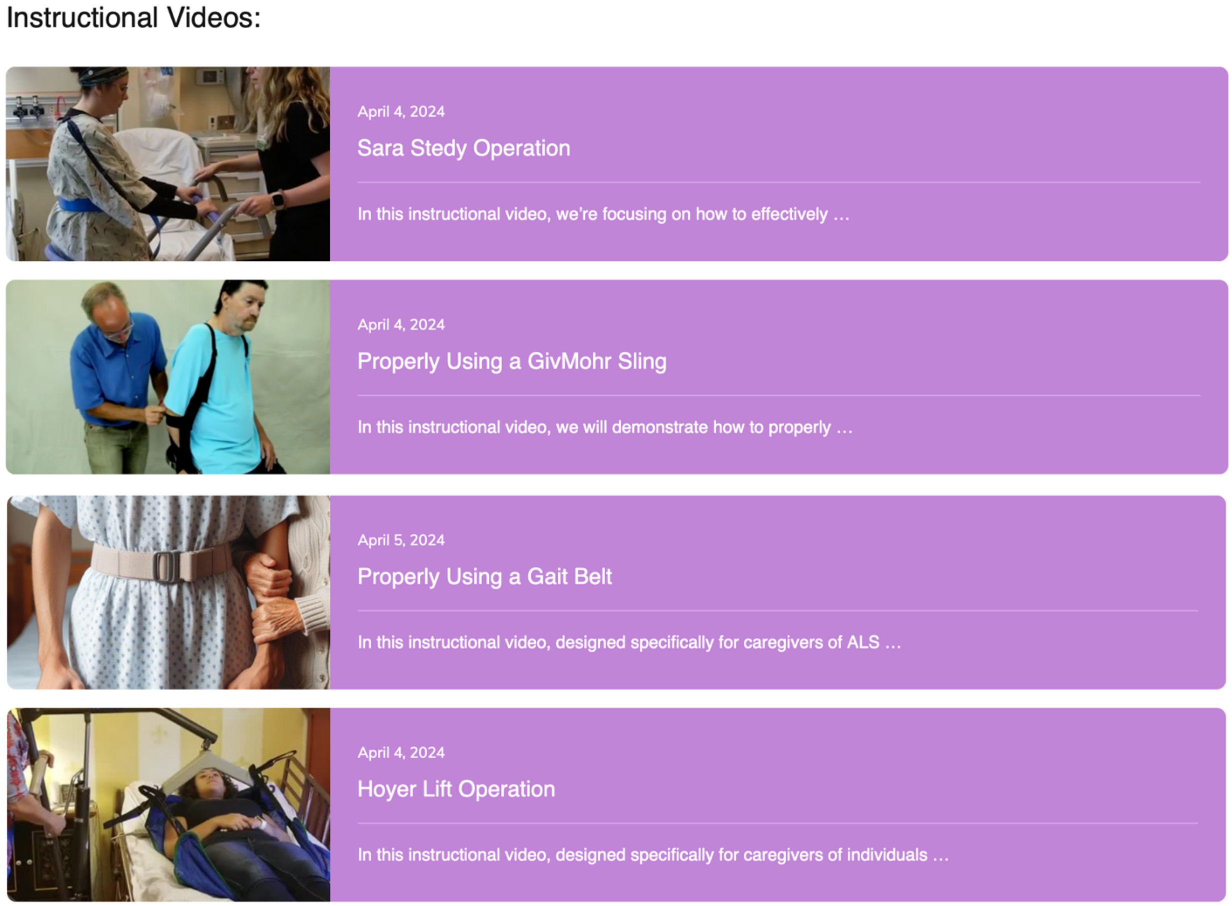
What is a Gait Belt? A gait belt is a supportive device used to assist individuals with mobility challenges. Typically made of a strong, durable fabric, it features a buckle that allows it to be securely fastened around a person's waist. Caregivers use gait belts to provide stability and support to individuals during transfers, such as moving from a bed to a wheelchair, or while walking. The belt offers a safe and convenient way to support the individual's weight, reducing the risk of falls and making it easier to maintain balance and control. By providing a firm grip point, a gait belt also helps prevent caregiver injuries, facilitating safer and more comfortable movement for individuals with limited mobility.

When to Look into Getting One: You should begin considering getting a gait belt at the early signs of mobility decline or when your loved one starts requiring assistance with standing, walking, or transferring. ALS is a progressive condition, and as muscle weakness advances, the risk of falls and the need for physical support increase significantly. The moment your loved one exhibits difficulty in maintaining balance, expresses fear of falling, or needs help to move from one position to another, it's crucial for you to explore devices that can enhance safety and support. Additionally, if you find yourself straining or at risk of injury while assisting your loved one, it's a clear indicator that a gait belt could be beneficial.

Figure 6. *Assistive Technology Catalog Example*

This list was compiled with the aid of Emory ALS Clinic's occupational therapist, Nichole Patel OTR/L, as these are among the most recommended items at the clinic. Each item has a picture, a purchase link, a description of the item, and the signs caregivers should look for to cue them to begin looking into acquiring the item. This ensures the caregiver can easily locate how to buy the item and have ample time to derive a plan for purchasing the item if financial assistance or insurance approval is needed. Overall, the page is designed to help caregivers make informed decisions about the tools most suited to their needs.

Instructional videos are provided to demonstrate the proper use of less intuitive assistive devices (Figure 7). A video is provided for the use of a gait belt, Hoyer lift, Sara Stedy, and GivMohr sling.



Instructional Videos:

April 4, 2024

Sara Stedy Operation

In this instructional video, we're focusing on how to effectively …

April 4, 2024

Properly Using a GivMohr Sling

In this instructional video, we will demonstrate how to properly …

April 5, 2024

Properly Using a Gait Belt

In this instructional video, designed specifically for caregivers of ALS …

April 4, 2024

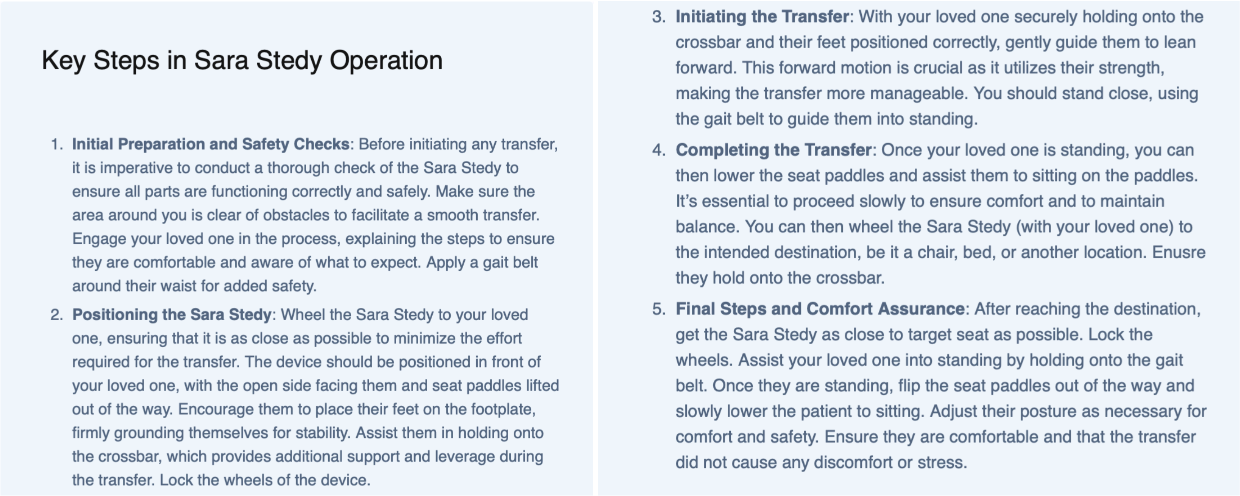
Hoyer Lift Operation

In this instructional video, designed specifically for caregivers of individuals …

Figure 7. *List of Assistive Technologies Instructional Videos*

Each video begins by covering the overall design and each component of the assistive technology to familiarize the caregiver. It also details important safety tips and how to properly prepare the person being assisted before transitioning into the demonstration. Then, a visual demonstration of the proper use of the item is provided with a synced voice-over that narrates the actions being shown and gives additional commentary and tips through an occupational therapy lens. The videos finalize by covering how to best ensure the comfort of the person being assisted both during and following the use of the assistive technology.

Similar to the instructional videos created for transfer techniques, supplemental written materials (Figure 8) are also provided with all assistive technology videos. These materials include a detailed summary of the appropriate uses for the piece of technology, the type of individual the device is best suited to, and when to seek the advice of a healthcare professional. The key steps for proper device use are also outlined with a "dos and don'ts" list that highlights correct equipment use, safety, and overall pointers.



Key Steps in Sara Stedy Operation

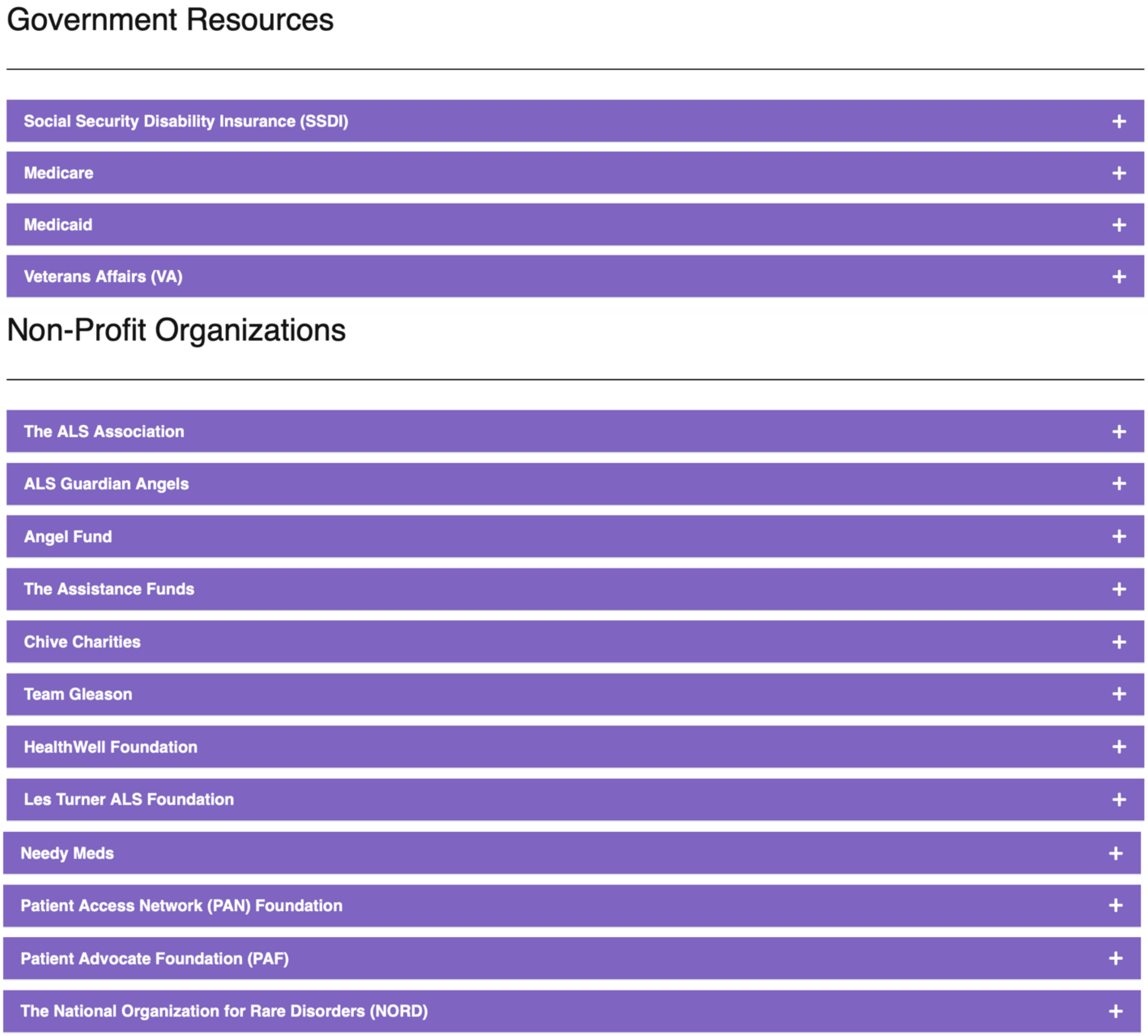
1. **Initial Preparation and Safety Checks**: Before initiating any transfer, it is imperative to conduct a thorough check of the Sara Stedy to ensure all parts are functioning correctly and safely. Make sure the area around you is clear of obstacles to facilitate a smooth transfer. Engage your loved one in the process, explaining the steps to ensure they are comfortable and aware of what to expect. Apply a gait belt around their waist for added safety.
2. **Positioning the Sara Stedy**: Wheel the Sara Stedy to your loved one, ensuring that it is as close as possible to minimize the effort required for the transfer. The device should be positioned in front of your loved one, with the open side facing them and seat paddles lifted out of the way. Encourage them to place their feet on the footplate, firmly grounding themselves for stability. Assist them in holding onto the crossbar, which provides additional support and leverage during the transfer. Lock the wheels of the device.
3. **Initiating the Transfer**: With your loved one securely holding onto the crossbar and their feet positioned correctly, gently guide them to lean forward. This forward motion is crucial as it utilizes their strength, making the transfer more manageable. You should stand close, using the gait belt to guide them into standing.
4. **Completing the Transfer**: Once your loved one is standing, you can then lower the seat paddles and assist them to sitting on the paddles. It's essential to proceed slowly to ensure comfort and to maintain balance. You can then wheel the Sara Stedy (with your loved one) to the intended destination, be it a chair, bed, or another location. Enusre they hold onto the crossbar.
5. **Final Steps and Comfort Assurance**: After reaching the destination, get the Sara Stedy as close to target seat as possible. Lock the wheels. Assist your loved one into standing by holding onto the gait belt. Once they are standing, flip the seat paddles out of the way and slowly lower the patient to sitting. Adjust their posture as necessary for comfort and safety. Ensure they are comfortable and that the transfer did not cause any discomfort or stress.

Figure 8. *Sara Stedy Key Steps for Proper Device Use Example*

Financial Resources

To address the financial challenges associated with ALS care, the platform offers a detailed guide on available financial resources (Figure 9). This section sorts the resources according to categories including government and non-profit organizations. The government resources include Social Security Disability Insurance (SSDI), Medicare, Medicaid, and Veteran's Affairs (VA). Non-profits include the ALS Association, ALS Guardian Angels, the

Angel Fund, the Assistance Funds, Chive Charities, Team Gleason, the HealthWell Foundation, Les Turner ALS Association, Needy Meds, Patient Access Network (PAN), Patient Advocate Foundation (PAF), the National Organization for Rare Disorders (NORD).



Government Resources

Social Security Disability Insurance (SSDI) +
Medicare +
Medicaid +
Veterans Affairs (VA) +

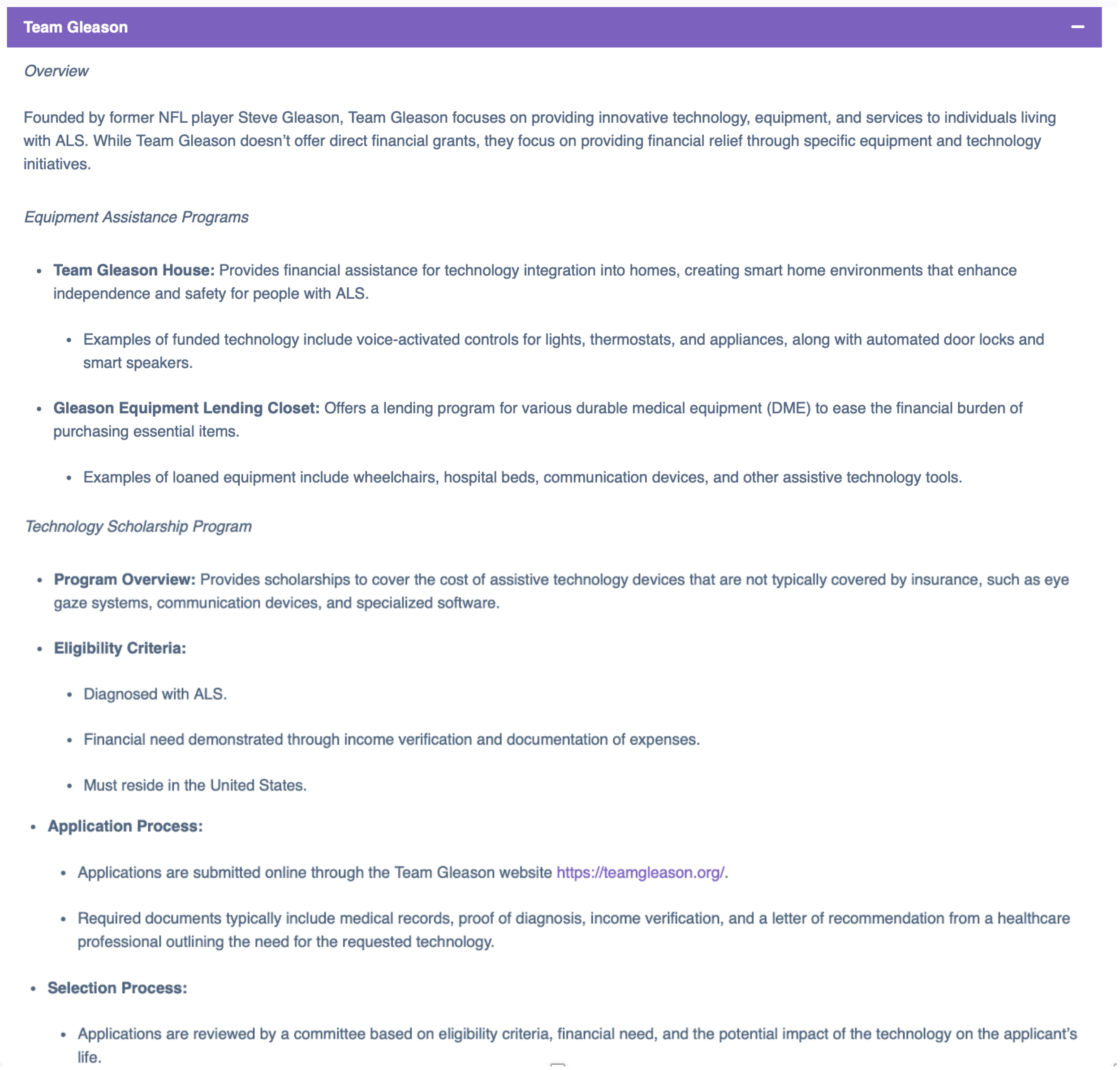
Non-Profit Organizations

The ALS Association +
ALS Guardian Angels +
Angel Fund +
The Assistance Funds +
Chive Charities +
Team Gleason +
HealthWell Foundation +
Les Turner ALS Foundation +
Needy Meds +
Patient Access Network (PAN) Foundation +
Patient Advocate Foundation (PAF) +
The National Organization for Rare Disorders (NORD) +

Figure 9. *Comprehensive List of Financial Resources Available on the Website*

All non-profit resources are equipped with a drop-down menu (Figure 10) that provides a detailed outline of the organization. This outline includes a general overview of the organization, its mission, the types of financial assistance it provides, and direct contact information.

Additionally, information regarding program benefits, eligibility criteria, the application process, and important notes.



Team Gleason

Overview

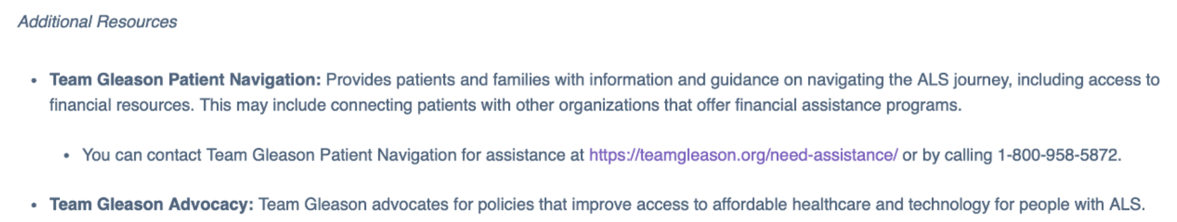
Founded by former NFL player Steve Gleason, Team Gleason focuses on providing innovative technology, equipment, and services to individuals living with ALS. While Team Gleason doesn't offer direct financial grants, they focus on providing financial relief through specific equipment and technology initiatives.

Equipment Assistance Programs

- **Team Gleason House:** Provides financial assistance for technology integration into homes, creating smart home environments that enhance independence and safety for people with ALS.
  - Examples of funded technology include voice-activated controls for lights, thermostats, and appliances, along with automated door locks and smart speakers.
- **Gleason Equipment Lending Closet:** Offers a lending program for various durable medical equipment (DME) to ease the financial burden of purchasing essential items.
  - Examples of loaned equipment include wheelchairs, hospital beds, communication devices, and other assistive technology tools.

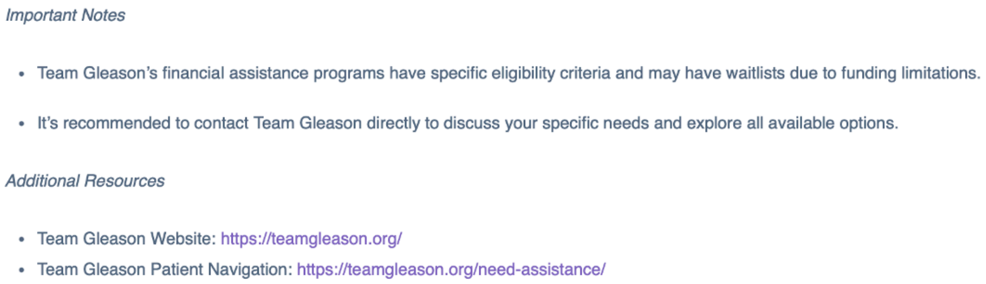
Technology Scholarship Program

- **Program Overview:** Provides scholarships to cover the cost of assistive technology devices that are not typically covered by insurance, such as eye gaze systems, communication devices, and specialized software.
- **Eligibility Criteria:**
  - Diagnosed with ALS.
  - Financial need demonstrated through income verification and documentation of expenses.
  - Must reside in the United States.
- **Application Process:**
  - Applications are submitted online through the Team Gleason website https://teamgleason.org/.
  - Required documents typically include medical records, proof of diagnosis, income verification, and a letter of recommendation from a healthcare professional outlining the need for the requested technology.
- **Selection Process:**
  - Applications are reviewed by a committee based on eligibility criteria, financial need, and the potential impact of the technology on the applicant's life.



Additional Resources

- **Team Gleason Patient Navigation:** Provides patients and families with information and guidance on navigating the ALS journey, including access to financial resources. This may include connecting patients with other organizations that offer financial assistance programs.
  - You can contact Team Gleason Patient Navigation for assistance at https://teamgleason.org/need-assistance/ or by calling 1-800-958-5872.
- **Team Gleason Advocacy:** Team Gleason advocates for policies that improve access to affordable healthcare and technology for people with ALS.



Important Notes

- Team Gleason's financial assistance programs have specific eligibility criteria and may have waitlists due to funding limitations.
- It's recommended to contact Team Gleason directly to discuss your specific needs and explore all available options.

Additional Resources

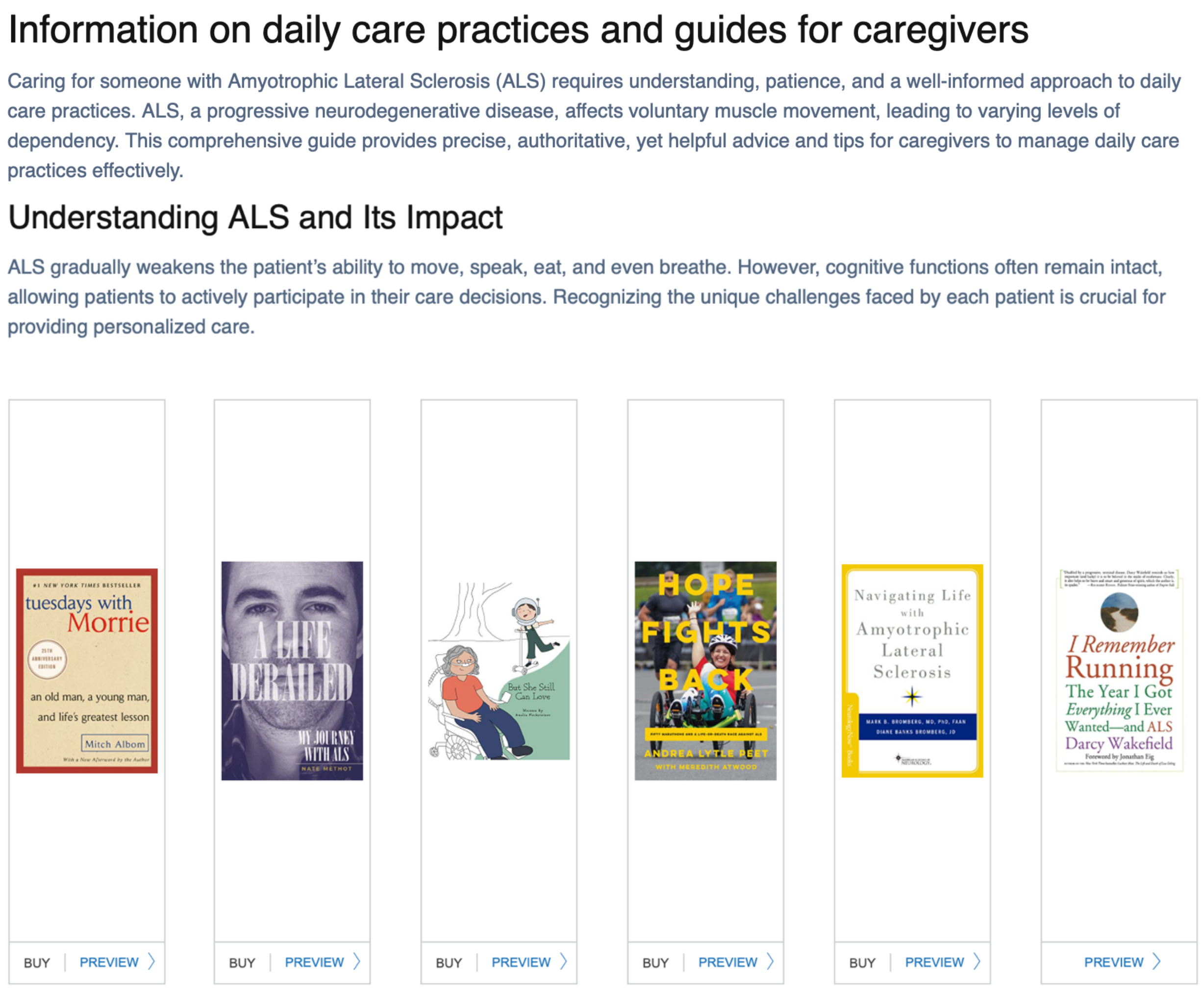
- Team Gleason Website: https://teamgleason.org/
- Team Gleason Patient Navigation: https://teamgleason.org/need-assistance/

Figure 10. *Team Gleason Drop-Down Menu Example*

The organizations selected are geared toward ALS patients and cover expenses such as home modifications, equipment purchases/loans, assistive technology, medications, and general living expenses. Some organizations, such as the Patient Advocacy Foundation and the National Organization for Rare Disorders, do not provide direct financial assistance but assist families battling ALS with navigating the challenges of private insurance, government benefits, and connecting to local resources. Due to the time constraints of the project and limited scope, only contact information is provided for the government resources, outside of the VA.

Additional Information

Although the focus of the website is to provide information regarding transfer techniques, assistive technology, and financial resources, to create a complete, well-rounded website, the website also includes information on communication, nutrition/feeding, support networks, end-of-life planning, and general caregiving tips. Each category has a page on the website and provides a brief overview of the most common issues faced by ALS caregivers related to each topic (Figure 11). The main purpose of these pages is to serve as a basic starting point, as they mostly provide links to other websites, PDFs, and books that address these issues in depth.



Information on daily care practices and guides for caregivers

Caring for someone with Amyotrophic Lateral Sclerosis (ALS) requires understanding, patience, and a well-informed approach to daily care practices. ALS, a progressive neurodegenerative disease, affects voluntary muscle movement, leading to varying levels of dependency. This comprehensive guide provides precise, authoritative, yet helpful advice and tips for caregivers to manage daily care practices effectively.

Understanding ALS and Its Impact

ALS gradually weakens the patient's ability to move, speak, eat, and even breathe. However, cognitive functions often remain intact, allowing patients to actively participate in their care decisions. Recognizing the unique challenges faced by each patient is crucial for providing personalized care.

Figure 11. *General Caregiving Guides Example*

By providing links to quality resources, the time caregivers must spend researching and combing through a sea of information is greatly reduced. They will also have the assurance that the information provided is of good quality and practical.

Overall, knowals.com serves as a comprehensive and thoughtfully designed platform specifically created to support ALS caregivers. By focusing on critical topics such as transfer techniques, assistive technology, and financial resources, the website aims to empower caregivers with the knowledge and tools necessary for providing high-quality care with confidence. The inclusion of instructional videos, detailed written guides, and direct links to purchasing essential items directly responds to the practical needs of caregivers, streamlining their access to vital resources. Furthermore, the extension of the site's content to cover broader caregiving concerns strives to address the multifaceted challenges faced by ALS caregivers. Through this holistic approach, knowals.com significantly contributes to easing the caregiving journey, offering a reliable, navigable, and informative resource that caregivers can turn to for support and guidance.

CHAPTER 5

Discussion and Impact

The launch and sustained operation of knowals.com is expected to have both immediate and long-lasting impacts on the ALS caregiving community. In the short term, caregivers will experience a substantial reduction in both the time and effort required to locate reliable and practical information on caring for their loved one with ALS. By combining instructional videos with written guides on transfer techniques and assistive technology use and acquisition, the website directly addresses the immediate needs of caregivers for clear, accessible guidance. This readily available resource not only enhances the safety and comfort of the person with ALS but also has the potential to preserve the caregiver's own personal health, both physically and mentally.

The platform targets the aspects of caregiving that most often contribute to physical strain and emotional distress. The instructional materials and detailed guides available on the website provide caregivers with the skills necessary to safely assist their loved ones. With practice, these skills effectively reduce the risk of injuries associated with manual transfers and the physical demands of caregiving. Moreover, the guides on assistive technology introduce caregivers to devices that can make daily care tasks more manageable. By providing video demonstrations of the proper use of these technologies, the website helps caregivers confidently perform their care routines, leading to less physical exertion and creating a more sustainable caregiving experience.

Moreover, the website’s detailed outlines of financial resources serve as a critical tool for caregivers navigating the often complex and overwhelming journey of financial assistance for ALS care. Financial concerns often weigh heavily on caregivers, with the costs associated with managing ALS causing significant stress and anxiety. By offering an exhaustive list of government and non-profit resources complete with application guidance, knowals.com aims to alleviate this potential financial strain. The website allows them to access necessary services and equipment sooner rather than later. This immediate alleviation of financial and informational burdens is expected to create a more supportive and less stressful caregiving experience.

In the long term, knowals.com is expected to establish itself as a pillar in the ALS community, building a network of informed, empowered caregivers who are better equipped to handle the immense challenges of ALS caregiving. As users engage with the site, share their experiences, and possibly contribute their insights, the platform can evolve into a dynamic, user-enhanced resource, continually updated with the latest best practices and innovations in ALS care. Furthermore, the site encourages caregivers to seek comprehensive, holistic care by emphasizing the importance of consulting healthcare professionals and providing links to in-depth resources on broader caregiving challenges. This guidance not only benefits the immediate physical needs of people diagnosed with ALS but also addresses the psychological well-being of both patients and caregivers, promoting a healthier, more resilient caregiving community over the long term.

Ultimately, the purpose of this project was to create an easy-to-access website specific to ALS caregivers that provides online educational materials and training videos with the overall desired outcome to be for caregivers of ALS patients to feel supported, to be able to adapt to the progression of the disease and their loved one’s changing needs, and to feel confident with their caregiving skill set. Knowals.com’s blend of practical assistance, educational resources, and community support achieves this. Overall, the website has the potential to significantly improve the quality of life for ALS patients and their caregivers, creating a lasting positive impact in the fight against ALS.

Limitations

While knowals.com ambitiously sets out to provide a comprehensive set of resources for ALS caregivers, focusing on transfer techniques, assistive technology, and financial resources, it's important to acknowledge the limitations caused by the time constraints put on the project. Given the expansive nature of ALS care, fully covering every aspect in depth within a limited timeframe poses challenges that impact the scope and depth of the website's content.

One limitation is the scope of the assistive technology and transfer techniques sections. Although these areas are well-developed with instructional materials and videos, the rapid advancement in assistive technologies and ever-evolving practices in caregiving techniques may mean that the website cannot always offer the latest information or innovations. As a result, caregivers might need to seek additional, up-to-date resources beyond what the site can provide within its current update cycle. Furthermore, the instructional content in these sections, may not fully encapsulate the broad range of scenarios caregivers might encounter. The progression of ALS greatly varies from person to person and the unique needs of each patient require personal guidance that can be challenging to create comprehensively, especially under imposed deadlines. The website relies on general instructions and demonstrations, which may not address all possible use cases or adaptations needed for individual circumstances.

Another area potentially affected by time constraints is the financial resources section. While the website offers a thorough guide to available financial assistance from various organizations, this information has the potential to quickly become outdated. This is because factors such as funding availability, program eligibility criteria, and application processes are constantly changing. The site may not always reflect the most current opportunities or changes in program requirements, leading caregivers to pursue resources that may no longer be available, fit their needs, or that they are ineligible for. Also, this section primarily offers summaries and direct contact information for non-profit organizations and government assistance programs to serve as a solid starting point. Detailed guidance on navigating these resources and personalized advice based on specific caregiver circumstances may be necessary, creating a limitation.

Additionally, the website's broader sections on topics such as communication, nutrition, support networks, and end-of-life planning primarily serve as starting points, directing users to external resources. While this approach still provides valuable information, it inherently limits the site's capacity to provide in-depth guidance on these important aspects of ALS care. Caregivers may find themselves needing to invest additional time in exploring these recommended resources to gain a full understanding of the topics. The website may need to be eventually expanded to cover these topics fully and deeply.

Overall, while knowals.com comes with inherent limitations due to time constraints and the dynamic nature of ALS care, its foundation as a comprehensive resource for caregivers remains by providing support and guidance. Despite these limitations, the website represents a significant step forward in supporting ALS caregivers by creating a central hub for essential information, demonstrations, and resources. These constraints highlight the need for ongoing updates, expansions, and the incorporation of user feedback to ensure the platform remains a relevant, accurate, and comprehensive resource for the ALS caregiving community.

Sustainability Plan

Developing a sustainability plan for a comprehensive website like knowals.com requires many parts to ensure the site’s long-term viability and relevance. To maintain and expand the website's offerings, continuous content updates, partnerships, and user engagement are essential components of the sustainability plan.

Ensuring that the website remains a current and accurate resource requires regular updates to the educational content, assistive technology reviews, and financial resources. This means staying on top of advancements in ALS research, emerging caregiving techniques, and new assistive devices. The site will undergo an established routine review process every six months to evaluate and refresh existing materials. Nichole Patel OTR/L, Emory ALS Clinic's occupational therapist, will be trained to navigate the site and make edits, add pages, create posts, etc. Therefore, she will be able to make necessary changes to existing materials and add new information if desired.

Moreover, building a dynamic, interactive community around the website will drive engagement and loyalty, leading to increased sustainability. Users will be provided with the chance to give feedback through the website's comment section, which will provide valuable insights into their needs and preferences. Their feedback will allow for continuous improvement of the website's content and usability. Users will also be encouraged to share their personal stories and caregiving tips to create an authentic and supportive online community, keeping people coming back to the website.

Finally, the website, although built for the needs of ALS caregivers, holds generalizable content. The focus on transfer techniques, assistive technology, and financial assistance applies to various diseases and disabilities that require intensive caregiving, such as Parkinson's Disease or Multiple Sclerosis. This will increase the website's number of users, amplifying the impact on caregivers and patients across different medical challenges and creating greater room for sustainability.

In essence, the sustainability and expansion of knowals.com hinges on the website remaining accurate and updated, continuously evolving in response to the needs of its users, and adapting to the advancements in healthcare and technology. By implementing these strategies, the website will remain a valuable resource for the Emory ALS Clinic, caregivers to ALS patients, and caregivers across an entire spectrum of conditions, contributing to improved care and quality of life for patients and their families.

Conclusions

The creation of knowals.com represents a significant stride towards the advancement of occupational therapy, particularly in enhancing care for ALS patients and their caregivers through the implementation of technology. The website brings occupational therapy into the digital form by providing caregivers with access to expert knowledge and practical guidance outside of traditional therapy sessions. This digital resource complements the hands-on training and personalized strategies that occupational therapists provide. This allows caregivers to review and practice techniques at their own pace and within the context of their daily routines at home. The website is a valuable resource that combines clinical knowledge and practical application in home settings, which aligns with occupational therapy's goal of empowering individuals to participate in everyday activities with a greater sense of ease and independence.

The detailed instructional demonstrations covering transfer techniques provided by knowals.com are directly aligned with occupational therapy's goal of facilitating safe and efficient functional mobility. These resources not only equip caregivers with the skills needed to minimize physical strain but also promote the dignity and comfort of their loved one with ALS during transfers. The website offers a wide range of techniques and acknowledges the unique needs and abilities at different stages of ALS, which allows for personalized care approaches. Individualized care is foundational in occupational therapy practice.

Moreover, the emphasis on assistive technology within knowals.com highlights the occupational therapy principle of adapting environments and tasks to fit the individual's personalized needs. The site's comprehensive catalog of assistive devices with instructional videos and written guides allows caregivers to implement solutions that promote patient independence and participation in daily activities. This focus is particularly crucial in ALS care, where progressive loss of muscle function leads to ever-changing adjustments to care strategies and tools.

The inclusion of financial resources addresses an important part of providing quality care for ALS patients that often impacts access to necessary services and equipment. By providing a detailed guide to financial assistance options, knowals.com aligns with occupational therapy's multifactorial approach to caring for patients. This is because it recognizes the deep significance of social, economic, and environmental factors in health and well-being.

For future work, knowals.com could expand its offerings to include virtual consultations or forums moderated by occupational therapists. Live webinars and Q&A sessions with healthcare professionals could also be implemented in the future as the website grows. These would provide the seemingly necessary personalized advice and support to caregivers. Additionally, developing partnerships with ALS research initiatives could facilitate the introduction of new treatments and assistive technologies into the platform. This would ensure that caregivers and patients have access to the latest advancements in ALS care. Finally, conducting studies in the future on the effectiveness of the website and its materials is also a critical future step. These studies would evaluate how well the website meets the needs of ALS caregivers and its impact on their caregiving practices. The results could potentially alter the course of the website and its offerings.

In conclusion, knowals.com significantly contributes to the field of occupational therapy by providing accessible, practical resources that support the care of ALS patients. Occupational therapists can utilize this platform as a supplementary resource in patient and caregiver education, reinforcing training provided during therapy sessions with accessible, easy-to-understand content. Future expansions to the platform and research could further fortify the value and utility of the website, ensuring it continues to deliver on its mission to empower caregivers and provide comfort to ALS patients.

References

Aoun, S. M., Connors, S. L., Priddis, L., Breen, L. J., & Colyer, S. (2012). Motor Neuron Disease family carers' experiences of caring, palliative care and bereavement: An exploratory qualitative study. *Palliative Medicine*, 26(6), 842–850. https://doi.org/10.1177/0269216311416036

Bassola, B., & Lusignani, M. (2017). Self-care in people with motor neuron disease: An integrative review. *Journal of Neuroscience Nursing*, 49(5), 11 317. https://doi.org/10.1097/JNN.0000000000000303

Bassola, B., Cilluffo, S., & Lusignani, M. (2020). Going inside the relationship between caregiver and care-receiver with amyotrophic lateral sclerosis in Italy, a grounded theory study. *Health & Social Care in the Community*, 29(4), 1083–1090. https://doi.org/10.1111/hsc.13142

Bergin, S., & Mockford, C. (2016). Recommendations to support informal carers of people living with motor neurone disease. *British Journal of Community Nursing*, 21(10), 518–524. https://doi.org/10.12968/bjcn.2016.21.10.518

Brizzi, K. T., Bridges, J. F., Yersak, J., Balas, C., Thakur, N., Galvin, M., Hardiman, O., Heatwole, C., Ravits, J., Simmons, Z., Bruijn, L., Chan, J., Bedlack, R., & Berry, J. D. (2020). Understanding the needs of people with ALS: A national survey of patients and Caregivers. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *21*(5–6), 355–363. https://doi.org/10.1080/21678421.2020.1760889

Centers for Disease Control and Prevention. (2022, May 13). *CDC* - Amyotrophic lateral sclerosis: About. *Centers for Disease Control and Prevention.*

De Wit, J., Schröder, C. D., El Mecky, J., Beelen, A., van den Berg, L. H., & Visser-Meily, J. M. A. (2019). Support needs of caregivers of patients with amyotrophic lateral sclerosis: A qualitative study. *Palliative & Supportive Care,* 17(2), 195–201. https://doi.org/10.1017/S1478951517001213

DiZazzo-Miller, R., Winston, K., Winkler, S. L., & Donovan, M. L. (2017). Family caregiver training program (FCTP): A randomized controlled trial. *The American Journal of Occupational Therapy*, 71(5). https://doi.org/10.5014/ajot.2017.022459

Foster, L. A., & Salajegheh, M. K. (2019). Motor neuron disease: Pathophysiology, diagnosis, and management. *American Journal of Medicine*, 132(1), 32 37. https://doi.org/10.1016/j.amjmed.2018.07.012

Galvin, M., Carney, S., Corr, B., Mays, I., Pender, N., & Hardiman, O. (2018). Needs of informal caregivers across the caregiving course in amyotrophic lateral sclerosis: A qualitative analysis. *BMJ Open*, *8*(1), e018721. https://doi.org/10.1136/bmjopen-2017-018721

Gillespie, J., Przybylak-Brouillard, A., & Watt, C. L. (2021). The palliative care information needs of patients with amyotrophic lateral sclerosis and their informal caregivers: A scoping review. *Journal of Pain and Symptom Management*, *62*(4), 848–862. https://doi.org/10.1016/j.jpainsymman.2021.03.008

Jensen, M., Agbata, I. N., Canavan, M., & McCarthy, G. (2014). Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: A systematic review and meta-analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry*, 30(2), 130–143. https://doi.org/10.1002/gps.4208

Kim, D., Peterson, N., & Lee, J. E. (2022). Caregiving outcomes of sub/urban and rural caregivers: the powerful tools for caregivers program. *Clinical Gerontologist*, 1–12. https://doi.org/10.1080/07317115.2022.2090878

Obermann, M., & Lyon, M. (2015). Financial cost of amyotrophic lateral sclerosis: A case study. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *16*(1-2), 54–57. https://doi.org/10.3109/21678421.2014.951946

O'Brien, M. R., Whitehead, B., Jack, B. A., & Mitchell, J. D. (2012). The need for support services for family carers of people with motor neurone disease (MND): Views of current and former family caregivers a qualitative study. *Disability and Rehabilitation*, 34(3), 247–256. https://doi.org/10.3109/09638288.2011.605511

Pinho, A. C., & Gonçalves, E. (2016). Are amyotrophic lateral sclerosis caregivers at higher risk for health problems?. Acta Médica Portuguesa, 29(1), 56–62. https://doi.org/10.20344/amp.6590

Rosney, D. M., F Noe, M., & J Horvath, P. (2017). Powerful tools for caregivers, a group psychoeducational skill-building intervention for family caregivers. *Journal of Caring Sciences*, 6(3), 187–198. https://doi.org/10.15171/jcs.2017.019

Schischlevskij, P., Cordts, I., Günther, R., Stolte, B., Zeller, D., Schröter, C., Weyen, U., Regensburger, M., Wolf, J., Schneider, I., Hermann, A., Metelmann, M., Kohl, Z., Linker, R. A., Koch, J. C., Stendel, C., Müschen, L. H., Osmanovic, A., Binz, C., Klopstock, T., … Schreiber-Katz, O. (2021). Informal caregiving in amyotrophic lateral sclerosis (ALS): A high caregiver burden and drastic consequences on caregivers' lives. *Brain sciences*, 11(6), 748. https://doi.org/10.3390/brainsci11060748

Valadi, N. (2015). Evaluation and management of amyotrophic lateral sclerosis. *Primary Care - Clinics in Office Practice*, 42(2), 177–187. https://doi.org/10.1016/j.pop.2015.01.009

Appendix 1

Learning Objectives

Learning objectives	Short-term objectives to reach learning objective	Learning activities to meet objectives	Outcome measure
1. Demonstrate the ability to identify the current programs in the literature related to ALS caregiver education/training and areas where further educational development is needed.	1a. Search the literature to compare current programs related to caregiver education/training. 1b. Search the literature to determine factors leading to low caregiver confidence in ALS caregivers.	1a. Identify articles identifying the current programs. Synthesize each article, breaking down the study design, outcome measures, major findings, and weaknesses. Identify the missing pieces in the current literature and determine what has/hasn't worked related to caregiving education/training. 1b. Identify articles related to factors leading to low caregiver confidence. Synthesize each article, breaking down the study design, outcome measures, major findings, and weaknesses. Identify the missing pieces in the current literature and determine the outstanding needs of ALS caregivers to further develop caregiver education/training.	1. Completed literature review table with at least 20 articles included
2. Demonstrate the ability to adequately assess the current needs of ALS caregivers about patient/caregiver education.	2a. Synthesize the common themes found in the literature review table to determine overarching factors leading to low caregiver confidence and what the current	2a. Write up a formal needs assessment outlining the gaps in the literature and plan for the website to fills these gaps	2. Completed needs assessment

	programs are missing.		
3. Demonstrate the ability to effectively relay information on assistive devices their use, how to safely perform transfers, and how to locate financial resources for ALS caregivers by creating a comprehensive website that includes written educational materials and training videos to increase caregiver confidence.	3a. Identify the best format and structure for the website and included materials/videos. 3b. Identify the topics and information that needs to be included on the website.	3a. Refer to literature to determine possible layouts for the website. Use feedback from staff and evidence found in literature review to create the final website layout and structure of the included materials/videos. 3b. Review proposed topics with staff and receive feedback. Create outline for website/materials and develop all needed materials.	3. Completed website with all included written educational materials and videos.

Appendix 2

Supervision Plan

Item	Deliverable	Item needs support from site mentor?	Item needs support from Dr. Chen?	Timeline	Completed?
Introductory meeting with clinic staff members	Hours log and visit summary	Yes	No	Jan 2024	Yes
Introductory meeting with site mentor	Hours log and visit summary	Yes	No	Jan 2024	Yes
Scheduled site visits every other Friday to gather additional needs and guide project direction	Hours log and final website	Yes	No	Jan 2024-April 2024	Yes
Literature search to compare current programs related to caregiver education/training	Literature search table and final review	No	No	Jan 2024	Yes
Literature search to find the effectiveness of current caregiver education/training programs	Literature search table and final review	No	No	Jan 2024	Yes
Meeting site mentor to discuss findings and possible topics to focus on/structure to use based on the evidence	Meeting summary	Yes	No	Jan 2024	Yes
Creation of video storyboards on proposed topics	Completed storyboards	No	No	Feb 2024	Yes
Creation of written material outlines	Completed outlines	No	No	Feb 2024	Yes
Meeting to gain feedback from site mentor on content materials	Hours log and meeting summary	Yes	No	Feb 2024	Yes
Mid-point meeting with Dr. Chen to gain feedback on materials completed	Meeting summary	No	Yes	Feb 2024	Yes
Completion of videos	Final videos	No	No	March 2024	Yes

Completion of written materials	Final written materials	No	No	March 2024	Yes
Meeting to gain feedback from site mentor on all content created	Meeting summary	Yes	No	March 2024	Yes
Create final website	Final website	No	No	March 2024	Yes
Final website testing period and updates	Final website launch	Yes	Yes	April 2024	Yes
Complete final paper draft	Final paper draft	Yes	Yes	April 2024	Yes
Final meetings with site mentor and Dr. Chen for final edits	Meeting summaries	Yes	Yes	April 2024	Yes
Complete final version of final paper	Final paper submission	Yes	Yes	April 2024	Yes