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## Lymphedema Management for those Living with Spinal Cord Disorders to Address Caregiver Burden

Nia L. Bolen-Daniels

Nova Southeastern University, nb1294@mynsu.nova.edu

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# Lymphedema Management for those Living with Spinal Cord Disorders to Address Caregiver Burden

Nia Bolen-Daniels, OTDS

Dr. Emily Bertoncini OTD, CLT, OTR/L, James A. Haley Veterans Hospital

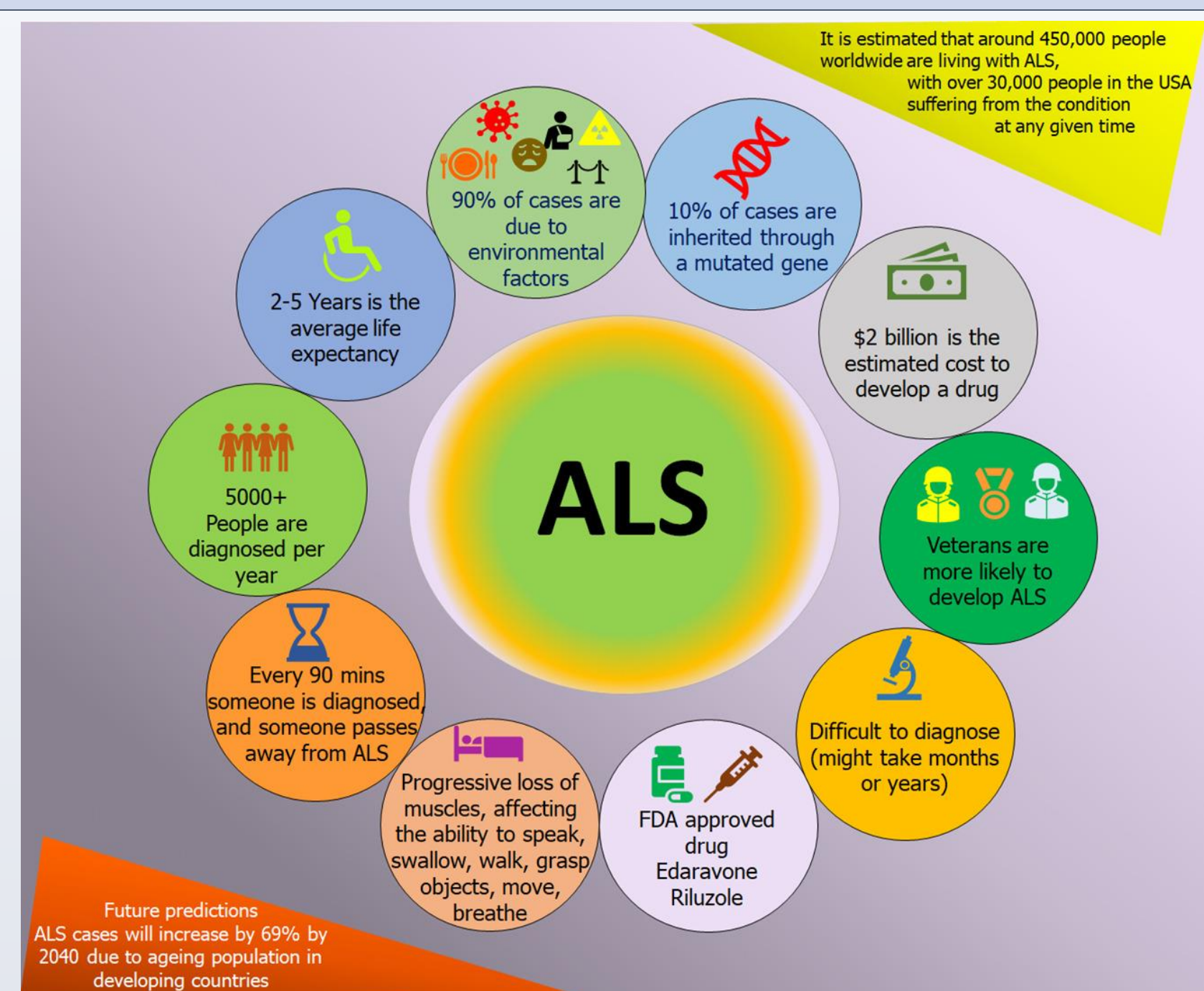


Figure 1: Dhasmana, S., Dhasmana, A., Narula, A. S., Jaggi, M., Yallau, M. M., & Chauhan, S. C. (2022, January 1). [Infographic describing ALS]. <https://www.sciencedirect.com/science/article/abs/pii/S0024320521011437>

## Introduction

The purpose of this capstone project and experience was to increase clinical practice skills with the adult population in the inpatient setting and creating a caregiver education program booklet for patients with Amyotrophic Lateral Sclerosis(ALS) that have lymphedema management needs.

## Site Description

Veterans Hospital system serves more than 27,000 veterans with SCIs and related disorders each year. This makes the VA the largest health care system in the world providing lifelong spinal cord care (Fyffe et al.,2019). James A. Haley Veteran Hospital is a Level 1a Trauma Hospital. The ALS Care Team is made up of 23 providers on an interdisciplinary team to provide care to patients with ALS through telemedicine and in person delivery of services .

## Summary of Needs Assessment

- The literature supports that caregivers of persons with ALS (pALS) often feel isolated, would benefit from increased support from the multidisciplinary team, and opportunities for self-care.
- Completing interviews with caregivers and service providers determined the most appropriate information to include in the booklet along with continued feedback from my mentor.

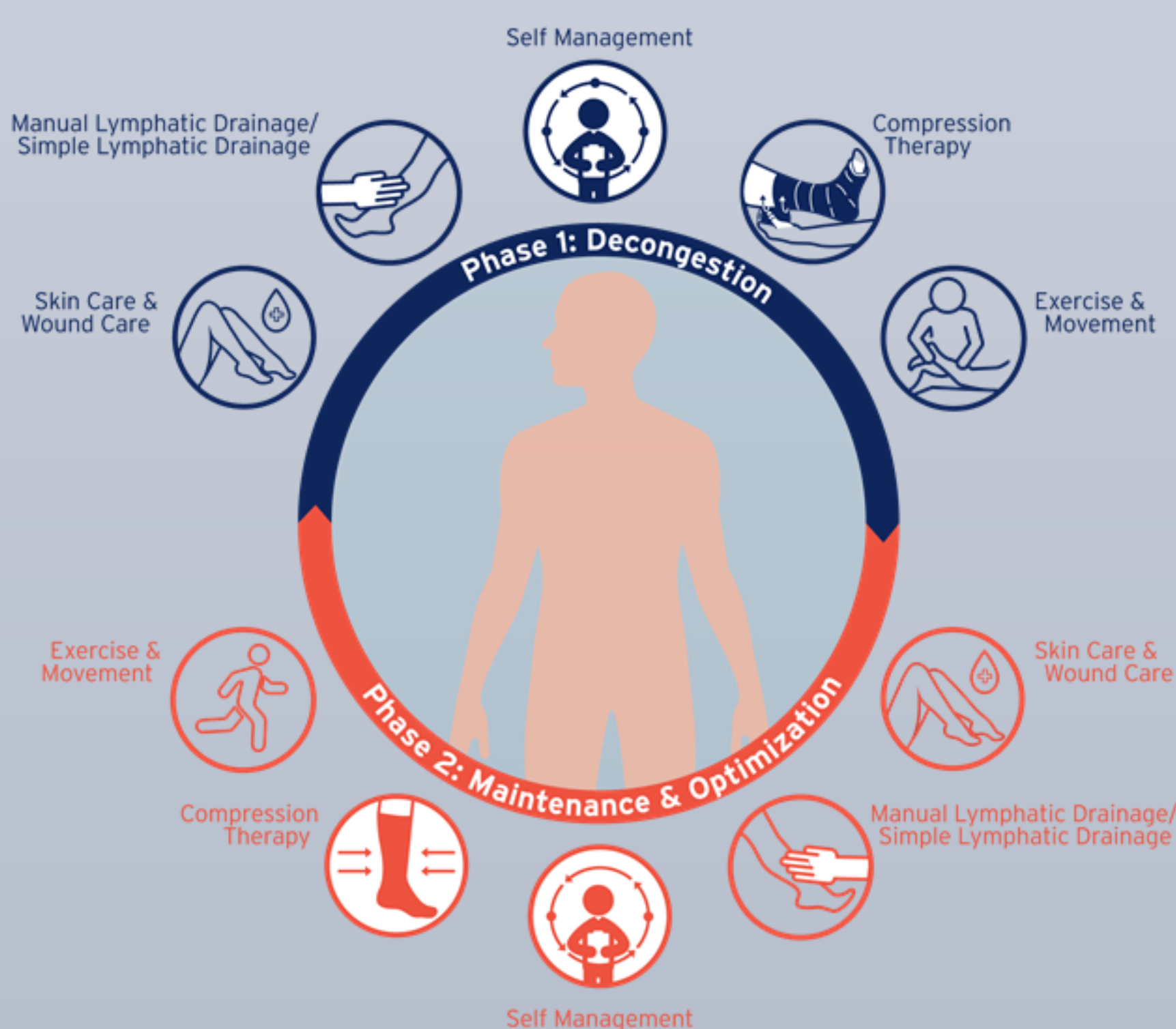


Figure 3: [Complex Decongestive Therapy (CDT)]. (2021). <https://www.lymphcare.com/na-en/treating-your-condition/treating-lymphedema/>

## Literature Review Summary

The occupational therapy profession's goal is to maximize the independence of the patient being seen for services. When providing care to a patient with a caregiver, it is important to consider the caregivers' needs to give them extra support. Caring for a loved one can be a taxing occupation that can go unnoticed by healthcare providers. Providing support and strategies can be crucial to decreasing caregiver burden and burnout.

Many caregivers of ALS patients experience a decline in their quality of life throughout caring for their loved ones because of the overall prognosis of the disease and currently not having a cure. Schischlevskij et al. (2021) state that a patient's functional status has an influence on the caregiver's burden, stating that an increase in burden was experienced based on the equipment the patient needs i.e., the use of ventilation.

The implication is the well-being of the caregiver is vital to the care of the ALS patient. The impact of caregiver burden determines if an ALS patient will receive care at home or in a facility. de Wit (2018) discussed a link between caregiver burden and the level of physical functioning of the patient which was found in other progressive diseases as well requiring a lot of adjustments from both the patient and the caregiver.

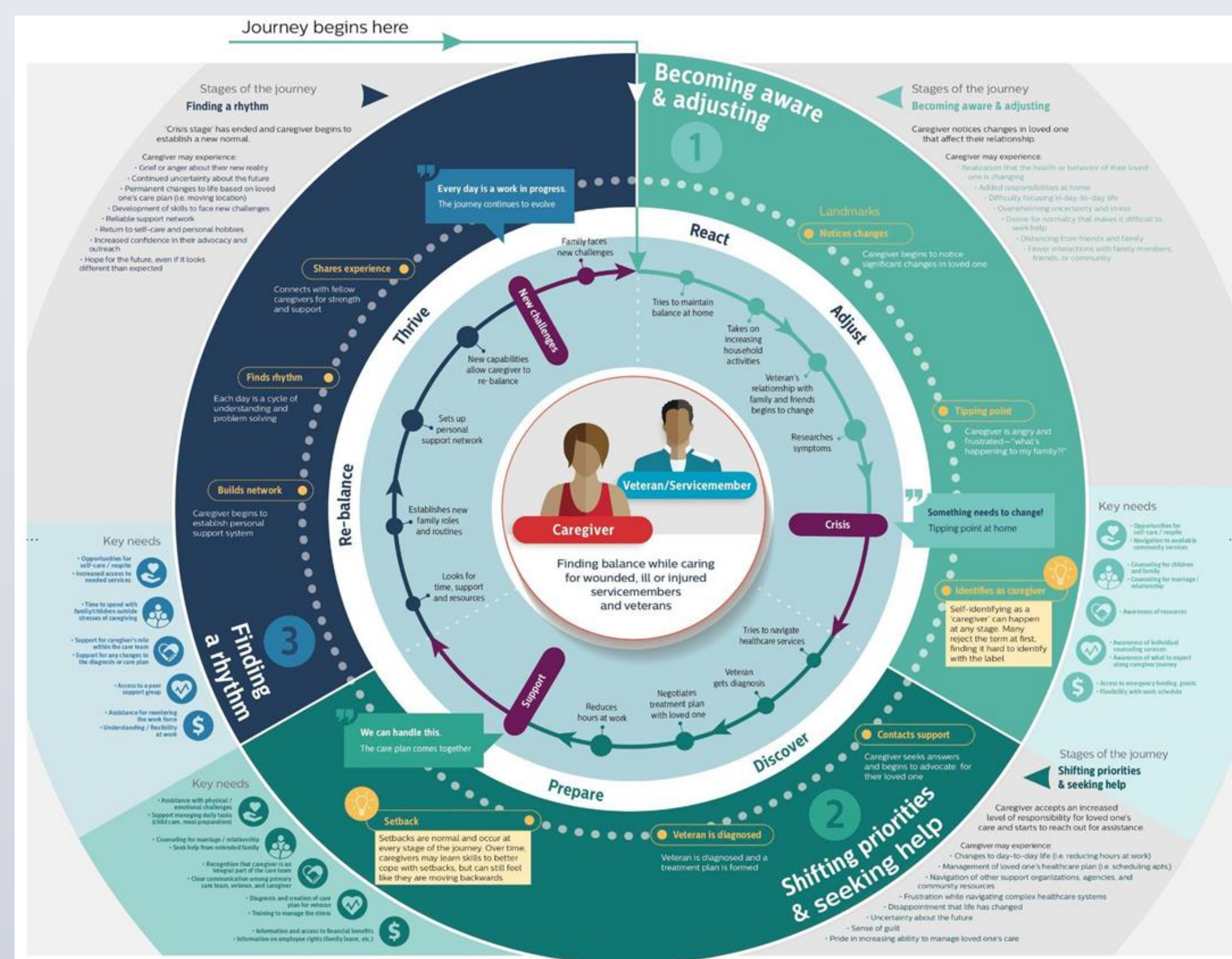


Figure 2: Elizabeth Dole Foundation. (2023). Military and Veteran Caregiver Experience Map [Infographic on Veteran Caregiver Experience]. <https://caregivers-homefront.org/news-events/caregiver-experience-map.html>

## Capstone Project Description

The capstone project booklet created is for ALS caregivers to provide a resource to assist with caregiver burden. This tool can be giving by anyone on the ALS team to support the caregivers. The resource is approximately 20 pages and includes a QR code link to lymphedema massage video that the caregiver will be able to perform.

### Features in the Booklet

Energy Conservation, Range of Motion, Resources, Supports for Survivors, Self-Care, Commonly Ordered AE, Lymphedema Management ( Techniques, Diet, Exercises , and Compression Garments)

Figure 5 : Caregiver booklet features

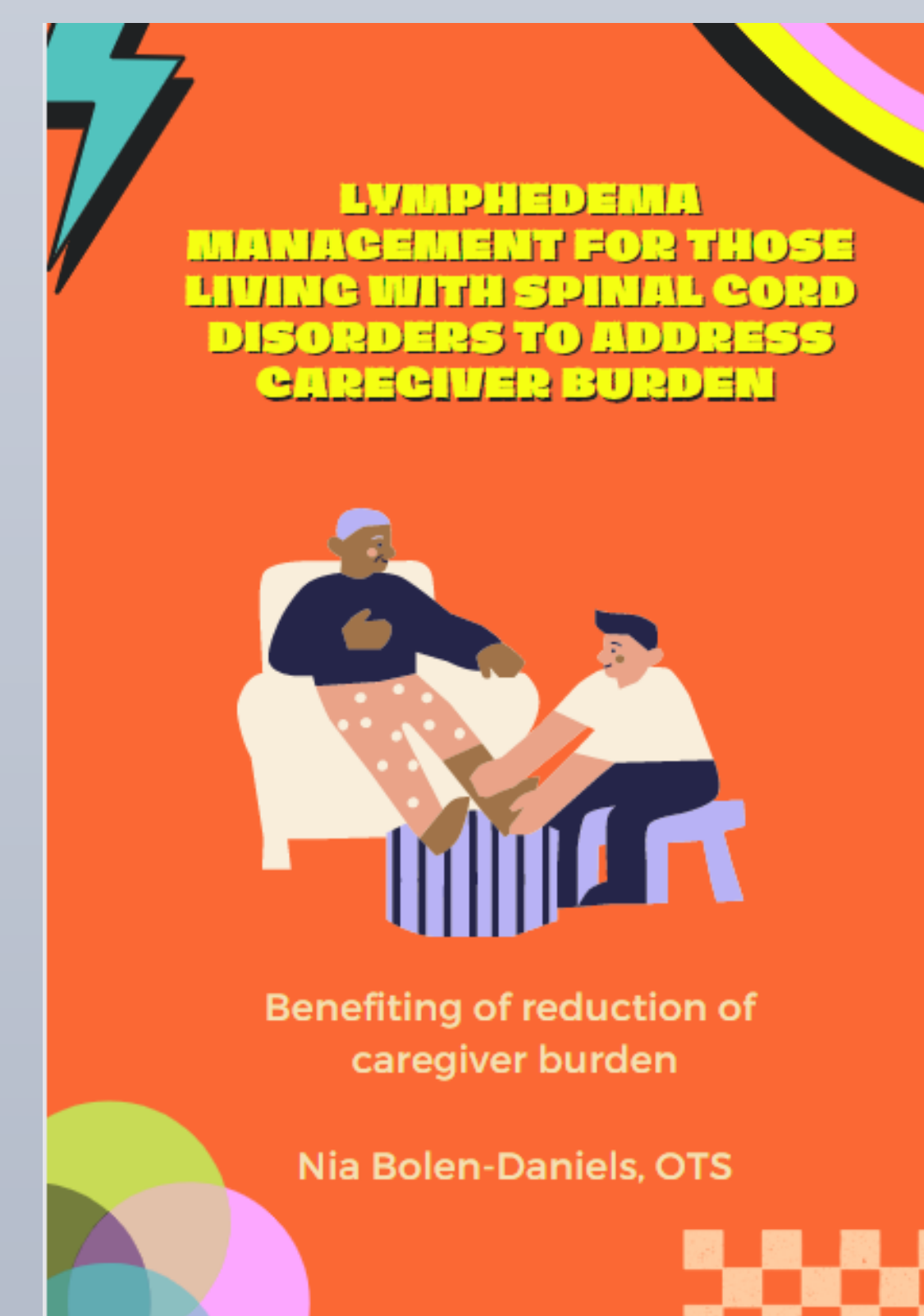


Figure 4 : Caregiver booklet final capstone project

## Learning Objectives Achieved

Capstone Experience Goals:

1. Determine the needs of the caregivers to decrease caregiver burden/burnout
2. Increase my clinical practice skills with the adult population in the inpatient setting
3. Develop an occupational-based booklet for caregivers that has guides for ADL and IADL care for loved ones



Figure 6: Wilkinson, J. (2020, August 21). [Hands all in infographic ]. <https://firespring.com/powered-by-purpose/elevate-your-impact-with-an-authentic-company-culture/>

## Implications for OT Practice

- Caregiver education is included in the OT Scope of Practice.
- Caregiving is a co-occupation that requires active participation by both the caregiver and the recipient of care.
- Consideration of co-occupations by practitioners supports an integrated view of the client's engagement in the context of relationship to significant others.
- Acknowledgement of clients can live in the community with the right amount of assistance they receive while completing occupations
- Consideration that interdependence or co-occupational performance can also be an indicator of personal success



Figure 7: Sud, K. (2023, April 19). [Caregiver pushing their loved one ]. <https://timesofindia.indiatimes.com/life-style/relationships/love-sex/being-single-i-do-feel-lonely-sometimes-but-an-ngo-for-senior-citizens-takes-care-of-that/articleshow/99609766.cms?from=mdr>

## REFERENCES & ACKNOWLEDGMENTS

Thank you to my mentor Dr. Bertoncini , the ALS Team , and the SCI OT department for their continued support as I completed this project. Each of them had a great impact on the clinician I am developing into.

-References Available Upon Request