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Program Development Addressing Sex and Intimacy in Acquired Brain Injury Rehabilitation

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Program Development Addressing Sex and Intimacy in Acquired Brain Injury Rehabilitation

By Rebecca Parker

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Disclaimer: This paper contains sensitive material regarding sex and intimacy with explicit content.

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Acknowledgement Form

CAPSTONE FIANL PAPER APPROVAL FORM

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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Degree Sought	Occupational Therapy Doctorate (OTD)
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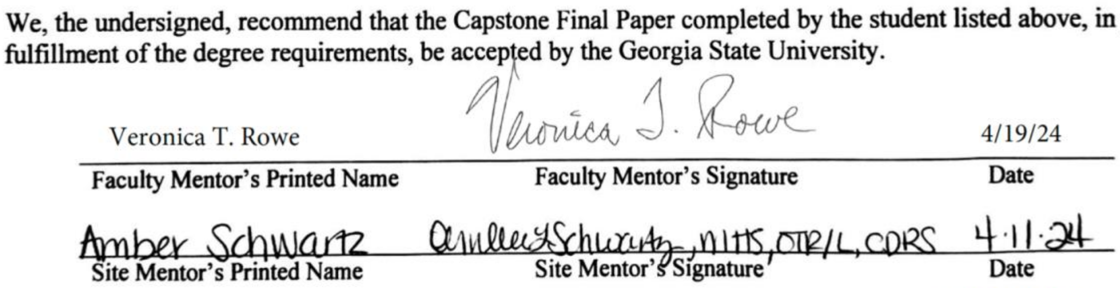

We, the undersigned, recommend that the Capstone Final Paper completed by the student listed above, in partial fulfillment of the degree requirements, be accepted by the Georgia State University.

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Abstract

Background: Some studies have shown that up to 75% of people with an acquired brain injury (Grubić Kezele et al.) have sexual dysfunction (O'Shea et al., 2020) and yet only 23% of healthcare professionals address sex and intimacy in the ABI population (Low et al., 2022).

Purpose: The purpose of this capstone project was to develop a program to address sex and intimacy in the ABI population by developing education, training, and resources for clinicians, families, and patients.

Outcome: Deliverables included educational handouts, focus groups, Ex-PLISSIT training, and enhanced tools for clinicians to utilize to address sex and intimacy in the ABI population.

Significance: This capstone provided education, resources, and supported clinician training to increase knowledge, access, and comfort with the topic of sex and intimacy.

Table of Contents

Summary

Background

The World Health Organization (WHO) and the World Federation of Occupational Therapy (WFOT) communicate that people have the right to participate in sexuality as an occupation through the right to sexual education, consensual sexual relationships, and a safe and pleasing sex life (Ellis & Ungco, 2023). Sexuality is within the scope of occupational therapy and can be described through the domains of occupational therapy, including occupations, contexts, performance patterns, performance skills, and client factors (Ellis & Ungco, 2023). However, most people living with a chronic disability are not offered the opportunity to talk about sex during the rehabilitation process (McGrath et al., 2021). One study found that only 23% of healthcare professionals address sex and intimacy in the acquired brain injury (Grubić Kezele et al.) population (Low et al., 2022). Simultaneously, some studies have shown that up to 75% of people with ABI have sexual dysfunction (O'Shea et al., 2020). Health professionals agree that sexuality is important to address but fail to routinely address sexuality in their practices (McGrath et al., 2021). Despite recent changes in views on sexuality, healthcare workers continue to fall short in addressing sex and intimacy with people with chronic disabilities, including acquired brain injury (McGrath et al., 2021). The lack of healthcare professionals addressing sex and intimacy in the chronically disabled population leads to an increase in depression and anxiety and a decrease in quality of life for these individuals (McGrath et al., 2021).

Problem

Sex and intimacy are not frequently addressed in the ABI population, and there is a need to address the topic because a high percentage of people with ABI have sexual dysfunction.

Purpose

The purpose of this capstone project is to develop a program to address sex and intimacy in the ABI population by developing education, training, and resources for clinicians, families, and patients.

Specific Aims

1. Coordinated focus groups to establish a baseline understanding of Shepherd Center's patient and caregiver needs regarding sexuality.
    a. Conducted a literature review on how sex/intimacy is addressed across the continuum of care to serve as preparation for effectively participating in meetings.
    b. Planned and executed three focus groups with interdisciplinary clinicians in different settings within the continuum of care for ABI.
    c. Observed across the continuum of care of ABI at the Shepherd Center.
2. Implemented a sustainable Ex-PLISSIT training program across interdisciplinary team members in brain injury rehab.
    a. Assisted in developing training materials by condensing and altering current training material.
    b. Assisted with preparation for whole staff training in April by training the trainers and co-leading the first full staff training.
3. Created four Shepherd Center branded educational materials for family, patients, and clinicians addressing sex/intimacy for individuals with ABI.
    a. Gathered information by observing and engaging in discussions with clinicians, patients, and families to determine the most needed education handouts.

   b. Researched, created, and edited four educational handouts, including the following: “Sexuality and Intimacy after ABI,” “Sex Positioning for Individuals with Hemiplegia,” Clinician Roles in Addressing Sexuality and Intimacy,” and “Sexuality and Intimacy Resource List.”

4. Cataloged and enhanced the therapists’ tools & materials to address sexuality needs in inpatient and post-acute settings.
   a. Determined the current therapist tools and equipment that required updating and enhancing.
   b. Proposed budget and purchased sexual adaptive equipment devices for patients with ABI at the Shepherd Center.
   c. Recorded audio for podcasts.

Output

This capstone produced four Shepherd Center branded educational handouts, three focus groups, Ex-PLISSIT training materials, and enhanced tools for clinicians to utilize to address sex and intimacy in the ABI population.

Significance

This capstone is significant because it addressed the gaps determined by the literature by providing resources, education, and training that will leave a sustained impact on clinicians, families, and individuals around the topic of sex and intimacy in ABI rehabilitation.

Chapter 1: Literature Review

Introduction

Some studies have shown that up to 75% of people with ABI have sexual dysfunction (O'Shea et al., 2020). The Australian Institute of Health and Welfare defines acquired brain injury (Grubić Kezele et al.) as: "multiple disabilities arising from damage to the brain acquired after birth. It results in deterioration in cognitive, physical, emotional, or independent functioning. It can be as a result of accidents, stroke, brain tumors, infection, poisoning, lack of oxygen, degenerative neurological disease, etc." (Health & Welfare, 2014, p. 2). The World Health Organization (WHO) identifies a wide definition of sexuality, including aspects such as gender identity and roles, self-concept, sexual orientation, intimacy, eroticism, and reproduction (McGrath et al., 2019). The WHO defines sexual health as "a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity…For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (*Sexual and Reproductive Health and Research (SRH)*, 2006, p. 1). The functions of sex include "social bonding, expression of love, maintaining relationships, stress reduction, and procreation" (Ellis & Ungco, 2023, p. 3). Sexual expression is not one concept or is easily defined; it can involve how a person dresses, how people view themselves, and how they communicate with others (Taylor & Davis, 2006). Sexuality is a complex and fundamental part of who a person is, including psychological, social, cultural, relational, and physical factors (Taylor & Davis, 2006).

The WHO and the World Federation of Occupational Therapy (WFOT) both advocate that people have the right to participate in sexuality as an occupation through the right to sexual education, consensual sexual relationships, and a safe and pleasing sex life (Ellis & Ungco, 2023). Sexuality impacts roles, occupations, social roles, and identity (Rose & Hughes, 2018). It is essential for any person to express ideas and needs around sexuality on an excellent quality of life (Mc Grath & Sakellariou, 2015). Humans are social by nature; therefore, if an individual does not have access to intimacy with others, health and wellness can be compromised (Walker, 2020). Sexuality influences how we approach relationships with ourselves and others (Walker, 2020).

In order to appropriately address sexuality, one must address sexual rights (*Sexual and Reproductive Health and Research (SRH)*, 2006). Sexual rights include "the right to privacy," "the right to marry and to found a family and enter into a marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage," "the rights to information, as well as education", and other fundamental sexual rights (Walker, 2020, p. 6). People with disabilities have the same rights to sexuality as able-bodied people (Mc Grath & Sakellariou, 2015). People with disabilities have a history of being desexualized, hypersexualized, or seen only as victims of sexual assault and not sexual beings (O'Shea et al., 2020). They are often denied sexual autonomy and can experience sexual suppression (O'Shea et al., 2020). People with disabilities are more likely to have a challenge finding someone to date and marry compared to those without a disability (Collisson et al., 2020). 41% of people with disabilities are married, compared to 52% of people without disabilities (Collisson et al., 2020). The viewpoint that people with disabilities are asexual and passive perpetuates therapists' failure to address sexuality in rehab (Rose & Hughes, 2018). Sexuality can be challenging to address in a clinical setting because patients can be desexualized to clinicians in this setting (Sharratt, 2017). However, sexuality is often a priority for people with disabilities and, therefore, should be addressed in rehab (Rose & Hughes, 2018). Encouraging sexual adaptations and adjustments for patients throughout the rehabilitation process could improve sexual and intimate relationships for individuals with ABI and their partners (Fraser et al., 2020).

Sexual Dysfunction

In recent studies, there were significant differences found in sexual function and sexual satisfaction using the Brain Injury Questionnaire of Sexuality (BIQS) when individuals with traumatic brain injury (TBI) were compared to healthy individuals (Downing & Ponsford, 2018). However, there is little and contradicting knowledge about the etiology, impacts, interactions, and intervention of sexual functioning after ABI (Fraser et al., 2020). Sexual dysfunction is known to affect 50% of people with a stroke, which is associated with an increased risk for depression and poor quality of life (Auger et al., 2022). Up to 70% of people with ABI have sexual dysfunction (O'Shea et al., 2020) and 36%-54% of adults with moderate to severe TBI have sexual difficulties (Fraser et al., 2020).

Sexual dysfunction in ABI includes a wide range of challenges: decreased ability to orgasm, decreased libido, increased desire, decreased self-value, mood and hormonal changes, muscular changes, and reduced communication between partners about sex and intimacy (Angelle M. Sander et al., 2011; Fraser et al., 2020). Common problems reported in individuals with ABI include a decrease in orgasms and the ability to produce lubrication in females and the ability to get an erection and orgasm in men (Downing & Ponsford, 2018). These challenges do not dissipate and appear to affect all sexes equally (Fraser et al., 2020). The difficulties with sex and intimacy with ABI can be attributed to but not limited to biological, psychological, and social factors (Fraser et al., 2020). Challenges with sexual expression and engaging in sexual activity can have a negative impact on a person's quality of life (Grasso, 2020). One study observed that changes in sexuality after ABI are more impacted by psychological factors compared to biological or social factors (Fraser et al., 2020).

Many cognitive and emotional aspects impact sexuality in individuals with ABI. Illness, injury, or disability can negatively impact a person's life, including lowered self-esteem, lowered self-confidence, and poor body image (Walker, 2020). Sexuality is affected by self-esteem and self-value (Taylor & Davis, 2007), and perceived diminished self-value can impact a person's willingness to seek out intimate situations (Sharratt, 2017). Depression is one of the strongest predictors of sexual dysfunction in TBI (Fraser et al., 2020). Medications for anxiety and depression can also lead to sexual dysfunction and impact sexuality (Fraser et al., 2020). In addition to mood, decreased cognitive functioning was found to be correlated with altered sexual arousal, decreased initiation of intimate relationships, and reduced initiation of sexual behavior (Fraser et al., 2020). For example, increased distractibility during intimate interactions could be interpreted as apathy from a partner (Fraser et al., 2020). The interactions of depression, social participation, and fatigue impact sexuality after ABI (Fraser et al., 2020), and therefore, a holistic approach to addressing sexuality, including biopsychosocial factors, is essential when addressing sexuality after ABI.

Partner Relationships

Another complexity of ABI is that people can experience the injury at any time and, therefore, have vastly different experiences (O'Shea et al., 2020). Research shows that one-third of caregivers for people with brain injury are spouses (Kreutzer et al., 2020). Some people with ABI have partners who are significantly impacted by the injury of their loved one, especially in the area of sexuality (Downing & Ponsford, 2018). Brain injury uniquely impacts personality and behavior in the individual, and consequently, there is an exceptional impact on the partner and partnership (Downing & Ponsford, 2018). There are also many role changes following an ABI, like balancing being a caregiver in addition to a spouse (Downing & Ponsford, 2018).

There are a variety of challenges related to sex and intimacy for individuals with ABI and their partners. Female spouses of males who experienced a TBI have reported a decrease in sexual satisfaction (Downing & Ponsford, 2018). Partners of those with a brain injury often have anxiety, depression, ambiguous grief, and caregiver burden (Kreutzer et al., 2020). Therefore, the divorce rate after a TBI has been reported to be 45-64% (Downing & Ponsford, 2018), while divorce rates after ABI vary significantly with some studies finding 78% and others finding 22% (Kreutzer et al., 2020). Consequently, divorce can negatively affect individuals with ABI as there is a health decline in individuals with ABI when their relationship dissolves (Kreutzer et al., 2020).

Sex and intimacy are difficult when individuals with ABI already have a partner, and they also are difficult when the individuals must learn to date again (Collisson et al., 2020). Beginning to date after becoming disabled is challenging, and it is partially due to the stigma of dating someone with a disability (Collisson et al., 2020). Research has shown that able bodied people are less likely to date people with disabilities partially because of a fear of associated stigma (Collisson et al., 2020). Able-bodied people infer that people with disabilities are unable to satisfy the needs of their partner, whether because of decreased physical or emotional ability (Collisson et al., 2020). People tend to assume that people with disabilities are childlike and therefore would not be appropriate or satisfying in a romantic relationship (Collisson et al., 2020). People also assume that they would need to take on the role of a caregiver and therefore their sexual needs would be unmet (Collisson et al., 2020). Some partners with a disability feel inadequate and unequal to their partner because of their disability and thus have a fear of not satisfying their partner (Collisson et al., 2020). Both partners can make the assumption that the partnership is inequitable due to the partner's disability, impacting the ability of individuals with brain injuries to have satisfying, long-term relationships (Collisson et al., 2020).

Occupational Therapy's Role in Addressing Sex and Intimacy

According to the Occupational Therapy Practice Framework, Fourth Edition (OTPF-4), occupational therapy practitioners holistically address the patient's engagement in occupations by creating occupation based goals that support growth in factors such as body functions, body structures, values, beliefs and spirituality in addition to motor process skills and social interaction skills ("OTPF-4," 2020). Valuable occupations in the realm of sexuality are "sexual activity, sexual expression, intimacy, sexual health, and family planning" (Walker, 2020, p. 3). Sexual activity is considered an activity of daily living and is defined as "engaging in broad possibilities for sexual expression and experiences with self or others (e.g. hugging, kissing, foreplay, masturbation, oral sex, intercourse)" ("OTPF-4," 2020, p. 30). Therefore, it is within the scope of occupational therapy to address sexuality when providing services for habituation, rehabilitation, and promotion of health and wellness ("OTPF-4," 2020).

Engagement in sex-related occupations is influenced by client factors, body functions, body structures, and performance skills and patterns (Walker, 2020). Client factors include sexual interest, sexual response, sexual knowledge, and sexual self-view (Walker, 2020). Occupational therapists have a unique set of skills to account for client factors and performance skills to address sex and intimacy holistically (Rose & Hughes, 2018). Multidisciplinary approaches are essential when addressing sexuality, and as part of the multidisciplinary team, occupational therapists have an important role in “understanding and reducing the impact of client factors, performance skills and patterns and contextual demands to promote optimal participation and performance in valued occupations” including sex and intimacy (Walker, 2020, p. 4). Even though most occupational therapists report they lack the knowledge and skills to address sexuality, occupational therapists’ basic knowledge of positioning, energy conservation, task analysis, and other familiar interventions are helpful when addressing sexuality (Rose & Hughes, 2018). Occupational therapists have a responsibility to “acknowledge the right to sexuality, respect sexual diversity, and recognize sexuality as an area of human occupation” (Mc Grath & Sakellariou, 2015, p. 3).

In general, the OTPF-4 mentions sex is a consideration in sexual activity as an occupation, social participation, and personal factors ("OTPF-4," 2020). In the OTPF-4, health management is a occupation that includes personal care device management which includes sexual devices ("OTPF-4," 2020). Under social participation, intimate partner relationships are discussed as a component of social participation ("OTPF-4," 2020). Whether or not the partners are having sex or not they are still engaging in an intimate relationship and therefore it is in the scope of occupational therapy ("OTPF-4," 2020). Sexual orientation is a personal factor that should be considered because it impacts the client’s context ("OTPF-4," 2020). Therefore, as the OTPF-4 includes a vast definition of sexuality, it is the responsibility of an occupational therapist to address sexuality ("OTPF-4," 2020). However, occupational therapists do not address sex often, and it impacts patients and the occupational therapy practice (Rose & Hughes, 2018).

Cultural Humility

There is a need for cultural humility while addressing sex and intimacy with all patients, including those with ABI (O'Shea et al., 2020). Because the topic of sexuality and intimacy is a sensitive topic, cultural sensitivity should be practiced when addressing the topic (O'Shea et al., 2020). Cultural humility, or awareness of how one's cultural background can impact how clinicians relate to their patients' cultures, is important to consider when addressing sexuality (Ellis & Ungco, 2023). Heterosexual, able-bodied, and young individuals are sexualized in Western Culture, and therefore those who do not fall in these categories can be neglected when addressing sexuality in occupational therapy (Mc Grath & Sakellariou, 2015). To most effectively discuss sex with patients, clinicians must not adopt heteronormative assumptions (Mc Grath & Sakellariou, 2015). Other considerations include gender minorities, partner as a caregiver role, sexual disinhibition, developing new relationships, children and adolescents with sexuality concerns, and many more (O'Shea et al., 2020). All individuals regardless of partnership need to be considered and it is important to consider the patient's current romantic relationships as well as potential relationships in the future (Taylor & Davis, 2007). Discussion around sex is often centered around penetrative sex and reproduction which neglects certain populations as well as other aspects of sex like relational and social (Mc Grath & Sakellariou, 2015). More research is needed in how sexuality is expressed across the lifespan, in diverse populations, and diverse socioeconomic populations (Mc Grath & Sakellariou, 2015). There is a "need to approach both research and intervention in relation to sexuality as extensions of broader struggles for human rights and social justice" (Mc Grath & Sakellariou, 2015, p. 4).

Clinician Competence

Health professionals consistently do not acknowledge or address sexuality with patients (McGrath et al., 2019). Health professionals agree that sexuality is important to address but fail to routinely address sexuality in their practices (McGrath et al., 2021). Because of the complex effects of an ABI, sexuality can be a low priority for some clinicians; however, one study found that 68% of individuals after experiencing a TBI wished that sexuality had been addressed during rehab (Downing & Ponsford, 2018). Only 23% of healthcare professionals address sex and intimacy in the ABI population (Low et al., 2022). There may be a gap between what people with disabilities want addressed and what is being addressed currently (McGrath et al., 2021). Research shows that most people living with a chronic disability are not offered the opportunity to talk about sex (McGrath et al., 2021). Simultaneously, research shows that the majority of people with chronic disabilities have challenges with sex and intimacy (McGrath et al., 2021).

Clinicians avoid the topic of sexuality, and it is still considered taboo even though most people with disabilities value discussing sex (Mc Grath & Sakellariou, 2015; McGrath et al., 2021). Reasons for clinicians not addressing sex include the following: lack of prioritizing due to heavy workload (McLeod & Hamilton, 2013), lack of confidence, lack of knowledge and skills, concern about the patient’s reaction, lack of support from institutions, client factors such as gender, age or marital status, personal beliefs or attitudes, lack of clarity in role in addressing sexuality, and fear of discreditation as a professional (Mc Grath & Sakellariou, 2015; Rose & Hughes, 2018). As a result, the responsibility is put on the patient to bring up the topic of sex and intimacy with the therapist (Walker, 2020). Clinicians believe that patients will bring up the topic, and if the topic isn't brought up then it isn't a problem (McGrath et al., 2021). However, many people with disabilities feel uncomfortable bringing up the topic with healthcare professionals, and even when patients initiate the conversation, many clinicians still avoid the topic (Mc Grath & Sakellariou, 2015; McGrath et al., 2021).

Research shows that patients are more likely to discuss sexuality when directly asked (Walker, 2020). Yet, clinicians have believed that using an indirect approach to sexuality is better because it is in line with social norms and does not risk embarrassment (McGrath et al., 2021). People with ABI require a more direct approach due to impaired communication or cognition (Low et al., 2022). Clinicians and individuals with stroke may have mismatched assumptions that the other will bring up the topic of sexuality (Low et al., 2022). Education and training programs have been cited to effectively change practices of addressing sexuality in a stroke setting (Low et al., 2022). Confidence, competence, and comfort are three things that affect a clinician's ability to address sex and intimacy with people with chronic disabilities (McGrath et al., 2021).

Clinicians are more likely to bring up the topic of sexuality and intimacy with some patients more than others (McGrath et al., 2021). Clinicians fear bringing up the topic of sexuality with patients with communication deficits because there is a fear it may lead to misunderstanding of the purpose of the conversation (Auger et al., 2022). Clinicians believe that it is more relevant and easier to discuss sexuality with a patient who is married compared to a patient who is single (Auger et al., 2022). Clinicians were more likely to talk to middle-aged patients about sex compared to older or younger people (McGrath et al., 2021). There is a need for clinicians to reflect on who they are addressing sexuality with to determine their own biases (Ellis & Ungco, 2023). Further, there is a need for clinicians to have sufficient knowledge and communication skills to address sexuality (McGrath et al., 2021).

Clinician Education

Education on sex and intimacy can increase clinician comfort and confidence, decrease fears of addressing sex and intimacy, and increase the likelihood of discussing sex and intimacy with patients (Grasso, 2020). Occupational therapists may not be receiving the education they need to adequately address sexuality (Walker, 2020). Including the perspectives of individuals with ABI in the development of educational materials for clinicians is important (O'Shea et al., 2020). A more comprehensive curriculum about addressing sex and intimacy in rehabilitation needs to be included in occupational therapy curriculum (Walker, 2020).

The Ex-PLISSIT Model

The PLISSIT model was developed by Annon in 1976 for healthcare clinicians to use to talk about sex with their patients (Taylor & Davis, 2006). PLISST stands for permission, limited information, specific suggestions, and then intensive therapy (Taylor & Davis, 2006). As you move from step to step, it requires more knowledge, comfortability, and training of the clinician (Taylor & Davis, 2006). Taylor & Davis (2006) created the Extended PLISSIT model. In Ex-PLISSIT, permission is consistently given throughout all of the steps of the PLISSIT model (Taylor & Davis, 2007). In every stage, reflection and review of interactions is completed to bring awareness to the clinician with intention to decrease bias (Ellis & Ungco, 2023; Taylor & Davis, 2006). An example of reviewing is a clinician bringing up what was discussed last session and asking how it has been since (Taylor & Davis, 2006). Examples of reflection include clinicians questioning their own comfort levels with discussing sex, identifying which partners they feel more at ease discussing these topics with, and assessing patients' comfort during these conversations (Taylor & Davis, 2006).

The permission-giving part in the PLISSIT model is often not addressed (Taylor & Davis, 2007). Clinicians assume that silence from patients communicates patients do not want to talk about sexuality (Taylor & Davis, 2007). Silence from the clinician on sexuality could communicate to patients that sexuality is not appropriate to talk about (Taylor & Davis, 2007). Clinicians also often move on to the limited information stage in the form of a booklet or education handout which does not serve as an efficient path to discussing sexuality (Taylor & Davis, 2007). In contrast, permission is about normalizing sexuality and opening the door to discussing sexuality without shame (Taylor & Davis, 2007). Sometimes the needs of the patient can be met by simply acknowledging that other people in their situation are experiencing similar challenges with sexuality and giving them the permission to think and feel their thoughts and emotions (Sharratt, 2017). Furthermore, permission should be given in a private and dignified space where the clinician uses plain language and inclusive language without underlying biases or assumptions (Sharratt, 2017).

Clinicians need to explicitly bring up permission to talk about sex and intimacy (Taylor & Davis, 2006) and should not assume discussing sexuality once is sufficient (Taylor & Davis, 2007). Sexual needs are dynamic and changing throughout a patient's experience, and therefore, permission-giving should be re-visited throughout a patient's experience (Taylor & Davis, 2007). Patients have the opportunity to decline discussing sex and may be uncomfortable talking about sex (Taylor & Davis, 2006). However, asking, “Would you like to talk further about this?” is beneficial, and clinicians should not assume that patients do not want to talk just because they are uncomfortable (Taylor & Davis, 2006). For clinicians, a script and a reminder system for discussing sexuality can be essential to addressing sexuality; one study showed these methods led to an 80% increase in opportunities for clinicians to address sexuality (Auger et al., 2022).

The permission stage can act as a script to begin the conversation and is an important step in addressing sex and intimacy with patients (Taylor & Davis, 2006).

The limited information stage is an opportunity to correct false information, clarify information, and give factual information to the patient (Taylor & Davis, 2006). The specific suggestions stage requires the clinician to gain a better understanding of the patient's sexual history to problem-solve for their unique needs (Taylor & Davis, 2007). A clinician should also explore a patient’s expectations and desires around sex and intimacy to provide adequate specific suggestions (Sharratt, 2017). Problem-solving and more knowledge are needed at this stage in Ex-PLISSIT to address the patients’ challenges (Taylor & Davis, 2006). Specific suggestions need to consider sexuality as a whole, not just sexual activity (Taylor & Davis, 2006). Intensive therapy can be brought up at any time and can involve diverse referrals depending on the topics discussed with the patient (Taylor & Davis, 2007). Intensive therapy could be needed when the patient discusses something beyond the competence of the current clinician, sexual trauma, psychosexual problems, or relational problems (Taylor & Davis, 2006).

Using the PLISSIT model has shown an increase in clinician comfort in addressing sex and intimacy (McLeod & Hamilton, 2013). Clinicians need to recognize their own limitations in comfort or knowledge and refer the patient to a different professional if their limit has been reached (Taylor & Davis, 2007). In the Ex-PLISSIT model, both the individual and clinician should engage in self-reflection throughout the entire process (Taylor & Davis, 2007).

Additional Tools and Approaches

The Sexuality Interview Guide (SIG) was founded on the PLISSIT model and has been used as a tool to discuss sexuality during rehabilitation with stroke patients (Auger et al., 2022).

Using the SIG has increased clinicians' confidence when addressing sex and intimacy (Auger et al., 2022). The SIG has helped clinicians be more comfortable addressing sex and intimacy, but clinicians then felt as though they did not have the resources to address the challenges that emerged during the conversations (Auger et al., 2022). Clinicians have agreed that the best time to use the SIG and address sex and intimacy in general was near the end of a patient's inpatient stay or in an outpatient setting (Auger et al., 2022). They felt that it was critical to build a trusting relationship with the patients or clients before having a conversation about sex and intimacy with their patients (Auger et al., 2022).

Another screening and assessment tool is the Occupational Performance Inventory of Sex and Intimacy (OPISI). The OPISI is a tool utilized to screen, assess, and measure performance for self-perceived change in factors involved in sexuality and intimacy (Walker, 2020). OPISI is a free online resource which can be administered by occupational therapists who register with the website. The tools are designed for English-speaking adults and to be LGBTQIA+ affirming (Walker, 2020). The instrument is meant to investigate "sexual activity, sexual interest, sexual response, sexual expression, sexual self-view, intimacy, and sexual health and family planning" (Walker, 2020, p. 3).

Additional strategies include peer to peer approaches and couple focused interventions. Peer-to-peer approaches could potentially be a more holistic way to address sex and intimacy with the ABI population (O'Shea et al., 2020). Couple focused interventions have shown to benefit the quality of a couples' relationship following a brain injury (Kreutzer et al., 2020). Future research should investigate if improving the relationship quality decreases the likelihood of the relationship dissolving (Kreutzer et al., 2020). Also, there continues to be a need for more resources and programs to address sex and intimacy (Fraser et al., 2020).

Chapter 2: Needs Assessment

My capstone supported a program development to address sex and intimacy in ABI rehabilitation. The Shepherd Center recently began a program to address sex and intimacy with their ABI population which includes individuals with cerebral vascular accidents, brain tumors, traumatic brain injuries, and other forms of brain injuries. This program involves an interdisciplinary team that includes neuropsychology, physical therapy, occupational therapy, speech language pathology, nursing, social work, and medical doctors. The teams have been working to develop family and patient resources, increase clinician training and confidence, create systematic and ethical practices, and utilize assessments to measure change. My capstone supported the greater effort of the Shepherd Center to address sex and intimacy across the continuum of care for ABI. I conducted a needs assessment by talking with ABI managers, ABI therapists, ABI patient care techs, neuropsychologists, the ABI educator, and conducting a literature review.

Research shows clinicians do not address sexuality with individuals who have experienced a brain injury due to a lack of confidence, knowledge, and skills (McGrath et al., 2019). There is a need to increase the comfortability and confidence of clinicians at the Shepherd Center to increase the rate at which sex and intimacy are addressed with patients with ABI. Increased discussion around sex and intimacy is needed to potentially increase clinicians' comfort. Further, there is also a need for better understanding of the unique reasons for lack of addressing sex and intimacy across the continuum of ABI at the Shepherd Center.

There is a lack of educational materials and resources for clinicians, families, and patients to address sex and intimacy at the Shepherd Center. There is a need to determine what resources were already accessible, how they could be updated or improved, and what resources are not present. The Shepherd Center had a few resources on sex and intimacy after brain injury, but the basic educational handout is more clinical and difficult for patients and families to understand. There is a need for sex positioning education for individuals with hemiplegia and their partners. The current education is gendered, not LGBTQIA+ inclusive, and limited to a few positions. It is necessary to have more LGBTQIA+ inclusive resources and training in addressing sex and intimacy in general (O'Shea et al., 2020). There is a "need to approach both research and intervention in relation to sexuality as extensions of broader struggles for human rights and social justice" (Mc Grath & Sakellariou, 2015, p. 4). It is important for educational handouts to account for health literacy in order to be effective because less than one third of the United States population is health literate (DeWalt et al., 2011). Health literacy is the ability of people to read health information and utilize it to make decisions (DeWalt et al., 2011). There is a need for overall inclusive and culturally sensitive education materials around the topic of sex and intimacy.

There is a lack of knowledge and access to sexual adaptive equipment devices at the Shepherd Center in ABI. It is necessary for sexual adaptive equipment devices to be accessible and listed in one place that is easily accessible to clinicians, patients, and families at the Shepherd Center. It would be beneficial for some of these devices to be physically available for patients to work with their rehab team to trial positioning or determine if the individual is able to use the item. Most websites with sexual devices do not have explanations for how the items can be supportive of people with disabilities. It is essential for clinicians to increase knowledge around sexual devices and engage in creativity with patients who need sexual devices to work towards their goals around sex and intimacy.

Research shows that using the PLISSIT model increases clinician comfort in addressing sex and intimacy (McLeod & Hamilton, 2013). The Shepherd Center is rolling out an Ex-PLISSIT model training to all ABI staff including nurses, medical doctors, physical therapist, speech language pathologists, occupational therapists, neuropsychologists, patient care techs, rehab aides, case workers, peer support staff, etc. There is a need for support in rolling out this training. Support is needed in condensing the extended Ex-PLISSIT training to a more manageable 45-minute training, gathering the supplies needed for the trainings and determining where they will be kept, and coaching the sexuality champions on how to lead the training. Sexuality champions are designated people from multiple discipline backgrounds who have gone through an extensive Ex-PLISSIT training prior to the staff wide training. I completed the sexuality champion training prior to beginning my capstone as well.

It is important to take inventory of the changes of sex and intimacy with patients and families. A screening tool and an in-depth assessment tool is needed to assist therapists in determining the needs of patients and making goals for them around sex and intimacy. There is a need for guidance around making goals related to sex and intimacy, which a screening and assessment tool could assist with.

It would be significant for the voices of patients and families to be heard by clinicians and other people in similar circumstances. There are many aftereffects of a brain injury on sex and intimacy, and it impacts the individual and the family (Fraser et al., 2020). Current patients could benefit from hearing examples of other experiences around sex and intimacy to normalize the challenges and possibly open up conversation with clinicians around the topic. Clinicians need to hear stories and the impacts of brain injury on sex and intimacy to become more aware of the devastating impacts on quality of life that brain injury can have by impacting sex and intimacy (McGrath et al., 2021).

Overall, there is a need for educational materials, access to resources, initiation of conversations around the topic, and clinician training to support the program development to address sex and intimacy in ABI at Shepherd Center.

Chapter 3: Capstone Experience Protocol

My program addressed the needs above by supporting clinician education, creating educational handouts, and developing and compiling resources for clinicians about sex and intimacy for people after ABI. Based on my literature review and needs assessment I created four objectives in conjunction with my faculty and site mentors:

- Objective 1: Implement a sustainable Ex-PLISSIT training program across interdisciplinary team members in brain injury rehab.
- Objective 2: Coordinate focus groups to establish a baseline of understanding for Shepherd Center patient and caregiver needs regarding sexuality.
- Objective 3: Create Shepherd Center branded education materials for family, patients, and clinicians addressing sex/intimacy with individuals with Acquired Brain Injury.
- Objective 4: Catalog and enhance the therapists' tools & materials to address sexuality needs on inpatient and post-acute settings.

Site Description

My capstone site, the Shepherd Center, is a private, not-for-profit hospital located in Atlanta, GA. Shepherd Center specializes in treatment, research, and rehabilitation for people with neurological conditions including ABI. Additional conditions treated include multiple sclerosis, spinal cord injury, spine and chronic pain, and other neuromuscular conditions. It is a nationally ranked patient rehabilitation center and has grown immensely since it first opened in 1975. For my capstone, I mostly spent time at the brain injury outpatient and day program facility, but also spent time in their inpatient ABI, concussion, and military program. I worked to support their program to address sex and intimacy within the continuum of brain injury.

Ex-PLISSIT Training

Shepherd Center rolled out an extended version of the Ex-PLISSIT training to individuals who are known as “sexuality champions” in Fall 2023. These are clinicians from multiple discipline backgrounds who feel comfortable addressing sexuality and have received an in-depth training. They are identified so that other clinicians can go to them when questions and situations arise around sex and intimacy. I attended the sexuality champions training to be on the same page with the other trainers. This training was an all-day training that entailed education on sexuality after ABI and the Ex-PLISSIT model and included significant time for discussion and questions. The sexuality champions led the trainings for all of the other ABI staff which began rolling out at the beginning of April 2024. I supported the ABI staff training by condensing the extended Ex-PLISSIT model training, presenting a mock presentation to the other sexuality champions in March, leading the first training in April, and organizing materials needed for the training to ensure easy access.

First, I completed a literature review to gain a deeper understanding of the Ex-PLISSIT model and how it has previously been implemented in different healthcare settings. I utilized the research to add examples of each stage of the model to the training. Then, I met with leadership at the Shepherd Center to discuss and prioritize sections of the extended training in order to condense it to a 45-minute version of the training for the rest of ABI staff. I condensed the extended training by cutting out less prioritized sections and combining some redundant slides while still maintaining the essence of the original presentation. I edited the script under the slides to ensure the slides fell within the time frame and to make it easier on those leading the trainings. I marked time stamps on each section of the PowerPoint to make time keeping easier during the trainings. Then, at the beginning of March 2024, I presented a mock presentation for the other trainers to give them a better idea of what they will be doing in the future. At the beginning of April 2024, I co-led the first training to ABI staff which Shepherd will continue to roll out over the next year.

Focus Groups

I completed three focus groups throughout my time at the Shepherd Center to gain an understanding of clinician comfort and confidence in addressing sex and intimacy with ABI as well as an understanding of what the current needs are for clinicians to better address sex and intimacy with ABI. I researched best practices for focus groups by looking up online resources and talking to clinicians at Shepherd Center that have done focus groups in the past. It is important to have open ended questions, to have non-judgmental responses, and to ask for more details from responses during a focus group (Beyea & Nicoll, 2000). I worked with managers from inpatient and outpatient to choose the best time and location that would allow the most people to attend the focus groups. It is important to have support when leading a focus group (Beyea & Nicoll, 2000). I asked specific people to be notetakers for me so that I could focus on the discussion. During the focus groups, I had a separate person taking detailed notes on a laptop so that I could give my full attention to the discussion. Here are the questions that were asked during all three focus groups:

1. What are the needs of clients at _______ [specific setting] in terms of sex and intimacy?
2. How do you feel about talking about sex and intimacy with patients in general?
    a. Do thumbs up, down, or middle rating scale for the room.
3. For those of you that feel confident, what has helped you feel this way?

4. This can be a hard topic to be comfortable with. For those of you that do not feel confident, what do you feel you need to increase in confidence?
    a. What situations do you feel the most uncomfortable in?
5. What tools or educational resources would be helpful?
6. Now that we have talked more, does anyone else have any additional examples?
7. Is there anything that someone did not get a chance to say or ask that you think would be helpful to share?

In focus groups, follow-up and probing questions need to be asked in a non-threatening manner (Beyea & Nicoll, 2000). I followed up statements and thoughts from clinicians with “can you tell me more about that?” or “can you expand on that thought?”. I concluded each session with the last question to make sure that any thoughts or ideas that had not been said could be.

Educational Handouts

I created four Shepherd Center branded handouts including a hemiplegia sex positioning handout, sexuality after ABI handout, roles of each discipline in addressing sex and intimacy, and a sex and intimacy resource list for patients, families, and clinicians. I determined the need for these topics based on clinician feedback and feedback from the ABI therapy educator at Shepherd Center.

To create the hemiplegia positioning handout, I searched the internet for positioning for people after stroke and ABI. I found a few sources, but they were biased towards one gender having the injury and heterosexual couples overall. I created one document where gender of the individual with ABI and the gender of the partner was ambiguous. Therefore, clinicians should be able to use it with any patient regardless of gender and/or sexual orientation. I created the document by drawing on my iPad and included 13 sex positions total.

Shepherd Center had a basic sexuality after brain injury handout. Still, according to a staff member who works on peer support, it was too clinical and challenging for patients and families to understand. The purpose of the handout is to communicate a foundational understanding of the impact that brain injury can have on sex and intimacy to individuals with brain injury and their family members. I organized the handout into sections of “sensory changes,” “mental changes,” “physical changes,” and “family changes.” I used Sexual Functioning and Satisfaction after Traumatic Brain Injury: An Educational Manual (Angelle M. Sander et al., 2011) as a basis for the information on the handout and simplified it.

For the third handout, I created a resource list for families and clinicians including books, articles, Instagram accounts, podcasts, counseling services, and disability inclusive sex shops. Throughout my time at capstone, I gathered these resources by talking to clinicians, patients, families, and community members in addition to performing my own internet searches. My last additional handout communicated the roles of each clinician in addressing sex and intimacy so that a patient could get an idea of which clinician to go to with their specific question or concern. I included roles of neuropsychology, counseling, medical doctors, occupational therapy, physical therapy, speech language pathology, social work, recreational therapy, and peer support.

Based on the need for education handouts to account for health literacy, I conducted research on strategies for creating education handouts that can be easily understood by most of the population. It is important to use plain language, short sentences, bullet points instead of paragraph form, graphics when appropriate, and small syllable words (*Writing and Testing Plain Langauge*, 2014). I used a readability test from WebFX as well to determine the reading level at which my education handouts were currently (*Web FX Readability Test*, 2024). My goal was to get the handouts' reading levels to 8th grade reading level which is 13–14-year-olds.

After I created each of the drafts of the educational materials, I sent them out to family members, patients, and clinicians to receive feedback. I worked with the therapy educator and the therapy managers as well. I sent people the following questions for guidance in giving feedback.

All handouts

1. What do you think about this handout?
2. What do you like about this handout?
3. What would you change about this handout?

Hemiplegia positioning handout

1. Do you like the words strong and weak side?
2. These were created with the aim of being useful no matter sexual orientation, race, culture- do you feel this is accurate?

Sexuality after ABI Handout

1. How do you like the sections of topics?

After I received the feedback, I incorporated the feedback into the resources and updated them. I continued to seek feedback and update the resources during my 14 weeks at capstone.

Updating Resources

To determine what education resources were needed, I completed an extensive search of the internet, searched through "MyShepherdConnection.org" which is Shepherd Center's resource platform, discussed ideas with current clinicians, discussed ideas with family members of patients, and investigated what the spinal cord injury side of Shepherd Center has done to address sex and intimacy.

In the past few years, Shepherd Center began an initiative to address sex and intimacy in their spinal cord injury population. They created an adaptive equipment sexual devices cart for individuals to utilize during treatment. These materials included positioning devices, stimulation devices, and adaptive undergarments. Individuals with ABI could benefit from similar devices. Therefore, I created a centralized resource with the links to the devices, QR codes, description of the devices, and how the devices would be beneficial to use. I created a budget proposal to send to the program director of brain injury to buy these devices for the ABI staff. Part of the challenge is that Shepherd Center's continuum of brain injury includes three separate buildings and thus may need duplicates of some of the devices. Through conversations with the outpatient occupational therapy manager, the number of items were determined, and a proposed budget was sent to the director of the brain injury program. Along with the budget proposal, I created an SBAR for the program director to succinctly communicate the situation, background, assessment, and recommendation for the adaptive equipment sexual device cart for ABI. The budget was approved, and I purchased the proposed items. When the items arrived, I unpacked and organized them with support from the outpatient occupational therapy manager.

Another need was for clinicians is to have a way to assess and gather data around addressing sex and intimacy in ABI. One screening and assessment tool that could be used to collect data is OPISI. I created another SBAR to propose the use of this assessment to the program director of brain injury and my mentor as well.

An additional resource that was needed was referrals for after patients and individuals leave Shepherd Center or more specialized intervention. The therapy educator sent me the name of a local counselor who is certified by the American Association of Sexuality Educators, Counselors, and Therapists (AASECT). I met with her on a meeting and discovered she has experience working with individuals with brain injury individually and as a couple. I passed along her name to be added to the internal references for neuropsychology. I included the AASECT directory link to the external resource educational handout.

To help address the need for access to sexual devices, I found local places around Atlanta that would be accessible for individuals with ABI and their partners. An occupational therapist at the military program found a local sex shop that is LGBTQIA+ and disability inclusive called Kiss and Ride in Little Five Points in Atlanta. I set up a meeting with the owner of the shop and met with them to see all that their store had to offer. I added the shop to my resource list for patients and discussed the opportunity to go there for an outing with patients. The owner of the shop referred me to another business called TouchBot. This is a disability led and owned shop that creates sex and intimacy devices with a 3D printer. I met with the owner and discussed her consultation services, individualized approaches, and the motivations behind the business. I added both businesses to the resource list. Additionally, when I met with staff from the comprehensive rehab unit at Shepherd Center, one of the therapists said she has taken patients on an outing to CVS in the past. I went to a CVS next to the inpatient facility and the outpatient facility and confirmed the types of sexual devices CVS carries that could be beneficial for patients if they went on an outing there.

Throughout my capstone experience, I connected with patients, families, clinicians, and businesses to better understand and create easier access to the resources to address sex and intimacy. The goal was to make these resources accessible to Shepherd Center and their patients.

Podcast

Through discussions with the therapy educator and multiple managers, we decided a podcast would be beneficial. The purpose of the podcast was to share patient and family stories with other families, patients, and clinicians to help gain an understanding of patient and family experiences. First, I reached out to clinicians and peer support to see if anyone had past or current patients or families who would be willing to talk to me about this topic. Then, I reached out to the people they connected me with to screen them to see if they were appropriate for the podcast. My criteria for individuals appropriate for the podcast included that the individuals were able to articulate their experiences and reflections on how sex and intimacy were impacted by the brain injury and that they were able to share without asking for advice and support. The following are the questions I asked during the screening meeting.

1. Can you tell me about your experience at the Shepherd Center?
2. What does your role look like as a mentor?
3. If you feel comfortable sharing, how was sex and intimacy impacted by the brain injury if at all? When I say intimacy, I mean even romantic relationship and communication and interaction.
4. Was sex and intimacy addressed when you or your partner was at the Shepherd center?
5. I am potentially making a podcast. This would look like us recording us having a conversation about your experience with sex and intimacy and brain injury. We would have pre-determined questions that I would give you beforehand and we could even chat about before, then we would record it and edit it. Anything that you would not want to be in there would not have to be in there. The purpose would be to share experiences with

> others that are going through something similar or clinicians to listen and learn from. Is this something you would be interested in?

I determined which individuals that would be appropriate for the podcast through these screening meetings and asked them if they would be willing to participate. I worked with the public relations (PR) department to ensure a recording studio space and consent forms were obtained. I met with technical staff to be trained on how to use the equipment and conducted trial recording to determine the process to record for best audio quality. I coordinated with these individuals and PR to determine the best time to complete the podcasts and then conducted the podcasts in the Shepherd Center recording studio. I recorded the podcasts during my last two weeks of my 14-week capstone. Then, the PR department edited and formatted the podcast to produce the final product.

Summary

My capstone addressed multiple needs previously mentioned regarding brain injury and sex and intimacy. My capstone addressed the needs of increasing clinician confidence and training by supporting the Ex-PLISSIT training and conducting focus groups with clinicians. I addressed the need for more knowledge and access to sex and intimacy resources by providing educational handouts, a list of resources, access to adaptive equipment, and recording four podcasts.

Chapter 4: Output

Through this capstone, I created a condensed Ex-PLISSIT training, educational handouts, adaptive equipment proposals and resources, podcast audio recordings, and additional resources for clinicians, families, and patients.

Ex-PLISSIT Training

The three outputs of the Ex-PLISSIT training were the presentation itself, the mock training presentation to the other leaders, and the first large group training to ABI staff. On March 8, I led a mock presentation to the other leaders and sexuality champions. On April 2, I led the first ABI staff training with a physical therapist as my co-leader. The presentation was developed initially by TBI Model Systems Clinical Leadership and Knowledge Translation Center. I condensed the original version to a 45-minute presentation while maintaining the essence of the original presentation. The objective of this presentation was to describe the Ex-PLISSIT model and to put the model into practice by discussing case studies during the training. The presentation described the difference between the original PLISSIT model and the Ex-PLISSIT model as well as all of the components of the model. It gave examples of each component and went through a case study example for each component. Then, the training participants were broken up into groups and each group was given a few additional case studies to discuss. After, the case studies were then discussed as a large group. The case studies intentionally represented examples of brain injury across the continuum to be inclusive of the patients at the Shepherd Center. The presentation also addressed barriers to discussing sexuality with patients and the importance of discussing sex and intimacy as well as incorporated a guided clinician reflection at the end of the presentation. The training will continue to be presented to all ABI staff over the next year and then to new employees.

Focus Groups

I completed three focus groups at inpatient ABI, the military program and concussion clinic, and finally, the outpatient and day program. I completed one at inpatient ABI where physical therapists, occupational therapists, speech language pathologists, therapy aides, neuropsychologists, medical doctors, nurses, and patient care techs attended. There was a lot of great discussion during this focus group. There were about 15 people in the group. Key takeaways from the inpatient focus group include the following:

1. There are concerns about discussing sex and intimacy with the adolescents as well as patients who may not have capacity to consent.
2. Few clinicians are comfortable addressing sex and intimacy. Neuropsychology was the most comfortable according to a scale of thumbs up, thumbs middle, and thumbs down.
3. Sex does not come up unless the clinician brings it up typically. If it does, it is right before discharge and there is not time to address it properly.
4. It would be helpful to have more resources to distribute to families to begin the conversation.
5. There is a fear of saying something that you are not supposed to say. Guidelines for what to say and what not to say might be helpful.
6. There is a need to address if it is a problem for a loved one to lie in bed with the individual with brain injury. There is a need for guidelines on what is okay intimacy wise, especially if capacity has not been determined.

The second focus group took place at Shepherd Center's complex concussion clinic and military program. There are different needs and concerns with this population. There was less fluid discussion possibly due to the more specific needs and the emphasis on mental health. There were no neuropsychologists in this focus group. There were physical therapists, occupational therapists, speech language pathologists, vocational therapists, and recreational therapists who attended. The main takeaways were the following:

1. Behavior health (BH) deals with relationship challenges mostly with this population and it might be helpful to allow BH to take the lead with sex and intimacy.
2. There is a fear of inappropriate interactions when bringing up sex and intimacy and that it will open the door for more inappropriate comments.
    a. Concern for female staff and this population interacting appropriately.
3. Incorporating more information around sex and intimacy in key classes could be helpful.
    a. Key classes are classes that clients already attend when they are a part of this program.
4. Over educating on medication side effects could have a negative impact due to placebo effect and clients then thinking they have the side effects educated on.
5. Transgender conversation:
    a. Standardized testing is normed by gender which can make assessing a transgender individual more complicated.
    b. Stickers for transgender clients are not being printed with gender and name to match from EPIC.

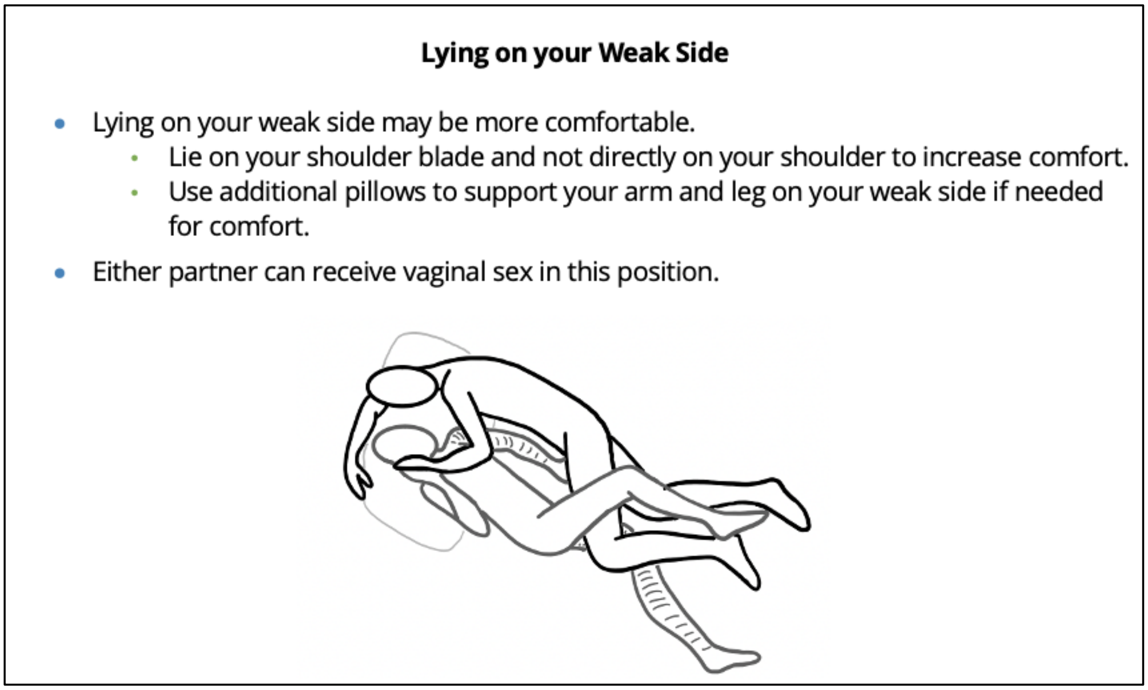
The third focus group was at Pathways which is the Shepherd Center's day program and outpatient program. This was the largest focus group I conducted with about 25 people. I had one person taking comprehensive typed notes on a computer with another person taking notes on a large sticky note so that everyone in the group could see the writing. There were physical therapists, occupational therapists, speech language pathologists, vocational therapists, and recreational therapists who attended. The main takeaways were the following:

1. Concerns about the population with sex and intimacy: family member uncomfortable, concerns about medical pieces, aphasia makes it difficult to communicate with partner, safety with dating apps and inappropriate pictures, cultural barriers, and caregiver role changing.
2. Comfort barriers: education around topic, age of the client, concern with overstepping, parent comfort, and has anyone already addressed it and what was said.
3. It would be helpful to have a checklist questionnaire to see if the patient wants to talk about it and what they would want to talk about specifically.
4. It would be helpful for patients to have a role handout to know who to go to for specific concerns/questions.
    a. This would be helpful specially if the client does not want the information broadcasted or passed along.

Overall, the focus groups helped me and Shepherd Center gain valuable insight into clinician experience, comfort, and confidence.

Education Handouts

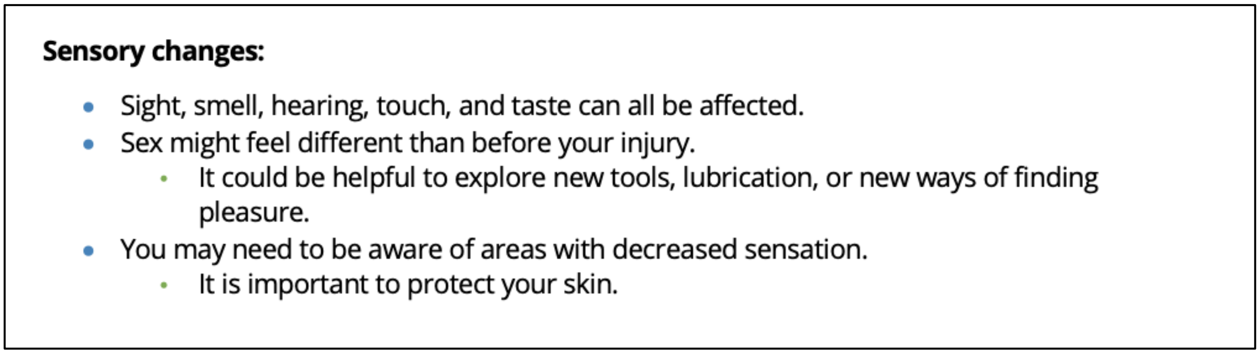
I finalized four Shepherd Center branded education handouts during my capstone. All handouts are at the reading level of 13-14 years old according to WebFX readability test (*Web FX Readability Test*, 2024). All feedback from clinicians, families, and patients was incorporated into the handouts as able. The following figures demonstrate parts of the handouts I have created. The full handouts can be found in Appendix 3.



Lying on your Weak Side

- Lying on your weak side may be more comfortable.
    - Lie on your shoulder blade and not directly on your shoulder to increase comfort.
    - Use additional pillows to support your arm and leg on your weak side if needed for comfort.
- Either partner can receive vaginal sex in this position.

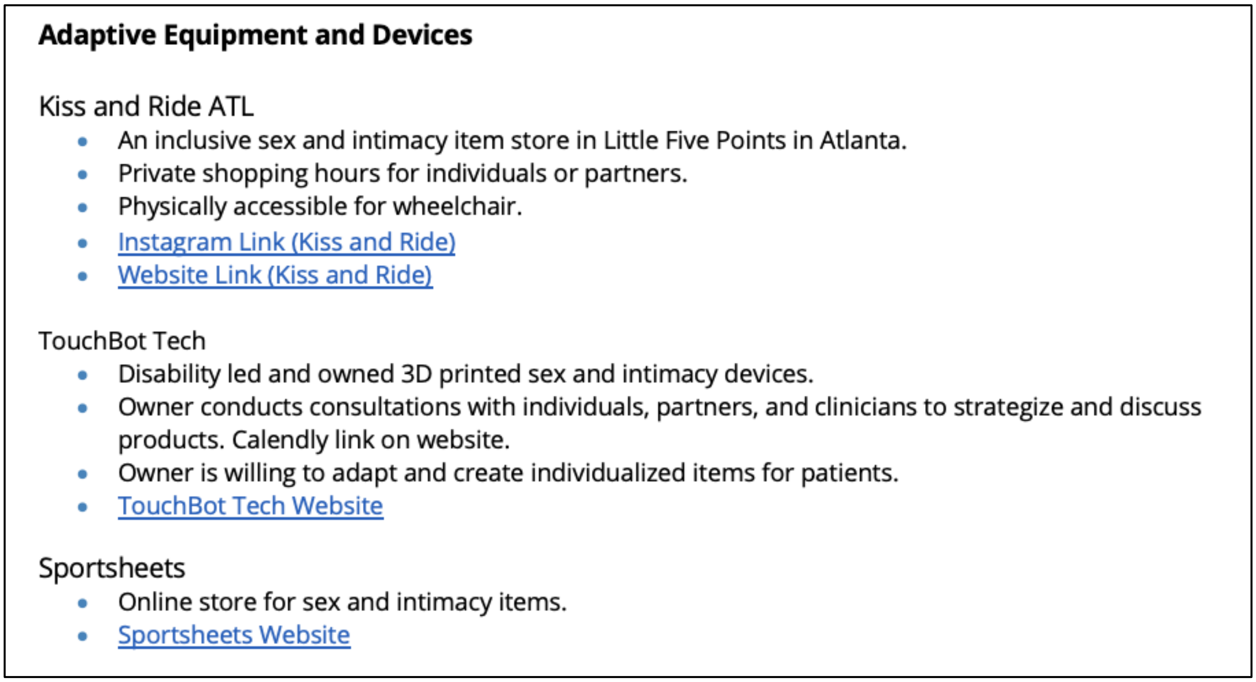
Figure 1. This is a part of the “Sex Positioning with Hemiplegia” handout. This is one example of 13 positionings included in this handout.



Sensory changes:

- Sight, smell, hearing, touch, and taste can all be affected.
- Sex might feel different than before your injury.
    - It could be helpful to explore new tools, lubrication, or new ways of finding pleasure.
- You may need to be aware of areas with decreased sensation.
    - It is important to protect your skin.

Figure 2. This figure is a part of the “Sex and Intimacy after ABI” generic handout. This is the sensory changes section. The other sections include mental changes, physical changes, and family changes.



Adaptive Equipment and Devices

Kiss and Ride ATL

- An inclusive sex and intimacy item store in Little Five Points in Atlanta.
- Private shopping hours for individuals or partners.
- Physically accessible for wheelchair.
- Instagram Link (Kiss and Ride)
- Website Link (Kiss and Ride)

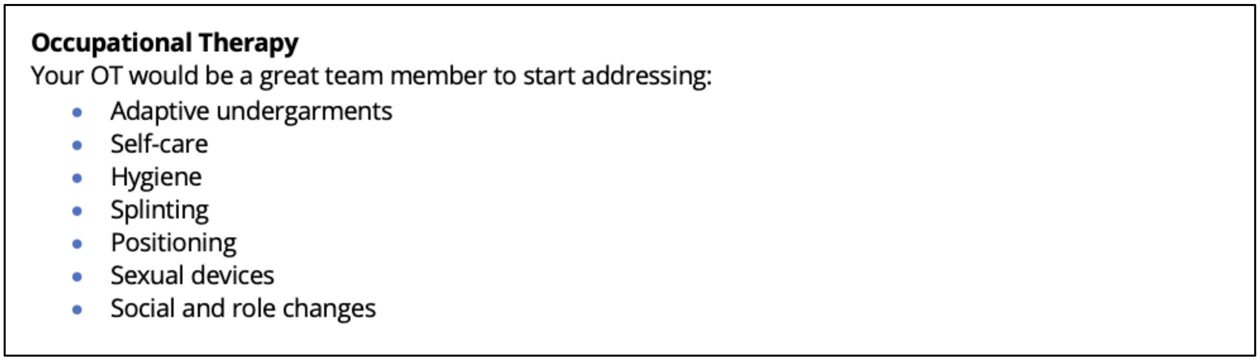
TouchBot Tech

- Disability led and owned 3D printed sex and intimacy devices.
- Owner conducts consultations with individuals, partners, and clinicians to strategize and discuss products. Calendly link on website.
- Owner is willing to adapt and create individualized items for patients.
- TouchBot Tech Website

Sportsheets

- Online store for sex and intimacy items.
- Sportsheets Website

Figure 3. This is a part of the “Sex and Intimacy Resources” handout. I have included counseling services, adaptive equipment and devices, positioning ideas, podcasts, Instagram accounts, books, and articles on this handout.



Occupational Therapy

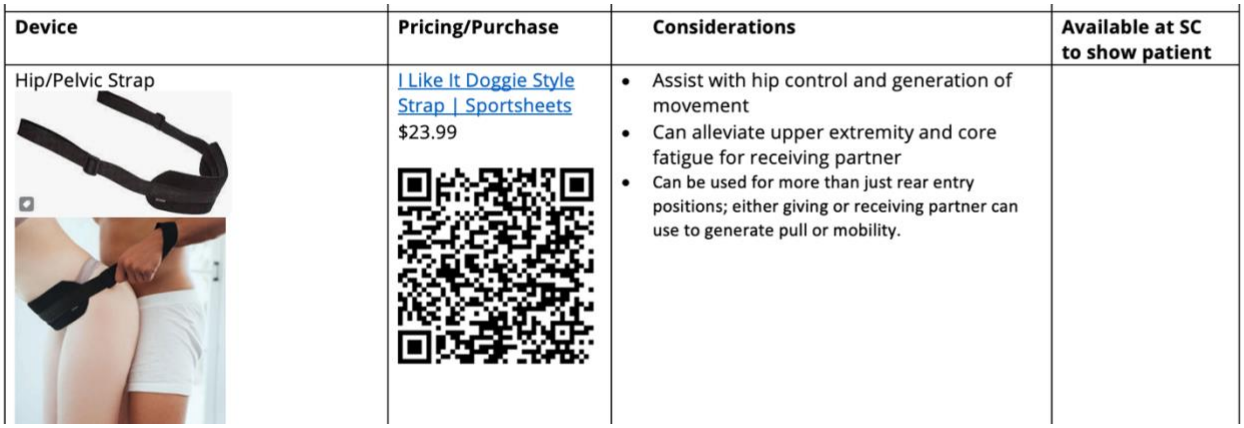
Your OT would be a great team member to start addressing:

- Adaptive undergarments
- Self-care
- Hygiene
- Splinting
- Positioning
- Sexual devices
- Social and role changes

Figure 4. This is a part of the “Clinician Roles with Sex and Intimacy” handout. The disciplines discussed are medical doctors, neuropsychologists, counselors, physical therapists, occupational therapists, speech therapists, recreational therapists, and peer support liaisons.

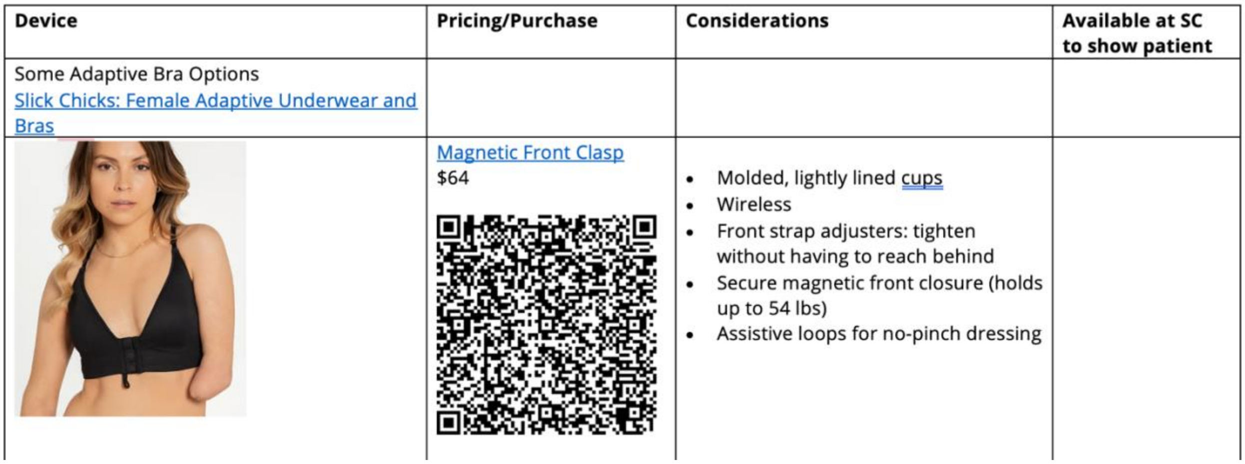
Updating Resources

Updating resources resulted in an adaptive equipment resource document, an adaptive equipment budget proposal, an adaptive equipment SBAR, an OPISI SBAR, and educational handouts discussed previously. The adaptive equipment resource included positioning devices, stimulation devices, and adaptive undergarments. In the listing, I included the name of the device, a photo, the link, a QR code, considerations for the device, and if the device is available at the Shepherd Center to trial physically with the therapist.



Device	Pricing/Purchase	Considerations	Available at SC to show patient
Hip/Pelvic Strap	I Like It Doggie Style Strap | Sportsheets $23.99	• Assist with hip control and generation of movement • Can alleviate upper extremity and core fatigue for receiving partner • Can be used for more than just rear entry positions; either giving or receiving partner can use to generate pull or mobility.	

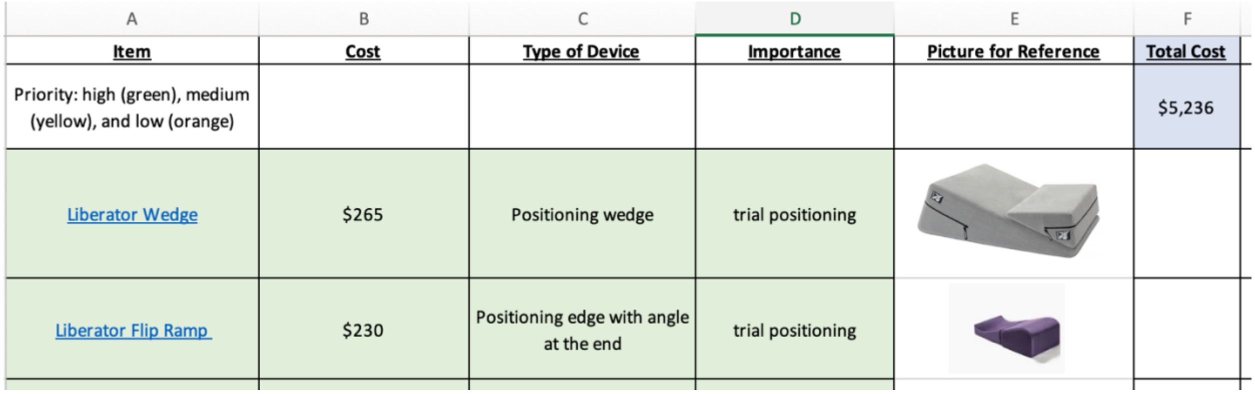
Figure 5. This is an example of one of the positioning devices included.



Device	Pricing/Purchase	Considerations	Available at SC to show patient
Some Adaptive Bra Options Slick Chicks: Female Adaptive Underwear and Bras			
	Magnetic Front Clasp $64	• Molded, lightly lined cups • Wireless • Front strap adjusters: tighten without having to reach behind • Secure magnetic front closure (holds up to 54 lbs) • Assistive loops for no-pinch dressing	

Figure 6. This is an example of one of the adaptive undergarments included.

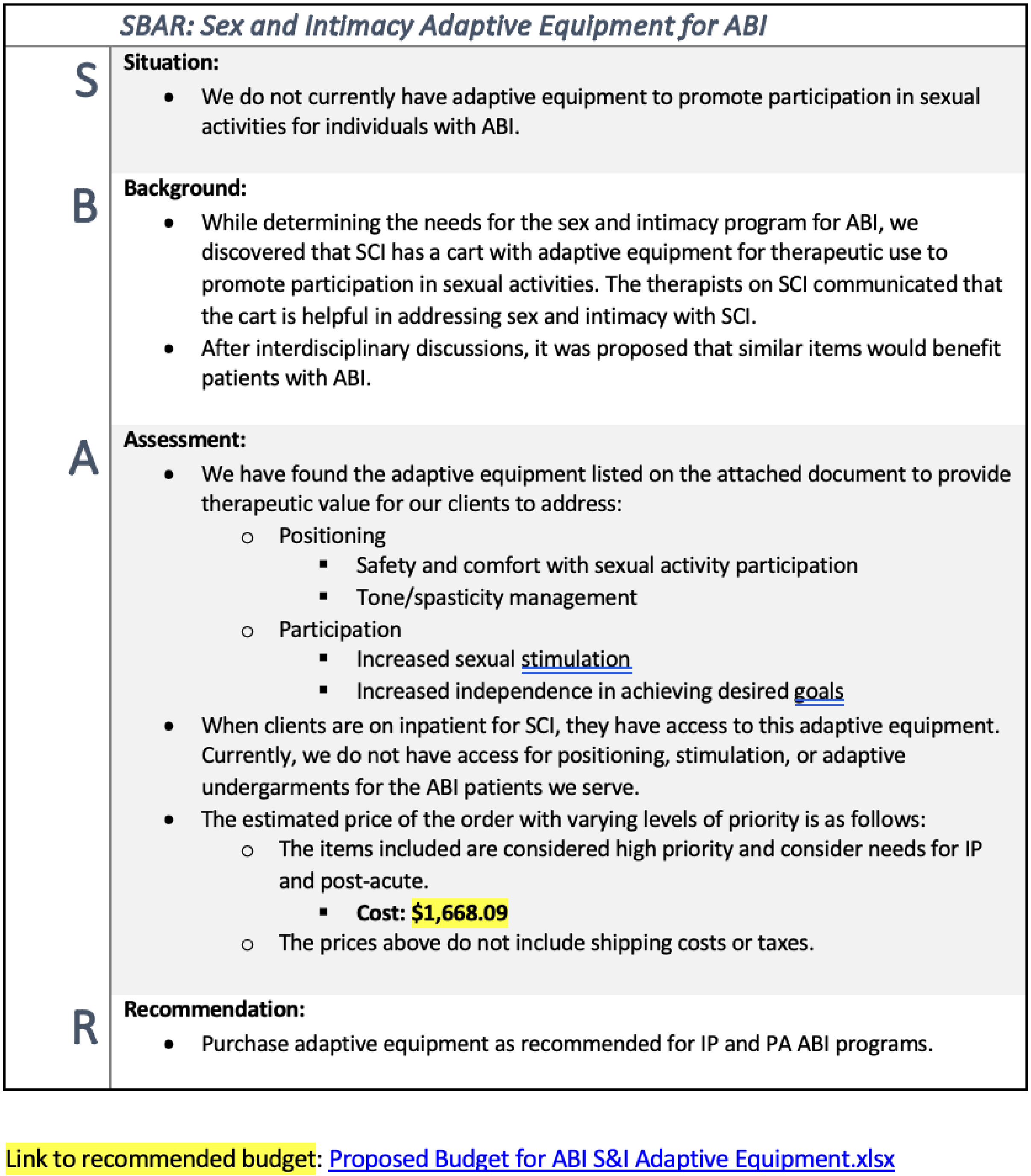
The budget proposal included most of the items on the adaptive equipment resource, broken down by priority of needing to buy by high, medium, and low. The first tab I created included all items and a picture of the items. The second tab included all items of high, medium, and low priority items and pricing. The third tab included high and medium priority items and pricing. The fourth tab included only the high-priority items and pricing. A simplified version of this budget proposal with the high priority items was sent over to the brain injury program director to determine how many resources could be allocated to the devices. The extended proposal will be used for purchasing future devices.



A	B	C	D	E	F
Item	**Cost**	**Type of Device**	**Importance**	**Picture for Reference**	**Total Cost**
Priority: high (green), medium (yellow), and low (orange)					$5,236
Liberator Wedge	$265	Positioning wedge	trial positioning		
Liberator Flip Ramp	$230	Positioning edge with angle at the end	trial positioning		

Figure 7. This is the first tab with all items and pictures with the grand total at the top right corner.

SBAR is the preferred form of quality improvement communication by the brain injury program director and therefore I completed one for the adaptive equipment and one for initiating use of the OPISI. Both are included below.



SBAR: Sex and Intimacy Adaptive Equipment for ABI

S

Situation:

- We do not currently have adaptive equipment to promote participation in sexual activities for individuals with ABI.

B

Background:

- While determining the needs for the sex and intimacy program for ABI, we discovered that SCI has a cart with adaptive equipment for therapeutic use to promote participation in sexual activities. The therapists on SCI communicated that the cart is helpful in addressing sex and intimacy with SCI.
- After interdisciplinary discussions, it was proposed that similar items would benefit patients with ABI.

A

Assessment:

- We have found the adaptive equipment listed on the attached document to provide therapeutic value for our clients to address:
    - Positioning
        - Safety and comfort with sexual activity participation
        - Tone/spasticity management
    - Participation
        - Increased sexual stimulation
        - Increased independence in achieving desired goals
- When clients are on inpatient for SCI, they have access to this adaptive equipment. Currently, we do not have access for positioning, stimulation, or adaptive undergarments for the ABI patients we serve.
- The estimated price of the order with varying levels of priority is as follows:
    - The items included are considered high priority and consider needs for IP and post-acute.
        - **Cost: $1,668.09**
    - The prices above do not include shipping costs or taxes.

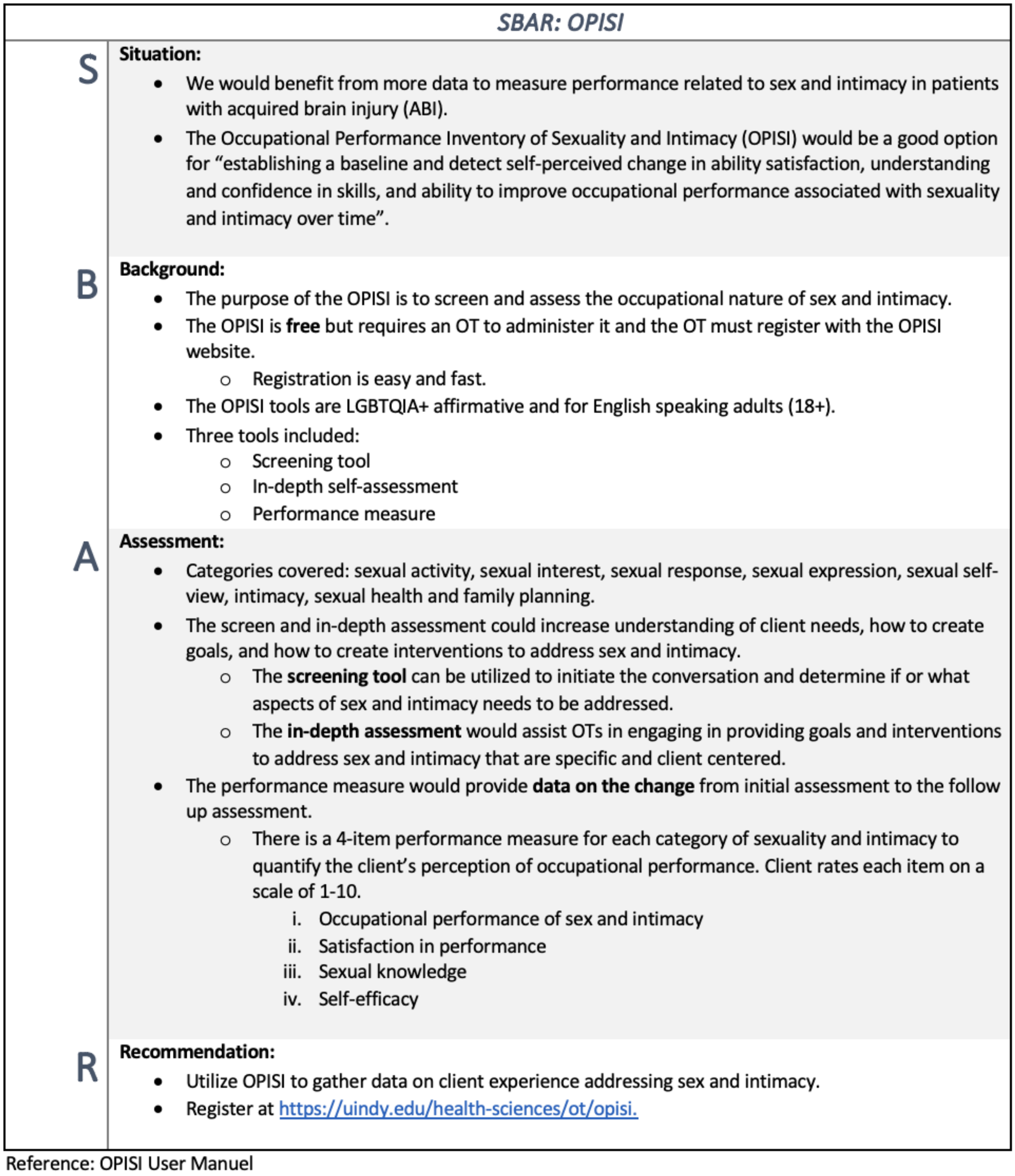
R

Recommendation:

- Purchase adaptive equipment as recommended for IP and PA ABI programs.

Link to recommended budget: Proposed Budget for ABI S&I Adaptive Equipment.xlsx

Figure 8. This is the SBAR to propose the adaptive equipment value, purpose, and cost.



SBAR: OPISI

S

Situation:
- We would benefit from more data to measure performance related to sex and intimacy in patients with acquired brain injury (ABI).
- The Occupational Performance Inventory of Sexuality and Intimacy (OPISI) would be a good option for "establishing a baseline and detect self-perceived change in ability satisfaction, understanding and confidence in skills, and ability to improve occupational performance associated with sexuality and intimacy over time".

B

Background:
- The purpose of the OPISI is to screen and assess the occupational nature of sex and intimacy.
- The OPISI is **free** but requires an OT to administer it and the OT must register with the OPISI website.
    - Registration is easy and fast.
- The OPISI tools are LGBTQIA+ affirmative and for English speaking adults (18+).
- Three tools included:
    - Screening tool
    - In-depth self-assessment
    - Performance measure

A

Assessment:
- Categories covered: sexual activity, sexual interest, sexual response, sexual expression, sexual self-view, intimacy, sexual health and family planning.
- The screen and in-depth assessment could increase understanding of client needs, how to create goals, and how to create interventions to address sex and intimacy.
    - The **screening tool** can be utilized to initiate the conversation and determine if or what aspects of sex and intimacy needs to be addressed.
    - The **in-depth assessment** would assist OTs in engaging in providing goals and interventions to address sex and intimacy that are specific and client centered.
- The performance measure would provide **data on the change** from initial assessment to the follow up assessment.
    - There is a 4-item performance measure for each category of sexuality and intimacy to quantify the client's perception of occupational performance. Client rates each item on a scale of 1-10.
        1. Occupational performance of sex and intimacy
        2. Satisfaction in performance
        3. Sexual knowledge
        4. Self-efficacy

R

Recommendation:
- Utilize OPISI to gather data on client experience addressing sex and intimacy.
- Register at https://uindy.edu/health-sciences/ot/opisi.

Reference: OPISI User Manuel

Figure 9. This is the SBAR to propose the value, purpose, and procedure for using the OPISI.

Podcast

I had meetings with six individuals to screen for potential participation in a podcast. Five out of the six individuals were appropriate to be on the podcast. I attempted to include diverse experiences on the podcast as demonstrated through the description of the podcast contributors in *Table 1.*

Table 1

Contributors to Sexuality and Intimacy Podcast

Identifier	**Background**
Couple contributor 1	Married for 25 years prior to husband having a stroke in 2021.
Couple contributor 2	Married for 8 years prior to wife having a brain aneurism burst in 2018.
Contributor 1	Married for 3 years prior to husband having a stroke in 2015. Husband passed away April 2023.
Contributor 2	Mom of a son who had a TBI.
Contributor 3	Mom of a son who had a TBI.

Note. This table includes the descriptions of the contributors who participated in the podcast about sexuality and intimacy.

For the structure of the podcast, I began with an introduction that explained the purpose of the podcast and who I am: "Hi everyone, my name is Becca Parker, and I am an occupational therapy doctorate student working with the Shepherd Center to address intimacy and sexuality in the brain injury population. This podcast shares unique stories from past Shepherd patients around this topic. Our hope is that by sharing these stories, we will speak to common questions and concerns that arise and provide some tools and resources for you to explore intimacy and sexuality following brain injury." Then, I asked similar questions that I asked during the screening process. The following are the questions I asked during the podcast recordings:

1. Tell me a little about your experience at Shepherd to give people listening a background.
2. What does sex and intimacy mean to you?
    a. What are the other aspects of intimacy?
3. How was sex and intimacy impacted by the brain injury?
4. Do you recall if sex and intimacy was ever brought up during rehab?
    a. How and when would you have liked it to have been brought up?
5. How did your role shift in your relationship and how did that affect you?
    a. With your partner
    b. With your family
    c. As the patient/individual
    d. Tell me examples of where role changes showed up.
6. For married couples:
    a. How have you kept your romance alive?
    b. What are you both excited for right now?
7. For parents:

a. How have you approached this conversation with your son/daughter?

I recorded the audio recordings in the Shepherd Center recording studio at the end of March 2024 and beginning of April 2024. Because the two mothers who have a son with a TBI knew each other, I conducted their audio recording together to promote conversation. The other audio recordings included each contributor as a couple or an individual with me leading the conversation. The podcasts will be posted to the Shepherd Center's resource hub called "MyShepherdConnection.org."

Summary

This capstone had multiple deliverables and outputs. The deliverables and outputs for the Ex-PLISSIT training were the condensed PowerPoint, the mock presentation, and the first large training in April. The output of the focus groups was the key takeaways which influenced the program development to address sex and intimacy in ABI. The education handouts will be physically available at the Shepherd Center for clinicians, patients, and families to utilize as well as online at MyShepherdConnection.org. The adaptive equipment proposals, resources, and SBAR as well as the OPISI SBAR and podcast recordings were delivered to the brain injury program director for review and further action.

Chapter 5: Discussion and Impact

This capstone left a lasting impact on the patients, families, and clinicians of the Shepherd Center by creating sustainable deliverables. This capstone challenged me in my public speaking skills, organizational skills, time management skills, and communication skills. I learned significant new information, had great experiences, and honed new skills. I received great support throughout my capstone from Georgia State University faculty and the Shepherd Center ABI leadership team.

Objective 1: Implement a sustainable Ex-PLISSIT training program across interdisciplinary team members in brain injury rehab.

I met my first objective of supporting the Ex-PLISSIT model training by condensing the original presentation, training the trainers, and co-leading the first in-person training for 60 ABI staff members. Clinicians rarely address sexuality and intimacy with their patients and some reasons are lack of knowledge, confidence, and skills (Mc Grath & Sakellariou, 2015). The goal of the training was to increase clinician competence, trust, and comfort in addressing sex and intimacy with families and patients with acquired brain injury. Using the PLISSIT model has shown an increase in clinician comfort in addressing sex and intimacy (McLeod & Hamilton, 2013). Through supporting the Ex-PLISSIT training, I learned how to prioritize and condense information when there is a time limitation. I gained a better understanding of all the moving parts that go into rolling out a large training including the preparation and implementation pieces. I am not always at ease when I engage in public speaking, and therefore, I was challenged when I presented the training to a larger group. Not every person who went through this training will gain comfort and implement the model into practice, but a significant amount of the people will begin to engage in addressing sex and intimacy with their patients at the Shepherd Center because of the training they received.

Objective 2: Coordinate focus groups to establish a baseline of understanding for Shepherd Center patient and caregiver needs regarding sexuality.

I conducted three focus groups with clinicians who work across the continuum of brain injury to address my second objective. The focus groups successfully gained information from clinicians and created a space for discussion around the topic. Clinicians are uncomfortable discussing sexuality with their patients (Rose & Hughes, 2018). The purpose of the focus groups was to create a safe space for clinicians to voice concerns and questions around addressing sexuality and intimacy with their brain injury patients. There was good attendance, conversation, and takeaways from each focus group. I learned how to gain more in-depth information from people when responses to questions are limited like saying statements like “tell me more about that” or “can you give me an example of that?”. I learned that food is a huge driving factor for people to attend meetings. I learned that people can still have a lot of thoughts and opinions on a topic that they deem “inappropriate” or “uncomfortable”. For example, the inpatient clinicians had been known to think addressing sex and intimacy in inpatient was inappropriate because it was too early. However, there were many stories shared where the patient or family was requested to discuss sex and/or intimacy. It is important to start discussions around sexuality and intimacy when trying to elicit change around how sex and intimacy are addressed in a clinical setting.

Objective 3: Create Shepherd Center branded education materials for family, patients, and clinicians addressing sex/intimacy with individuals with Acquired Brain Injury.

I created four Shepherd Center branded education handouts. My needs assessment determined there was a need for educational handouts to allow patients and families to access resources more easily and to support clinicians in addressing sexuality and intimacy. My needs assessment also determined the need for handouts with simple and plain language to account for health literacy. It is vital to account for health literacy when creating health education handouts due to the average medical literacy of our country (DeWalt et al., 2011). The most challenging parts of creating the handouts were organizing the handouts and implementing health literacy strategies. I learned how to simplify ideas, find alternative wording to more complex medical verbiage, use intriguing language, and format education handouts to best provide accessible resources for patients, families, and clinicians. The handouts received great feedback from the ABI leadership and the program director appeared excited to begin using them with patients and families. The handouts will provide education on sexuality and intimacy and serve as a strategy for opening the door to discussing sexuality and intimacy with patients and families.

Objective 4: Catalog and enhance the therapists' tools & materials to address sexuality needs on inpatient and post-acute settings.

I met my fourth objective by creating and proposing adaptive equipment resources, updating online resources, and recording audio for the podcasts. My needs assessment found adaptive equipment needed to be accessible at inpatient and post-acute ABI, online resources needed updating, and patient voices needed to be heard by clinicians, patients, and families. Proposing the use of adaptive equipment was a team effort of me, my mentor, and an occupational therapist on the spinal cord injury unit working together to gather materials and present information to the program director. Researching and proposing the SBAR for OPISI helped me learn about the importance of gathering data when implementing a new program and quality improvement tools. It is important to see if an implemented program is making an impact and the OPISI is one way for occupational therapists at the Shepherd Center to gather data on this topic. Through this, I learned more about the business side of a hospital and how to prioritize tools and equipment based on needs of a population and a facility. The process of updating the current resources was an ongoing process and required collaboration with leadership and clinicians throughout my capstone experience.

The podcast process was the most difficult to navigate because I needed to be connected to and communicate with a lot of people. I needed to plan with PR as well as get connected to patients and family members that might be appropriate for the podcast. I engaged in deep and difficult conversations with partners and patients with brain injury when I screened them for the podcast and when I completed the podcast. I had to determine if the person I was interviewing was appropriate for the podcast recording. I deemed one person inappropriate for the podcast. The discussion was rich with great information, but the topic appeared raw to the partner, and he had not discussed the information with his partner who had the brain injury. Therefore, I decided to not ask him to do the podcast.

Overall, my third objective involved many diverse aspects. I learned about the business side of a hospital and about quality improvement. I learned the importance of summarizing and including research to provide evidence for proposed ideas. The ideas that I proposed will lead to access to adaptive equipment for patients at the Shepherd Center ABI department, increased screening and assessment of sexuality and intimacy utilizing the OPISI, and the podcast will allow for more clinicians, families, and patients to hear patient and family experiences around sexuality and intimacy after ABI.

Future Directions

At the end of my capstone, I presented the outcomes of my capstone and future next steps to the ABI leadership. The leadership needs to determine the location of where the clinician resources I have gathered will be accessible. Once a year, they will need to check and make sure links are updated and add any additional appropriate resources to all the handouts I have created. There is also a need to determine if the handouts are being utilized or if they are not being dispersed for unforeseen reasons. Once a year, they will need to make sure the adaptive equipment resource cart has the items it is supposed to have. They will need to continue the conversation around sexuality and intimacy with clinicians whether through focus groups or by other means. The leadership will need to continue to foster the relationships I have made, specifically with Kiss&Ride and TouchBot businesses. The plan is for the Ex-PLISSIT model training to continue rolling out to all ABI staff over the next year, but a plan for new staff members to engage in the training needs to be determined. Overall, the future steps are to continue to develop this program over time and adapt it as needed to fit the Shepherd Center's needs.

Limitations

There were a few limitations to my capstone. Some of the aspects of my site, the Shepherd Center, led to constraints. Effectively entering, communicating, and accomplishing tasks within a hospital system leads to limitations and hoops to jump through. In order to achieve my objectives, I consistently communicated with leadership and requested permission for taking next steps which sometimes required more time than it would if I was able to move forward on my own. At the Shepherd Center, patients and families are often from across the country and therefore my ability to find appropriate resources was limited to online or in the Atlanta area since that is where the Shepherd Center is location. Due to the time limitation of 14 weeks, I could only accomplish so much, and I prioritized finding resources across the country when time allowed for it.

The topic of sexuality and intimacy is a sensitive topic and, therefore, is a limitation within itself. Specifically, sexuality is a taboo subject where the Shepherd Center is located in the southern region of the United States. Also, with Shepherd Center's population of patients, there are nuances and difficulties with roles, such as who is the patient's caregiver and who is the legal guardian if the patient needs a legal guardian either because of age or because of effects of the brain injury. For the podcast, it was difficult to find participants who were willing to discuss a very sensitive topic on a recording that was going to be sent out to the public. Clinicians' willingness to share their opinions could have been limited by the nature of the topic as well, whether that is because they are uncomfortable around the topic in general or uncomfortable sharing their opinions in front of their coworkers or leadership. Overall, time, hospital organization, and the sensitive nature of my topic led to limitations for my capstone.

Sustainability Plan

The Shepherd Center will continue to develop and adapt the program to address sex and intimacy after I have completed my capstone. The Shepherd Center is rolling out the Ex-PLISSIT trainings until November of 2024. There will be a total of 9 trainings for all ABI staff, including nursing, patient care techs, medical doctors, occupational therapy, physical therapy, speech therapy, neuropsychology, psychology, recreational therapy, vocational therapy, peer support, and any other ABI staff. All ABI staff are required to attend the in-person training. Then, the Shepherd Center will require new hires to attend the training.

The educational handouts are posted to MyShepherdConnection.org for easy online access for patients, families, and clinicians. The handouts will also be printed out and available at the inpatient and outpatient facilities. Clinicians will be informed of these handouts through the Ex-PLISSIT in-person trainings and therefore will know where to find them. The podcast I recorded with patients will be posted to MyShepherdConnection.org and be easily accessed by patients, families, and clinicians from there. It is a single session podcast, and the current plan is that future episodes will not be recorded. The adaptive equipment will eventually be physically available for ABI patients to utilize during therapy sessions. The relationships with businesses will be continued through the introductions I made to staff at Shepherd and completing outings with patients to the businesses located in Atlanta.

In summary, the deliverables I created will continue to be accessible to patients, families, and clinicians. The relationships I created will be accessible to Shepherd staff through my introductions. The Ex-PLISSIT training will continue to be a part of the required training for any ABI staff.

Conclusion

In conclusion, my capstone supported the implementation of an Ex-PLISSIT model training to all ABI staff, conducted three focus groups, and created and collected educational resources for patients, families, and clinicians at the Shepherd Center. This project supported the overall efforts of the Shepherd Center to address sexuality and intimacy in their brain injury population across the continuum. The objectives of this project could be used as a guide for other facilities to make an effort to address sexuality and intimacy in the brain injury population. It provides a framework for similar projects, as well as highlights the importance and need for addressing sexuality and intimacy in the brain injury population. This project will leave a lasting impact on the patients, families, and clinicians of the Shepherd Center in their efforts to address the topic of sexuality and intimacy in their brain injury population as well as hopefully influence other healthcare facilities to address this under addressed topic.

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Appendixes

Appendix 1: Learning Objectives

<u>Objective 1:</u> Implement a sustainable Ex-PLISSIT training program across interdisciplinary team members in brain injury rehab.

<u>Objective 2:</u> Coordinate focus groups to establish a baseline of understanding for Shepherd Center patient and caregiver needs regarding sexuality.

<u>Objective 3:</u> Create 3 Shepherd Center branded education materials for family, patients, and clinicians addressing sex/intimacy with individuals with Acquired Brain Injury.

<u>Objective 4:</u> Catalog and enhance the therapists' tools & materials to address sexuality needs on inpatient and post-acute settings.

Appendix 2: Supervision Plan

A. Scheduled Meetings
    a. Meetings will occur once a month from June 2023 to December 2023 leading up to Capstone experience.
    b. The student will attend meetings that are relevant to the capstone leading up to January 2024.
    c. During the capstone experience, meetings will occur on an as needed basis with a standing weekly meeting on Wednesdays.
B. Communication methods
    a. Logistics
        i. In person, email, and phone communication will be the primary forms of communication.

- b. How to Resolve Possible Disputes
  - i. Clear, kind, and timely communication is prioritized.
  - ii. Expectations for each piece of the capstone are clearly discussed.
  - iii. How each person best receives feedback is discussed prior to needing to deliver feedback.
- c. Types of expertise desired from site mentor.
  - i. Provide expertise regarding inner workings of the Shepherd Center and the groups already addressing sex and intimacy in brain injury.
  - ii. Provide expertise of working with individuals with brain injury and their families.
  - iii. Provide expertise of working with an interdisciplinary group and the relationships between clinicians.

C. Tracking Student’s Measurable Goals

- a. Specific Project Requirements
  - i. All requirements are laid out in the learning objectives and the MOU.
  - ii. The student will plan and complete the tasks that are outlined on a weekly and sometimes daily basis.
- b. Timeline of Deliverables
  - i. Ex-PLISSIT training will occur in April.
  - ii. Resources will be created, completed, and edited by April.
  - iii. Focus groups will be completed by end of February.

D. Roles and responsibilities

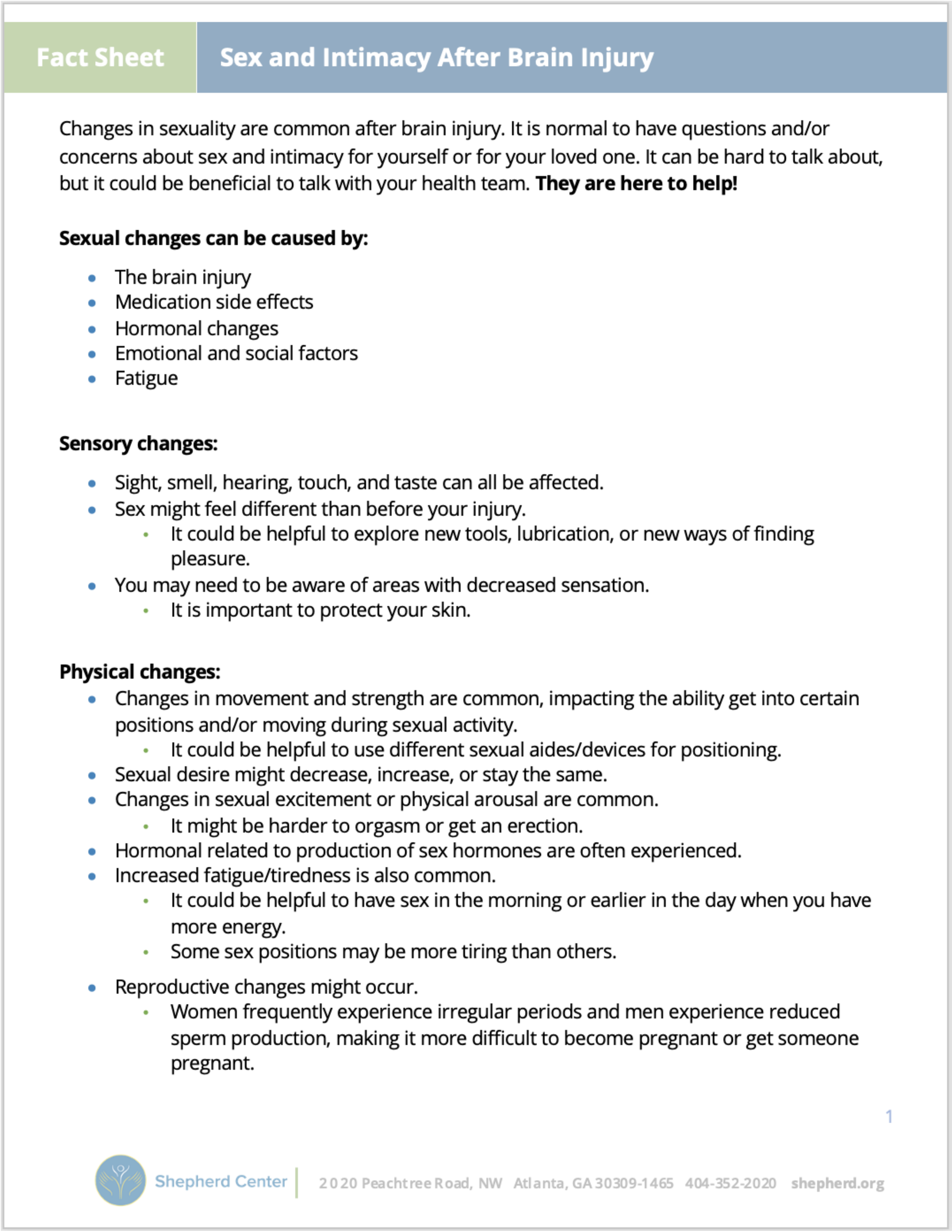
- a. Student

    i. Work towards learning objectives and activities in accordance with the MOU.
    ii. Adapting when needed to meet the needs of Shepherd Center and the student capstone experience.
    iii. Communicate clearly with mentor on progress and concerns about project.
    iv. Take initiative and self-directed actions to further the capstone project.

b. Mentor
    i. Orient student to capstone site, policy and procedures, expectations, other personnel, and stakeholders.
    ii. Provide distant supervision throughout capstone experience.
    iii. Assist student as needed to perform specific learning activities consistent with the student's learning objectives.
    iv. Meet with student during required meeting times.
    v. Proactively communicate when potential concerns arise.
    vi. Provide meaningful and timely feedback as needed.
    vii. Support engagement in leadership level communication.

Appendix 3: Educational Handouts

Sex and Intimacy After Brain Injury



Fact Sheet

Sex and Intimacy After Brain Injury

Changes in sexuality are common after brain injury. It is normal to have questions and/or concerns about sex and intimacy for yourself or for your loved one. It can be hard to talk about, but it could be beneficial to talk with your health team. **They are here to help!**

Sexual changes can be caused by:

- The brain injury
- Medication side effects
- Hormonal changes
- Emotional and social factors
- Fatigue

Sensory changes:

- Sight, smell, hearing, touch, and taste can all be affected.
- Sex might feel different than before your injury.
  - It could be helpful to explore new tools, lubrication, or new ways of finding pleasure.
- You may need to be aware of areas with decreased sensation.
  - It is important to protect your skin.

Physical changes:

- Changes in movement and strength are common, impacting the ability get into certain positions and/or moving during sexual activity.
  - It could be helpful to use different sexual aides/devices for positioning.
- Sexual desire might decrease, increase, or stay the same.
- Changes in sexual excitement or physical arousal are common.
  - It might be harder to orgasm or get an erection.
- Hormonal related to production of sex hormones are often experienced.
- Increased fatigue/tiredness is also common.
  - It could be helpful to have sex in the morning or earlier in the day when you have more energy.
  - Some sex positions may be more tiring than others.
- Reproductive changes might occur.
  - Women frequently experience irregular periods and men experience reduced sperm production, making it more difficult to become pregnant or get someone pregnant.

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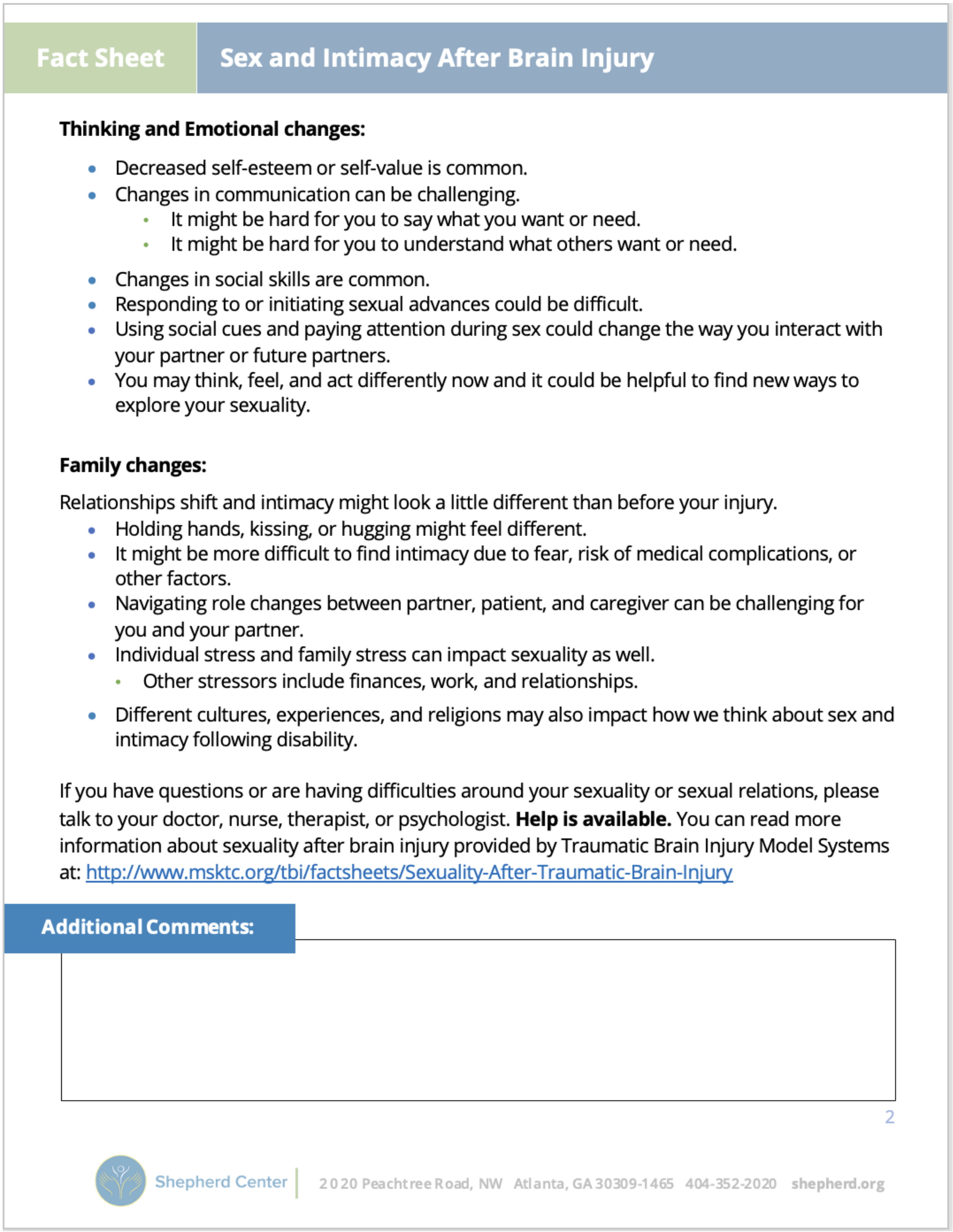

Fact Sheet **Sex and Intimacy After Brain Injury**

Thinking and Emotional changes:

- Decreased self-esteem or self-value is common.
- Changes in communication can be challenging.
    - It might be hard for you to say what you want or need.
    - It might be hard for you to understand what others want or need.
- Changes in social skills are common.
- Responding to or initiating sexual advances could be difficult.
- Using social cues and paying attention during sex could change the way you interact with your partner or future partners.
- You may think, feel, and act differently now and it could be helpful to find new ways to explore your sexuality.

Family changes:

Relationships shift and intimacy might look a little different than before your injury.

- Holding hands, kissing, or hugging might feel different.
- It might be more difficult to find intimacy due to fear, risk of medical complications, or other factors.
- Navigating role changes between partner, patient, and caregiver can be challenging for you and your partner.
- Individual stress and family stress can impact sexuality as well.
    - Other stressors include finances, work, and relationships.
- Different cultures, experiences, and religions may also impact how we think about sex and intimacy following disability.

If you have questions or are having difficulties around your sexuality or sexual relations, please talk to your doctor, nurse, therapist, or psychologist. **Help is available.** You can read more information about sexuality after brain injury provided by Traumatic Brain Injury Model Systems at: http://www.msktc.org/tbi/factsheets/Sexuality-After-Traumatic-Brain-Injury

Additional Comments:

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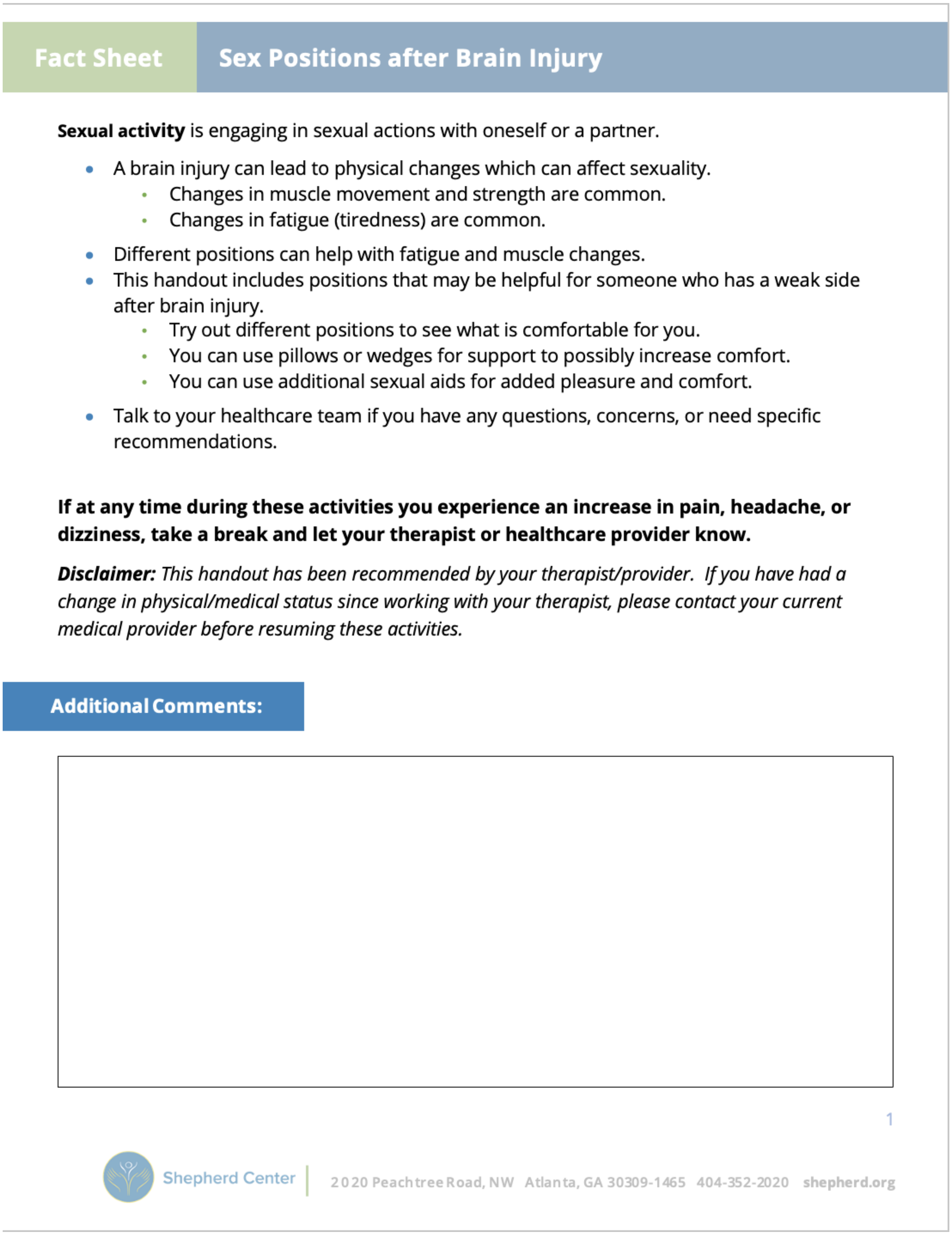
Sex Positions After Brain Injury



Fact Sheet **Sex Positions after Brain Injury**

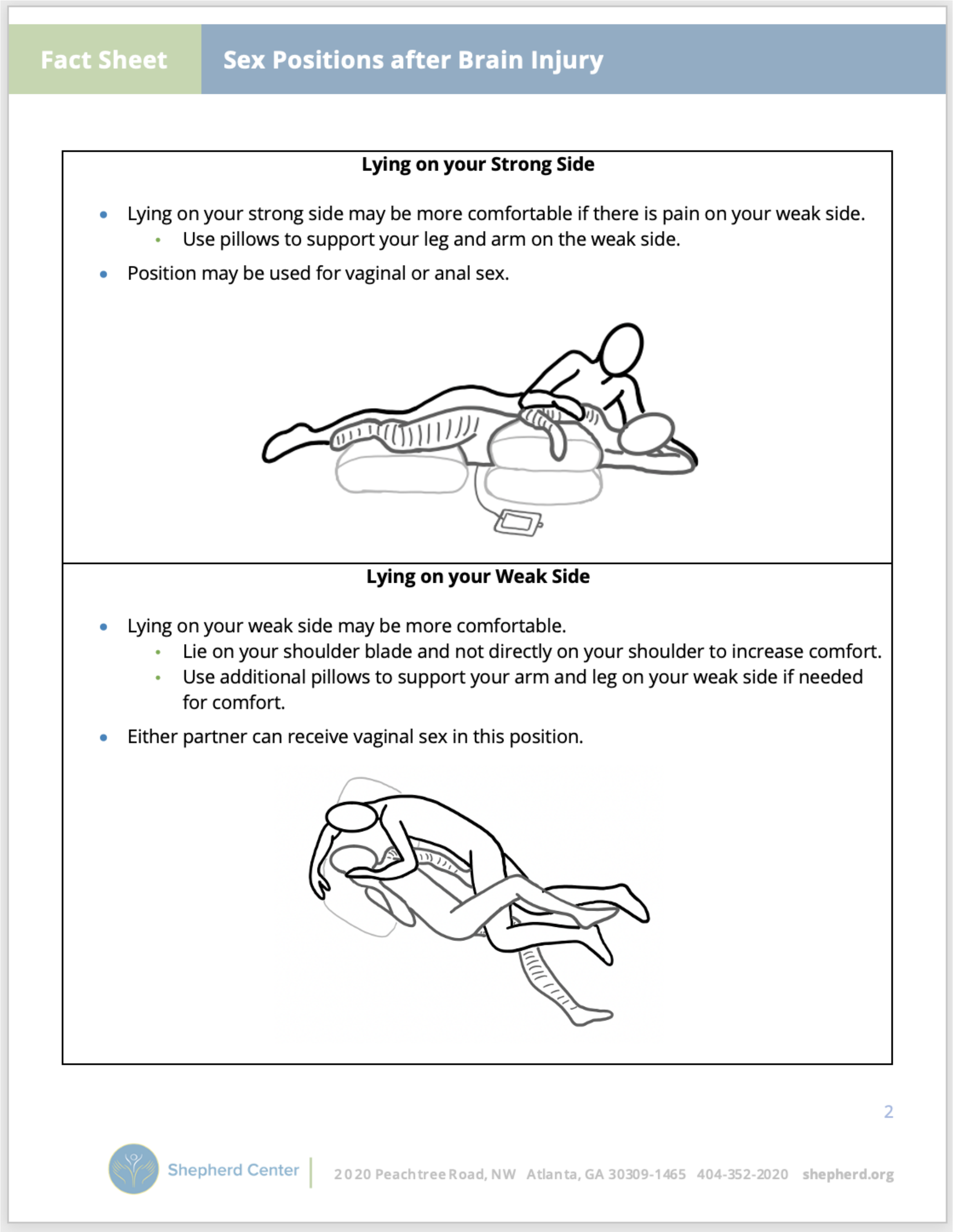
Sexual activity is engaging in sexual actions with oneself or a partner.

- A brain injury can lead to physical changes which can affect sexuality.
  - Changes in muscle movement and strength are common.
  - Changes in fatigue (tiredness) are common.
- Different positions can help with fatigue and muscle changes.
- This handout includes positions that may be helpful for someone who has a weak side after brain injury.
  - Try out different positions to see what is comfortable for you.
  - You can use pillows or wedges for support to possibly increase comfort.
  - You can use additional sexual aids for added pleasure and comfort.
- Talk to your healthcare team if you have any questions, concerns, or need specific recommendations.

If at any time during these activities you experience an increase in pain, headache, or dizziness, take a break and let your therapist or healthcare provider know.

Disclaimer: *This handout has been recommended by your therapist/provider. If you have had a change in physical/medical status since working with your therapist, please contact your current medical provider before resuming these activities.*

Additional Comments:



Fact Sheet **Sex Positions after Brain Injury**

Lying on your Strong Side

- Lying on your strong side may be more comfortable if there is pain on your weak side.
  - Use pillows to support your leg and arm on the weak side.
- Position may be used for vaginal or anal sex.

Lying on your Weak Side

- Lying on your weak side may be more comfortable.
  - Lie on your shoulder blade and not directly on your shoulder to increase comfort.
  - Use additional pillows to support your arm and leg on your weak side if needed for comfort.
- Either partner can receive vaginal sex in this position.

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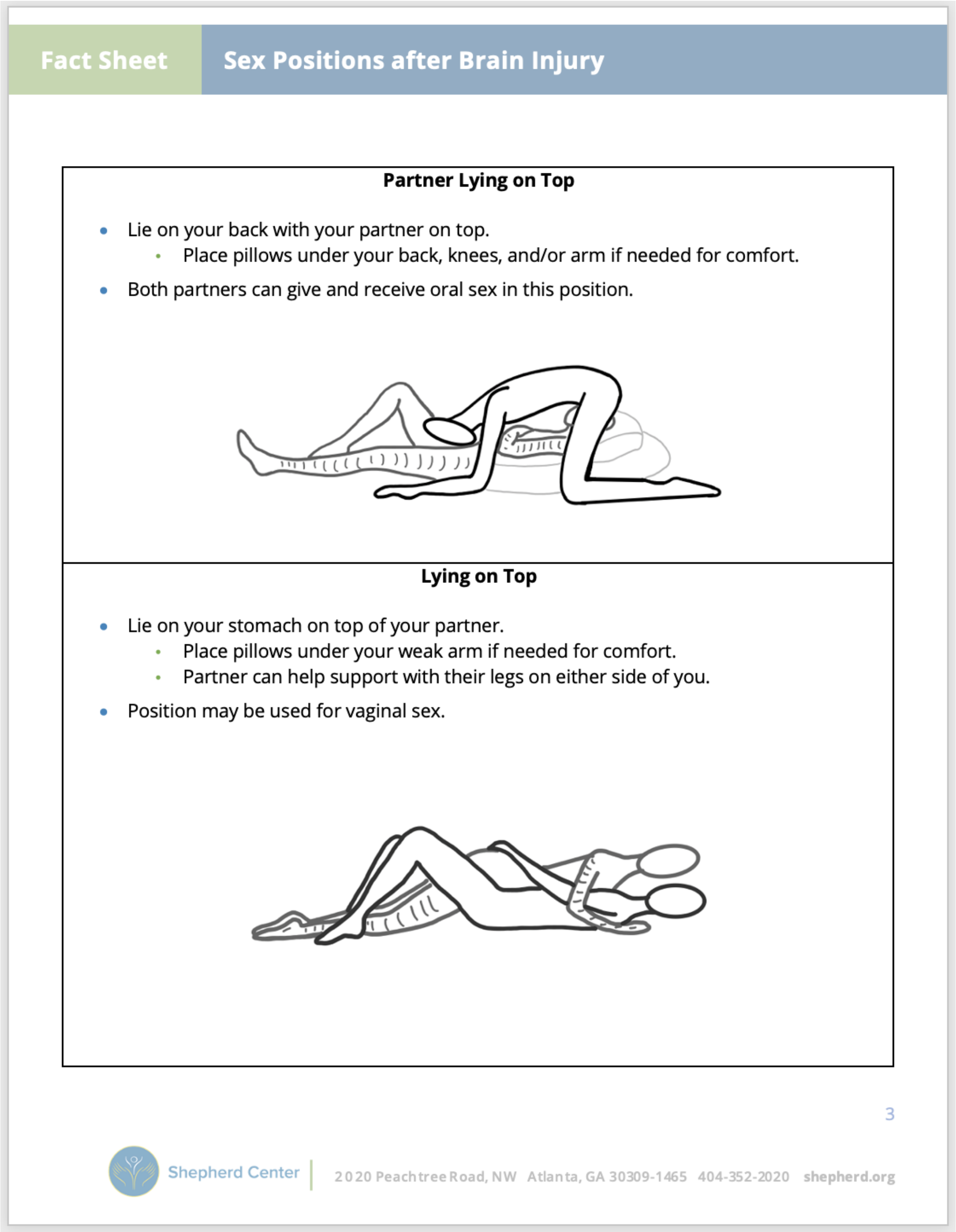


Fact Sheet **Sex Positions after Brain Injury**

Partner Lying on Top

- Lie on your back with your partner on top.
  - Place pillows under your back, knees, and/or arm if needed for comfort.
- Both partners can give and receive oral sex in this position.

Lying on Top

- Lie on your stomach on top of your partner.
  - Place pillows under your weak arm if needed for comfort.
  - Partner can help support with their legs on either side of you.
- Position may be used for vaginal sex.

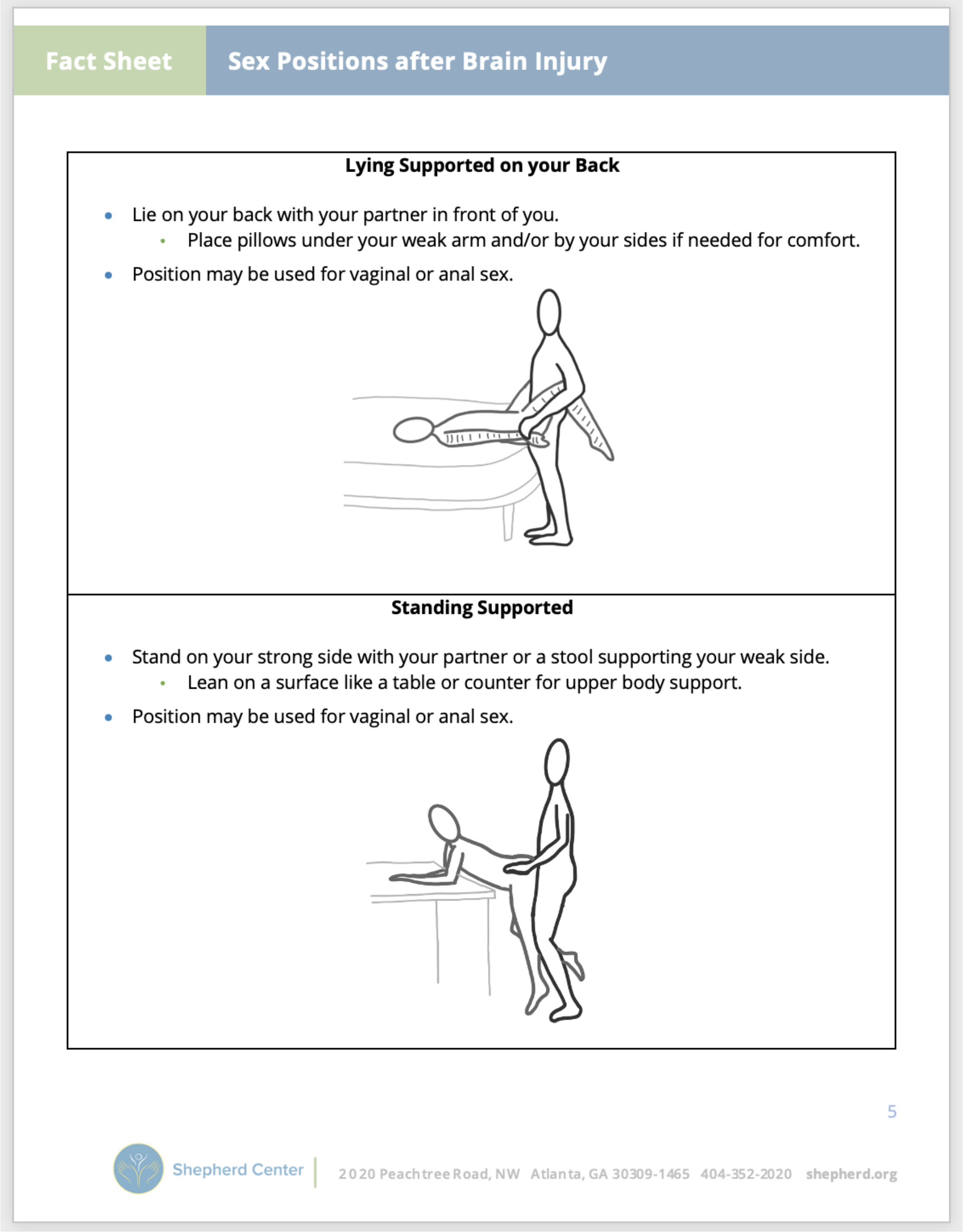
Fact Sheet **Sex Positions after Brain Injury**

Partner on Top from Behind

- Lie on your stomach with your partner on top.
  - Place pillows under your hips and/or legs if needed for comfort.
- Position may be used for vaginal or anal sex.

Partner on Top from an Angle

- Lie on your strong side with your partner supporting your weak side.
  - Place pillows under weak arm if needed for comfort.
- Position may be used for vaginal or anal sex.



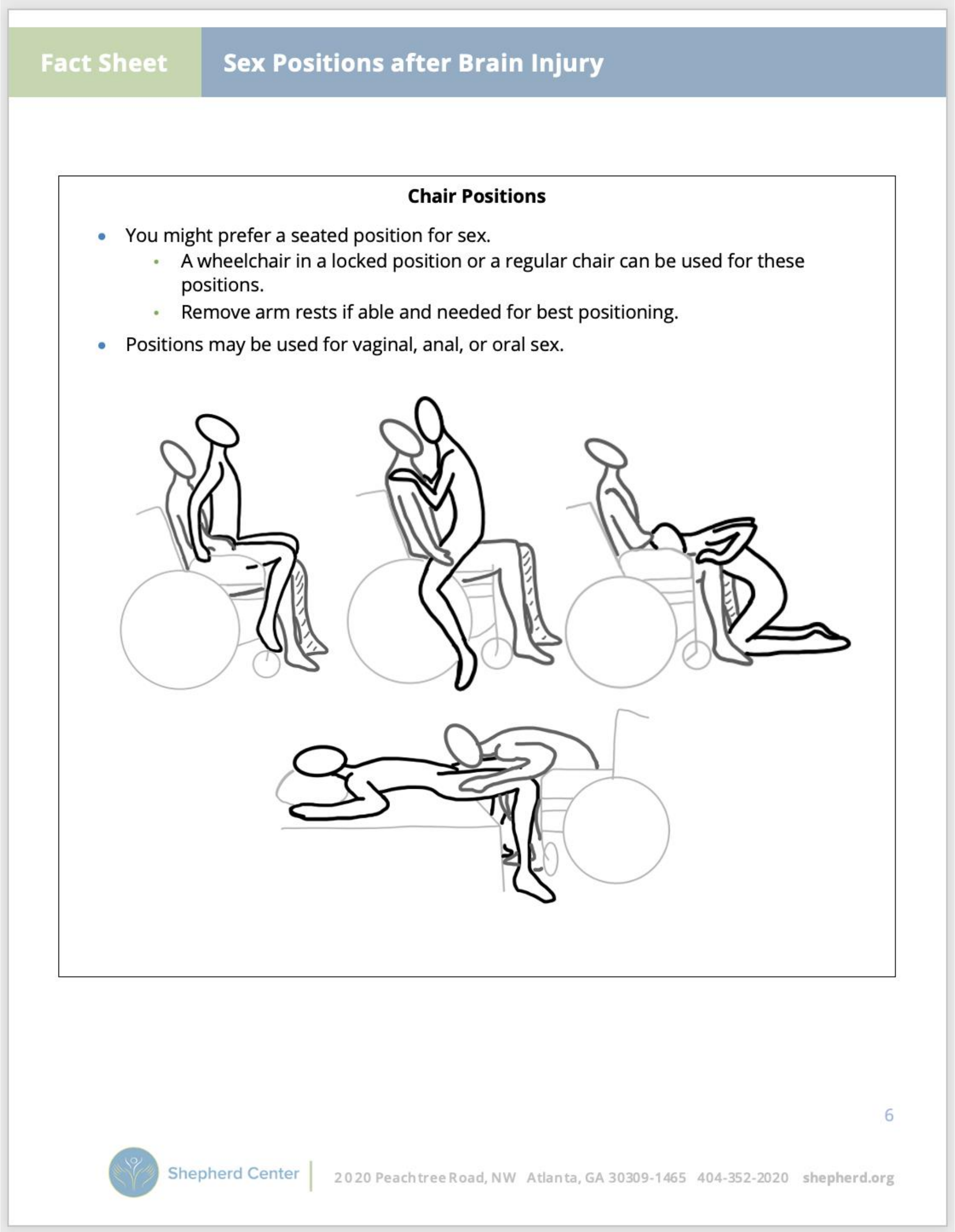
Fact Sheet **Sex Positions after Brain Injury**

Lying Supported on your Back

- Lie on your back with your partner in front of you.
  - Place pillows under your weak arm and/or by your sides if needed for comfort.
- Position may be used for vaginal or anal sex.

Standing Supported

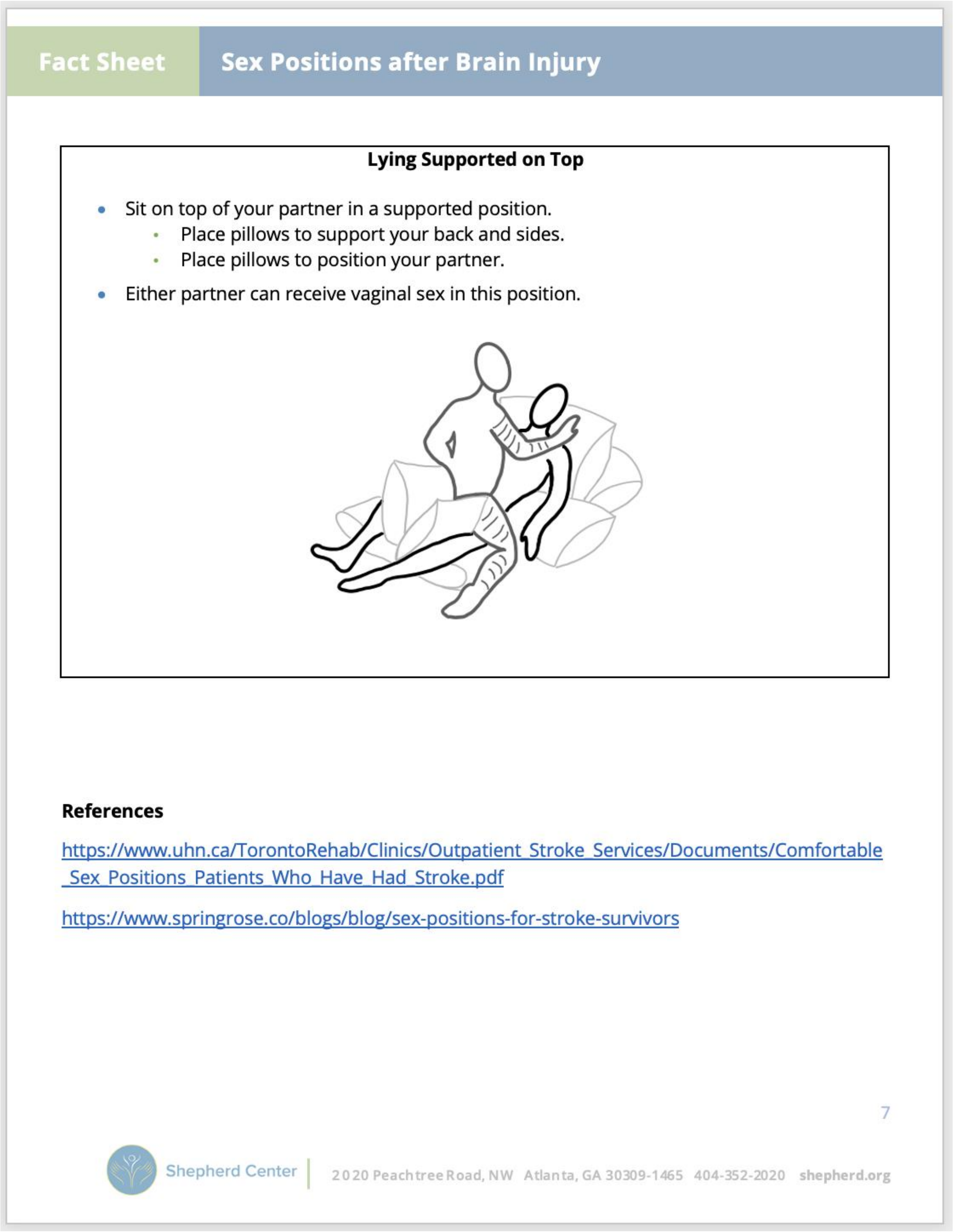
- Stand on your strong side with your partner or a stool supporting your weak side.
  - Lean on a surface like a table or counter for upper body support.
- Position may be used for vaginal or anal sex.



Fact Sheet **Sex Positions after Brain Injury**

Chair Positions

- You might prefer a seated position for sex.
  - A wheelchair in a locked position or a regular chair can be used for these positions.
  - Remove arm rests if able and needed for best positioning.
- Positions may be used for vaginal, anal, or oral sex.



Fact Sheet **Sex Positions after Brain Injury**

Lying Supported on Top

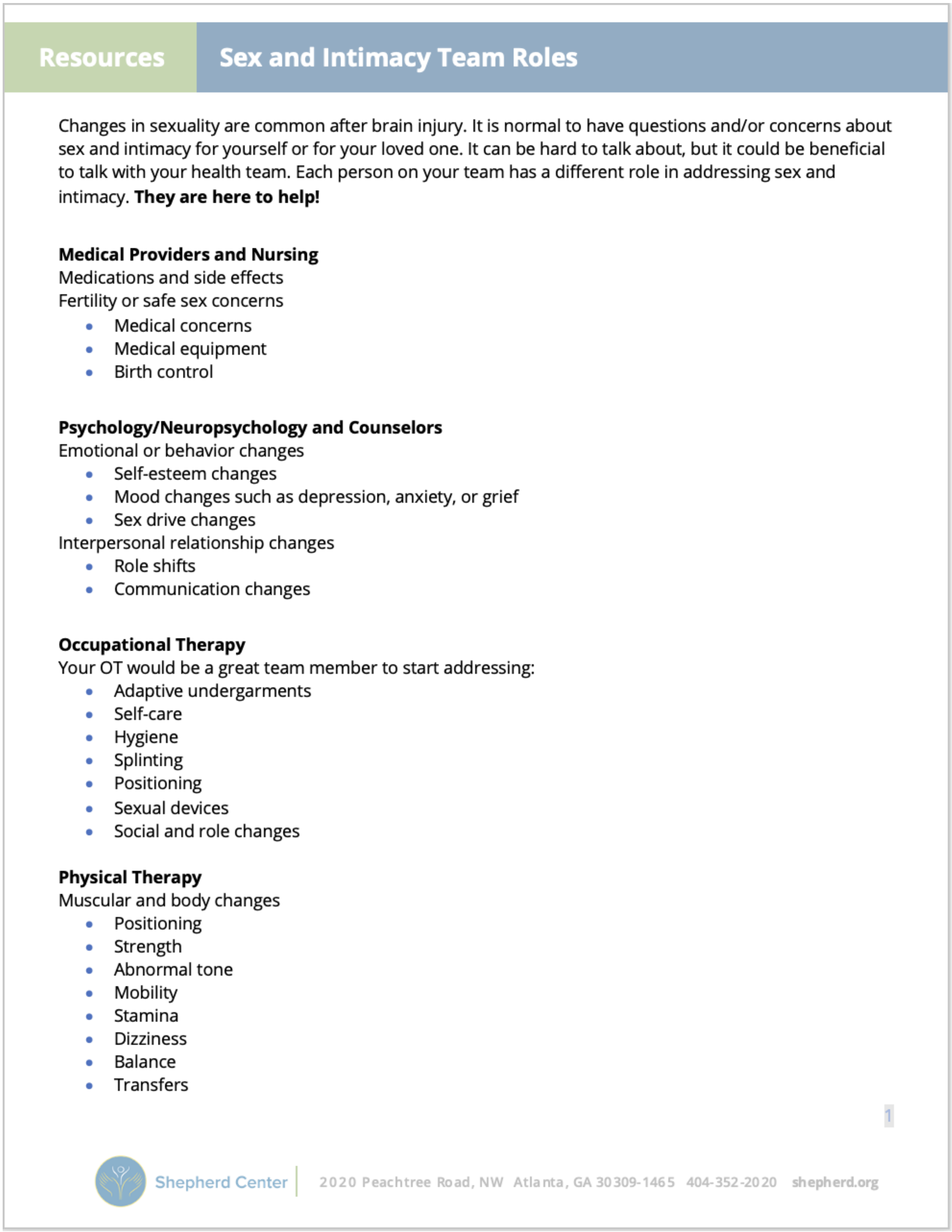
- Sit on top of your partner in a supported position.
    - Place pillows to support your back and sides.
    - Place pillows to position your partner.
- Either partner can receive vaginal sex in this position.

References

https://www.uhn.ca/TorontoRehab/Clinics/Outpatient_Stroke_Services/Documents/Comfortable_Sex_Positions_Patients_Who_Have_Had_Stroke.pdf

https://www.springrose.co/blogs/blog/sex-positions-for-stroke-survivors

Sex and Intimacy Team Roles



Resources | **Sex and Intimacy Team Roles**

Changes in sexuality are common after brain injury. It is normal to have questions and/or concerns about sex and intimacy for yourself or for your loved one. It can be hard to talk about, but it could be beneficial to talk with your health team. Each person on your team has a different role in addressing sex and intimacy. **They are here to help!**

Medical Providers and Nursing
Medications and side effects
Fertility or safe sex concerns

- Medical concerns
- Medical equipment
- Birth control

Psychology/Neuropsychology and Counselors
Emotional or behavior changes

- Self-esteem changes
- Mood changes such as depression, anxiety, or grief
- Sex drive changes

Interpersonal relationship changes

- Role shifts
- Communication changes

Occupational Therapy
Your OT would be a great team member to start addressing:

- Adaptive undergarments
- Self-care
- Hygiene
- Splinting
- Positioning
- Sexual devices
- Social and role changes

Physical Therapy
Muscular and body changes

- Positioning
- Strength
- Abnormal tone
- Mobility
- Stamina
- Dizziness
- Balance
- Transfers

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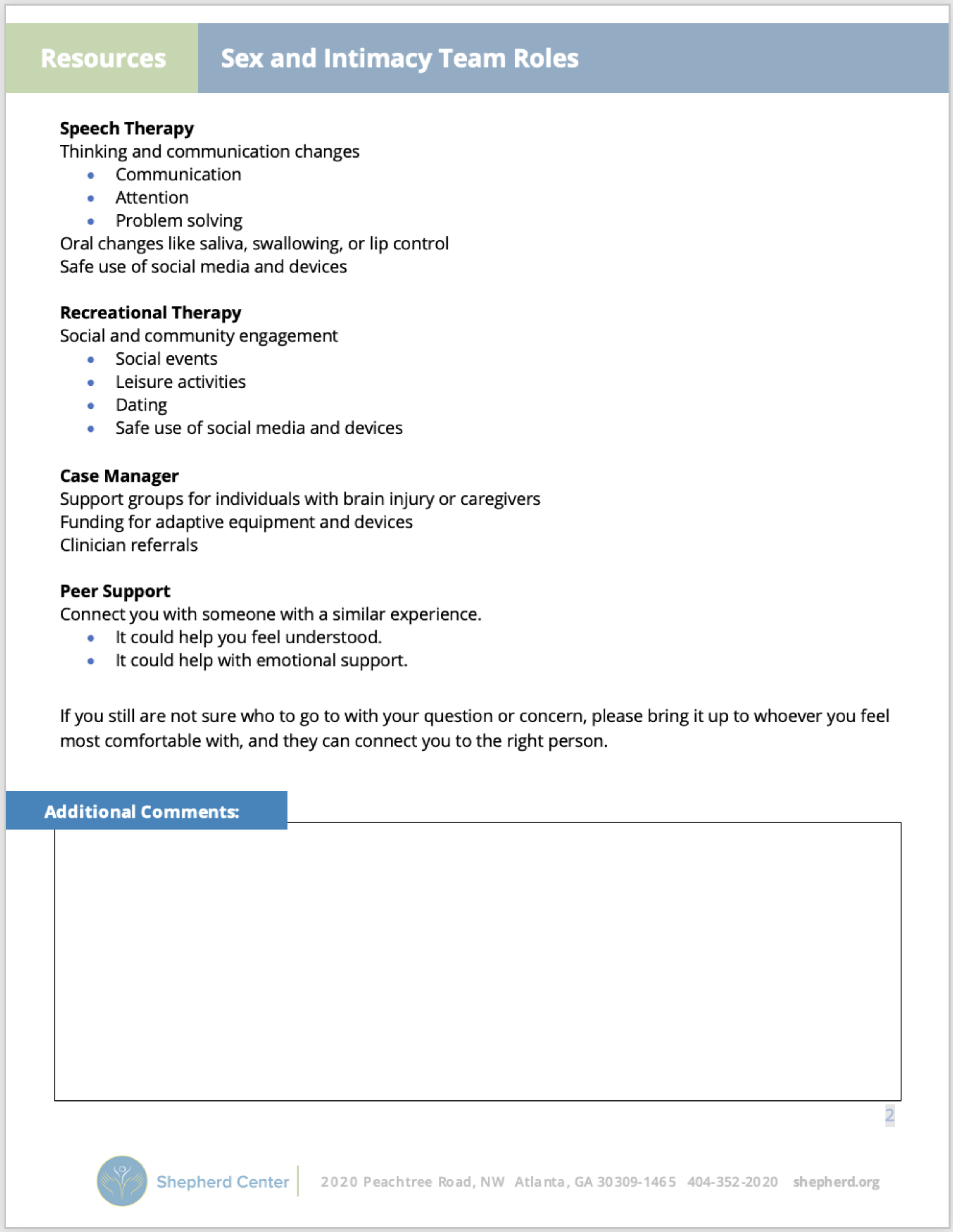

Resources **Sex and Intimacy Team Roles**

Speech Therapy

Thinking and communication changes

- Communication
- Attention
- Problem solving

Oral changes like saliva, swallowing, or lip control

Safe use of social media and devices

Recreational Therapy

Social and community engagement

- Social events
- Leisure activities
- Dating
- Safe use of social media and devices

Case Manager

Support groups for individuals with brain injury or caregivers

Funding for adaptive equipment and devices

Clinician referrals

Peer Support

Connect you with someone with a similar experience.

- It could help you feel understood.
- It could help with emotional support.

If you still are not sure who to go to with your question or concern, please bring it up to whoever you feel most comfortable with, and they can connect you to the right person.

Additional Comments:

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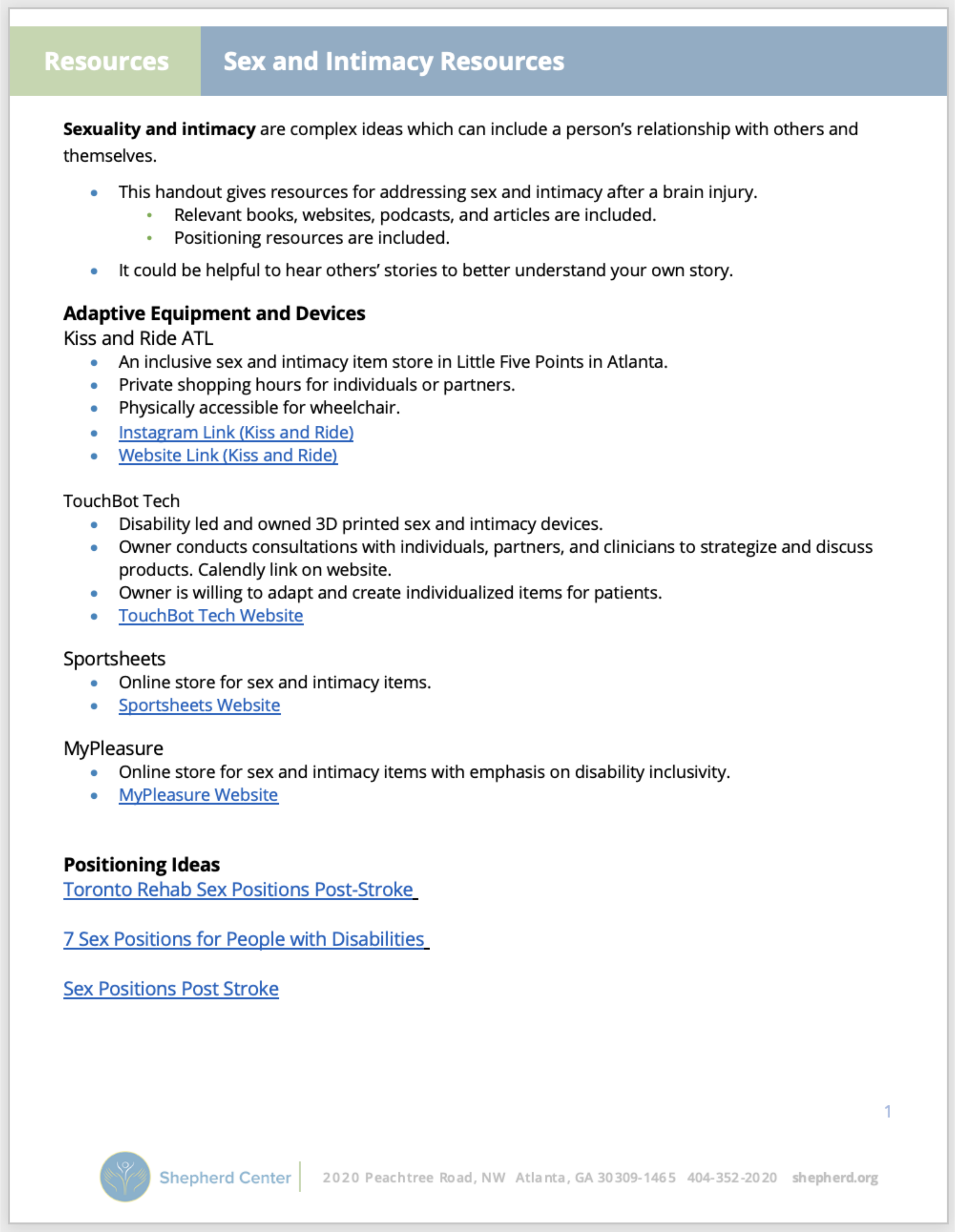
Sexuality and Intimacy Resources



Resources **Sex and Intimacy Resources**

Sexuality and intimacy are complex ideas which can include a person's relationship with others and themselves.

- This handout gives resources for addressing sex and intimacy after a brain injury.
  - Relevant books, websites, podcasts, and articles are included.
  - Positioning resources are included.
- It could be helpful to hear others' stories to better understand your own story.

Adaptive Equipment and Devices

Kiss and Ride ATL

- An inclusive sex and intimacy item store in Little Five Points in Atlanta.
- Private shopping hours for individuals or partners.
- Physically accessible for wheelchair.
- Instagram Link (Kiss and Ride)
- Website Link (Kiss and Ride)

TouchBot Tech

- Disability led and owned 3D printed sex and intimacy devices.
- Owner conducts consultations with individuals, partners, and clinicians to strategize and discuss products. Calendly link on website.
- Owner is willing to adapt and create individualized items for patients.
- TouchBot Tech Website

Sportsheets

- Online store for sex and intimacy items.
- Sportsheets Website

MyPleasure

- Online store for sex and intimacy items with emphasis on disability inclusivity.
- MyPleasure Website

Positioning Ideas

Toronto Rehab Sex Positions Post-Stroke

7 Sex Positions for People with Disabilities

Sex Positions Post Stroke

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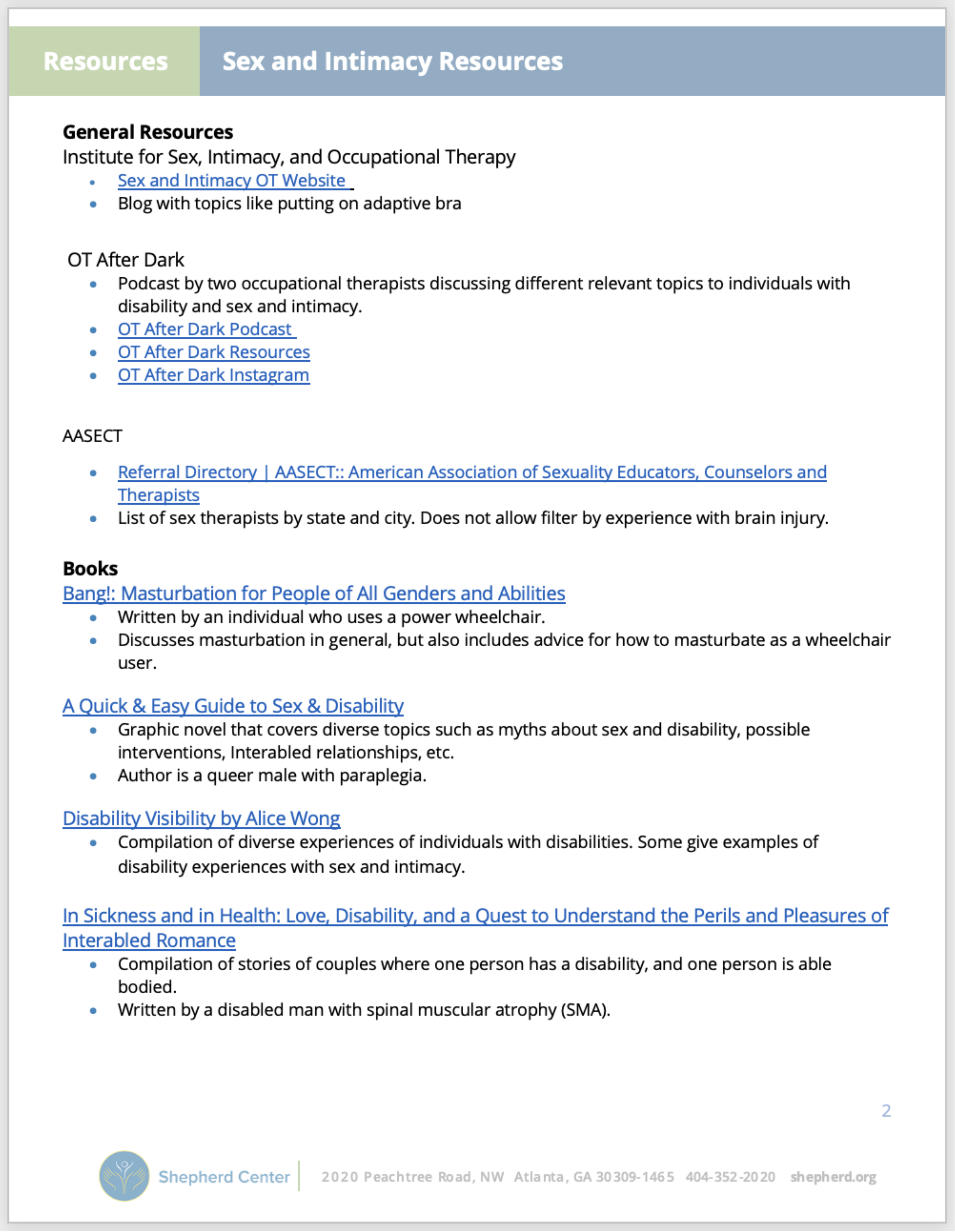


Resources **Sex and Intimacy Resources**

General Resources

Institute for Sex, Intimacy, and Occupational Therapy

- Sex and Intimacy OT Website
- Blog with topics like putting on adaptive bra

OT After Dark

- Podcast by two occupational therapists discussing different relevant topics to individuals with disability and sex and intimacy.
- OT After Dark Podcast
- OT After Dark Resources
- OT After Dark Instagram

AASECT

- Referral Directory | AASECT:: American Association of Sexuality Educators, Counselors and Therapists
- List of sex therapists by state and city. Does not allow filter by experience with brain injury.

Books

Bang!: Masturbation for People of All Genders and Abilities

- Written by an individual who uses a power wheelchair.
- Discusses masturbation in general, but also includes advice for how to masturbate as a wheelchair user.

A Quick & Easy Guide to Sex & Disability

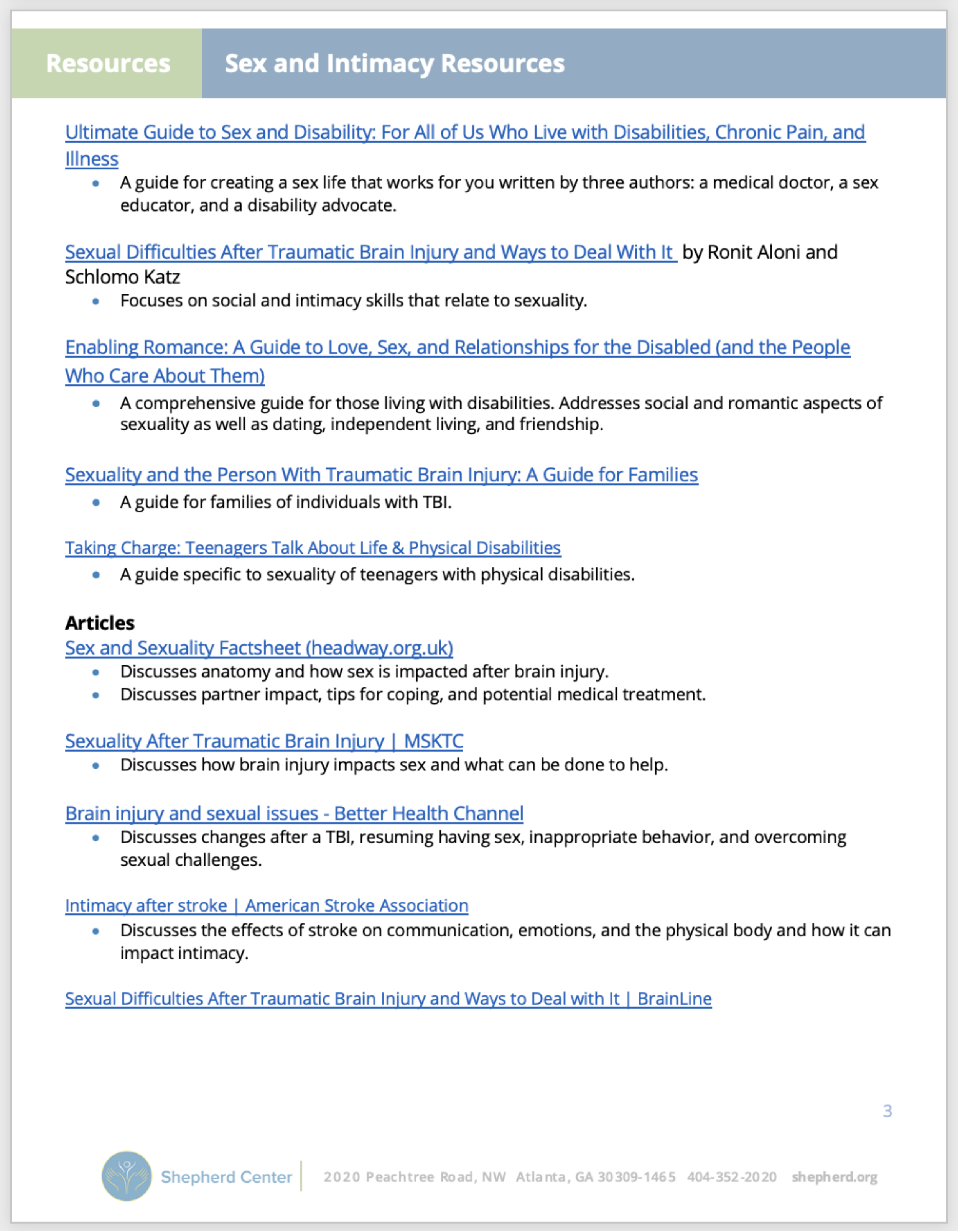
- Graphic novel that covers diverse topics such as myths about sex and disability, possible interventions, Interabled relationships, etc.
- Author is a queer male with paraplegia.

Disability Visibility by Alice Wong

- Compilation of diverse experiences of individuals with disabilities. Some give examples of disability experiences with sex and intimacy.

In Sickness and in Health: Love, Disability, and a Quest to Understand the Perils and Pleasures of Interabled Romance

- Compilation of stories of couples where one person has a disability, and one person is able bodied.
- Written by a disabled man with spinal muscular atrophy (SMA).



Resources

Sex and Intimacy Resources

Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness

- A guide for creating a sex life that works for you written by three authors: a medical doctor, a sex educator, and a disability advocate.

Sexual Difficulties After Traumatic Brain Injury and Ways to Deal With It by Ronit Aloni and Schlomo Katz

- Focuses on social and intimacy skills that relate to sexuality.

Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People Who Care About Them)

- A comprehensive guide for those living with disabilities. Addresses social and romantic aspects of sexuality as well as dating, independent living, and friendship.

Sexuality and the Person With Traumatic Brain Injury: A Guide for Families

- A guide for families of individuals with TBI.

Taking Charge: Teenagers Talk About Life & Physical Disabilities

- A guide specific to sexuality of teenagers with physical disabilities.

Articles

Sex and Sexuality Factsheet (headway.org.uk)

- Discusses anatomy and how sex is impacted after brain injury.
- Discusses partner impact, tips for coping, and potential medical treatment.

Sexuality After Traumatic Brain Injury | MSKTC

- Discusses how brain injury impacts sex and what can be done to help.

Brain injury and sexual issues - Better Health Channel

- Discusses changes after a TBI, resuming having sex, inappropriate behavior, and overcoming sexual challenges.

Intimacy after stroke | American Stroke Association

- Discusses the effects of stroke on communication, emotions, and the physical body and how it can impact intimacy.

Sexual Difficulties After Traumatic Brain Injury and Ways to Deal with It | BrainLine