Cooper Neurological Institute

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Cooper Neurological Institute

Kayla Cupano

Final Culminating Project

Nova Southeastern University
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Abstract

Cooper Neurological Institute (CNI) is part of Cooper Specialty Care, a state-of-the-art center that offers several medical specialties and services for individuals with neurological disorders. The mentor that I collaborated and worked with throughout the capstone experience was a licensed clinical social worker, that worked directly with neurologists particularly those that specialized in movement disorders. The Accreditation Council for Occupational Therapy Education (ACOTE) focus areas that I am complete d my capstone experience and culminating project on were education and advocacy. I identified several gaps and areas of need within the site and population that I could contribute to and complete my culminating project in. I have produced several projects to meet the needs of the site and the population that include: two presentations at education days, a resource booklet for patients and healthcare professionals, and three resource guides for the Huntington’s Disease Society of America (HDSA). The products that I have created throughout this capstone experience, provide opportunities to be continued and sustained in the future by my mentor and the site.
Introduction to Capstone Project

Cooper Neurological Institute (CNI) is part of Cooper Specialty Care, a state-of-the-art center that offers several medical specialties and services including: cardiology, endocrinology, nephrology, neurology, orthopedics, physical medicine and rehabilitation, physical, occupational, and speech therapies, primary care, podiatry, and pulmonology, at one convenient location. CNI is designed to offer diagnosis, treatment, and supportive services for individuals with neurological and neurosurgical issues. Treatment options and programs are offered to patients such as support groups, integrative medicine, nutrition, psychological counseling, the latest information on research and clinical trials, and case management. The population served at this site include individuals with cognitive disorders, balance problems, brain tumors, dystonia, epilepsy, tremors, seizure disorders, headaches, and movement disorders such as Huntington’s Disease (HD) and Parkinson’s Disease (PD). Case management is provided to patients of the Neurologists at CNI and a Licensed Clinical Social Worker (LCSW) may provide assistance, knowledge, and resources for individuals that experience challenges. These challenges may consist of insurance issues, coverage for durable medical equipment (DME) and mobility devices, inquiries about financial assistance programs for home-care, medication management issues, and offers support groups, education days, and additional communication between the physician and patient.

The mentor that I collaborated and worked with throughout the capstone experience, is Corlynn Hullfish, LCSW, who is the social worker at CNI. She works directly with the Neurologists, and specifically with those that are movement disorder specialists. The population that Corlynn most often works with are individuals with HD and PD. In addition to the Cooper Neurology population, Corlynn also works directly with the Parkinson Council, The American
Parkinson Disease Association (APDA), and the Huntington’s Disease Society of America (HDSA) to provide symposiums, support groups, resource guides, and education days. During my capstone experience, I participated and was involved in the implementation of these activities.

The Accreditation Council for Occupational Therapy Education (ACOTE) focus areas that I am completing my capstone experience and culminating project on are education and advocacy. More specifically throughout my capstone experience, I have created a presentation for the Parkinson’s Disease Symposium, to educate those with PD, their care partners, physicians, and social workers, on what occupational therapy (OT) is, strategies for improving function and independence, transfer and caregiver recommendations, and adaptive equipment information. In addition, I also presented on daily living strategies for individuals with Huntington’s Disease, and their care partners, from an OT perspective for the HDSA education day. Throughout my capstone experience, I also created a resource on DME and AE for the neurology physicians and medical assistants, social workers, care partners, and patients to educate on the equipment that can improve the likelihood of an individual with HD or PD to remain at home longer with improved function and independence. Lastly, I have also updated the current New Jersey Caregiver Resource Guide that is provided through HDSA, and have created a guide that is specific to the Eastern Pennsylvania and Delaware areas.

**Literature Review**

Huntington Disease (HD) is a rare, progressive, genetic, neurodegenerative disease that affects the basal ganglia and frontal lobe of the brain, and impacts an individual’s movement, cognition, and behavior. Signs and symptoms consist of cognitive, physical, emotional, and behavioral changes, and may begin during youth (juvenile HD), however typical onset is near
forty years old. Cognitive symptoms include impaired memory, problem solving, planning, and concentration (Domaradzki, 2015). Physical symptoms consist of involuntary muscle movements called chorea, balance and gait deficits, and difficulty with speech and communication. Emotional symptoms may include impulsivity, mood changes, and disinhibition. Lastly, behavioral changes such as depression, antisocial behaviors, and aggression may occur. HD is a genetic condition caused by the repetition of a mutated gene, that has a fifty percent risk of being passed from parent to child (Domaradzki, 2015).

Literature indicates that in 2018, the prevalence of HD in the United States was approximately 40,000 individuals, and that it is possible that there are nearly 200,000 individuals currently at risk of being gene positive for HD (Yohrling et al., 2020). Individuals with HD have decreased postural stability, and therefore can be at a greater risk for falls due to balance issues and the presence of akinesia and chorea movements. Postural control facilitates more purposeful movement and may promote independence during activities of daily living (ADLs). In a study by Panzera et al. (2010), the posture of individuals with HD was compared to a control group of non-HD individuals, while performing three functional motor tasks (stepping up and over an object, moving from a sitting to standing position, and stepping and turning). Results from this study indicated that individuals with HD were significantly slower to complete the functional tasks, had an increase in center of gravity sway, and demonstrated a reduced amount of force to lift lower limbs to step over an obstacle (Panzera et al., 2010).

This literature, indicated that bradykinesia may occur during dynamic functional tasks that involve posture, stability, and sequential motor and mobility movements. It also indicated individuals with HD demonstrate difficulty changing their base of support, shifting weight from one foot to another, and maintaining postural stability during dynamic tasks (Panzera et al.,
Caregivers are an essential part of the care team for an individual with HD, due to the early onset of symptoms and the nature and progression of the disease. In a national survey for individuals with HD and their caregivers, Anderson et al. (2019), discovered that caregivers reported the need of assistance with ADLs such as dressing, bathing, and feeding, and with instrumental activities of daily living (IADLs) such as home management and financial responsibilities. Utilization of online forums, HD social media outlets, and researching clinical trials were noted as common ways for caregivers to access care.

However, the need and concern for accessible and credible information for individuals with HD and their families was expressed, as well as medical education on the progression of HD, support for financial planning, and the resources to access care on a day-to-day basis (Anderson et al., 2019). There is often a shift in roles and responsibilities that occur in the dynamic of a family throughout the different stages of the disease and family life cycle, and therefore, it is pertinent that healthcare professionals be mindful of this impact and provide the support and appropriate care during this time. In a study by Rothing (2014), Malterud (2014), and Frich (2014), fifteen family caregivers in families affected by HD were interviewed and voiced the issue that the family roles and the ability to maintain a reciprocal relationship to a spouse, sibling, or parent significantly changes. It was also expressed that feelings of guilt, vulnerability, and isolation may occur due to the chance of being affected in the family, a fragmented family structure, and difficulties maintaining social relationships and connection of experiences with others.

Due to the stages of HD and the different speed that progression may occur, family structure and stability may often change, and therefore vary the level of burden, stress, and worry of families affected by HD (Rothing, 2014, Malterud, 2014, Frich, 2014). Exercise has been
indicated throughout literature as effective in enhancing strength and range of motion for individuals with Parkinson’s Disease (PD) (Horne et al., 2019). However, there is limited research pertaining to the effectiveness of strength training for individuals with HD due to the motor control deficits. In a study by Quinn et al. (2010), the view and attitude on independent exercise programs for individuals with PD and HD were assessed, specifically what factors are considered when prescribing and designing the exercise program, and client perspective on implementation of exercise at home. The focus groups and interviews from this study showed that exercise may enhance function and strength, and that there were several forms of encouragement provided by the therapists to exercise in various ways (Quinn et al., 2010).

It was noted, that both individuals and therapists recognized the barriers to engaging in at-home exercise such as disease-specific limitations, safety, and location of exercise (Quinn et al., 2010). Individuals with HD and PD felt that chorea, stiffness, and bradykinesia could impact their ability to exercise, and therapist’s thought that cognition is the main factor impacting an individual’s ability to comply with the exercise program independently with accurate memory and judgement. Due to this decreased judgements for all individuals, safety was not a noted concern from individuals with PD and HD. However, safety within the home environment such as a safe space and positioning during exercise tasks, especially balance exercises, was a primary concern and implication for therapists when designing and prescribing this type of program (Quinn et al., 2010). Location of exercise and an individual’s comfortability exercising alone or within a group was an important theme that therapist’s noted impacted an individual’s compliance and motivation to continue exercise. In this study, therapist’s provided strategies for motivation and made recommendations and increased knowledge for barriers to exercise within
the home environment independently and safely for individuals with PD and HD (Quinn et al., 2010).

Parkinson’s disease (PD) is a neurological condition that occurs when cells in the substantia nigra die, therefore reducing the amount of dopamine in the brain, which impacts coordinated, smooth movements of the body. Other symptoms of PD include tremor, muscular rigidity, bradykinesia, postural deficits, and speech issues (Parkinson’s Foundation, 2021). Individuals with PD may also develop Parkinson’s dementia, if the memory deficits occur after the motor symptoms (Fleisher, 2021). This is due to the overall decreased brain function and is typically related to Lewy bodies. Parkinson’s dementia affects executive functioning, memory, mood, and speed of thinking. Parkinson’s is a clinical diagnosis, through the presentation of a combination of symptoms and a neurological examination (Fleisher, 2021).

A DaTscan (dopamine transporter scan) is not required to diagnosis PD; however, it can be a helpful imaging assessment tool to see the amount and disbursement of dopamine levels in the brain, and can be used to differentiate between the diagnosis of PD or other movement disorders such as essential tremor (Parkinson’s Foundation, 2021). PD is the second most common neurodegenerative disorder, with approximately 60,000 individuals in the United States (US) diagnosed each year 50 (Parkinson’s Foundation, 2021). More than 10 million people worldwide are living with PD, affecting men 1.5 times more than women. PD is more prevalent in individuals 80 years of age and older, with more than 1,900 people per 100,000 diagnosed. 41 people per 100,000 are diagnosed before age 50 (Parkinson’s Disease Statistics, 2021).

In a study by Savica et al. (2017), that projected the prevalence of PD with and without dementia in the US by 2060, found that there will be a doubled amount of individuals with PD without dementia, and a tripled amount of individuals with PD with dementia. The symptoms
and impact of PD to an individual’s life, vary from person to person, and it is important that the needs and treatment plan is individualized and client-centered. An occupational therapist (OT) is part of the rehabilitation team and utilizes evidence-based research to increase function and independence during day to day living, and provides task and environmental modifications and adaptive equipment for ADLs. OTs may address medication management such as providing cognitive strategies for adherence to a medication schedule, utilization of external supports such as an alarm or pill box, and increase fine motor skills required for opening small containers and to pinch and pick up a small pill (Jackson, 2019).

To address mobility in PD, an OT may provide recommendations for handrails, grab bars, and bed rails for increased safety and independence during functional mobility within the home environment. Adaptive equipment such as a commode, shower chair, tub-transfer bench, and a long-handled sponge may also be suggested to increase independence during bathing and toileting tasks (Jackson, 2019). Utilization of weighted utensils can assist in stabilization of tremor and increase independence during eating and feeding. Additional equipment recommendations may include a rocking t-knife, plate guard, non-slip grip mats, and nosey cups to facilitate independence during meal times (Jackson, 2019).

In an article by Brock et al. (2019), the importance of a multi-disciplinary team was discussed in ensuring that individuals with PD have a direct point of contact with specialist services, and that care is accessible in order to manage their condition. Individuals with PD may experience increased impulsivity and engage in repetitive reward-based behaviors such as gambling, hypersexuality, shopping, and binge eating (Brock et al., 2019). The progression and nature of the disease, requires that an individual with PD has the support to manage these behaviors, assistance with decision making, and proper medication administration times. Early
referral to skilled services such as physical, occupational, and speech therapy are crucial to
address and facilitate improvements with balance, medication management, fine and gross motor
skills, activities of daily living, communication, and swallowing (Brock et al., 2019).

In a study by Amboni (2013), Barone (2013), and Hausdorff (2013), it was found that
gait and an individual’s balance is not independent from other tasks, and that it incorporates
cognitive function such as executive functioning, attention, and judgement in order to create
smooth, coordinated movements during functional mobility. This study showed that cognition
directly contributes to an individual’s ability to maintain balance and control during gait and fall
prevention. This knowledge creates clinical implications such as utilizing integrated assessment
tools that assess several domains, as well as cognitive therapy strategies for fall prevention and
maintaining coordination while using a mobility device, such as cane, walker, or wheelchair
(Amboni, 2013, Barone, 2013, Hausdorff, 2013). In addition to the internal supports, individuals
with PD benefit from external supports and cues from care-partners. In an article by Benton
(2019) and Meyer (2019), care-partners may experience stress, burden, and day to day
challenges, and would benefit from healthcare professionals to provide accessibility to resources
and support throughout the stages and progression of PD.

This article encourages healthcare professionals to understand that care-partners and
family members may not be able or willing to provide care for a loved one (Benton, 2019,
Meyer, 2019). At the same time, to also include family during sessions, appointments, and in the
plan of care when appropriate and with permission to do so. It is critical to address care-partner
needs, capacity, and accessibility to resources. In this article, it is said that, “The negative
consequences associated with caregiving are not inevitable.” With proper implementation of
caregiver resources, support, community-based programs, knowledge, and empowerment of
understanding what services their loved one may be eligible for, care-partners will feel better equipped and therefore provide better care for themselves and their loved ones (Benton, 2019, Meyer, 2019).

**Needs Assessment**

When I completed a needs assessment at my capstone site, I identified several gaps and areas of need within the site and population that I could contribute to and complete my culminating project in. In the specialty care building, there is a rehabilitation department; however, it consisted of mostly physical therapists, and one OT that was a certified hand therapist, and there were no other OTs at this site. I worked closely with my mentor, to identify the areas within the neurology department that I could utilize an occupation-based approach to benefit the needs of the facility and population. The evidence obtained from the literature review that I completed, as well as from the several encounters that my mentor and I had with patients and care-partners regarding day to day challenges, led me to see an opportunity and need for an occupational therapist in this setting. OTs can utilize their knowledge and expertise to implement interventions and strategies that enhance function and maximize independence in all areas of occupation.

I identified an area of need for increased patient and care-partner education and accessibility to resources and support. As a result, I presented at a Parkinson’s Disease Symposium and at an Huntington’s Disease Education Day. The purpose of these educational presentations were to: provide knowledge on performance and participation during ADLs and IADLs, the utilization and coverage of AE and DME, steps for proper transfers, challenges and strategies related to mobility, posture, mental health, cognition, and balance, and home environment safety and modification. I recognized that the education days would provide
immediate knowledge, but that there was a gap in the immediate access to these resources during difficult situations and in time of need. It would be beneficial for patients, care-partners, and healthcare professionals to have a resource booklet available at any moment to look back on, available in physical and virtual format, that would provide strategies across several areas of occupation that were frequently identified as challenges for both of these populations. The resource booklet that I created included sections related to: ADLs, AE and DME, fall prevention, mental health tools, cognitive, mobility, postural, and motor-based activities, and types of therapies.

It was also found through the experience of conversations with patients and care-partners and evident throughout literature, that an OT could advocate for patients and families, but also provide strategies for these individuals to advocate for themselves and feel empowered to do so. Accessibility to other individuals with similar experiences through the utilization of support groups are of importance and benefit to an individual’s mental health, social participation, and for support and advice during day to day challenges. I identified that my participation and assistance in the implementation of four different support groups related to PD, would be beneficial in sharing my knowledge related to advocacy, education, environment and task adaptation, and occupational performance. For individuals with HD and their families, I also identified a similar need for accessibility to resources. An online resource guide available on the state chapter websites would be useful for immediate access to contact information for several resources available by county. Therefore, I updated the current NJ resource guide, and created a resource guide for both the Eastern PA and DE chapters.
Goals & Objectives Achieved during the Capstone Project and Experience

Throughout my capstone experience, I achieved three goals along with two objectives for each goal, that I addressed through the completion of my capstone project. The first goal that I set was to obtain knowledge on the process of case management and the responsibilities and roles of a social worker in a medical setting for patients with neurological conditions. To achieve this goal, I created two objectives. The first objective was to learn about government and state insurance coverage, state-funded assistance programs that provide respite care, meals, support, and skilled therapy service coverage through insurance, including coverage of DME. The second objective was to become educated on medications that patients with neurological conditions typically are prescribed, and the role of a social worker in regards to communication between patient, care-partners, and physicians. I advanced my knowledge in these topics each week by attending webinars and education courses, participating in support groups and education days with healthcare professionals, and through the observation and experience that I gained first-hand working alongside the social worker. The experience that I gained from the observation of the social worker’s direct conversation with patients, care-partners, and physicians, showcased the essential role in communication, holistic care, and the support and access to resources that a social worker brings to this setting and population.

The second goal that I worked to achieve during my capstone project, was to participate and present at HDSA, Parkinson Council, and Cooper Neurological Institute’s symposiums and education days. The two objectives that I set in order to achieve this goal, was to present as a speaker at Parkinson’s Disease Symposium and at the Education Day for the Huntington’s Disease Society of America (HDSA). The second objective was to participate, present, and assist in the implementation of support groups from the Parkinson Council and the American
Parkinson Disease Association (APDA) for individuals with PD and their care-partners. On the third week of my capstone experience, I presented at the PD Symposium which consisted of over ninety attendees. The presentation was titled, *Occupational Therapy (OT): A Holistic Approach to Adapting to Life with Parkinson’s Disease*.

The topics that I presented on included: what OT is and how it is covered, the differences between the types of therapy available for individuals with PD, cognition, postural, balance, and mobility strategies, environmental modification and home safety assessments, adaptive equipment for all areas of occupation, and transfers and caregiver safety. I also presented alongside two neurologists, during the thirteenth week of my capstone experience, at HDSA’s education day for individuals with HD and their families. The presentation was titled, *Daily Living Strategies for Individuals with HD: From an Occupational Therapy Perspective*. The topics that I presented on included: strategies for chorea, cognition, mental health, and visual perceptual skills, exercise and balance, as well as daily living tips for areas of occupation such as employment, driving, social participation, ADLs and IADLs, and medication management. The passion and experience that I have gained working with HDSA, has led to an interest to be a part of the board in the future.

I also assisted and participated in five support groups related to PD, participants of the groups included: men with PD, active/high-functioning men with PD, women with PD, care-partners of an individual with PD, and a Parkinson’s Roadmap for Education and Support Services (PRESS) group for individuals recently diagnosed with PD in the last five years. The PRESS group is an eight-week commitment with set topics each week that include: motor and non-motor symptoms, medication management, exercise, physical symptoms, daily coping and relationships, tips for daily living, caring for yourself and others, and building your healthcare
team. In these groups, I was able to educate the participants and provide information related to exercise, daily living, adaptive equipment, and home safety. In addition to the PRESS group, I also participated in a support group for young individuals that recently had a stroke. The positive impact that several of the support groups had on me, has led to the discussion with my mentor of creating a similar support group in the future for individuals recently diagnosed with Huntington’s Disease.

The final goal that I achieved during my capstone experience was to create resources and educate patients and caregivers to promote improved well-being, function, and independence during daily tasks. The first objective to this goal was to create resources of adaptive and durable medical equipment with visuals, that explain the purpose and coverage to educate patients, caregivers, social workers, and physicians of the equipment that is often recommended. The second objective was to update the current NJ resource guide, and to develop a resource guide for the Eastern Pennsylvania and Delaware chapters. At the beginning of the capstone experience, the initial thought was to create a resource with only equipment, as that was an area that my mentor felt the setting could benefit from. However, through my own assessment of the needs of the site and population, I found that it would be beneficial to create a booklet with topics pertaining to: daily living tips, fall prevention, mental health strategies, types of therapy, and cognitive, postural/mobility, and motor-based strategies. I created this resource booklet for patients, care-partners, and healthcare professionals, both in physical and virtual format.

In addition to the resource booklet, I completed three resource guides that will be posted onto the HDSA state chapter website pages. These included the creation of a guide for the Eastern Pennsylvania and Delaware chapters, and I updated and made additions to the current NJ chapter resource guide. The resource guides provide a one spot location of resources that
individuals with HD or their family members may need quick access to. The resources are organized by county for convenience of not needing to navigate through the entire guide to locate needed supports. The guides offer support and resources for: county assistance offices, caregiver programs, adult protective services, crisis centers, homeless prevention services, nursing homes with dedicated HD units, HDSA support groups, counseling services, social clubs, center of excellences and other centers specializing in HD care, independent physicians treating HD, elder care/disability attorneys, driving evaluations, swallowing studies, cookbooks and nutrition, preimplantation genetic diagnosis (PGD) and in-vitro fertilization (IVF), help with medications, brain donation, financial assistance, therapies for individuals with HD, long-term care, HD youth, internet resources, and a crisis flow sheet.

The sixteen week capstone experience, has created several learning opportunities that have enhanced my knowledge within the OT and social work fields, and has increased my understanding of neurological conditions, and the specific populations that are impacted. During this time, I have engaged in a variety of planned and unplanned experiences that have improved my interdisciplinary communication, increased my connections and network to OTs and other healthcare professionals, and furthered my education on specific areas of interest. Twice a week during the capstone experience, I was in-person with my mentor at the outpatient neurology physician office. In the office, we worked together on case management, and understanding the whole-person and situation when presented with questions or sought out for support from patients, care-partners, and physicians. If a patient specifically with HD or PD, was at the office for a visit with one of the movement-disorder specialists, we visited with the patient and provided the social worker’s contact information should any support be needed throughout the progression of the disease. Interdisciplinary written and verbal communication, through in-
person conversations, phone calls, and emails, was noted to be crucial to ensure that the patient was receiving the most effective all-around care.

Three times per week, I worked remotely. I was in constant communication with my mentor throughout the day pertaining to providing assistance for patients, participating in support groups, and through the work of the several projects I was completing for my capstone project. I communicated with my mentor with any questions I had when creating the resource guides and presentations, to ensure that my work met the standards that we had set during my time working from home. My mentor and I discussed the goals for the week that I had set for myself to complete, and at the end of each day, I sent an email to my mentor explaining what I had completed that day, and my overall progress for each project. This helped to ensure that we were on the same page and that expectations were being met during remote work.

In addition to the planned experiences that I had, I was fortunate to have several unplanned, however extremely meaningful and beneficial, experiences that directly enhanced my learning within specific areas of OT. I had opportunities to observe three OTs working in different settings, which included an out-patient hand therapy clinic, in-patient acute care in the hospital, and an out-patient setting. These observation experiences, provided knowledge and expertise, and the ability for me to make connections to what I have learned thus far throughout my capstone experience with clinical practice. I also was able to participate in several exercise classes specific for individuals with PD, such as boxing and dance, and observe an LSVT-LOUD group speech therapy session virtually. The unplanned experiences that I have gained throughout my capstone experience, has led me to meet several OTs and other healthcare professionals that work in the settings and with the populations that I have become passionate about. I also was able to go to a Good Will Medical Supply store with my mentor, that offers several refurbished
home medical equipment to individuals and families, with no script needed at an affordable price. This provided me with additional knowledge of the types of equipment and a place to refer patients and families, to obtain equipment that may not otherwise be covered by insurance.

Finally, the last unplanned experiences that I was able to engage in during the sixteen weeks, was becoming certified in Lee Silverman Voice Treatment (LSVT) BIG. LSVT-BIG is for individuals with PD or other neurological conditions that improves self-care, balance, walking, and teaches individuals to use extra effort to produce bigger movements that often become smaller and slower with the disease. In addition, I also applied and was selected as one of two students for the OT field, to participate in the Parkinson’s Foundation Team Training, which is an intensive curriculum and interactive training for nurse practitioners, physician assistants, nurses, PTs, OTs, SLPs, and social workers, to increase knowledge about PD and to enhance interprofessional care in the treatment of PD. Both of these trainings will be beneficial in my practice and for the populations that I work with as an occupational therapist.

**Summary**

**Results**

Throughout the capstone experience, I have produced several projects to meet the needs of the site and the population of individuals with neurological conditions that my mentor directly provided assistance to. I created two presentations for the HD and PD communities that were presented during education days with numerous attendees. The presentations were titled, *Occupational Therapy (OT): A Holistic Approach to Adapting to Life with Parkinson’s Disease* (Appendix A) and *Daily Living Strategies for Individuals with HD: From an Occupational Therapy Perspective* (Appendix B). The HD presentation was posted on the HDSA NJ Chapter website and was sent to several support groups for those that requested it or were not able to
attend. The PD presentation was also presented a second time to members of the JCC Katz PD group.

An additional product that was created during my capstone experience, was a resource booklet that is available in physical form for the site and virtually to be sent out electronically. This document is titled, *Resources for Patients, Care-Partners, & Healthcare Professionals, A Holistic Approach: From an Occupational Therapy Perspective* (Appendix C). This resource includes information that consists of: the purpose and possible coverage of DME, AE, and mobility devices, activity of daily living tips, fall prevention strategies, cognitive, postural, motor-based, and mobility strategies, types of therapy, and mental health tools. This resource has been beneficial to my mentor, specifically when contacted by a patient or physician requesting recommendations and resources. This resource booklet was also mentioned at both the HD and PD education days during my presentation. In addition throughout my capstone experience, I also participated in several support groups, and created a presentation on, *Daily Living Strategies* (Appendix D), for the PRESS Parkinson Disease group.

Another result of my capstone experience was the creation of two resource guides for families living with HD titled, *Resource Guide for Eastern Pennsylvania Families Living with HD* (Appendix E) and *Resource Guide for Delaware Families Living with HD* (Appendix F). I also updated the New Jersey chapter guide titled, *Resource Guide for New Jersey Families Living with HD*, (Appendix G), that was already created by my mentor in the past. These resource guides were posted on the respective HDSA chapter websites, and were referred to by email sent to those affiliated with HDSA. The resource guides provided information and resources split into county. Examples of information that the guides consisted of include: help
with caregiving, support groups, driving evaluations, help with medication, long-term care information, and physicians and centers specializing in HD care.

Lessons Learned and Recommendations

The capstone experience provided me with opportunity and knowledge that enhanced skills related to the specialized areas of advocacy and education. Through this experience, I gained an advancement of clinical practice skills, education related to the social work scope of practice, and became an advocate for occupational therapy and learned how to advocate for patient needs as a healthcare professional. I learned the true meaning of interdisciplinary communication and collaboration, and joining the expertise and scopes of practice together to best meet the needs of a patient or family. Also through the capstone experience, I learned the benefit in being resourceful and reliable when explaining information and providing accessibility to resources for patients and their families. This type of communication and efficiency will improve my documentation, advance my communication with other professionals, and enhance the education I provide to patients, families, and care-partners as a clinician.

For future work with the site and mentor during a capstone experience, I would recommend further advocacy opportunities such as advocating to congress and state legislatures, insurance companies, and durable medical equipment suppliers. I would also recommend the development of a support group that is similar to the PRESS PD group, for individuals that are newly diagnosed with HD, that is a safe-place program designed to provide information on several topics and areas of life impacted by the progression of the disease. Lastly, I would recommend involvement related to the several PD organizations and the HDSA board to continue education and advocacy related to OT and its benefits for these communities.
Project Sustainability

The products that I have created throughout this capstone experience, provide opportunities to be continued and sustained in the future by my mentor and the site. My mentor and I have discussed future utilization and the setup of information that I presented during support groups, such as pre-recorded presentations. Also, the two presentations that I gave during education days, have been requested and sent to individuals outside of the Cooper Neurology department, including those at a nursing home with a dedicated HD unit. The physical and virtual resource booklets, provide information and strategies for individuals with a variety of neurological conditions, and can be sustained and added onto for continued use in the future as evidence-based research progresses. The three resource guides that I have created for families living with HD, are sustainable and posted on chapter websites. I also provided my mentor with document versions of these guides, that are able to be edited as information and resource contact information may change.
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https://doi.org/10.3109/09638280903362712


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https://parkinsonsnewstoday.com/parkinsons-disease-statistics/


https://www.parkison.org/

Occupational Therapy (OT):
A Holistic Approach to Adapting to Life with Parkinson’s Disease

By: Kayla Cupano, OTD Student, kcupano@gmail.com
Nova Southeastern University, Doctorate of Occupational Therapy Program

OT Video

https://www.youtube.com/watch?v=ETcPH5-LmDw
What is Occupational Therapy?

- An evidence-based healthcare profession and part of the rehabilitation team that assists individuals across the lifespan, and aims to solve problems and barriers that interfere with a person’s ability to engage in activities meaningful to them, known as occupations.
- OT’s provide the most effective treatment that is up to date with current research
  - Client-centered & Culturally relevant

What is an Occupation?

Occupation:

- Activities that hold meaning and provide purpose within an individual’s daily life
- May be things that an individual wants to, needs to, or is expected to do (role)
- For example:
**8 Areas of Occupation that OT’s Address:**

**WHAT ARE IADLS?**
The Instrumental Activities of Daily Living

- **Cooking**
  - Preparing meals
- **House Cleaning**
  - Keeping living areas clean
- **Shopping**
  - Shopping for groceries
- **Personal Hygiene**
  - Bathing
- **Communication**
  - Talking on the telephone
- **Transportation**
  - Driving a car

**WHAT ARE ADLS?**
The Activities of Daily Living

- **Bathing**
  - Washing and maintaining body cleanliness
- **Dental Hygiene**
  - Keeping teeth clean and healthy
- **Toileting**
  - Using a toilet and独角

**Rest and Sleep**

- **Improve ability to perform movement**
- **Biomechanical approach**
- **Therapeutic exercise, mobility, and manual therapy**
- **Helps person get from point A to point B**

**Work**

- **Improve ability to communicate**
- **Cognitive/thinking skills, chewing/swallowing, language skills, and memory**
- **LSVT-LOUD**
- **Augmentative and alternative communication device**

**Education**

- **Holistic approach**
- **Environment, Routines, Expected roles, Activity demands, Supports and barriers**
- **Helps person do things at point A and B**

**Leisure**

- **Holistic approach**

**Play**

- **Holistic approach**

**Social Participation**

- **Holistic approach**

**Instrumental Activities of Daily Living (IADLS)**

- **Rest and Sleep**
- **Work**
- **Education**
- **Leisure**
- **Play**
- **Social Participation**

**Activities of Daily Living (ADLS)**

- **Rest and Sleep**
- **Work**
- **Education**
- **Leisure**
- **Play**
- **Social Participation**

**PT & OT: LSVT-BIG**

- **Improve ability to perform ADLs to maximize function and independence**
- **Holistic approach**
- **Environment, Routines, Expected roles, Activity demands, Supports and barriers**
- **Helps person do things at point A and B**
**OT Services**

- Physician script/referral for OT services
- **OT's:**
  - Create & promote occupational performance
  - Modify the task and environment via compensation & adaptation
  - Provide assistive equipment when necessary and appropriate
  - Establish & restore a skill or ability that has been impaired
  - Provide patient and caregiver education

- **OT & Parkinson's Disease:** Therapeutic exercise, ADL training, Balance/Proprioception Training, Fall prevention, Home modification and Home Safety Evaluation, Low vision, Cognition, Motor planning

- **Process:**
  - Evaluation: occupations, goals, supports, and barriers
  - Individualized tailored interventions
  - Upgrade/downgrades activities and goals
  - Modifies the task, Adapt the environment, provide assistive equipment

---

**Cognitive Strategies:**

- Daily Routine
- Provide Cues (gestural, verbal, physical, tactile) when needed
- Label frequently used drawers/cabinets around the home
- Short, concise when giving direction
- Reduce distracting stimuli as much as possible
- List, calendars, or notes to keep track of tasks
- Complex Tasks → Simple Tasks
- Visual schedule/Cue Cards for steps of an activity
- Encourage completion of step before moving to next step

**OT & PD**

---

**Postural Control Strategies:**

- Self-awareness of posture with verbal cues
- High-backed chair with armrests
- TV in front of person, not to the side
- Chair raiser or an electric chair that rises
### Balance
- Balance retraining
  - Speed
  - Endurance
  - Dynamic movements
  - Step over or Step around
  - Various surfaces
  - Doorways
  - Different feet positions
- Static before dynamic exercises
- Incorporate functional activity into balance exercises
- Sitting/Standing balance
- Sit to stand, Stand to sit transfers
- Functional reaching
- Turn, march, side-steps, retrieve items

### Exercise
- Balance and coordination
  - Stepping and direction changes
  - Dance steps
  - Throwing/catching
- Strengthening
  - Upper and lower extremities
  - Resistance training

### Motor-Based Activities:
- Boxing
- LSVT-Big
- Music/Dance Therapy
- Tai Chi
- Swimming
- Progressive cycling
- **These activities can help to progress:** speed, balance, endurance and ambulation

### OT & PD
- Strategy for Mobility:
  - Practice concentration on walking and not talking
  - Stop before changing direction
  - Walk in direction of an arc to turn in a wide space, safer than abrupt turn
  - Feet shoulder-width apart
  - Promote flow of walking: count to a beat, sing a song
  - Ensure good lighting on stairs, automatic when possible
Home/Environmental Modifications

**Kitchen**
- Arrange cabinets & drawers for frequently used items
- Sturdy step stool if needed, not a chair
- Remove clutter, extra furniture
- Frequently used items within reach

**Bathroom**
- Grab bars installed near toilet and in shower
- Raised toilet seat, Shower chair or bench
- Long-handled sponge, sponge mitt
- Items positioned in shower for easy access
- Non-skid mats
- Nightlights

**Living Area & Bedroom**
- Stabilize furniture
- Chairs with high backs and armrests
- Remove throw rugs and clutter
- Bed at a safe height for functional transfers
- Pillows and rolled towels for support in maintaining posture

---

Home Safety Assessments

- **Includes:**
  - Home hazard assessment
  - Home modifications and recommendations
  - Home walk-through using a checklist
  - OT’s complete, determine if in-home skilled therapy services may be beneficial if individual is homebound and utilizes home environment majority of time

- **Floor:** clutter, wires, throw rugs, uneven surfaces
- **Lighting:** stairway, hallway, throughout home, easy to find light switches, inside/outside
- **Outside:** well-lit walkways, even pathway, slippery surfaces, outside tools put away
- **Furniture:** steady, storing items, handrails on stairs, bed rails, grab bars in bathroom
Adapting the Visual Environment

- Central coffee tables moved to the side
- Avoid patterned floors/carpets when possible
- Plan a route to navigate any obstacles prior to walking
- Floor markers: for increased stride length use colored tape in contrasting color on floor in places where freezing often occurs or difficult turns (fan tape around the bend)
- Cue cards: step by step instructions to completing a task

Example:

Fasten button:

1. Grip button
2. Find hole
3. Push button into hole
4. Pull

<table>
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<tr>
<th>Problem</th>
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<tr>
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<td>2. Bend knees</td>
</tr>
<tr>
<td></td>
<td>3. Reach opposite arm across body</td>
</tr>
<tr>
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<td>4. Roll</td>
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</tbody>
</table>

Dressing

- Pair parts of an outfit together, label
- Sit in a chair to get dressed
- Use reacher to pull up pants
- Keychain ring on zippers to aide with opening and closing
- Allow plenty of time
Dressing

SOCK AID

https://www.silverts.com/shop-by-need/parkinson-s
https://magnaready.com/pages/about-us

Bathing/Grooming

LONG-HANDED SPONGE

SHOWER CHAIR

TUB TRANSFER BENCH

EASYHOLD GRIP
**Bathing/Grooming**

- **TRANSFER POLE**
- **ELECTRIC TOOTHBRUSH OR BUILT-UP HANDLE FOR TOOTHBRUSH/RAZOR**
- **GRAB BARS**

**Medication Management**

- **BRIGHTLY COLORED PILL BOX WITH SPRING-LOADED ASSISTANCE**
- **TABTIME VIBE PILL TIMER REMINDER**
- **HERO PILL DISPENSER**
  - Use the Hero app to program any pill regimen, simple or complex
  - Hero stores, sorts and dispenses up to a 90-day’s supply of 10 different medications
  - Push button for auto sort and dispense when Hero alerts you it’s pill time

© Can Stock Photo
Medication Management

Using a High-Contrast tray

Audio description of Using a High-Contrast Tray

Transcript

News: Using a tray when you are opening pill bottles is a good idea if you are blind or visually impaired because the pill, if you drop it, will land in the tray and not roll onto the floor. It will be contained and you can find it more easily.

If the tray can contrast with the pills you are opening, it’s even more helpful if you have low vision and can see the contrast of the white pill against a black tray or a purple pill against a white tray.

Transfering

Bed Rail

Bed Cane

Stand-n-Go

Couch Cane
Energy Conservation

- Plan scheduled rest breaks throughout the day.
- Plan out the day and prioritize activities during times of day with most energy.
- Sit down when able to for dressing, grooming, bathing, meal preparation.

Transfering

Uplift Seat Assist

Transfer Board

Eating/Feeding

DYCEM

NOSEY CUP

REDC

TABLEWARE

ROCKING T-KNIFE

PLATE GUARD
### Eating/Feeding

- Weighted utensils provide additional weight to stabilize hand tremors and support weakened grasps
- Each utensil weighs approx 8 oz. (½ lb)
- Wider grip requires less use of intricate finger muscles

### Toileting

- **Commode**
- **Raised Toilet Seat**
- **Toilet to Tub Sliding Transfer Bench**
- **WALL TO FLOOR U-SHAPED GRAB BAR**
- **FreedomWand® Ultimate Kit**
  - Includes Carry Bag, Straps & Extra Extension
Finger Dexterity

Typing Aid

Universal Turning Handle

Accessibility feature on smartphones

VoiceOver Off
Zoom Off
Magnifier Off
Display Accommodations On
Speech
Larger Text Off
Bold Text
Button Shapes
Reduce Transparency Off
Increase Contrast Off
Reduce Motion On
On/Off Labels
Face ID & Attention

Finger Dexterity

Key Turner

Enlarged and bright keyboard

Page Turner

Multi-Purpose Jar Opener
Car & Driving Evaluation

- OT’s can receive special driver rehabilitation certification to administer comprehensive driving evaluations (in office and behind the wheel) to assess the physical, mental, and visual abilities for safe driving:
  - Reaction time, Basic visual acuity, Decision making, Judgement, and Planning.
- Physician: medical assessment
- OT: functional assessment
- Based on performance, OTs work with individual to:
  - Develop a plan
  - Recommend strategies, equipment, and training
  - Increase awareness of resources available in the community to transition to alternative forms of transportation

Transfer Guidelines

- Set up the surfaces that will be transferring to and from
- Give clear and concise directions before and during the transfer
- Demonstrate
- Agree on timing - Counting to 3 before trying to transfer
- When changing positions to/ from lying, sitting, or standing- Individual remain in the new position for a few for blood pressure changes
- If accessible, use a gait belt at all times during transfers
- When possible, have the individual move towards his or her stronger side of their body.
Caregiver Safety & Body Mechanics

- Keep individual close and facing you.
- Keep knees bent, and use leg muscles instead of back muscles as much as possible.
- Keep a straight, neutral spine (not arched or curved forwards or backwards).
- Place feet shoulders width apart, and heels planted on ground.
- Consider the individual's weight and assistance level needed. Do not attempt more than you can handle for own safety.
- Avoid twisting or rotating your trunk. Use pivots or steps instead of rotating and twisting.
- Avoid combining movements, such as rotating and bending at the same time.

Log Roll Assisted Technique for Bed Transfer

[Video Link: https://www.youtube.com/watch?v=G4YMmodurWY]
Stand Pivot Transfer - Chair to Bed

https://www.youtube.com/watch?v=GHBFrHP8Bpo

By: Kayla Cupano, OTD Student, kcupano@gmail.com
Nova Southeastern University, Doctorate of Occupational Therapy Program
References


Daily Living Strategies for Individuals with HD: From an Occupational Therapy Perspective

By: Kayla Cupano, OTD Student
Nova Southeastern University, Doctorate of Occupational Therapy Program
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- An evidence-based healthcare profession and part of the rehabilitation team that assists individuals across the lifespan, and aims to solve problems and barriers that interfere with a person’s ability to engage in activities meaningful to them, known as occupations.
- OT’s provide the most effective treatment that is up to date with current research
  - Client-centered
What is an Occupation?

Occupation:

- Activities that hold meaning and provide purpose within an individual’s daily life
- May be things that an individual wants to, needs to, or is expected to do (role)
- For example:
  - Driving
  - Handwriting
  - Typing
  - Meal Prep
  - Pet Care
  - Dressing
  - Gardening
  - Grooming

8 Areas of Occupation that OT’s Address:

- Rest and Sleep
- Education
- Work
- Leisure
- Play
- Social Participation
- Instrumental Activities of Daily Living (IADLS)
- Activities of Daily Living (ADLs)

WHAT ARE IADLS?
The Instrumental Activities of Daily Living

WHAT ARE ADLs?
The Activities of Daily Living

- Bathing
- Dental Hygiene
- Toileting
- Eating
- Dressing
- Transfer & Mobility

- Properly washing your face and body
- Keeping mouth, teeth, gums clean and healthy by regular brushing and flossing
- Using a toilet and cleaning oneself appropriately
- The ability to feed oneself
- Choosing and putting on appropriate clothing
- Safely moving from one location to another (bedroom to living room)
● Improve ability to perform movement
● Biomechanical approach
● Therapeutic exercise, mobility, and manual therapy
● Helps person get from point A to point B

● Improve ability to perform ADLs to maximize function and independence
● Holistic approach
● Environment, Routines, Expected roles, Activity demands, Supports and barriers
● Helps person do things at point A and B

● Improve ability to communicate
● Cognitive/thinking skills, Chewing/swallowing, language skills, and memory
● Augmentative and alternative communication device

---

**OT Services**

- Physician script/referral for OT services, Covered as a skilled therapy service
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  - Modify the task and environment via compensation & adaptation
  - Provide assistive equipment when necessary and appropriate
  - Establish & restore a skill or ability that has been impaired
  - Provide patient and caregiver education

- **OT & Huntington’s Disease:** Therapeutic exercise, ADL training, Balance Training, Fall prevention, Home modification and Home Safety Evaluation, Cognition, Motor planning, Mental Health
Cognition:
- Activity demands
- Attention
- Short Term Memory
- Understanding medication schedule and organization
- Start/Finish tasks
- Mental health and irritability
- Establishment of a routine

Chorea:
- Coordination of fine motor tasks
  (grooming tasks, feeding, leisure activities, medication management)
- Understanding what areas are impacted by chorea and decreased coordination
  (self care, work responsibilities, function and safety in the home)

Balance:
- Adaptive Equipment (hygiene, meal preparation)
- Exercise and balance training
- Advocate for equipment and assistance with utilizing mobility devices

Visual Perceptual Skills:
- Functional mobility and navigating the environment
- Driving and dialogue of how to prepare for retiring from driving

Engagement in Meaningful Activities
- Establishing activities that are important to the routine or role of the person (pet care, getting the mail, household cleaning etc.)
- Modifying activity components to meet the needs of the individual

Home Safety Assessments

- Includes:
  - Home hazard assessment
  - Home modifications and recommendations
  - Home walk-through using a checklist
  - OT’s complete, determine if in-home skilled therapy services may be beneficial if individual is homebound and utilizes home environment majority of time
- Floor: clutter, wires, throw rugs, uneven surfaces
- Lighting: stairway, hallway, throughout home, easy to find light switches, inside/outside
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- Furniture: steady, storing items, handrails on stairs, bed rails, grab bars in bathroom
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- Central coffee tables moved to the side
- Plan a route to navigate any obstacles prior to mobility
- Cue cards: step by step instructions to completing a task

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Strategies

Cognitive Strategies:
- Daily Routine
- Provide Cues (gestural, verbal, physical, tactile)
- Label frequently used drawers/cabinets
- Short, concise when giving direction
- Reduce distracting stimuli as much as possible
- List, calendars, or notes to keep track of tasks
- Complex Tasks → Simple Tasks
- Visual schedule/Cue Cards for steps of an activity
- Encourage completion of step before moving to next step

Postural Control Strategies:
- Self-awareness of posture with verbal cues
- High-backed chair with armrests
- TV in front, not to the side
- Chair raiser or an electric chair that rises
Exercise & Balance

Exercise may work on: Flexibility, Balance, Cardio, Core Strength, Lateral Movement, Squats

Active Range of Motion (AROM) Exercises: to prevent muscle or joint contracture, can be completed lying down or seated in a supportive chair to maintain balance. Should be stopped with any pain. Limit use of weights.

Functional strength-training to maintain strength
- Sit to stand
- Lift object onto shelf
- Push/pull wheeled object

Excessive trunk movements & decreased insight may cause decreased balance and increased fall risk. Complete balance activities under physician and therapist care and recommendations only.

OT may work on:
- Positioning of feet, Balance positions
- Various head and arm positions
- Standing on different surfaces
- Incorporate a functional activity into balance

ADA Employment

- Reduce distracting stimuli as much as possible
- Modify responsibilities or task, utilize adaptive equipment appropriate
- Consider a change in employment to a different, more accommodating position
- Consider volunteer positions if able to and interested
- Reduce responsibilities that may be fast-paced, detailed-oriented or with variable conditions
- An OT can be a valuable team member in addressing function, communication with an employer, and accommodations/modifications of task demands in the workplace
Driving

- OT’s can receive special driver rehabilitation certification (CDRS) to administer comprehensive driving evaluations (in office and behind the wheel) to assess the physical, mental, and visual abilities for safe driving:
  - Reaction time, Basic visual acuity, Decision making, Judgement, and Planning.

- Physician: medical assessment
- OT: functional assessment
  - Assist in the initiation of dialogue for planning and retirement of driving

- Based on performance, OTs work with individual to:
  - Develop a plan
  - Recommend strategies, equipment, and training
  - Increase awareness of resources available in the community to transition to alternative forms of transportation

Social Participation & Leisure

Social Participation

Leisure

- Routine
  - Past/Present Hobbies
- Visual and Verbal reminders
- Virtual communication, groups, and events
- Talk on the phone, write letter, email

- Exercise, Tai Chi, Yoga

“Ensure that the activity is adapted to fit the person, not the other way around” (Blacker, 2008)
Home Management

Laundry: timer for when complete, laundry basket with wheels, supportive seating while using reacher

Meal Preparation: One task at a time, simple meals, utilize adaptive equipment, frequently used items within reach

Dressing & Toileting

VELCRO OR ELASTIC WAIST BANDS

ELASTIC SHOE LACES

SOCK AID

RAISED TOILET SEAT

LONG-HANDED SHOE HORN

DRESSING STICK

COMMODE
Dressing Tips

- Sit down when able during dressing activities to decrease fall risk and for supported posture and balance when reaching/bending
- Pair/label outfits together ahead of time

Bathing & Grooming

- TUB TRANSFER BENCH
- LONG-HANDED SPONGE
- ELECTRIC TOOTHBRUSH OR BUILT-UP HANDLE FOR TOOTHBRUSH/RAZOR
- EASYHOLD GRIP
- TRANSFER POLE
- GRAB BARS
- SHOWER CHAIR
Medication Management

- BRIGHTLY COLORED PILL BOX WITH SPRING-LOADED ASSISTANCE
- VIBRATION STORAGE & REMINDER
- HERO PILL DISPENSER
  - Use the hero app to program any pill regimen, simple or complex
  - Hero stores, sorts, and dispenses up to a 70-day supply of 10 different medications
  - Hero stores different pill sizes and reminds you when it's time to refill

Using a High-Contrast tray

- BENDABLE STRAW
- WEIGHTED UTENSILS
- UNIVERSAL CUFF
- ORALFLO
- NOSEY CUP

Eating & Feeding
Eating & Meal Times

- Weighted utensils provide additional weight to stabilize hand and support weakened grasps. Each utensil weighs approx 8 oz. (½ lb).
- May require higher calorie diet
- Encourage to eat at the table to reduce spills, promote social interaction and conversation, and for reduced distractions
- Prepare meals/snacks in advance for easy retrieval throughout the day. Create a list of simple meals
- Promote as much independence during meal times

Transferring

Transfer Board

Bed Cane

POWER LIFT CHAIR

Bed Rail
Mobility

- Plan scheduled rest breaks throughout day
- Plan out day and prioritize activities during times of day with most energy

TREKKING POLES

Mobility

TYPES OF CANES

CONE CANE  FUNCTIONAL GAIT CANE  OFFSET HANDLE  QUAD CANE  HEMI WALKER  FOLDING WALKING CANE

ROLLATOR

VS

STANDARD

2-WHEELED
Log Roll Assisted Bed Transfer & Stand Pivot Transfer from Chair to Bed
Daily Living Tools

Key Turner

Reacher

Universal Turning Handle

Page Turner

Multi-Purpose Jar Opener

Enlarged and bright keyboard

Typing Aid

Accessibility feature on smartphones

Access to VoiceOver, Zoom, and Magnifier is off.

Display Accommodations is on.

Speech, Larger Text, Bold Text, Button Shapes, Reduce Transparency, Increase Contrast, Reduce Motion, On/Off Labels, Face ID & Attention are currently off.

INTERACTION and Reachability settings are not specified.
Mental Health Impact

COVID-19 Impact:
- Media outlets display continuous coverage with increased panic
- Worry may increase about securing food, household items, and medications
- Unsure about safety of caregivers, transportation, procedures, and appointments
- Decreased social interactions with others
- Stop of daily routine, habits, and roles
- Exacerbation of mental health conditions

Supporting Older Americans Act of 2020 (OAA):
- Funding
- Resources
- Support for caregivers (Education and Respite Care)
- Pension counseling, Nutritional Services
- Disease prevention
- Community workforce training

OTs provide interventions, support and programs related to community-based settings, health promotion, and disease prevention. OTs also promote participation and engagement in meaningful activities (occupations), and recommend adaptations and modifications to the environment to support safe aging in place and reduce social isolation.

Mental Health Strategies

- Routine, Balance of exercise and relaxation
- Alternative forms of communication with others
- Name or have picture of face to identifying caregivers from PPE
- Validate feelings a
- Encourage self-advocacy self-expression
- Accessible, safe areas to walk around in to increase movement and exercise throughout the day
- Allow time to complete an activity
- Try to plan the day, stay active, and to maintain connection to others
- Ensure that adaptive devices and equipment are available and within reach,
  - Reminisce, Stay positive- breathing exercises, music, enjoyed activities, creativity, Purposeful activities- checklist for the day and plan for the next day, Laugh/Humor, Connect with others- write letters, send artwork, cards, Virtual experiences- email, video chat, religious services, support groups, Engage the 5 senses
References


Berner, Theresa. “Special Issues for People and Families with Huntington’s Disease.” Huntington's Disease: A Primer for Community-Based Occupational Therapists . Lecture presented at the The American Occupational Therapy Association, Inc. .


References Continued


RESOURCES FOR PATIENTS, CARE-PARTNERS, & HEALTHCARE PROFESSIONALS

A Holistic Approach:
From an Occupational Therapy Perspective

By: Kayla Cupano, OTD-S
Capstone Experience
Nova Southeastern University
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Durable Medical Equipment (DME) & Adaptive Equipment (AE)

- DME is covered under Medicare Part B up to 80%, patient responsible for remaining 20%. Supplemental plans or Medicaid, may cover the 20% patient responsibility.
- DME is durable and therefore made with the intent to be utilized multiple times, and is considered medically necessary to treat or manage a disease, injury, or illness. DME suppliers must be enrolled in Medicare.
- Medicare does not cover equipment for ADLs (reacher, sock aid, utensil, shower chair etc.)
- Adaptive equipment are used to complete activities of daily living such as bathing, dressing, self-care, grooming, toileting, and feeding. Typically, these items are not covered by insurance, however are more easily accessible and affordable.

<table>
<thead>
<tr>
<th>Equipment</th>
<th>Description</th>
<th>Coverage/Where to Find</th>
</tr>
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<tbody>
<tr>
<td>DRESSING</td>
<td>Mechanism that allows independence in putting on socks for individuals with limited mobility and with difficulty leaning forward.</td>
<td>Part of the equipment provided, and covered by Medicare in “hip-kit” following hip surgery</td>
</tr>
<tr>
<td></td>
<td>Steps to use:</td>
<td>Not covered by Medicare individually</td>
</tr>
<tr>
<td></td>
<td>o Place sock aid in between knees, and pull sock over the side without straps</td>
<td>Can be found on Amazon, at local drug stores, and retail stores</td>
</tr>
<tr>
<td></td>
<td>o Place sock aid on floor in front of you</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Place toes into the sock opening</td>
<td></td>
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<td></td>
<td>o Pull on the handles, until toes are completely inside</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o When the sock reaches the heel, pull handles of sock aid upward toward ceiling to place heel into sock</td>
<td></td>
</tr>
<tr>
<td>SOCK AID (with foam handles)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Equipment tool for individuals with limited flexibility, to place shoe on and take off more easily</td>
<td>Part of the equipment provided, and covered by Medicare in “hip-kit” following hip surgery</td>
<td></td>
</tr>
<tr>
<td>Length, design, and handle vary</td>
<td>Not covered by Medicare individually</td>
<td></td>
</tr>
<tr>
<td>Can be found on Amazon, at local drug stores, and retail stores</td>
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<td></td>
</tr>
</tbody>
</table>

**LONG-HANDED SHOE HORN**

**ELASTIC SHOE LACES**

**VELCRO OR ELASTIC WAIST BANDS**

**Elastic Shoe Laces:**
- Designed for individuals with limited finger dexterity, and allows slip-on of shoes without tying required.
  - Type, design, and color vary

**Elastic Waist Band:**
- Easier waist band on pants to pull up and down, and are stretchable.
  - Used in a variety of clothing types, dressy to casual.

**Magna-Ready:**
- Adaptive clothing line
- Magnets for dress shirts

Not covered by Medicare

Affordable and easily obtainable
## BATHING

- Bathroom safety devices that provide support when transferring to/from positions and get into shower/bath safely
- Provides stability during bathing tasks from back of chair and removable arm rests

## TUB TRANSFER BENCH

- Not covered by Medicare
- Affordable and easily obtainable

## SHOWER CHAIR

- Improves independence and increases stability when reaching to parts of body.
- Decreased effort required for energy conservation
- Some handles are flexible and bend

## LONG-HANDLED SPONGE

- Part of the equipment provided, covered by Medicare if in “hip-kit” following hip surgery
- Not covered by Medicare individually
### Grab Bars

- Grab bars should be installed by a contractor/professional for optimal safety and proper positioning.
- Suction cup grab bars are unsteady and can increase fall risk.
- Grab bars are typically stainless steel to prevent corrosion.
- Texture/grips may be added to grab bars for increased tactile input and safety.

- Not covered by Medicare, considered a home modification.
- Can be purchased on own and installed by a professional.
- Home modification companies also provide this service for a fee.

### Toileting

#### Raised Toilet Seat

- Standard toilets can be modified to be raised a few inches, for decreased bend at the knees to sit required.
- Detachable arm rests can be installed, to the frame of the toilet (not to the toilet seat) for increased stability.
- Can purchase a raised toilet seat, instead of modifying a standard one.

- Not covered by Medicare.
- Accessible at furniture/appliance stores.
### 3-IN-1 COMMODE

- **Has 3 features:**
  - Can be used at bedside with removable bucket
  - Used as a toilet riser, remove bucket and place over existing toilet
  - Also, utilized as a toilet seat frame and provides safety hand rails to lower onto/stand up from

- **Covered by Medicare, when ordered by physician that patient cannot use regular toilet at home**

### COMMUNITY MOBILITY

#### WALKER

- **Standard:** Four nonskid legs for stability, needs to be picked up to move
- **2-Wheeled:** Has two wheels in the front legs, helpful if some weight-bearing assistance is needed
- **Rollator:** Has 4-wheels, handle bars, brakes, and a seat

- **All options are covered by Medicare if necessary for functional mobility inside the home**
- **Medicare will replace a walker for the same walker if worn out and no longer able**

---

**Example of long-handle wand that can be used for toilet hygiene, bathing, and grooming tasks**

- **Not covered by Medicare**
- **Affordable and easily obtainable**
**POWER WHEELCHAIR**

<table>
<thead>
<tr>
<th>Powerchair</th>
<th>Scooter</th>
</tr>
</thead>
<tbody>
<tr>
<td>to be used, every 5 years if worn out</td>
<td>Covered by Medicare if considered medically necessary for mobility inside the home</td>
</tr>
<tr>
<td></td>
<td>Requires face-to-face wheelchair assessment to determine appropriate size and features</td>
</tr>
<tr>
<td></td>
<td>May need to get prior authorization for power wheelchairs</td>
</tr>
<tr>
<td></td>
<td>Can take time for assessment, approval, and delivery of wheelchairs</td>
</tr>
</tbody>
</table>

- **Powerchair**: can be controlled by joystick, chin or head control. Allow for: tilt-in-space, recline, elevated leg rests
  - Pressure relief
  - May manage autonomic dysreflexia and orthostatic hypotension, and edema
  - Positioning, trunk control, and balance

- **Scooter**:
  - 3-wheeled: best for smooth, level ground, offer more leg room, lighter and less expensive, good for maneuvering turns in tight spaces
  - 4-wheeled: even weight distribution, good stability on various types of terrain, require more space to turn, more expensive and heavier in weight

---

**POWER WHEELCHAIR vs. Scooter**
### Manual Wheelchair

- **Wheelchair:**
  - **Types:** Lightweight, standard, bariatric/heavy duty, tilt/recliner, and transport
  - **Features:** gel, memory foam cushion, cushioned backrest, armrests, leg rests, removable headrest, safety belts, wheels for terrain

### Cane

- **Single-Point/Standard Cane**
  - C-cane, Functional grip, Offset handle
  - Most commonly available, most affordable
  - Increases balance and stability

- **Quad Cane**
  - Increased base of support for individual’s with increased risk of slipping/falls
  - Larger grip handle

- **Folding Cane**

- **Covered by Medicare, except white canes for the blind.**
<table>
<thead>
<tr>
<th>QUAD</th>
<th>RUBBER</th>
<th>METAL</th>
</tr>
</thead>
</table>
| • **Specialty canes:**
  | Hiking sticks and sticks for the blind |
| • **Tips for Cane:**
  | • Rubber tip for traction |
|  | • Quad tips for mobility and durability |
|  | • Metal tips for various terrain |

<table>
<thead>
<tr>
<th>TRANSFERS:</th>
</tr>
</thead>
</table>
| • **Transfer Board:**
  | • Used to transfer from surfaces such as wheelchair to bed, toilet seat to chair, or into/out of car |
|  | • Several types with range of price |
|  | • Anti-slip for decreased fall risk |
|  | • Keep hands flat on surface during transfer |
| • **Uplift Seat Assist:**
  | • Non-electric portable seat with a spring that lifts/lowers 70% of weight |

<table>
<thead>
<tr>
<th>Uplift Seat Assist</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Medicare covers bed side rails</td>
</tr>
<tr>
<td>• Does not cover transfer board or bed cane</td>
</tr>
<tr>
<td>• May cover cushion lift power seat</td>
</tr>
</tbody>
</table>
Bed Rail & Bed Cane:
- Provide assistance when transferring in/out of bed, reduce risk of falls, assistance with repositioning in bed
### Car Caddie & Car Handle:
- Affordable and available
- Easy installation/take down
- Provides support during transfers

### Swivel Seat Cushion:
- Portable cushion that pivots 360 degrees for easier swing of legs and hips to transfer out of the car, with decreased pain during transfer

### Universal Cuff:
- Fits around palm of hand with strap
- Can be utilized for multiple ADL items: toothbrush, eating utensil, brush, writing utensil
- For individuals with decreased grip strength and dexterity

### Weighted Utensils:
- Provide additional weight to stabilize hand tremors and support weakened grasp. Weighs approx. 8 oz. (½ lb)
- Wider grip requires less use of intricate finger muscles

### Not covered by Medicare
- Easily accessible and affordable with range of prices

## EATING / FEEDING EQUIPMENT:

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### Not covered by Medicare
- Easily accessible and affordable with range of prices
### Rocking T-Knife:
- Uses a rocking motion to cut food, and requires less strength and dexterity to cut food.
- T-shape handle for grasp, with decreased risk for cutting injury.

### Plate Guard:
- Increases independence during feeding at mealtime.
- Attaches to any standard round plate to prevent messy spillage of food off of plate when eating.
- Available in a variety of colors to blend with color of plate.

### Pizza Cutter:
- Cuts through the center of pizza, making it easier to slice.
- Blade is designed to follow the shape of the pizza, ensuring even cuts.

### MEDICATION MANAGEMENT

#### Pill Box:
- Various types, with some that have 1 box per day, AM/PM box per day, and boxes for 2 weeks of medication.
- Spring-loaded allows for easier open/close for individuals with limited finger dexterity, strength, or arthritis.

#### Oralflo:
- Pill is in the spout of cup, and does not sit on the tongue at all.
- Designed for individuals with pill-taking anxiety, or for individuals with increase tongue/mouth.

#### None are covered by Medicare.
- Some options are affordable, and easily accessible.
- Should be discussed with patient, caregiver, and physician to determine the most appropriate management routine of medications.
- Automatic pill dispensers are the most costly.
movements or swallowing difficulties

- **Medication Reminder Apps:**
  - Applications on smart phones that provide a reminder for patient and can be sent to caregiver, to take medication at specific times

- **Pill Dispenser:**
  - Automatic pill dispensers can be costly, but can hold large amounts of medication and be automatically dispensed on the correct days/times

- **Vibe Pill Timer Reminder:**
  - Pill reminder timer that vibrates and visually reminds individual to take medication

- **High Contrast Tray:**
  - Strategy for individuals with visual impairments, if pill drops or to see the amount of pills, place on a contrasting colored plate
## Grooming / Limited Dexterity

<table>
<thead>
<tr>
<th>Eazyhold Grip:</th>
<th>Electric Toothbrush or Built-up Handle:</th>
<th>None of these are covered by Medicare</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Increases independence during tasks, and is a strap that goes across hand for a better grip on objects</td>
<td>- Electric toothbrush provides the assistance to brush teeth, with decreased effort needed due to electric movement of brush</td>
<td>- Affordable, and easily obtainable</td>
</tr>
<tr>
<td>- Can be used on writing/eating utensils, grooming/hygiene objects, toys, cups etc.</td>
<td>- Built-up handle provides extra weight to reduce hand tremors and increase stability during grooming tasks</td>
<td>- Simple, yet beneficial adaptive equipment to increase independence during daily living tasks</td>
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### Eazyhold Grip
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- Electric toothbrush provides the assistance to brush teeth, with decreased effort needed due to electric movement of brush.
- Built-up handle provides extra weight to reduce hand tremors and increase stability during grooming tasks.
**Key Turner:**
- Provides wider handle for grasp of key to unlock/lock doors
- Requires less strength and pressure, and less use of intricate finger muscles to maintain pincer grasp and turn key

**Multi-purpose Jar Opener:**
- Ergonomically designed with a comfortable grasp to easily open various size jar lids

**Page Turner:**
- Allows for a looser grasp to use pointer end to turn pages of a book
- Increases independence during leisure activity of reading

**Typing Aid:**
- Designed for individuals with limited hand function and mobility
- Can be used on keyboards and calculators
- Does require some coordination to accurately align the pointer with the correct button
Universal Turning Handle

- **Universal Turning Handle:**
  - For individuals with decreased hand strength
  - Allows for power grip on turn knobs, such as on stove, microwave, dishwasher, and faucets


default: Reacher

- **Reacher:**
  - For individuals with limited range of motion to grab out of reach items at various heights
  - Available in several designs and types
Activities of Daily Living (ADL) & Instrumental Activities of Daily Living (IADL) Tips:

**Dressing:**
- Pair parts of an outfit together on a hanger and label for the week
- Sit down in chair when getting dressed, and use reacher to pull up pants or to retrieve items off of floor
- Use a keychain ring on zippers to aid with zippering
- Allow plenty of time during dressing tasks, take breaks when needed
- If affordable and accessible, utilize adaptive clothing lines
- Utilize Assistive Equipment (AE) such as: long-handled shoe horn, sock aid, dressing stick, elastic shoe laces, velcro/elastic waist bands

**Bathing:**
- Ensure safety during bathing tasks due to slippery surfaces
- Install grab bars professionally into tile to optimize safety, steadiness, and for appropriate positioning during transferring in and out area (do not use the suction cup grab bars)
- Non-skid bath mats in bathtub and shower stalls
- Sit down during bathing tasks utilizing a shower chair or tub transfer bench, both with a high back and detachable arm rests
- Use a handheld showerhead if possible and long-handled sponge
- Place all items needed during bathing, together and within reach

**Toileting/Toilet Hygiene:**
- Use a bedside commode, commode frame over a regular toilet, or an elevated toilet seat for less effort and increased stability during transfers on/off toilet
- Keep a nightlight on in bathroom, or use automatic sensor lights in bathroom/hallways
- Utilize AE such as the freedom wand, to put toilet paper for increased range of motion during toilet hygiene
- Keep bathroom space organized and free of clutter, to decrease fall risk

**Community Mobility:**
- Prioritize energy conservation and utilize strategies, mobility devices, and adaptive equipment when necessary
- Consult with physician and therapist to determine if cane, walker, or wheelchair may be appropriate, and ensure proper training of device
- Plan rest breaks throughout the day, and prioritize activities of importance during times of day with most energy
- Utilize alternative forms of transportation and mobility when possible

**Transfers:**
- Set up the surfaces that you will be transferring to and from
- Caregiver should provide clear and concise directions before and during the transfer, and demonstrate what the transfer will look like
- Agree on timing (such as counting to 3) before transfer
- When changing position to/from lying, sitting or standing, remain in the new position for a few minutes prior to changing positions for possible changes in blood pressure or orthostatic hypotension
- If possible, use a gait belt at all times during transfers
- When appropriate, the individual that is transferring should move towards their stronger side of the body
- **Bed Mobility:** Use log roll technique, can be completed for an individual that is dependent on caregiver, or individual can initiate and caregiver provides assistance
- **Caregiver Body Mechanics:**
  - Individual close and facing caregiver
  - Utilize legs during transfer and not back, maintain knees in a bent position
  - Keep a straight, neutral spine
  - Place feet shoulders width apart, and heels planted on ground
  - Consider the individual’s weight and assistance level needed, do not attempt more than you can handle for own safety
  - Avoid twisting/rotating trunk, use pivots or small steps instead
- **Adaptive Equipment:**
  - Bed rail or Bed cane, Power-lift chairs, or Transfer boards, or other transfer devices like Stand-N-Go or a Couch cane

**Eating/Feeding:**
- Weighted/Built-up utensils provide additional weight to stabilize hand tremors and support weakened grasps. Each utensil weighs approx.. 8oz, and a wider grip requires less use of intricate finger muscles. Also available in curved/swivel options for decreased spillage
- Red tableware promotes visual attention and is often an alerting color
- Gather all necessary ingredients prior to cooking, and sit down when able to during meal preparation
- **Adaptive Equipment:**
  - Rocking T-Knife, Universal Cuff, Plate Guard, Dycem,
Nosey Cup, Multi-Purpose Jar Opener, Universal Turning Handle

**Grooming**
- Use an electric toothbrush or razor when possible
- Built-up handle or Long-handle can be added onto hairbrush, comb, regular razor, toothbrush
- Consider a hair dryer stand, foam tubing grips on brushes for makeup
- Sit down to complete grooming tasks when possible, and rest arm on a surface to apply makeup
- Utilize visual cue cards with pictures and words for steps to complete grooming tasks (i.e. wash face, brush teeth etc.)

**Driving**
- Physician completes the medical assessment, and Occupational Therapists (OT) complete the functional assessment, based on physician referral
- OTs can receive special driver rehabilitation certification to administer a comprehensive in office and behind the wheel assessment, to assess physical, mental, and visual abilities for safe driving such as: reaction time, visual acuity, decision making, judgement, and planning
- OTs can work with individual to develop a plan, recommend strategies, equipment and training, and increase awareness of resources available in the community to transition to alternative forms of transportation
- **Adaptive Equipment:**
  - Car Caddie, Car Handle, Slide-N-Ride, Car Door Opener, Key Turner, and Portable Swivel Seat Cushion

**Medication Management**
- OTs can analyze individual performance and current medication management routine, identify barriers and supports, collaborate with health providers and individual, teach individual self-advocacy skills, and treat specific deficits that may impact compliance and ability to follow medication management routine
- **Health Literacy:**
  - **Consider:** Is the individual able to navigate their health to manage medications? Can they fill their prescriptions and know the dosage and schedule? Do they know why they’re taking each medication? Do they have insight into their deficits to know what questions to ask physician that prescribes the medication?
- **Strategies**: Collaborate with client and family to form a simple document that lists name of medication, reason for taking it, dosage, and reminders about the medication

  - **Cognitive**:
    - **Consider**: Are they able to self-administer medication with a pillbox, if they have an alarm set to remind them? Can they problem solve to know when it is appropriate to take “as needed” medication? Do they need adaptations to the environment such as visual or audio cues?
    - **Strategies**: Utilize reminder applications to smart phone, Visual schedule or checklist, and incorporate auditory reminders (alarm), Automatic medication dispenser, Utilize family/caregiver support and assistance throughout.

  - **Community Mobility**:
    - **Consider**: Are they mobile? Can they go into the community to access the medication? Do they have endurance to use public transportation?
    - **Strategies**: Utilize local community services such as transportation companies that have personnel trained to handle any equipment or mobility device that the individual needs to safely move within the community. Medication delivery services from online vendors or direct from local pharmacy

  - **Fine Motor**:
    - **Consider**: Does the individual have finger dexterity to open pill bottles? Are they able to bring the pills to their mouth without dropping them?
    - **Strategies**: Hook/Loop system with universal cuff to open slots of spring-loaded medication pillboxes, Incorporate fine motor strengthening activities. There are arthritis medication bottles that are available at pharmacies, that can be asked for specifically

  - **Vision**:
    - **Consider**: Is the individual able to read the medication labels? Can they read a medication schedule? Is the individual able to differentiate between two pills? Can they use a pill dispenser correctly?
    - **Strategies**: Color contrast using pillboxes or trays to see different pills, color-coded pillboxes or visual cues such as stickers to indicate different times of day, magnifier
Safety:

- Consider: Can the individual safely access the area in home where medications are stored? Is the individual at risk of falling if they need to reach into a higher cabinet? Is there adequate lighting in the area? Are all of the medications stored together or in multiple areas of the house?

- Strategies: Organize medications into one bin, and fill medication pillboxes weekly or monthly, and after each medication is placed into the pillbox or dispenser, place bottle back into bin.

Equipment

- Types: Variations of medication pillboxes (to-go pillbox, weekly pillbox, monthly pillbox, multiple dosage slots such as morning, lunch, evening, bedtime). Automatic pill dispensers that can hold a large amount of medications inside, and some provide voice and visual cues or contact caregiver if missed dose. Single dosage medication dispenser for monthly supplies that dispenses in small plastic packets. Also, timers with a smartphone or alarm.

Home Safety

- Kitchen: Arrange cabinets and drawers for frequently used items within reach, remove clutter and extra furniture, area to sit down for meal preparation near-by

- Bathroom: Grab bars professional installed near toilet and in shower/tub, Raised toilet seat or Commode, Shower chair or tub transfer bench, Long-handled showerhead and sponge, Items within reach for easy access, Non-skid mats, and nightlights

- Living Area/Bedroom: Steady and stable furniture, Chairs with high backs and armrests, Remove throw rugs and clutter, Bed and chairs at safe height for easier transfers, Pillows or rolled towels for support in maintaining posture

- Lighting: Easily accessible light switches, Lights inside and outside the home, Automatic lights if possible in stairway, hallway, and throughout the home

- Outside: Well-lit walkways, even pathway and stairs, handrails on stairs, no slippery surfaces, and tools and equipment set aside and not in way of direct path,
Fall Prevention

Risk Factors

• Home Safety Assessment
  o Includes:
    ■ Home hazard assessment
    ■ Home modifications and recommendations
    ■ Home walk-through using a checklist
    ■ OT’s complete assessment and determine if in-home skilled therapy services may be beneficial if individual is homebound and utilizes home environment majority of time
  o Floor: clutter, wires, throw rugs, uneven surfaces
  o Lighting: stairway, hallway, throughout home, easy to find light switches, inside/outside lighting
  o Outside: well-lit walkways, even pathway, slippery surfaces, outside tools put away
  o Furniture: steady and stable, storing items within reach, handrails on stairs, bed rails, grab bars in bathroom

• Orthostatic Hypotension
  o Rise slowly or sit edge of bed, and allow body to adjust to new position for several minutes before standing
  o Raise head of bed when sleeping, to reduce risk of sudden drop in blood pressure
  o Elastic stockings can assist with venous pooling, consult with physician if appropriate
  o In hot weather, avoid heavy meals and vigorous activity

• Medications Management
• Consult with physician and pharmacist to stabilize medical conditions and side-effects of medications
• Assess what medications may be contributing to falls
• Consult with physician about intake of Vitamin D

Footwear
• Identify and manage foot conditions
• Consider shoes of low heel height and high surface contact, consult with physician
• Use non-slip, well-fitting footwear

Vision
• Obtain a comprehensive vision assessment to identify any visual impairments
• Adapt the visual environment when necessary:
  ▪ Move central coffee table to the side
  ▪ Avoid patterned flooring when possible
  ▪ Plan a route prior to walking to navigate any obstacles
  ▪ Use floor markers in contrasting tape color, for increased stride length during difficult turns, and in places where freezing gait often occurs
  ▪ Use picture/written cue cards for step by step instructions to complete task such as washing face, brushing teeth, or getting in/out of bed

Patient Education
• Educate on self-awareness of: What causes falls? Why are falls dangerous? What increases the risk for falling? How to prevent falls?
• Consult with physician, exercise regularly, proper footwear, remove home hazards, improve lighting in living space, use mobility devices and assistive equipment when necessary and appropriate

Staff Education
• Ask patients if they’ve fallen in the past year
• Identify risk factors
• Refer to specialists when needed
• Assess the fall risk and situation from a multifactorial approach—consider overall health, balance and gait, rehabilitation services to assist functional activity, medications, environment, community mobility, vision, and home hazards.
**Cognitive Strategies**

- Daily Routine
- Provide Cues (gestural, verbal, physical, tactile) when needed
- Label frequently used drawers/cabinets around the home
- Short, concise when giving direction
- Reduce distracting stimuli as much as possible
- List, calendars, or notes to keep track of tasks
- Complex Tasks → Simple Tasks
- Visual schedule/Cue Cards for steps of an activity
- Encourage completion of step before moving to next step

**Postural Strategies**

- Improve self-awareness of posture with verbal cues
- Utilize high-backed chair with armrests
- When watching TV, have TV directly in front, rather than to the side to prevent lateral lean
- Use chair raiser or an electric power chair to assist with transfers
Motor-Based Activities

- Boxing
- LSVT-Big
- Music/Dance Therapy
- Tai Chi
- Swimming
- Progressive cycling
- These activities can assist to improve: speed, balance, endurance and ambulation

Mobility Strategies

- Practice concentration on walking and not talking at the same time initially
- Stop before changing direction
- Walk in direction of an arc to turn in a wide space, and use contrasting tape as floor markers
- Maintain feet shoulder-width apart
- To promote flow of walking: count, step to a beat, march first
- Ensure good lighting on stairs, automatic when possible in places such as hallways and bathrooms
- Verbal cuing such as BIG to encourage big movements
Mental Health Impact and Strategies During the COVID-19 Pandemic:

Negative Impacts of COVID-19:
- Media outlets display continuous coverage about the virus and increase panic
- Worry may increase about securing food, household items, and medications
- Unsure about safety of caregivers, transportation, procedures, and appointments
- Decreased social interactions with others due to quarantining and social distancing
- Stop of daily routine, habits, and roles, impacting participation in occupations, which may lead to occupational deprivation
- Exacerbation of mental health conditions such as, anxiety, depression, loneliness, hallucinations, paranoia, PTSD, panic attacks, and bipolar.

Occupational Deprivation:
- “A structural restriction on participation in meaningful occupations (Darawsheh, 2019).”
- “Occupational deprivation negatively affects a person’s sense of occupational choice and demeans the person's power (Darawsheh, 2019).”
- “These consequences may affect the health and well-being, they can cause disruption, restriction, loss of occupational performance, and the inability to adapt to the new displacement context (Darawsheh, 2019).”

Supporting Older Americans Act of 2020 (OAA) (Marfeo, 2020):
- Reauthorized from the Older Americans Act of 1965
- Provides funding, resources, and support for caregivers through training, education, and respite care, information services such as pension counseling, nutritional services such as meal delivery, disease prevention and health promotion services, community and workforce training regarding elder care, and abuse and neglect prevention services.
- The revised OAA, identifies the negative impact of social isolation and loneliness on well-being and health. It also recognizes the need for the following:
  - Client-centered services
• Access to assistive technology and equipment
• Information on infectious disease and sexually transmitted disease and vaccination
• Recommends suicide risk assessment when appropriate
• Improves coordination and access to rehabilitation services for fall prevention and injury

- Occupational therapists (OT) provide interventions, support, and programs related to community-based settings, health promotion, and disease prevention. OTs also promote participation and engagement in meaningful activities (occupations), and recommend adaptations and modifications to the environment to support safe aging in place and reduce social isolation.

**Strategies to Optimize Mental Health & Response to Negative Impact:**
- Create a routine as best as possible, that provides cognitive stimulating leisure and social activities.
- Incorporate exercise and also relaxation into daily routine
- Utilize alternative forms of communication with others (i.e. phone call, video chat, email, write letters)
- Write down name or have picture of face, for individuals that may have difficulty identifying caregivers due to coverage for PPE
- Validate feelings and provide emotional/physical support for individuals that may likely experience paranoia, anxiety, panic, and depression.
- Encourage self-advocacy and assist in the advocacy for self-expression, communication of needs and wants, and restoration of alternative forms of human interaction and participation in meaningful activities.
- Provide assistance to individual’s that may have activities working technology as a form of communication
- Have accessible, safe, areas to walk around in to increase movement and exercise throughout the day
- Allow time for an individual to complete an activity that may be important to him/her independently if safe and possible, to improve confidence and lessen stress
- Try to plan the day, stay active, and to maintain connection to others
- Ensure that adaptive devices and equipment are available, within reach, and appropriate for individual to improve independence and function
- Safe Ideas:
  - Reminisce
  - Stay positive- breathing exercises, music, enjoyed activities, creativity
  - Purposeful activities- checklist for the day and plan for the next day
  - Laugh/Humor
  - Connect with others- write letters, send artwork, cards,
  - Virtual experiences- email, video chat, religious services, groups
  - Engage the 5 senses
Types of Therapy

**Physical Therapy and Occupational Therapy:**
Can receive certification in the LSVT-BIG program

**Physical Therapy (PT):**
- Improve ability to perform movement
- Biomechanical approach
- Therapeutic exercise, mobility, and manual therapy
- Helps person get from point A to point B

- PT Strategies for PD: Improve gait, improve transfers, improve balance, and strengthen joints and muscles

- PT is a healthcare profession with experience in diagnosing physical abnormalities, restoring physical function and mobility, maintaining physical function, and promoting physical activity and proper function.
- PTs are movement experts who improve quality of life through prescribed exercise, hand’s on care, and patient education.
**Occupational Therapy (OT):**
- Improve ability to perform ADLs to maximize **function** and **independence**
- Holistic approach
- Environment, Routines, Expected roles, Activity demands, Supports and barriers
- Helps person **do things at** point A and B

- OT Strategies for PD: Changing the nature, time, and duration of an activity, simplifying activities by breaking down complex tasks into simpler ones, arranging items and provide and recommend environmental modifications, and recommending aids to reduce fall risk.

- OT is an evidence-based healthcare profession and part of the rehabilitation team that assists individuals across the lifespan, and aims to solve problems and barriers that interfere with a person’s ability to engage in activities meaningful to them, known as occupations. OTs provide the most effective treatment that is up to date with current research, and is client-centered and culturally relevant.

- An occupation is an activity that holds meaning and provides purpose within an individual’s daily life. These can be things that an individual wants to, needs to, or is expected to do.

**Speech Therapy (ST):**
- Improve ability to **communicate**
- Cognitive/thinking skills, Chewing/swallowing, language skills, and memory
- **LSVT- LOUD**
- Utilize augmentative and alternative communication devices

- ST Strategies for PD: Evaluate swallowing function, can utilize LSVT-LOUD program, recommends communication technologies, assists with voice volume, speed of speech, facial expression, and pronunciation of words.

- SLPs work with people of all ages to prevent, assess, diagnose, and treat communication and swallowing problems. These include speech sounds, language, literacy, social communication, voice, fluency, cognitive-communication, and feeding and swallowing.
References


WHAT IS OCCUPATIONAL THERAPY?

- An evidence-based healthcare profession and part of the rehabilitation team that assists individuals across the lifespan, and aims to solve problems and barriers that interfere with a person’s ability to engage in activities meaningful to them, known as occupations.

- OTs provide the most effective treatment that is up to date with current research
  - Client-centered

- “Ensure that the activity is adapted to fit the person, and not the other way around”

  (Blacker, 2008)
WHAT IS AN OCCUPATION?

• Activities that hold meaning and provide purpose within an individual’s daily life
• May be things that an individual wants to, needs to, or is expected to do (role)
• For example:

8 AREAS THAT OTS ADDRESS:
Home/Environmental Modifications

**Kitchen**
- Arrange cabinets & drawers for frequently used items
- Sturdy step stool if needed, not a chair
- Remove clutter, extra furniture
- Frequently used items within reach

**Bathroom**
- Grab bars installed near toilet and in shower
- Raised toilet seat, Shower chair or bench
- Long-handled sponge, sponge mitt
- Items positioned in shower for easy access
- Non-skid mats
- Nightlights

**Living Area & Bedroom**
- Stabilize furniture
- Chairs with high backs and armrests
- Remove throw rugs and clutter
- Bed at a safe height for functional transfers
- Pillows and rolled towels for support in maintaining posture

---

**Dressing**

- Pair parts of an outfit together, label
- Sit in a chair to get dressed
- Use reacher to pull up pants
- Keychain ring on zippers to aide with opening and closing
- Allow plenty of time
DRESSING VIDEOS

BATHING

- Ensure safety during bathing tasks due to slippery surfaces
- Install grab bars professionally into tile to optimize safety, steadiness, and for appropriate positioning during transferring in and out area (do not use the suction cup grab bars)
- Non-skid bath mats in bathtub and shower stalls
- Sit down during bathing tasks utilizing a shower chair or tub transfer bench, both with a high back and detachable arm rests
- Use a handheld showerhead if possible and long-handled sponge
- Place all items needed during bathing, together and within reach
MEDICATION MANAGEMENT

• OTs can analyze individual performance and current medication management routine, identify barriers and supports, collaborate with health providers and individual, teach individual self-advocacy skills, and treat specific deficits that may impact compliance and ability to follow medication management routine

• Health Literacy, Cognition, Community Mobility, Fine Motor, Vision, Safety, Equipment
Eating & Meal Times

- Weighted utensils provide additional weight to stabilize hand tremors and support weakened grasps. Each utensil weighs approx 8 oz. (½ lb).

- Encourage to eat at the table to reduce spills, promote social interaction and conversation, and for reduced distractions.

- Prepare meals/snacks in advance for easy retrieval throughout the day. Create a list of simple meals.

- Promote as much independence during meal times.

Eating & Feeding

- Weighted utensils
- Plate guard
- Bendable straw
- Nosey cup
- Universal cuff
- Rocking T-Knife
- DyceM
Prioritize energy conservation and utilize strategies, mobility devices, and adaptive equipment when necessary
Consult with physician and therapist to determine if cane, walker, or wheelchair may be appropriate, and ensure proper training of device
Plan rest breaks throughout the day, and prioritize activities of importance during times of day with most energy
Utilize alternative forms of transportation and mobility when possible
Mobility

- Plan scheduled rest breaks throughout day
- Plan out day and prioritize activities during times of day with most energy

RECUMBENT BIKE

TREKKING POLES

Mobility

ROLLATOR

VS

STANDARD

2-WHEELED

TYPES OF CANES

C CANE
FUNCTIONAL GRIP CANE
OFFSET HANDLE
QUAD CANE
HEMI WALKER
FOLDING WALKING CANE
TOILETING AND TOILET HYGIENE

• Use a bedside commode, commode frame over a regular toilet, or an elevated toilet seat for less effort and increased stability during transfers on/off toilet
• Keep a nightlight on in bathroom, or use automatic sensor lights in bathroom/hallways
• Utilize AE such as the freedom wand, to put toilet paper for increased range of motion during toilet hygiene
• Keep bathroom space organized and free of clutter, to decrease fall risk
Toileting

- Commode
- Raised Toilet Seat
- Toilet to Tub Sliding Transfer Bench

Finger Dexterity

- Reacher
- Typing Aid
- Universal Turning Handle

Accessibility feature on smartphones
Finger Dexterity

- Key Turner
- Enlarged and bright keyboard
- Page Turner

HOUSEHOLD ACTIVITIES

**Laundry:** timer for when complete, laundry basket with wheels, supportive seating while using reacher

**Meal Preparation:** One task at a time, simple meals, utilize adaptive equipment, frequently used items within reach
Driving

- OT’s can receive special driver rehabilitation certification (CDRS) to administer comprehensive driving evaluations (in office and behind the wheel) to assess the physical, mental, and visual abilities for safe driving:
  - Reaction time, Basic visual acuity, Decision making, Judgement, and Planning.
- Physician: medical assessment
- OT: functional assessment
  - Assist in the initiation of dialogue for planning and retirement of driving
- Based on performance, OTs work with individual to:
  - Develop a plan
  - Recommend strategies, equipment, and training
  - Increase awareness of resources available in the community to transition to alternative forms of transportation
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<tr>
<td>Adams County Assistance Office</td>
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<tr>
<td>225 South Franklin St., P.O. Box 4446</td>
</tr>
<tr>
<td>Gettysburg, PA 17325</td>
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<tr>
<td>717-334-6241</td>
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<tr>
<td>M-F 8:30am-5:00pm</td>
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<tr>
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<tr>
<td>Berks County Assistance Office</td>
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<tr>
<td>Reading State Office Building</td>
</tr>
<tr>
<td>625 Cherry Street</td>
</tr>
<tr>
<td>Reading, PA 19602</td>
</tr>
<tr>
<td>610-736-4211</td>
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<tr>
<td>M-F 8:00am-5:00pm</td>
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<td><strong>Bucks County</strong></td>
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<tr>
<td>1214 Veterans Highway</td>
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<tr>
<td>Bristol, PA 19007</td>
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<tr>
<td>215-781-3300</td>
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<tr>
<td><strong>Carbon County</strong></td>
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<td>101 Lehigh Drive</td>
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<tr>
<td>Lehighton, PA 18235</td>
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<tr>
<td>610-577-9020</td>
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<td>100 James Buchanan Drive</td>
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<tr>
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<tr>
<td>610-466-1000</td>
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<td>Bloomsburg, PA 17815</td>
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<tr>
<td>570-387-4200</td>
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<td>Harrisburg, PA 17110</td>
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<td>701 Crosby St., Suite A</td>
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<tr>
<td>845 Main St.</td>
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<tr>
<td>Darby, PA 19023</td>
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<tr>
<td>610-461-3800</td>
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<td>620 Norland Avenue</td>
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<td>Chambersburg, PA 17201</td>
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<tr>
<td>101 Meadow Lane, P.O. Box 65</td>
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<tr>
<td>Mifflintown, PA 17059</td>
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<td>717-436-2158</td>
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<tr>
<td>200 Scranton State Office Building</td>
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<tr>
<td>100 Lackawanna Avenue</td>
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<tr>
<td>Scranton, PA 18503</td>
</tr>
<tr>
<td>570-963-4325</td>
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<td>832 Manor Street, P.O. Box 4967</td>
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<td>Lancaster, PA 17604</td>
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717-299-7411  
M-F 8:00am-5:00pm

Lebanon County  
625 South 8th St.  
Lebanon, PA 17042  
717-270-3600  
M-F 8:00am-5:00pm

Lehigh County  
555 Union Blvd., Suite 3  
Allentown, PA 18109  
610-821-6509  
M-F 7:30am-5:00pm

Luzerne County  
205 South Washington Street  
Wilkes-Barre, PA 18711  
570-826-2100  
M-F 7:30am-5:00pm

Hazleton District  
Center Plaza Building  
10 West Chestnut Street  
Hazleton, PA 18201  
570-459-3800  
M-F 7:30am-5:00pm

Monroe County  
1972 West Main Street, Suite 101  
Stroudsburg, PA 18360  
570-424-3030  
M-F 7:30am-5:00pm

Montgomery County  
Norristown District  
1931 New Hope Street  
Norristown, PA 19401  
610-270-3500  
M-F 8:00-5:00pm

Pottstown District  
24 Robinson Street  
Pottstown, PA 19464

610-327-4280  
M-F 8:00am-5:00pm

Northampton County  
201 Larry Holmes Drive, P.O. Box 10  
Easton, PA 18044  
610-250-1700  
M-F 7:30am-5:00pm

Northumberland County  
320 Chestnut Street  
Sunbury, PA 17801  
570-988-5900  
M-F 8:00am-5:00pm

Perry County  
100 Centre Drive, P.O. Box 280  
New Bloomfield, PA 17068  
717-582-2127  
M-F 8:30am-5:00pm

Philadelphia County  
801 Market Street  
Philadelphia, PA 19107  
215-560-7226  
M-F 8:00am-5:00pm

Boulevard District  
4109 Frankford Avenue  
Philadelphia, PA 19124  
215-560-6500

Chelten District  
301 East Chelten Avenue, 1st Floor  
Philadelphia, PA 19144  
215-560-5200

Delancey District  
5740 Market Street, 2nd Floor  
Philadelphia, PA 19139  
215-560-3700

Glendale District  
5201 Old York Road
Philadelphia, PA 19141
215-561-4600

Liberty District
219 East Lehigh Avenue
Philadelphia, PA 19125
215-560-4000

Ridge/Tioga District
1350 West Sedgley Avenue
Philadelphia, PA 19132
215-560-4900

Somerset District
2701 North Broad Street, 2nd Floor
Philadelphia, PA 19132
215-560-5400

South District
1163 South Broad Street
Philadelphia, PA 19147
215-560-4400

Unity District
4111 Frankford Avenue
Philadelphia, PA 19124
215-560-6400

West District
5070 Parkside Avenue
Philadelphia, PA 19131
215-560-6100

Pike County
Milford Professional Park, Suite 101
10 Buist Road
Milford, PA 18337
570-296-6114
M-F 8:30am-5:00pm

Schuylkill County
2640 Woodglen Road, P.O. Box 1100
Pottsville, PA 17901
570-621-3000
M-F 8:30am-5:00pm

Snyder County
83 Maple Lane
Selinsgrove, PA 17870
570-374-8126
M-F 8:30am-5:00pm

Union County
1610 Industrial Blvd., Suite 300
Lewisburg, PA 17837
570-524-2201
M-F 8:30am-5:00pm

Wayne County
15 Innovation Drive
Lake Ariel, PA 18436
570-253-7100
M-F 8:30am-5:00pm

York County
130 North Duke Street, P.O. Box 15041
York, PA 17405
717-771-1100
M-F 8:00am-5:00pm
HELP WITH CAREGIVING

Aging & Disability Resource Connection/Area Agency on Aging (ADRC/AAA)
An Area Agency on Aging (AAA) is designated in each of Pennsylvania’s counties to serve as the primary entity responsible for developing comprehensive, coordinated systems of community-based services for older adults. https://www.aging.pa.gov/local-resources/Pages/AAA.aspx

The ADRC in Pennsylvania is known as the Link. The Link easily connects you to local services/supports through any Link partner agency, explores existing options to ensure a secure plan for independence, assist consumers with applications to determine funding eligibility, and helps consumers remain or return to their community because of a disability, an illness or accident, or a transition from an institute back to the community.

PA Toll-Free Helpline: 1-800-753-8827

Medical Assistance and Payment of Long Term Care Services
Long-term care (LTC) services include both home and community-based services (HCBS) and LTC facility services (also called nursing facilities). A person who needs LTC services may apply for Medical Assistance (Medicaid) and payment of LTC services but must meet all eligibility requirements.

Requirements: https://www.dhs.pa.gov/Services/Assistance/Pages/MA-General-Eligibility.aspx
Contact local county assistance office with questions, or apply through COMPASS

Pennsylvania Caregiver Support Program
The Pennsylvania Caregiver Support Program works to ease the stresses of caregiving by focusing on the well-being of the caregiver. The program provides the primary caregiver with reimbursement for out of pocket costs with caregiving, such as respite, caregiving-related services and supplies. The program also offers training, education, and counseling. The program is administered by your local Area Agency on Aging. Each caregiver is assigned a case manager who will come to the care receivers’ home, conduct a comprehensive assessment of the needs of the caregiver, provide support, and work with them to develop a person-centered plan of care.

https://www.aging.pa.gov/aging-services/caregiver-support/Pages/default.aspx
Search for your county’s agency on aging:
https://www.aging.pa.gov/local-resources/Pages/AAA.aspx

Resources for Caregivers:
http://www.ltltrainingpa.org/caregiver-information/family-caregivers-webinar-series
https://www.caregiver.org/
https://www.caring.com/caregivers/caregiver-support/
ADULT PROTECTIVE SERVICES BY EASTERN PA COUNTY

Statewide Elder Abuse Hotline: 1-800-490-8505

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<tr>
<td>ADAMS</td>
<td>717-771-9610</td>
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<tr>
<td>BERKS</td>
<td>1-800-490-8505</td>
</tr>
<tr>
<td>BUCKS</td>
<td>1-800-243-3767</td>
</tr>
<tr>
<td>CARBON</td>
<td>610-824-7830</td>
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<tr>
<td></td>
<td>For afterhours, Call 1-800-441-1315, Option 1</td>
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<tr>
<td>CHESTER</td>
<td>800-564-7000</td>
</tr>
<tr>
<td>COLUMBIA</td>
<td>570-784-9272</td>
</tr>
<tr>
<td>CUMBERLAND</td>
<td>1-888-697-0371 x6110 (between 8:00am-4:30pm)</td>
</tr>
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<td></td>
<td>1-888-697-0371 x4121 (between 4:30pm-8:00am)</td>
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<tr>
<td>DAUPHIN</td>
<td>1-866-723-3111</td>
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<tr>
<td>DELAWARE</td>
<td>610-490-1300</td>
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<tr>
<td>FRANKLIN</td>
<td>717-263-2153</td>
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<td>JUNIATA</td>
<td>717-242-0315</td>
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<td>LACKAWANNA</td>
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<td>LANCASTER</td>
<td>717-299-7979</td>
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<td>LEBANON</td>
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<tr>
<td>LEHIGH</td>
<td>610-782-3034</td>
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<tr>
<td>LUZERENE</td>
<td>717-736-7116</td>
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<tr>
<td>MONROE</td>
<td>1-800-498-0330</td>
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<td>MONTGOMERY</td>
<td>1-800-734-2020</td>
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<tr>
<td>NORTHHAMPTON</td>
<td>610-252-9060</td>
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<tr>
<td>NORTHERMBERLAND</td>
<td>1-855-313-4387</td>
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<td>717-582-5128</td>
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<td>PHILADELPHIA</td>
<td>215-765-9040</td>
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<td>PIKE</td>
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DESIGNATED PSYCHIATRIC SCREENING/CRISIS CENTERS

Adams County
WellSpan Gettysburg Hospital
147 Gettys St. Gettysburg, PA 17325
HOTLINE: 717-851-5320

Berks County
Service Access and Management (SAM)
19 North 6th St. Reading, PA 19601
HOTLINE: 610-236-0530

Bucks County
Central Bucks Crisis
Doylestown Hospital Emergency Room
595 West State St. Doylestown, PA 18901
HOTLINE: 215-345-2273

Lower Bucks Crisis
Lower Bucks Hospital Emergency Room
501 Bath Road. Bristol, PA 19007
HOTLINE: 215-785-9765

Carbon County
Resources for Human Development
1321 Middle Easton Belmont Pike
Stroudsburg, PA 18360
HOTLINE: 570-992-0879

Chester County
Holcomb Behavioral Health Systems
Valley Creek Crisis Center
469 Creamery Way
Exton, PA 19341
HOTLINE: 610-280-3270

Columbia County
TAPline Crisis
1-800-222-9016

Cumberland County
Carlisle Regional Medical Center Emergency Room, 45 Spring Drive, Carlisle, PA 17013
HOTLINE: 717-243-6005

Holy Spirit Hospital Emergency Room
503 North 21st Street, Camp Hill, PA 17011
HOTLINE: 717-763-2222

Dauphin County
Crisis Intervention
100 Chestnut Street, Harrisburg, PA 17101
HOTLINE: 717-232-7514

Delaware County
Crozer Chester Medical Center
1 Medical Center Blvd. Chester, PA 19013
HOTLINE: 610-447-7600

Mercy Fitzgerald Hospital
1500 Lansdowne Ave. Darby, PA 19013
HOTLINE: 610-23-4210
**Franklin County**
Keystone Health Crisis Intervention
Next to Chambersburg Hospital ER
112 North 7th Street, Chambersburg, PA 17201
HOTLINE: 717-264-2555

TruNorth Wellness Services
272 South Main Street
Chambersburg, PA 17201
HOTLINE: 717-632-4900

**Juniata County**
University Community Behavioral Health
The Meadows- Outpatient Services
132 The Meadows Drive
Centre Hall, PA 16828
HOTLINE: 800-929-9583

**Lackawanna County**
Geisinger Community Medical Center
1800 Mulberry St. Scranton, PA 18510
HOTLINE: 570-348-6100

**Lancaster County**
Crisis Intervention Program
750 Eden Road, Lancaster, PA 17601
HOTLINE: 717-394-2631

**Lebanon County**
WellSpan Behavioral Health
283 South Butler Road, P.O. Box 550
Mt. Gretna, PA 17064
HOTLINE: 717-274-3363

**Lehigh County**
Lehigh Valley Hospital – Cedar Crest
1200 South Cedar Crest Blvd.
Allentown, PA 18103
HOTLINE: 610-782-3127

**Luzerne County**
Commonwealth Health
Wilkes-Barre General Hospital
Crisis Response and Recovery Center of NEPA
575 North River St. Wilkes-Barre, PA 18764
HOTLINE: 855-600-6372

**Monroe County**
Resources for Human Development
1321 Middle Easton Belmont Pike
Stroudsburg, PA 18360
HOTLINE: 570-992-0879

**Montgomery County**
Abington Memorial Hospital, Crisis Program
1200 Old York Road
Abington, PA 19001
HOTLINE: 215-481-2525

Montgomery County Mobile Crisis
HOTLINE: 1-855-634-4673

**Northampton County**
Lehigh Valley Health Network
Muhlenberg
2545 Schoenersville Rd.
Bethlehem, PA 18017
HOTLINE: 610-829-4801

**Northumberland County**
Behavioral Health
217 North Center St.
Sunbury, PA 17801
HOTLINE: 1-855-313-4387
**Perry County**
Carlisle Regional Medical Center
Emergency Room, 45 Spring Drive,
Carlisle, PA 17013
HOTLINE: 717-243-6005

Holy Spirit Hospital Emergency Room
503 North 21st Street, Camp Hill, PA 17011
HOTLINE: 717-763-2222

**Philadelphia County**
Friends Hospital
4641 Roosevelt Blvd. Philadelphia, PA 19124
HOTLINE: 800-889-0548

Einstein Medical Center Philadelphia
5501 Old York Road
Philadelphia, PA 19141
HOTLINE: 215-951-8300

Temple University Hospital
Episcopal Campus
100 East Lehigh Ave. Philadelphia, PA 19125
HOTLINE: 215-707-2577

Hall Mercer Crisis Response Center
At Pennsylvania Hospital
245 South 8th Street Philadelphia, PA 19107
HOTLINE: 215-829-7271

Mercy Hospital
501 S 54th Street Philadelphia, PA 19143
HOTLINE: 516-705-2248

**Pike County**
Resources for Human Development
1321 Middle Easton Belmont Pike
Stroudsburg, PA 18360
HOTLINE: 570-992-0879

**Schuylkill County**
Schuylkill County Mental Health
108 South Claude A Lord Blvd., 2nd Floor
Pottsville, PA 17901
HOTLINE: 1-877-993-4357

**Snyder County**
TAPline Crisis
1-800-222-9016

**Union County**
TAPline Crisis
1-800-222-9016

**Wayne County**
Wayne UNC Health Care Emergency Room
2700 Wayne Memorial Drive
Goldsboro, NC 27534
HOTLINE: 570-253-0321

**York County**
WellSpan Health, York Hospital
1101 Edgar St., Unit C
York, PA 17403
HOTLINE: 717-851-5320

**HOMELESSNESS PREVENTION SERVICES**

AMiracle4Sure, Inc.
4218 William Penn Highway
Mifflintown, PA 17059
717-436-1113

1735 State Street Harrisburg, PA 17103
717-232-0100
Bell Socialization Services, Inc.
16 West King Street, York, PA 17401
717-356-2957

Bridge of Hope National
1 North Bacton Hill Road, Malvern, PA 19341
610-280-0280

Bucks County Housing Group
853 2nd Street Pike, Richboro, PA 18954
800-810-4434

Carbon County Action Committee for Human Services
267 South 2nd Street, Lehighton, PA 18235
610-377-6400, x223

Catherine McAuley Center
430 Pittston Ave. Scranton, PA 18505
570-342-1342

Catholic Charities, for Veteran Families
900 South Woodward Street
Lehigh/Northampton County Office
Allentown, PA 18103
610-435-1541

Central PA Family Support Services
320 South Hanover Street, Carlisle, PA 17013
717-614-0130

Commission on Economic Opportunity
165 Amber Lane Wilkes-Barre, PA 18702
570-826-0510

Diversified Community Services, Veterans
1529 South 22nd Street
Philadelphia, PA 19146
215-336-5505

Family Promise of Monroe County
905 Main Street, Stroudsburg, PA 18360
570-420-8589

Gatehouse- Transitional Housing and Care
21 Gatehouse Drive, Danville, PA 17821
570-275-6766

HAVEN Women, Female Veterans
4108 Baltimore Avenue
Philadelphia, PA 19104
267-292-2052

Horizon House
120 South 30th Street, Philadelphia, PA 19104
215-386-3838

Pennsylvania Interfaith Community Program
40 East High Street, Gettysburg, PA 17325
717-334-1518

Service Access and Management
590 Terry Reily Way, Pottsville, PA 17901

Southwest Community Development Corp.
6328 Paschall Avenue, Philadelphia, PA 19142
215-729-0800

Tabor Community Services, Veterans
105 East King Street, Lancaster, PA 17602
717-358-9394

United Neighborhood Centers of Northeastern Pennsylvania
631 Cedar Avenue, Scranton, PA 18505
570-346-6203, x112

Utility Emergency Services Fund
608 Walnut Street, Suite 600
Philadelphia, PA 19103
215-972-5170
Volunteers of America, Master Leasing  
25 North River Street, Wilkes-Barre, PA 18702  
570-825-5261 x3  

YWCA Greater Harrisburg  
1101 Market Street, Harrisburg, PA 17103  
717-234-7931 x3078  

NURSING HOMES NEAR PA WITH DEDICATED HD UNITS  

Rosemond Center  
35 Rosemont Ave.  
Bryn Mawr, PA 19010  
610-580-0400  

Hartwyck at Cedar Brook  
1340 Park Ave., Plainfield, NJ 07060  
908-754-3100  
Contact is Karen Petrin  

Leisure Chateau Rehabilitation  
962 River Avenue, Lakewood, NJ 08701  
732-370-8600  
Contact is Judy Cerciello  

Sitrin NeuroCare  
2050 Tilden Avenue, P.O. Box 1000  
New Hartford, NY 13413  
315-737-2338  

SUPPORT GROUPS  

Plymouth  
Meets Monthly  
Contact: Jennifer Ruggiano  
Phone: 302-733-1000  
rugg1194@yahoo.com  

Philadelphia  
Meets Monthly  
Contact: Jennifer Klapper, RN  
Phone: 215-829-5176  
Jennifer.Klapper@pennmedicine.upenn.edu  

Hershey  
Meets 3rd Saturdays of Each Month  
Contact: Helene Knapp  
Phone: 610-944-0445 ext. 327  
hknapp@concern4kids.org  

Lehigh Valley  
Meets 2nd Saturdays of Each Month  
Contact: Eileen Coulehan  
Phone: 60-207-6273  
ecoulehan@msn.com  

Online Support Groups offered by HDSA  

Online Groups:  
- HD Positive, Early Symptoms  
- Parent Caregiver  
- Caregiver Support Group  
- At Risk/Not Tested  
- Youth Support Group  
- Family Planning  

Online Support Groups offered by Philly Cure HD  
https://phillycurehd.org/  
Caregiver Support Group  
Virtually on the 2nd Tuesday of the month, at 7pm
Support Group for At Risk, Gene Positive, or Diagnosed with HD
Virtually on 4th Tuesday of the month, at 7pm

General Support Group – Philly Cure HD
Virtually on the 3rd Tuesday bi-monthly at 7pm
February, April, June, August, October, December. Open to all of the HD Community

Contact: Sherri,
socialworker@phillycurehd.org
215-219-3521

HD COUNSELING SUPPORT
https://hdsa.org/find-help/community-social-support/hdsa-telehealth/
For families affected by HD, every family member can receive counseling with up to 8 telehealth visits per year.

SOCIAL CLUBS
Easterseals of Eastern Pennsylvania
1501 Lehigh Street,
Suite 201
Allentown, PA 18103
610-289-0114
- Creates life-changing solutions for individuals with disabilities and their families in their community by increasing independence, maximizing opportunities, minimizing barriers and enhancing quality of life.

The Social Scene:
https://thesocialsceneclub.com/e-scene/
A Club for Adults with Special Needs
601 Riverside Ave., Unit 120.
Lyndhurst, NJ 07071

PA CENTERS SPECIALIZING IN HD CARE:
HDSA Center of Excellence at University of Pennsylvania HD Center
Parkinson’s Disease and Movement Disorders Center
330 South 9th Street
Philadelphia, PA 19107
Phone: 215-829-5176
Website:
http://www.uphs.upenn.edu/neuro/

OTHER CENTERS OF EXCELLENCE SPECIALIZING IN HD CARE NEAR PA
HDSA Center of Excellence at Rutgers University and Rowan University
42 East Laurel Road
Rowan University-School of Osteopathic Medicine, Department of Pathology – Huntington Disease Center
Stratford, NJ 08084
Phone: 732-235-5993

HDSA Center of Excellence at Columbia University/NYS Psychiatric Institute
1051 Riverside Drive New York, NY
10032 Phone: 212-305-4597
Website: http://hdny.org/
INDEPENDENT PA
PHYSICIANS TREATING
HD

Nancy Diaz-Pechar, MD
Movement Disorder
Specialist
St. Luke’s University Health
Bethlehem & Macungie, PA
484-526-5210

Aaron Lasker, MD
Movement Disorder
Specialist
St. Luke’s University Health
Bethlehem, Easton, &
Allentown, PA
484-426-2626

Behrang Saminejad, MD
Movement Disorder
Specialist
Lehigh Valley Health
Allentown, PA 18103
610-402-8420

ELDER CARE/DISABILITY ATTORNEYS

Allison Bartlett, Esq.
HDSA Manager of Disability Programs
abartlett@hdsa.org
(212) 242-1968

The Elder Law Firm of Robert Clofine
340 Pine Grove Commons
York, PA 17403
717-747-5995

David Nesbit – Keystone Elder Law
555 Gettysburg Pike
Mechanicsburg, PA 17055
717-697-3223

Michael Giordano- Giordano Law
221 West Main Street
Mechanicsburg, PA 17055

Curran Estate & Elder Law
222 Kenhorst Blvd.
Reading, PA 19607
610-406-5377

Henry Carpenter II, Esq.
301 Oxford Valley Rd., #101B
Yardley, PA 19067
888-378-8200

The Law Offices of Nancy Busch
825 North 9th St.
Allentown, PA 18104
610-432-3337

Barry S. Rabin Law Offices
797 East Lancaster Ave., #13
Downington, PA 19335
610-873-1600
<table>
<thead>
<tr>
<th>Law Firm</th>
<th>Address</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson Elder Law</td>
<td>206 State Rd. Media, PA 19063</td>
<td>610-566-4700</td>
</tr>
<tr>
<td>Schlesinger &amp; Kerstetter, LLP</td>
<td>545 North 2nd St. Shamokin, PA 17872</td>
<td></td>
</tr>
<tr>
<td>Marshall, Parker, &amp; Weber, LLC</td>
<td>201 Lackawanna Ave., Unit 301 Scranton, PA 18503</td>
<td>570-969-2127</td>
</tr>
<tr>
<td>Bregman &amp; Lantz, LLC</td>
<td>1205 Wyoming Ave. Forty Fort, PA 18705</td>
<td>570-28-1800</td>
</tr>
<tr>
<td>Gerhard &amp; Gerhard, P.C</td>
<td>815 Greenwood Ave, #8 Jenkintown, PA 19046</td>
<td>215-885-6785</td>
</tr>
<tr>
<td>R Thomas Murphy &amp; Associates</td>
<td>237 East Queen Street Chambersburg, PA 17201</td>
<td>717-261-0117</td>
</tr>
<tr>
<td>Good Shepherd Rehabilitation</td>
<td>850 South 5th Street Allentown, PA 18103</td>
<td>610-776-8302</td>
</tr>
<tr>
<td>Bryn Mawr Rehab Hospital</td>
<td>414 Paoli Pike Malvern, PA 19355</td>
<td>484-596-5000</td>
</tr>
<tr>
<td>Encompass Health</td>
<td>1850 Normandie Drive York, PA 17408</td>
<td>717-767-6941</td>
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</tbody>
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**DRIVING EVALUATIONS**

<table>
<thead>
<tr>
<th>Driving School</th>
<th>Address</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>Moss Rehab Driving School</td>
<td>201 Old York Road Jenkintown, PA 19046</td>
<td>Contact: Dan Basore, CDRS or Lynne Mason, OTR, CDRS Phone: (215) 886-7706 Fax: (215) 886-7709 <a href="https://www.mossrehab.com/driving">https://www.mossrehab.com/driving</a></td>
</tr>
<tr>
<td>Clark Outpatient Rehabilitation Center</td>
<td>Doylestown Hospital, Ambulatory Center</td>
<td></td>
</tr>
</tbody>
</table>

**Adaptive Mobility Services**
Services several areas of eastern and southern Pennsylvania 1120 Centre Turnpike Orwigsburg, PA 17961 484-650-2280 [susie@adaptivemobility.com](mailto:susie@adaptivemobility.com) [https://adaptivemobility.com/services/for-drivers/](https://adaptivemobility.com/services/for-drivers/)

**Good Shepherd Rehabilitation**
Center for Assistive Technology 850 South 5th Street Allentown, PA 18103 610-776-8302 [https://www.goodshepherdrehab.org/condition/driving-evaluation/](https://www.goodshepherdrehab.org/condition/driving-evaluation/)

**Bryn Mawr Rehab Hospital**
414 Paoli Pike Malvern, PA 19355 484-596-5000 [https://www.mainlinehealth.org/specialties/rehab-driver-rehab-program](https://www.mainlinehealth.org/specialties/rehab-driver-rehab-program)

**Encompass Health**
**SWALLOW STUDIES**

**Penn Medicine**
HD Center of Excellence
330 South 9th St. 4th Floor
Philadelphia, PA 19107
215-829-5176

**Riddle Hospital**
1068 West Baltimore Pike
Media, PA 19063
484-227-3200

**Clark Outpatient Rehabilitation Center**
Doylestown Hospital, Ambulatory Center
1st Floor, 593 West State Street
Doylestown, PA 18901
215-345-2894

**Lehigh Valley Health Network**
Several locations
888-402-5846

**Philadelphia Mobile FEES, LLC**
215-806-2481
april@philamobilefees.com

**WellSpan Health**
Several locations
Adams and York Counties 1-877-734-2213
Franklin County 717-262-4600

**PREIMPLANTATION GENETIC DIAGNOSIS (PGD) & GENETIC COUNSELING**

**Hospital of the University of Pennsylvania**
3400 Spruce Street
Philadelphia, PA 19104
Phone: 215-662-4000
https://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/penn-fertility-care/embryo-screening/treatments-and-procedures

**Family Fertility Center**
95 Highland Avenue, Suite #100
Bethlehem, PA 18017
Phone: 610-868-8600

**RMA**
1151 Old York Road
Abington, Pennsylvania 19001
Phone: 215-938-1515

**COOKBOOKS AND NUTRITION**

“Pass the Calories, Please”
By F. Gail

“The Non-Chew Cookbook”
By J. Randy Wilson

“Easy to Swallow, Easy to Chew”
By Donna L. Weihofen

“Soft Foods for Easier Eating Cookbook”
By Sandra Woodruff

“The Dysphagia Cookbook”
By Todd Levine, MD

“The I Can’t Chew Cookbook”
By J. Randi Wilson
Find a Genetic Counselor
https://www.findageneticcounselor.com/
(312) 321-6834

HDSA

HELP WITH MEDICATIONS

Generic Tetrabenazine
TAGI Pharma Customer Service 1-855-225-8244

Austedo
Teva Shared Solutions
1-800-887-8100
www.sharedsolutions.com

Xenazine
Lundbeck
1-888-882-6013
www.xenazineusa.com

BioTek
reMedys
Specialty Pharmacy
646-294 - 9866
www.biotekrx.com

1-800-BRAIN BANK or 617-855-2400
http://mcleanhospital.org/hbtrc/

Massachusetts General Hospital
HDSA supported brain bank through MGH
The 24-hour contact number is 617-724-5700
Page #21300

HD RELATED FINANCIAL ASSISTANCE

HealthWell
Disease Funds: Grant applications for chronic or life-altering diseases, that provides support for prescription copays, health insurance premiums, deductibles, and coinsurance, and travel costs.
https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/

NORD
Provides assistance programs to help patients obtain life-saving or lifesustaining medication, and financial assistance with insurance premiums and copays, diagnostic testing assistance, and travel assistance for clinical trials.

Patient Services
Financial support and guidance for patients with chronic diseases.
https://www.patientservicesinc.org/

PACE Prescription Assistance
Pennsylvania’s prescription assistance program for older adults, offers low-cost

BRAIN DONATION
Harvard Brain Tissue Resource Center at McLean Hospital
prescription medication to qualified residents, age 65 and older.
https://www.aging.pa.gov/aging-services/prescriptions/Pages/default.aspx

THERAPY FOR INDIVIDUALS WITH HD

Occupational Therapy:
OTs help people across the lifespan do the things they want, need, and are expected to do through the therapeutic use of daily activities (occupations), and aim to solve problems and barriers that may interfere. OTs assist with ADLs (Self-care, Dressing, Feeding), IADLS (Home and Medication Management), Play, Education, Sleep, Work, Leisure, and Social Participation. (AOTA)
https://pota.site-ym.com/

Physical Therapy:
PTs are movement experts who diagnose and treat individuals of all ages, to improve quality of life through prescribed exercise, hands-on care, and patient education. PTs develop a treatment plan to improve a person’s ability to move, reduce, or manage pain, restore function, and prevent disability. (APTA)
https://aptaapps.apta.org//APTAPTDirect ory/FindAPTDirectory.aspx

Speech-Language-Hearing Pathologist:
SLPs work with people of all ages to treat communication and swallowing problems such as speech sounds, language, literacy, social communication, voice, fluency, cognitive-communication, and feeding and swallowing. (ASHA)
https://psha.org/members-only/member-login.html#/public-search

LONG-TERM CARE

Search for long-term care facilities specifically by county in PA:

Long Term Care Ombudsman Program
Pennsylvania Ombudsmen are federally mandated, legally-based and state certified via standardized training to actively advocate and give voice to older consumers of long-term care services, whether delivered in the community or a facility-based setting.
Phone: 717-783-8975

DEPARTMENT OF AGING

Area Agencies on Aging by County
https://www.aging.pa.gov/local-resources/Pages/AAA.aspx

Adult Day Centers by County
https://www.aging.pa.gov/local-resources/Pages/Adult-Day-Center.aspx

Senior Community Centers
https://www.aging.pa.gov/local-resources/Pages/Senior-Center.aspx

Pennsylvania Link to Aging and Disability Resources
1-800-753-8827

PA HEALTHCARE RESOURCES

COMPASS
A single access point for application for Pennsylvanians to apply for many health and human service programs and manage
benefit information. It offers health care coverage, supplemental nutrition assistance programs, cash assistance, long-term living services, low-income home assistance programs, free/reduced price school meals, and child care works. https://www.compass.state.pa.us/compass.web/Public/CMPHome

HDSA YOUTH

HDSA National Youth Alliance
https://nya.hdsa.org/
Motivates youth to get involved in their local HDSA Chapters, Affiliates, and Support Groups in efforts through education, fundraising, advocacy and awareness for Huntington’s disease. The NYA is a collection of children, teens and young adults from across the country.

Huntington’s Disease Youth Organization (HDYO)
https://en.hdyo.org/
A non-profit set up to provide support and education to young people impacted by HD around the world. HDYO provides support and education, creates education content for all age groups, connect young people with peers, makes events such as youth camps and conferences, and provides opportunities for young people to get involved.

INTERNET RESOURCES

COMMUNICATING WITH HEALTHCARE PROVIDERS

LONG TERM CARE

CAREGIVER GUIDES

LIFTING THE VEIL

ADVANCE DIRECTIVES

GENETIC TESTING

JUVENILE HD
HD AND THE LAW

SPEECH & SWALLOWING

NUTRITION

TALKING WITH KIDS ABOUT HD

PHYSICAL AND OCCUPATIONAL THERAPY


DRIVING
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/driving-and-huntingtons-disease/

HOME SAFETY
https://www.winchesterhospital.org/health-library/article?id=21068

BRAIN DONATION
http://www.brainbank.mclean.org/donate/

NJ STATE DISABILITY APPLICATION
http://lwd.dol.state.nj.us/labor/tdi/state/sp_clt_menu.html

SOCIAL SECURITY DISABILITY
https://www.ssa.gov/disability/

PSYCHIATRIC SCREENING (CRISIS CENTERS)
http://www.state.nj.us/humanservices/dmhas/home/hotlines/MH_Screening_Centers.pdf

NJ COUNTY WELFARE AGENCIES
http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/

MEDICAID NJ-MLTSS
http://www.nj.gov/humanservices/dmahs/home/mltss.html

BEHAVIOR AND HD
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/the-behavioral-symptoms-of-huntingtons-disease/

ADULT PROTECTIVE SERVICES
http://www.state.nj.us/humanservices/doas/documents/APS%20flyer.pdf

CRISIS FLOW SHEET ON NEXT PAGE
Help for HD patients and families in crisis

911

1. Person is in imminent danger
2. Has intent and means to hurt self or others
3. MH crisis is severe (psychosis, emotionally unstable, etc.)

APS

Types of elder/disabled adult abuse:
1. Physical harm or injury
2. Neglect
3. Financial exploitation
4. Verbal or emotional abuse
5. Involuntary seclusion
6. Physical or chemical restraint
7. Unwanted sexual contact
8. Self-neglect (individual lacks capacity)

CPS

Suspected or known abuse: parent or caregiver, whether through action or failing to act, causes injury, death, emotional harm or risk of serious harm to a child.

Police Non-Emergency

1. Person in need of a welfare check
2. Reporting a crime that was already committed
3. Third party reported SI/HI or emotional instability and no one can connect with the person on the phone

ER

1. Person is willing to get help for SI/HI or emotional instability AND is:
   2. accompanied by a responsible person
RESOURCE GUIDE FOR
DELAWARE FAMILIES LIVING
WITH HUNTINGTON’S DISEASE

Created by:

Corlynn Hullfish, LCSW
chullfish@hdsa.org

Kayla Cupano OTD-S
kcotd0@gmail.com
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COUNTY ASSISTANCE

Kent County
James W. William State Service Center
805 River Road
Dover, DE 19901
(302) 857-5000
8:00am- 4:30pm M-F

Smyrna State Service Center
200 South DuPont Blvd., Suite 101
Smyrna, DE 19977
(302) 514-4500
8:00am- 4:30pm M-F

New Castle County
Appoquinimink State Service Center
122 Silver Lake Road
Middletown, DE 19709
(302) 696-3120 or (302) 378-5781
8:00am-4:30pm M-F

Belvedere State Service Center
310 Kiamensi Road
Wilmington, DE 19804
(302) 892-5972
8:00am-4:30pm M-F

Claymont State Service Center
3301 Green Street
Claymont, DE 19703
(302) 792-6505 or (302) 798-4093
8:00am-4:30pm M-F

DeLaWarr State Service Center
500 Rogers Road
New Castle, DE 19720
(302) 622-4500 or (302) 577-3814
8:00am-4:30pm M-F

Floyd I. Hudson State Service Center
501 Ogletown Road
Newark, DE 19711
(302) 283-7500
8:00am-4:30pm M,Tu,Th,F. till 7:00pm Wed.

Northeast State Service Center
1624 Jessup Street
Wilmington, DE 19802
(302) 552-3500 or (302) 552-3503
8:00am-4:30pm M-F

Winder Laird Porter State Service Center
509 West 8th Street
Wilmington, DE 19801
(302) 777-2800 or (302) 777-2830
8:00am-4:30pm M-F

Sussex County
Bridgeville State Service Center
400 Mills Streets
Bridgeville, DE 19933
(302) 721-7005 or (302) 337-8261
8:00am-4:30pm M-F

Edward W. Pyle State Service Center
34314 Pyle Center Road
Frankford, DE 19945
(302) 732-1700 or (302) 732-9504
7:30am-4:30pm M-F

Laurel State Service Center
31039 North Poplar Street
Laurel, DE 19956
(302) 875-8402 or (302) 875-2280
8:00am-4:30pm M-F

Thurman Adams State Service Center
546 South Bedford Street
Georgetown, DE 19947
(302) 515-3000 or (302) 515-3080
8:00am- 4:30pm M-F

Anna C. Shipley State Service Center
350 Virginia Ave.
Seaford, DE 19973
(302) 628-6700 or (302) 628-2011
8:00am-4:30pm M-F
HELP WITH CAREGIVING

Delaware Aging and Disability Resources (ADRC)
One-stop access point for information and services for older persons and adults with physical disabilities throughout the state. ADRC provides information and assistance and options counseling. **Phone:** 1-800-223-9074 [http://www.delawareadrc.com/](http://www.delawareadrc.com/)


Diamond State Health Plan- PLUS (DSHP-Plus)
DSHP-Plus is a managed long-term care program for Delaware Medicaid. This program is intended to provide a full suite of services to low income, elderly state residents, including: nursing home care, assisted living, and a variety of home and community supports that assist disabled individuals to remain living at home. Under DSHP-Plus, there are two sub-programs:

Long-Term Care Community Services (LTCSS) refers to the delivery of long-term services and supports through Delaware’s Division of Medicaid & Medical Assistance (DMMA). [https://dhss.delaware.gov/dhss/dmma/files/dshpplus_booklet.pdf](https://dhss.delaware.gov/dhss/dmma/files/dshpplus_booklet.pdf)

Long-Term Care Community Services (LTCCS) includes: Personal Care; Respite; Care Management; Medical and Social Day Care; Home-Delivered Meals; Nursing Home Care; Emergency Response System; Cognitive Services; Assisted Living; Mental Health Services; Supplemental Nutrition

**Nursing Facility Program** pays for the cost of care in nursing facilities in Delaware that have contracts with the Managed Care Organizations (MCOs). These facilities provide room, board, and nursing services to persons who are elderly and/or disabled.

**Delaware’s Division of Medicaid & Medical Assistance (DMMA):** 1-866-940-8963 [https://www.dhss.delaware.gov/dhss/dmma/ltcmedicaid.html](https://www.dhss.delaware.gov/dhss/dmma/ltcmedicaid.html)

**Personal Attendant Services**
Programs to allow participants to hire, train, and supervise their own personal care attendants (including family members and friends). The person receiving care must be eligible for and enrolled in a Personal Attendant Services Program through Division of Services for Aging and Adults with Physical Disabilities, Diamond State Health Plan Plus, or Pathways to Employment. [https://www.dhss.delaware.gov/dhss/dsaapd/faq_attendant.html](https://www.dhss.delaware.gov/dhss/dsaapd/faq_attendant.html)

**Statewide Respite Program**
This program provides respite care services for elderly and functionally impaired persons age 18 and older to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. Services available include: Companions, homemaker/home health aides (hourly/overnight) medical or social adult day care, temporary care in licensed medical facilities, camperships, private duty nursing service, and caregiver-directed option.

**Call ADRC for Respite in your county:** 1-800-223-9074
ADULT PROTECTIVE SERVICES

New Castle County
University Office Plaza
256 Chapman Rd., Suite 200
Newark, DE 19702
Call: 1-800-223-9074 (ADRC)
or 302-453-3820

Kent/Sussex Counties
Milford State Service Center
18 North Walnut St., 1st Floor
Milford, DE 19963
Call: 1-800-223-9074 (ADRC)
or 302-424-7310

MENTAL HEALTH & CRISIS CENTERS

Northern Delaware:
New Castle County and greater Smyrna in Northern Kent County

Mobile Crisis Intervention Services (MCIS)
Fernhook Building
14 Central Avenue, New Castle, DE 19720
(800) 652-2929

Recovery Response Center (RRC)
65 East Chestnut Hill Rd., Newark, DE 19713
(302) 318-6070

Southern Delaware:
Sussex County and Kent County south of greater Smyrna

Mobile Crisis Intervention Services (MCIS)
700 Main Street, Ellendale, DE 19941
(800) 345-6785

Recovery Response Center (RRC)
700 Mail Street, Ellendale, DE 19941
(302) 424-5660

Mental Health Association in DE
100 West 10th St., Suite 600
Wilmington, DE 19801
(302) 654-6833
8am-4pm M-F
Promotes improved mental well-being for all individuals and families in Delaware through education, support, and advocacy

Connections
Community Support Programs, Inc.
(833) 886-2277
New Castle, Kent, and Sussex Counties

Delaware Psychiatric Center
Herman M. Holloway, Sr. Campus
Springer Building
1901 North Du Pont Highway
New Castle, DE 19720
(302) 577-2484

ChristianaCare Wilmington
Hospital Emergency Department
C.A.P.E.S Unit
501 West 14th St
Wilmington, DE 19801
(302) 428-2118

HOMELESSNESS PREVENTION

Contact your County State Service Center for assistance on emergency housing

Connections
Community Support Programs, Inc.
New Castle County
590 Naamans Road
Claymont, DE 19703

Kent County
1114 South DePONT Highway
Dover, DE 19901
Sussex County
123 Pennsylvania Ave.
Seaford, DE 19973

Housing Alliance Delaware
100 West 10th Street, Suite 611
Wilmington, DE 19801
(302) 654-0126

The Shepherd Place Homeless Shelter
1362 South Governor Ave.
Dover, DE 19904
(302) 678-1909

Interfaith Community Housing of Delaware
613 North Washington Street
Wilmington, DE 19801
(302) 652-3991

SUPPORT GROUPS

Northern Delaware Support Group
Meets Monthly
Contact: Jennifer Ruggiano
302-733-1000
Rugg1194@yahoo.com

ONLINE SUPPORT GROUPS by HDSA
- HD Positive, Early Symptoms
- Parent Caregiver
- Caregiver Support Group
- At Risk/Not Tested
- Youth Support Group
- Family Planning

NURSING HOMES NEAR DE WITH DEDICATED HD UNITS

Rosemond Center
35 Rosemont Ave. Bryn Mawr, PA 19010
610-580-0400

Hartwyck at Cedar Brook
1340 Park Ave., Plainfield, NJ 07060
908-754-3100
Contact is Karen Petrin

Leisure Chateau Rehabilitation
962 River Avenue, Lakewood, NJ 08701
732-370-8600
Contact is Judy Cerciello

Sitrin NeuroCare
2050 Tilden Avenue, P.O. Box 1000 New Hartford, NY 13413 315-737-2338

Other Licensed Nursing Homes in DE without specific HD units:
https://www.dhss.delaware.gov/dhss/dhcq/licensednursinghomes.html

HD COUNSELING SUPPORT
https://hdsa.org/find-help/community-social-support/hdsa-telehealth/
For families affected by HD, every family member can receive counseling with up to 8 telehealth visits per year.

SOCIAL CLUBS
Easterseals Delaware & Maryland Eastern Shore
61 Corporate Circle
New Castle, DE 19720
(302) 324-4444
https://www.easterseals.com/de/

Smyrna Adult Day Services
699 South Carter Road Smyrna, DE 19977
(302) 653-3514
CENTER OF EXCELLENCES
SPECIALIZING IN
HD CARE NEAR DE

HDSA Center of Excellence for Huntington’s Disease at Johns Hopkins
Meyer 2-181
600 N. Wolfe Street
Baltimore, MD 21287
Phone: 410-955-2497
Website:
https://www.hopkinsmedicine.org/psychiatry/specialty_areas/huntingtons_disease/

HDSA Center of Excellence at University of Pennsylvania HD Center
Parkinson’s Disease and Movement Disorders Center
330 South 9th Street Philadelphia, PA 19107
Phone: 215-829-5176
Website:
http://www.uphs.upenn.edu/neuro/

HDSA Center of Excellence at Rutgers University and Rowan University
42 East Laurel Road
Rowan University-School of Osteopathic Medicine
Department of Pathology-Huntington Disease Center
Stratford, NJ 08084
Phone: 732-235-5993

HDSA Center of Excellence at Columbia University/NYS Psychiatric Institute
1051 Riverside Drive New York, NY 10032 Phone: 212-305-4597
Website: http://hdny.org/

INDEPENDENT PHYSICIANS TREATING HD NEAR DE

Christopher Ross, MD
Movement Disorder Specialist
John Hopkins Medicine
(410) 955-2398

Jee Bang, MD
Movement Disorder Specialist
John Hopkins Medicine
(410) 955-2398

Pedro Gonzalez-Alegre, MD
University of Pennsylvania Movement Disorder Specialist
(215) 829-5176

Nabila Dahodwala, MD
University of Pennsylvania Movement Disorder Specialist
(215) 829-5176

Amy Colcher, MD
Movement Disorder Specialist
Cooper Neurological Institute
856-546-8525

Andrew McGarry, MD
Movement Disorder Specialist
Cooper Neurological Institute
856-546-8525

ELDER CARE/DISABILITY ATTORNEYS

Allison Bartlett, Esq.
HDSA Manager of Disability Programs
abartlett@hdsa.org
(212)242-1968
The Delaware Elder Law Center
3711 Kennett Pike, #110
Wilmington, DE 19807
(302) 300-4390

Procino-Wells & Woodland, LLC
225 High Street Seaford, DE 19973
(302) 628-4140

Law Offices of Bonnie M. Benson, P.A.
306 East Camden Wyoming Avenue
Camden, DE 1993
(302) 697-4900

Estate & Elder Law Services
2961 Centerville Rd., #350
Wilmington, DE 19808
(302) 651-0113

Denise D. Nordheimer, Esquire, LLC
2001 Baynard Blvd. Wilmington, DE 19802
(302) 655-4500

Morris James LLP
803 North Broom St. Wilmington, DE 19806

DRIVING EVALUATIONS
Occupational Therapy of Delaware
550 South DuPont Hwy, Suite E
Milford, DE 19963

Fox Rehab Driving Assessment Program
(877) 407-3422

MossRehab
201 Old York Road, Suite 100 Jenkintown, PA
(215) 886-7706

Christiana Care Rehabilitation Services
124 Sleepy Hollow Drive
Middletown, DE 19709
(302) 449-3050

St. Lawrence Rehabilitation Center
2381 Lawrenceville Road
Lawrenceville, NJ 08648
(609) 896-9500 x2494

SWALLOW STUDIES

Restore Therapy Services – Mobile
(609) 561-1088

Christiana Care
In Glasgow, Middletown,
Newark, & Wilmington
(800) 693-2273

Beebe Healthcare
19324 Lighthouse Plaza Blvd.
Rehoboth Beach, DE 19971
(302) 260-7346

Bayhealth
640 South State Street
Dover, DE 19901

COOKBOOKS AND NUTRITION

“Pass the Calories, Please”
By F. Gail

“The Non-Chew Cookbook”
By J. Randy Wilson

“Easy to Swallow, Easy to Chew”
By Donna L. Weihofen

“Soft Foods for Easier Eating Cookbook”
By Sandra Woodruff
“The Dysphagia Cookbook”  
By Todd Levine, MD  

“The I Can’t Chew Cookbook”  
By J. Randi Wilson

PREIMPLANTATION GENETIC DIAGNOSIS (PGD) & GENETIC COUNSELING

RADfertility  
(302) 602-8822  
https://radfertility.com/

Christiana Care  
(302) 623-4593  

Find a Genetic Counselor  
https://www.findageneticcounselor.com/  
(312) 321-6834

HDFA  

HELP WITH MEDICATIONS

Generic Tetrabenazine  
TAGI Pharma Customer Service 1-855-225-8244

Austedo  
Teva Shared Solutions  
1-800-887-8100  
www.sharesolutions.com

Xenazine  
Lundbeck  
1-888-882-6013  
www.xenazineusa.com

BioTek  
reMedys  
Specialty Pharmacy  
646-294 - 9866  
www.biotekrx.com

BRAIN DONATION

Harvard Brain Tissue Resource Center at McLean Hospital  
1-800-BRAIN BANK or 617-855-2400  
http://mcleanhospital.org/hbtrc/

Massachusetts General Hospital  
HDSA supported brain bank through MGH  
The 24-hour contact number is 617-724-5700, Page 21300

HD RELATED FINANCIAL ASSISTANCE

HealthWell  
Disease Funds: Grant applications for chronic or life-altering diseases, that provides support for prescription copays, health insurance premiums, deductibles, and coinsurance, and travel costs.  
https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/

NORD  
Provides assistance programs to help patients obtain life-saving or life-sustaining medication, and financial assistance with insurance premiums and copays, diagnostic testing assistance, and travel assistance for clinical trials.  
https://rarediseases.org/wp-
THERAPY FOR INDIVIDUALS WITH HD

Occupational Therapy:
OTs help people across the lifespan do the things they want, need, and are expected to do through the therapeutic use of daily activities (occupations), and aim to solve problems and barriers that may interfere. OTs assist with ADLs (Self-care, Dressing, Feeding), IADLS (Home and Medication Management), Play, Education, Sleep, Work, Leisure, and Social Participation. (AOTA) https://www.dotaonline.org/

Physical Therapy:
PTs are movement experts who diagnose and treat individuals of all ages, to improve quality of life through prescribed exercise, hands-on care, and patient education. PTs develop a treatment plan to improve a person’s ability to move, reduce, or manage pain, restore function, and prevent disability. (APTA) https://aptaapps.apta.org//APTAPTDirectory/FindAPTDirectory.aspx

Speech-Language-Hearing Pathologist:
SLPs work with people of all ages to treat communication and swallowing problems such as speech sounds, language, literacy, social communication, voice, fluency, cognitive-communication, and feeding and swallowing. (ASHA) https://www.asha.org/

DE HEALTHCARE RESOURCES

Choose Health Delaware
The state’s free official program that helps individuals and businesses learn more about the low-cost, high-quality health coverage available through the Health Insurance Marketplace https://www.choosehealthde.com/

Delaware Prescription Assistance Program
DPAP helps pay for prescription medications for elderly and/or disabled individuals who cannot afford the full cost of filling their doctor’s prescriptions. https://dhss.delaware.gov/dhss/dmma/dpap.html

HD YOUTH

HDSA National Youth Alliance
https://nya.hdsa.org/
Motivates youth to get involved in their local HDSA Chapters, Affiliates, and Support Groups in efforts through education, fundraising, advocacy and awareness for Huntington’s disease. The NYA is a collection of children, teens and young adults from across the country.

Huntington’s Disease Youth Organization (HDYO)
https://en.hdyo.org/
A non-profit set up to provide support and education to young people impacted by HD around the world. HDYO provides support and education, creates education content for all age groups, connect young people with peers, makes events such as youth camps and conferences, and provides opportunities for young people to get involved.
LONG TERM CARE

Delaware Aging and Disability Resource Center (ADRC) One-stop access point for aging and disability information, such as learning about resources available in Delaware, decide what services would be best for you or someone you know, and get help in finding the services that you need.
Call 1(800) 223-9074
http://www.delawareadrc.com/

The Nursing Facility Program
An individual applying must be a Delaware resident, must be willing to enter a nursing facility, and accept Medicaid coverage.

Long-Term Care Information- Useful Links
https://dhss.delaware.gov/dhss/dsaapd/linksltc.html

Long Term Care Ombudsman Program
Advocates for residents who live in long-term care facilities as well as those who live in other settings (such as their homes), and receive home and community-based services. The Ombudsman program investigates and resolves complaints on behalf of these individuals.
Call ADRC: 1(800) 223-9074
https://dhss.delaware.gov/dhss/dsaapd/contact.html

INTERNET RESOURCES

COMMUNICATING WITH HEALTHCARE PROVIDERS

LONG TERM CARE

CAREGIVER GUIDES

LIFTING THE VEIL

ADVANCE DIRECTIVES

GENETIC TESTING
http://hdsa.org/wp-content/uploads/2015/03/GeneticTesting-for-
HD.pdf

**JUVENILE HD**


**HD AND THE LAW**

**SPEECH & SWALLOWING**

**NUTRITION**

**TALKING WITH KIDS ABOUT HD**

**PHYSICAL AND OCCUPATIONAL THERAPY**


**DRIVING**
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/driving-and-huntingtons-disease/

**HOME SAFETY**
https://www.winchesterhospital.org/health-library/article?id=21068

**BRAIN DONATION**
http://www.brainbank.mclean.org/donate/

**NJ STATE DISABILITY APPLICATION**
http://lwd.dol.state.nj.us/labor/tdi/state/spclt_menu.html

**SOCIAL SECURITY DISABILITY**
https://www.ssa.gov/disability/


**PSYCHIATRIC SCREENING (CRISIS CENTERS)**
http://www.state.nj.us/humanservices/dmhas/home/hotlines/MH_Screening_Centers.pdf

**NJ COUNTY WELFARE AGENCIES**
http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/

**MEDICAID NJ-MLTSS**
http://www.nj.gov/humanservices/dmahs/home/mltss.html

**BEHAVIOR AND HD**
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/the-behavioral-symptoms-of-huntingtions-disease/

**ADULT PROTECTIVE SERVICES**
http://www.state.nj.us/humanservices/doas/documents/APS%20flyer.pdf

**CRISIS FLOW SHEET ON NEXT PAGE**
Help for HD patients and families in crisis

911

1. Person is in imminent danger
2. Has intent and means to hurt self or others
3. MH crisis is severe (psychosis, emotionally unstable, etc.)

APS

Types of elder/disabled adult abuse:
1. Physical harm or injury
2. Neglect
3. Financial exploitation
4. Verbal or emotion abuse
5. Involuntary seclusion
6. Physical or chemical restraint
7. Unwanted sexual contact
8. Self-neglect (individual lacks capacity)

CPS

Suspected or known abuse: parent or caregiver, whether through action or failing to act, causes injury, death, emotional harm or risk of serious harm to a child.

Forms of child maltreatment:
1. Neglect
2. Physical abuse
3. Sexual abuse
4. Exploitation
5. Emotional abuse

Police Non-Emergency

1. Person in need of a welfare check
2. Reporting a crime that was already committed
3. Third party reported SI/HI or emotional instability and no one can connect with the person on the phone

ER

1. Person is willing to get help for SI/HI or emotional instability
   AND is:
   2. accompanied by a responsible person
RESOURCE GUIDE FOR
NEW JERSEY FAMILIES LIVING
WITH HUNTINGTON’S DISEASE

Created by:
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chullfish@hdsa.org

Kayla Cupano OTD-S
kcotd0@gmail.com
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COUNTY SOCIAL SERVICES AGENCIES

**Atlantic County**  
Department of Family and Community Development  
1333 Atlantic Ave, Atlantic City, NJ 08401 (609) 348-3001  
Fax: (609) 343-2374  
Hours: 8:00 AM - 5:00 PM

**Bergen County**  
Bergen County Board of Social Services  
218 Route 17 North - Building A  
Rochelle Park, NJ 07662  
(201) 368-4200, Fax: (201) 368-8710  
Hours: 7:45 AM - 4:45 PM Tues. till 8:00 PM

**Burlington County**  
Burlington County Board of Social Services  
795 Woodlane Road, Mount Holly, NJ 08060  
(609) 261-1000, Fax: (609) 261-0463  
Hours: 8:00 AM - 5:00 PM

**Camden County**  
Camden County Board of Social Services  
600 Market Street, Camden, NJ 08102-1255  
(856) 225-8800, Fax: (856) 225-7797  
Hours: 8:30 AM - 4:30 AM

**Cape May County**  
Cape May County Board of Social Services  
4005 Route 9 South, Rio Grande, NJ 08242  
(609) 886-6200, Fax: (609) 889-9332  
Hours: 8:30 AM - 4:30 PM

**Cumberland County**  
Cumberland County Board of Social Services  
275 North Delsea Dr., Vineland, NJ 08360  
(856) 691-4600, Fax: (856) 692-7635  
Hours: 8:30 AM - 4:30 PM

**Essex County**  
Essex County Dept of Citizen Services  
18 Rector Street - 9th Fl, Newark, NJ 07102  
(973) 733-3000, Fax: (973) 643-3985  
Hours: 7:30 AM - 4:00 PM Weds by appt  
*Closed to public every 3rd Thursday

**Gloucester County**  
Gloucester County Social Services  
400 Hollydell Drive, Sewell, NJ 08080  
(856) 582-9200, Fax: (856) 582-6587  
Hours: 8:30 AM - 4:30 PM  
1st & 3rd Tues. 8:30 AM - 6:30 PM

**Hudson County**  
Hudson County Dept of Family Services  
257 Cornelison Ave., Jersey City, NJ 07302  
(201) 420-3000, Fax: (201) 420-0343  
Hours: 8:00 AM - 4:15 PM

**Monmouth County**  
Division of Social Services  
PO Box 3000  
3000 Kozloski Road, Freehold, NJ 07728  
(732) 431-6000, Fax: (732) 431-6017  
Freehold Hours: 8:30 AM - 4:40 PM  
Thurs.: 8:30 AM - 8:00 PM  
Ocean Field Office: 8:30 AM - 4:30 PM  
Tues. & Weds.: 8:30 AM - 8:00 PM
Hunterdon County
Division of Social Services
6 Gauntt Place, Flemington, NJ 08822
(908) 788-1300, Fax: (908) 806-4588
Hours: 8:30 AM - 4:30 AM

Mercer County
Mercer County Board of Social Services
200 Woolverton Street, Trenton, NJ 08611
(609) 989-4320, Fax: (609) 989-0405
Hours: 8:30 AM - 4:30 PM
Tues.: 8:30 AM - 8:30 PM

Middlesex County
Middlesex County Board of Social Services
181 How Lane New Brunswick, NJ 08903
(732) 745-3500, Fax: (732) 745-4558
Hours: 8:30 AM - 4:15 PM

Passaic County
Passaic County Board of Social Services
80 Hamilton St., Paterson, NJ 07505-2057
(973) 881-0100, Fax: (973) 881-3232
Hours: 7:30 AM - 4:30 PM
(Doors are closed to the public at 4:15 PM)

Salem County
Salem County Board of Social Services
147 S Virginia Ave, Penns Grove, NJ 08069
(856) 299-7200, Fax: (856) 299-3245
Hours: 8:00 AM - 4:00 PM

Somerset County
Somerset County Board of Social Services
PO Box 936
73 East High St. Somerville, NJ 08876
(908) 526-8800, Fax: (908) 231-9010
Hours: 8:15 AM - 6:00 PM

Morris County
Office of Temporary Assistance
340 W. Hanover Ave
Morristown, NJ 07960
(973) 326-7800, Fax: 973-326-7875
Hours: 8:30 AM - 4:30 PM
Every Other Tues.: 8:30 - 7:30 PM

Ocean County
Ocean County Board of Social Services
1027 Hooper Avenue, Toms River, NJ 08753
(732) 349-1500, Fax: (732) 244-8075
Hours: 8:30 AM - 4:30 PM
Tues.: 8:30 AM - 6:00 PM

Sussex County
Sussex County Division of Social Services
83 Spring Street, Suite 203
Newton, NJ 07860
(973) 383-3600, Fax: 973-579-9894
Hours: 8:30 AM - 4:30 PM

Union County
Union County Division of Social Services
342 Westminster Ave., Elizabeth, NJ 07208
(908) 965-2700, Fax: (908) 965-2752
Hours: 8:30 AM - 4:30 PM

Warren County
Division of Temporary Assistance and Social Services
1 Shotwell Dr., Belvidere, NJ 07823
(908) 475-6301, Fax: (908) 475-1533
Hours: 8:30 AM - 4:30 PM
HELP WITH CAREGIVING

**Aging & Disability Resource Connection/Area Agency on Aging (ADRC/AAA)**

An Area Agency on Aging (AAA) is designated in each of New Jersey's 21 counties to serve as the primary entity responsible for developing comprehensive, coordinated systems of community-based services for older adults.

**Toll Free Nationwide:** 1-877-222-3737


**Managed Long-term Services and Supports (MLTSS)**

Managed Long Term Services and Supports (MLTSS) refers to the delivery of long-term services and supports through New Jersey Medicaid's NJ Family Care managed care program. MLTSS is designed to expand home and community-based services, promote community inclusion and ensure quality and efficiency.

Managed Long Term Services and Supports (MLTSS) includes: Personal Care; Respite; Care Management; Home and Vehicle Modifications; Home Delivered Meals; Personal Emergency Response Systems; Mental Health and Addiction Services; Assisted Living; Community Residential Services; and Nursing Home Care.

**Contact your local Board of Social Services or call:** 1-877-222-3737

**Jersey Assistance for Community Caregiving (JACC)**

JACC is a State-funded program (for people who are not Medicaid eligible) that provides a broad array of in-home services to enable an individual, at risk of placement in a nursing facility and who meets income and resource requirements, to remain in his or her community home. By providing a uniquely designed package of supports for the individual, JACC delays or prevents placement in a nursing facility.

Individuals interested in receiving services through JACC may contact the Aging & Disability Resource Connection (ADRC) site in their county.

**Their local ADRC can be reached toll free by dialing:** 1-877-222-3737.

ADRC workers will assist callers and refer individuals to the proper application point

**Statewide Respite Program**

This program provides respite care services for elderly and functionally impaired persons age 18 and older to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. A secondary goal of the program is to provide the support necessary to help families avoid making nursing home placement of their relatives. Services available under the Statewide Respite Care Program include: Companions, homemaker/home health aides (on an hourly or overnight basis), medical or social adult day care, temporary care in licensed medical facilities, camperships, private duty nursing service, and caregiver-directed option.

**To reach the Statewide Respite Care Program in your county, call Aging & Disability Resource Connection (ADRC) toll-free at:** 1-877-222-3737
<table>
<thead>
<tr>
<th>COUNTY</th>
<th>PHONE</th>
<th>AFTER HOURS PHONE</th>
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<tbody>
<tr>
<td>ATLANTIC</td>
<td>609-645-7700 x4348</td>
<td>888-426-9243</td>
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<td>BERGEN</td>
<td>201-368-4300</td>
<td>800-624-0275</td>
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<tr>
<td>BURLINGTON</td>
<td>609-261-1000 X4797</td>
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<td>CAMDEN</td>
<td>856-225-8178</td>
<td>800-786-5080</td>
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<tr>
<td>CAPE MAY</td>
<td>609-886-6200 X358</td>
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<td>CUMBERLAND</td>
<td>856-825-6810 X219</td>
<td>856-455-5555</td>
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<td>ESSEX</td>
<td>973-624-2528 X135</td>
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<td>GLOUCESTER</td>
<td>856-582-9200</td>
<td>800-648-0132</td>
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<td>HUDSON</td>
<td>201-295-5160</td>
<td>800-792-8610</td>
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<td>HUNTERDON</td>
<td>908-788-1300</td>
<td>800-272-4630</td>
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<td>MERCER</td>
<td>609-989-4346</td>
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<td>MIDDLESEX</td>
<td>732-745-3635</td>
<td>911</td>
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<tr>
<td>MONMOUTH</td>
<td>732-531-9191</td>
<td>732-531-9111</td>
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<td>MORRIS</td>
<td>973-326-7282</td>
<td>973-285-2900</td>
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<tr>
<td>OCEAN</td>
<td>732-349-1500/732-286-5929</td>
<td>732-240-6100</td>
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<td>PASSAIC</td>
<td>973-881-2616/881-0100</td>
<td>973-345-2676</td>
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<td>SALEM</td>
<td>856-935-7510</td>
<td>911</td>
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<td>SOMERSET</td>
<td>908-526-8800</td>
<td>800-287-3607</td>
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<td>SUSSEX</td>
<td>973-383-3600X140</td>
<td>800-280-8845</td>
</tr>
<tr>
<td>UNION</td>
<td>908-497-3900/497-3902</td>
<td>911</td>
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<tr>
<td>WARREN</td>
<td>908-475-6301</td>
<td>911</td>
</tr>
</tbody>
</table>
### DESIGNATED PSYCHIATRIC SCREENING/CRISIS CENTERS

<table>
<thead>
<tr>
<th>County</th>
<th>Center Name</th>
<th>Address</th>
<th>Zip Code</th>
<th>HOTLINE:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Atlantic County</strong></td>
<td>Psychiatric Intervention Program (PIP)</td>
<td>@ Atlanticare Regional Medical Center</td>
<td>08401</td>
<td>(609) 344-1118</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1925 Pacific Avenue Atlantic City</td>
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<tr>
<td><strong>Bergen County</strong></td>
<td>Psychiatric Emergency Screening Care Plus</td>
<td>NJ Inc. @ Bergen Regional Medical Center</td>
<td>07652</td>
<td>(201) 262-4357</td>
</tr>
<tr>
<td></td>
<td></td>
<td>230 East Ridgewood Avenue</td>
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<td></td>
<td>Legacy Treatment Services</td>
<td>Lords Medical Center</td>
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<tr>
<td></td>
<td>Legacy Treatment Services</td>
<td>218A Sunset Road</td>
<td>08046</td>
<td>(609) 835-6180</td>
</tr>
<tr>
<td><strong>Burlington County</strong></td>
<td></td>
<td>218A Sunset Road</td>
<td>08046</td>
<td></td>
</tr>
<tr>
<td><strong>Camden County</strong></td>
<td>Oaks Integrated Care</td>
<td>@ Kennedy Memorial Hospital</td>
<td>08002</td>
<td>(856) 428-4357</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2201 West Chapel Ave.</td>
<td></td>
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<tr>
<td><strong>Cape May County</strong></td>
<td>Acenda Integrated Health</td>
<td>Acenda Integrated Health</td>
<td>08210</td>
<td>(609) 465-5999</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cape Medical Regional Center</td>
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<tr>
<td></td>
<td></td>
<td>2 Stone Harbor Blvd.</td>
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<td>Cape May Court House</td>
<td></td>
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<tr>
<td><strong>Cumberland County</strong></td>
<td>Acenda Integrated Health</td>
<td>Cumberland County Guidance Center</td>
<td>08302</td>
<td>(856) 455-5555</td>
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<tr>
<td></td>
<td></td>
<td>@ Inspira Medical Centers</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>333 Irving Avenue</td>
<td></td>
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<tr>
<td><strong>Essex County</strong></td>
<td>Clara Maass Medical Center</td>
<td>1 Clara Maass Drive.</td>
<td>07109</td>
<td>(973) 844-4357</td>
</tr>
<tr>
<td></td>
<td>Newark Beth Israel Medical Center</td>
<td>201 Lyons Avenue</td>
<td>07112</td>
<td>(973) 926-7444</td>
</tr>
<tr>
<td></td>
<td>University Behavioral Health Care</td>
<td>150 Bergen Street</td>
<td>07101</td>
<td>(973) 623-2323</td>
</tr>
<tr>
<td><strong>Gloucester County</strong></td>
<td>Acenda Integrated Health</td>
<td>Acenda Integrated Health</td>
<td>08028</td>
<td>(856) 845-9100</td>
</tr>
<tr>
<td></td>
<td></td>
<td>42 South Delsea Drive</td>
<td></td>
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</tr>
<tr>
<td><strong>Hudson County</strong></td>
<td>Jersey City Medical Center</td>
<td>Jersey City Medical Center</td>
<td>07340</td>
<td>(866) 367-6023</td>
</tr>
<tr>
<td></td>
<td></td>
<td>355 Grand Street</td>
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</tbody>
</table>
Palisades Medical Center AES
7600 River Road
North Bergen, NJ 07047
HOTLINE: (201) 854-6300

Christ Hospital AES
176 Palisade Avenue, Jersey City, NJ 07304
HOTLINE: (201) 795-8374

Hoboken University Medical Center AES
308 Willow Avenue
Hoboken, NJ 07030
HOTLINE: (201) 418-2090

**Hunterdon County**
Hunterdon Medical Center Emergency Svcs Behavioral Health
2100 Wescott Drive
Flemington, NJ 08822
HOTLINE: (908) 788-6400

**Mercer County**
Capital Health Regional Medical Center
750 Brunswick Avenue
Trenton, NJ 08638
HOTLINES: (609) 396-4357 or (609) 989-7297

**Middlesex County**
University Behavioral Health Care
671 Hoes Lane
Piscataway, NJ 08855

HOTLINE: (732) 235-5700

Raritan Bay Medical Center AES
530 New Brunswick Avenue Perth Amboy, NJ 08861
HOTLINE: (732) 442-3794

**Monmouth County**
Monmouth Medical Center
300 Second Avenue
Long Branch, NJ 07740 HOTLINE: (732) 923-6999

Centra State Medical Center AES
901 West Main Street
Freehold, NJ 07728
HOTLINE: (732) 294-2595

Jersey Shore University Medical Center AES
1945 Route 33
Neptune, NJ 07753
HOTLINE: (732) 776-4555

Riverview Medical Center AES
1 Riverview Plaza
Red Bank, NJ 07701
HOTLINE: (732) 219-5325

**Morris County**
Prime Healthcare Services, St. Clare's LLC
25 Pocono Road
Denville, NJ 07834
HOTLINE: (973) 625-6160

Morristown Memorial Hospital AES
100 Madison Avenue
Morristown, NJ 07960
HOTLINE: (973) 540-0100
<table>
<thead>
<tr>
<th>County</th>
<th>Address</th>
<th>Telephone</th>
</tr>
</thead>
</table>
| Chilton Memorial Hospital | AES  
97 West Parkway  
Pompton Plains, NJ 07444  
HOTLINE: (973) 831-5078 |                           |
| Ocean County | Monmouth Medical Center (PESS)  
600 River Avenue, Lakewood, NJ 08701  
HOTLINE: (866) 904-4474 or (732) 886-4474 |                           |
| Passaic County | St. Joseph's Hospital Health Care System  
703 Main Street  
Paterson, NJ 07503  
HOTLINE: (973) 754-2230 |                           |
| Salem County | Healthcare Commons, Inc.  
@ Salem Medical center  
310 Woodstown Road  
Salem, NJ 08079  
HOTLINE: (856) 299-3001 |                           |
| Somerset County | Bridgeway Rehabilitation, Inc.  
282 East Main Street  
Somerville, NJ 08876  
HOTLINE: (908) 526-4100 |                           |
| Sussex County | Newton Medical Center  
175 High Street  
Newton, NJ 07860  
HOTLINE: (973) 383-0973 |                           |
| Union County | Trinitias Regional Mental Health and Homelessness Prevention Services  
655 East Jersey Street  
Elizabeth, NJ 07201  
HOTLINE: (908) 994-7131 |                           |
| Overlook Medical Center AES | 99 Beauvoir Road  
Summit, NJ 07206  
HOTLINE: (201) 841-8078 |                           |
| Rahway Hospital AES | 865 Stone Street  
Rahway, NJ 07065  
HOTLINE: (732) 381-4949/(732) 499-6165 |                           |
| Warren County | Family Guidance Center of Warren County  
370 Memorial Parkway  
Phillipsburg, NJ 08865  
HOTLINE: (908) 454-5141 |                           |
| MENTAL HEALTH AND HOMELESSNESS PREVENTION SERVICES |                           |                           |
| Bridgeway Rehabilitation Services | 265 West Grand Street, Elizabeth, NJ 07202  
(908) 289-7330 |                           |
| Catholic Charities - Diocese of Metuchen | 26 Safran Avenue, Edison, NJ 08817  
(732) 738-1323 |                           |
| Comprehensive Behavioral Healthcare, Inc. | 395 Main Street, Hackensack, NJ 07601  
(201) 646-0333 |                           |
| East Orange General Hospital | 300 Central Avenue, East Orange, NJ 07018  
(973) 395-4164 |                           |
Easter Seal Society of N.J.
2083 Route 57, Washington, NJ 07882
(908) 689-6600

Healthcare Commons Family
Health Services
500 Pennsville-Auburn Road
Carney's Point, NJ 08069
(856) 299-3200

Jewish Family Services of Atlantic County
607 North Jerome Ave, Margate, NJ 08402
(609) 822-1108

Mental Health Association of Morris County
100 Route 46 - Bldg. C,
Mountain Lakes, NJ 07046
(973) 334-3496

Bridgeway Rehabilitation Services
93 Stickles Pond Road, Newton, NJ 07860
(973) 383-8670

Cape Counseling Services
1129 Route 9 South
Cape May Courthouse, NJ 08210
(609) 886-6200

Cumberland County Guidance Center
2038 Carmel Road Millville, NJ 08332
(856) 825-6810

Easter Seal Society of N.J.
200 Rt 31 N- Ste 115 Flemington, NJ 08822
(908) 788-7580

Jersey City Medical Center
953 Garfield Avenue – 1st Floor
Jersey City, NJ 07304
(201) 915-2980

Legacy Treatment Services
1289 Rt 38, Ste 200, Hainesport, NJ 08036
(609) 261-7672, ext. 3201

Mental Health Association
of Monmouth County
119 Ave @ the Commons - Suite 5
Shrewsbury, NJ 07701
(732) 542-6422

New Point Behavioral Health
1070 Main Street, Sewell, NJ 08080
(856) 256-3320

Oaks Integrated Care
499 Cooper Landing Rd
Cherry Hill, NJ 08034
(856) 428-1300

Project Live, Inc.
465-475 Broadway, Newark, NJ 07104
(973) 481-1211

Richard Hall CMHC Project
500 North Bridge St.
Bridgewater, NJ 08807
(908) 253-3128

St. Joseph's Regional Medical Center
645 Main St – 2nd Fl
Paterson, NJ 07503
(973) 754-4781

Oaks Integrated Care
31 Lexington Avenue, Ewing, NJ 08618
(609) 583-1900

Ocean Mental Health Services, Inc.
687 Route 9, Bayville, NJ 08721
(732) 269-4849
SUPPORT GROUPS

Northern NJ
Participants: Mixed Group
3rd Tuesday of every month
Phone: 973-250-6660
Email: finewine@ptd.net

North Central NJ
Participants: Caregivers
Hartwyck @ Cedar Brook
Call for information:
Facilitator: Christine Hogan, LCSW
Phone: 732-235-5993
Hoganch1@rutgers.edu

Central NJ
Participants: Mixed Group
Call for information:
Judy Rokeach, RN
732-235-5993,
jar464@rwjms.rutgers.edu

Southern NJ
Meets 1st Wednesday of every month
Facilitator: Nancy Alterman, LCSW

Online Support Groups offered by HDSA

Online Groups:
- HD Positive, Early Symptoms
- Parent Caregiver
- Caregiver Support Group
- At Risk/Not Tested
- Youth Support Group
- Family Planning


HD COUNSELING SUPPORT
https://hdsa.org/find-help/community-social-support/hdsa-telehealth/
For families affected by HD, every family member can receive counseling with up to 8 telehealth visits per year.

SOCIAL CLUBS
The Social Scene:
A Club for Adults with Special Needs
- Virtual E-Social Scene offered
Members can:
Socialize, exercise, learn life skills, and be active in their community
www.thesocialsceneclub.com
thesocialscenenj@gmail.com
201-241-0476

Easterseals of New Jersey
25 Kennedy Blvd., Suite
600 East Brunswick, NJ
08816 732-257-6662
- Creates life-changing solutions for individuals with disabilities and their families in their community by increasing independence, maximizing opportunities, minimizing barriers and enhancing quality of life.

HDSA NJ CENTER OF EXCELLENCE SPECIALIZING IN HD CARE:

HDSA Center of Excellence at Rutgers University and Rowan University
42 East Laurel Road
Rowan University-School of Osteopathic Medicine
Department of Pathology-Huntington Disease Center
Stratford, NJ 08084
Phone: 732-235-5993

OTHER CENTERS SPECIALIZING IN HD CARE NEAR NJ

HDSA Center of Excellence at University of Pennsylvania HD Center
Parkinson’s Disease and Movement Disorders Center
330 South 9th Street Philadelphia, PA 19107
Phone: 215-829-5176
Website: http://www.uphs.upenn.edu/neuro/

HDSA Center of Excellence at Columbia University/NYS Psychiatric Institute
1051 Riverside Drive New York, NY 10032
Phone: 212-305-4597
Website: http://hdny.org/

HDSA Center of Excellence for Huntington’s Disease at Johns Hopkins
Meyer 2-181
600 N. Wolfe Street
Baltimore, MD 21287
Phone: 410-955-2497
Website:
https://www.hopkinsmedicine.org/psychiatry/specialty_areas/huntingtons_disease/

INDEPENDENT NJ PHYSICIANS TREATING HD

Amy Colcher, MD
Movement Disorder Specialist
Cooper Neurological Institute
856-546-8525

Andrew McGarry, MD
Movement Disorder Specialist
Cooper Neurological Institute
856-546-8525

Anjali Patel, DO
Movement Disorders
Atlantic Neuroscience Institute
908-522-2829

**Fiona Gupta, MD**
Movement Disorder Specialist North Jersey
Brain & Spine Center
201-342-2550

**Jia Zhen Cheng, MD**
Movement Disorder Specialist
CentraState Medical Center
Phone: 732-431-2000

**Marcie Rabin, MD**
Movement Disorders
Atlantic Neuroscience Institute
908-522-2829

**Roger Kurlan, MD**
Movement Disorder Specialist
The Cognitive and Research Center
973-850-4622

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**Allison Bartlett, Esq.**
HDSA Manager of Disability Programs
abartlett@hdsa.org
(212)242-1968

**Suzanne M. Carter, Esq.**
7612 Bergenline Ave North Bergen, NJ
07047
(877) 706-3335

**Doug Fendrick & Jamie Morgan**
1307 White Horse Road Bldg. B, Suite 200 Voorhees, NJ
08043

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**Dana Bookbinder, LLC**
8000 Sagemore Drive, Suite 8303, Marlton, NJ 08053
(856) 722-8500

**Scott Counsel Elder Law Attorneys**
1230 Brace Road
Cherry Hill, NJ 08034
(856) 281-3131

**Richard M. Cohen, Esq**
2090 East Route 70 Cherry Hill, NJ 08003
(856) 616-0757

**Robert J. Keltos, Esq**
Rothamel Law
525 Route 73 North, Suite 104, Marlton, NJ 08053
(856) 795-3400

**Daniel Del Collo, III**
309 Fellowship Road, Suite 200
Mount Laurel, NJ 08054
(856) 533-2405

**Bratton Estate & Elder Care Attorneys**
18 Kings Hwy West
Haddonfield, NJ 08033
(856) 517-0239

**Poserina & McHugh**
1029 South Route 9
Cape May Court House, NJ 08210
(609) 463-8125

**Michael A Manna & Associates**
66 South Maple Avenue
Ridgewood, NJ 07450
(866) 678-0459

Donald D. Vanarelli, Esq
242 St. Paul Street
Westfield, NJ 07090
(908) 232-7400

Witman Stadtmauer, PA
26 Columbia Turnpike, Suite 100
Florham Park, NJ 07932
(973) 822-0220

James DeMartino Elder Law
PO Box 126
Belvidere, NJ 07823
(908) 874-5636

DRIVING EVALUATIONS

Bacharach Institute for Rehabilitation
61 West Jimmie Leeds Road
Pomona, NJ 08240
Contact: Claire McLaughlin, OTR, CDRS
Phone: (609) 748-6866
Fax: (609) 652-9581
https://www.bacharach.org/services/driving-program/

Kessler Institute for Rehabilitation
300 Market Street
Saddle Brook, NJ 07663
Contact: Beth Rolland, OTR, CDRS
Phone: (201) 368-0672
Fax: (201) 368-6075
https://www.kessler-rehab.com/conditions-and-services/neurologic-rehabilitation/

Kessler Institute for Rehabilitation
1199 Pleasant Valley Way
West Orange, NJ 07052
Contact: Rich Nead, CDRS
or David Massler, COTA, DRS
Phone: (973) 731-3900 x2322
Fax: (973) 243-6842
https://www.kessler-rehab.com/conditions-and-services/neurologic-rehabilitation/

JFK Johnson Rehabilitation Institute at JFK Health System
65 James Street
P.O. Box 3059
Edison, NJ 08818-3059
Contact: Katie J. Hutzayluk, MS OTR/L, CDRS or Brigitte A. Muehlbauer, MS OTR/L, CDRS
Phone: (732) 321-7056
Fax: (732) 205-1463
https://jfkjohnson.org/outpatient-services/occupational-therapy/

St. Lawrence Rehabilitation Center 2381
Lawrenceville Road
Lawrenceville, NJ 08648
Contact: Carrie Monagle, OTR, CDRS Phone: (609) 896-9500 x2494
Fax: (609) 896-0698
www.slrc.org

Moss Rehab Driving School
201 Old York Road Jenkintown, PA 19046
Contact: Dan Basore, CDRS
or Lynne Mason, OTR, CDRS
Phone: (215) 886-7706
Fax: (215) 886-7709
https://www.mossrehab.com/driving
COOKBOOKS AND NUTRITION

“Pass the Calories, Please”
By F. Gail

“The Non-Chew Cookbook”
By J. Randy Wilson

“Easy to Swallow, Easy to Chew”
By Donna L. Weihofen

“Soft Foods for Easier Eating Cookbook”
By Sandra Woodruff

“The Dysphagia Cookbook”
By Todd Levine, MD

“The I Can't Chew Cookbook”
By J. Randi Wilson
PREIMPLANTATION GENETIC DIAGNOSIS (PGD) & GENETIC COUNSELING

Robert Wood Johnson Medical School
Department of OB/GYN
Division of Maternal- Fetal Medicine
Section of Perinatal Genetics

125 Paterson St- CAB 2151
New Brunswick, NJ 08901
732-235-6630

Reproductive Science Center of New Jersey
Eatontown, Toms River, Lawrenceville
1-877-487-3447

Find a Genetic Counselor
https://www.findagnosticcounselor.com/
(312) 321-6834

HDSA

HELP WITH MEDICATIONS
Generic Tetrabenazine
TAGI Pharma Customer Service
1-855-225-8244

Austedo
Teva Shared Solutions
1-800-887-8100
www.sharesolutions.com

Xenazine
Lundbeck
1-888-882-6013
www.xenazineusa.com

BioTek
reMedys
Specialty Pharmacy
646-294 - 9866
www.biotekrx.com

BRAIN DONATION
Harvard Brain Tissue Resource Center at McLean Hospital
1-800-BRAIN BANK or 617-855-2400
http://mcleanhospital.org/hbtrc/

Massachusetts General Hospital
HDSA supported brain bank through MGH
The 24-hour contact number is
617-724-5700
Page #21300

HD RELATED FINANCIAL ASSISTANCE

HealthWell
Disease Funds: Grant applications for chronic or life-altering diseases, that provides support for prescription copays, health insurance premiums, deductibles, and coinsurance, and travel costs.
https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/
NORD
Provides assistance programs to help patients obtain life-saving or life-sustaining medication, and financial assistance with insurance premiums and copays, diagnostic testing assistance, and travel assistance for clinical trials.

Patient Services
Financial support and guidance for patients with chronic diseases.
https://www.patientservicesinc.org/

THERAPY FOR INDIVIDUALS WITH HD

Occupational Therapy:
OTs help people across the lifespan do the things they want, need, and are expected to do through the therapeutic use of daily activities (occupations), and aim to solve problems and barriers that may interfere. OTs assist with ADLs (Self-care, Dressing, Feeding), IADLS (Home and Medication Management), Play, Education, Sleep, Work, Leisure, and Social Participation. (AOTA)
https://www.njota.org/find-a-therapist#/ 

Physical Therapy:
PTs are movement experts who diagnose and treat individuals of all ages, to improve quality of life through prescribed exercise, hands-on care, and patient education. PTs develop a treatment plan to improve a person’s ability to move, reduce, or manage pain, restore function, and prevent disability. (APTA)

Speech-Language-Hearing Pathologist:
SLPs work with people of all ages to treat communication and swallowing problems such as speech sounds, language, literacy, social communication, voice, fluency, cognitive-communication, and feeding and swallowing. (ASHA)
https://www.njsha.org/member-center/#/public-search

LONG-TERM CARE

Search for long-term care and assisted living facilities, as well as adult day programs in NJ, specifically by county:
https://healthapps.state.nj.us/facilities/fsSearch.aspx

Long Term Care Ombudsman (NJLTCO)
Responsible for securing, preserving, and promoting the health, safety, and welfare of NJs elderly population, through investigations of abuse, neglect, and exploitation; legislative and regulatory advocacy; policy work; and education and outreach.
Phone: 877-582-6995
https://www.state.nj.us/ooie/

Aging & Disability Resource Connection NJ
Visible and trusted source of information on long-term services and supports for persons of all incomes. ADRC assists and empowers seniors, adults, and their caregivers to make informed decisions, and in finding benefits and services they need such.
Phone: 877-222-3737
https://adrcnj.org/find-services-and-provider
HD YOUTH

HDSA National Youth Alliance
https://nya.hdsa.org/
Motivates youth to get involved in their local HDSA Chapters, Affiliates, and Support Groups in efforts through education, fundraising, advocacy and awareness for Huntington’s disease. The NYA is a collection of children, teens and young adults from across the country.

Huntington’s Disease Youth Organization (HDYO)
https://en.hdyo.org/
A non-profit set up to provide support and education to young people impacted by HD around the world. HDYO provides support and education, creates education content for all age groups, connect young people with peers, makes events such as youth camps and conferences, and provides opportunities for young people to get involved.

INTERNET RESOURCES

COMMUNICATING WITH HEALTHCARE PROVIDERS

LONG TERM CARE

CAREGIVER GUIDES


LIFTING THE VEIL

ADVANCE DIRECTIVES

GENETIC TESTING

JUVENILE HD

HD AND THE LAW

SPEECH & SWALLOWING
http://hdsa.org/wp-
content/uploads/2015/03/Speech-Language-Swallowing-Difficulties.pdf

NUTRITION

TALKING WITH KIDS ABOUT HD

PHYSICAL AND OCCUPATIONAL THERAPY


DRIVING
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/driving-and-huntingtons-disease/

HOME SAFETY
https://www.winchesterhospital.org/health-library/article?id=21068

BRAIN DONATION
http://www.brainbank.mclean.org/donate/

NJ STATE DISABILITY APPLICATION
http://lwd.dol.state.nj.us/labor/tdi/state/s_p_clt_menu.html

SOCIAL SECURITY DISABILITY
https://www.ssa.gov/disability/


PSYCHIATRIC SCREENING (CRISIS CENTERS)
http://www.state.nj.us/humanservices/dmhas/home/hotlines/MH_Screening_Centers.pdf

NJ COUNTY WELFARE AGENCIES
http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/

MEDICAID NJ-MLTSS
http://www.nj.gov/humanservices/dmahs/home/mltss.html

BEHAVIOR AND HD
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/the-behavioral-symptoms-of-huntingtons-disease/

ADULT PROTECTIVE SERVICES
http://www.state.nj.us/humanservices/doas/documents/APS%20flyer.pdf

CRISIS FLOW SHEET ON NEXT PAGE
Help for HD patients and families in crisis

1. **Person is in imminent danger**
   - Has intent and means to hurt self or others
   - MH crisis is severe (psychosis, emotionally unstable, etc.)

2. **Types of elder/disabled adult abuse:**
   - Physical harm or injury
   - Neglect
   - Financial exploitation
   - Verbal or emotional abuse
   - Involuntary seclusion
   - Physical or chemical restraint
   - Unwanted sexual contact
   - Self-neglect (individual lacks capacity)

3. **Suspected or known abuse:**
   - Parent or caregiver, whether through action or failing to act, causes injury, death, emotional harm or risk of serious harm to a child.
   - Forms of child maltreatment:
     - Neglect
     - Physical abuse
     - Sexual abuse
     - Exploitation
     - Emotional abuse

4. **Person in need of a welfare check**
   - Reporting a crime that was already committed
   - Third party reported SI/HI or emotional instability and no one can connect with the person on the phone

5. **Person is willing to get help for SI/HI or emotional instability**
   - AND is:
     - Accompanied by a responsible person