Bridging the Gap

Between Physical Therapy and Lifelong Physical Activity and Exercise in People with Neurologic Conditions

A Toolkit for Physical Therapists and Physical Therapist Assistants

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Introduction (return to table of contents)

People with neurological conditions have varied options for continued physical activity and exercise after their physical therapy (PT) plan of care is completed based on their interests, ability, community resources, and personal resources. However, there is limited information available to guide individuals in choosing the best options based on these factors. This toolkit, including this document and its guidelines, is intended for use by the treating physical therapist and physical therapist assistant alongside their client living with a neurologic condition. It provides information and recommendations to guide shared decision-making in determining plans for continued physical activity and exercise upon discharge.

Objectives: The purpose of this document is to...

1. Understand the duration and scope of physical therapy for maximizing recovery and planning for lifelong physical activity and exercise.
2. Outline recommendations for a long-term relationship with physical therapy, including reassessments and reasons to re-initiate care.
3. Describe the reasons for lifelong physical activity and exercise after physical therapy; this includes continued recovery of physical function as well as maintenance of physical function.
4. Provide recommendations for setting and achieving goals, including providing criteria and considerations for evaluating resources and modifying physical activity plans.

Overview:

Following this introduction, the Detailed Recommendations and Objective section provides an in-depth description of the process for decision-making during the transition from physical therapy to a lifelong physical activity and exercise training program. Supporting references are provided. The Appendices contains multiple supplemental Handouts and Resources to assist individuals living with a neurological condition (aka, clients/consumers) to participate in this process with physical therapists and physical therapist assistants and to achieve the four objectives listed above. Recommendations for how to use the supplemental handouts and resources are provided.

Target audience:

The primary target audience is physical therapists (PTs) or physical therapist assistants (PTAs) who are working with individuals with neurological conditions. Supplemental handouts and resources target either PTs and PTAs, Clients/Consumers, or PT-Clients/Consumers together.
Objective 1: Understand the duration and scope of physical therapy for maximizing recovery and planning for lifelong physical activity and exercise.

During a PT episode of care, people with a neurologic condition may undergo treatment to address the following areas:

- Maximizing recovery of motor function
- Improve ability and independence with functional activities and walking
- Return to previous home and community roles, as well as, return to leisure physical activity participation
- Minimizing risk of future injury/medical problems
- Maximizing health, wellness, and adjustment to changes in abilities.

An initial episode of PT may begin anywhere along the continuum of care (see Figure 1). It is commonly initiated in either the acute care or outpatient setting, based on the complexity and acuity of medical and rehabilitation needs. The following description of practice is focused on outpatient PT care.

Figure 1: Continuum of Physical Therapy for Individuals with Neurological Conditions

The duration of outpatient PT varies widely from a single visit to several visits occurring over many months. The plan of care for outpatient PT for each individual with a neurologic condition should be determined as a team by the person with the neurologic condition, the physical therapist, any involved family, other health care professionals, and the physician.

The initial bout of PT may be discontinued for several reasons such as: goals have been met; limitations in funding; lack of improvement and ability to justify need for skilled PT intervention; personal circumstances or priorities. (Note, lack of improvement does not
necessarily indicate discontinuation of care. Ongoing skilled PT care may be appropriate under current Medicare guidelines for prevention, maintenance, and slowed disease progression if skilled care is medically justified and appropriately documented. See https://www.apta.org/your-practice/payment/medicare-payment/coverage-issues/skilled-maintenance-therapy-under-medicare for more information.)

Prior to discontinuing an episode of PT care, planning for lifelong physical activity and exercise is needed. Planning should start in the initial setting and ensure completion prior to discharge and transition to community fitness and wellness. During the planning process, it is important to discuss the role of a long-term relationship with PT.

Objective 2: Outline recommendations for a long-term relationship with physical therapy, including reassessments and reasons to re-initiate care.

Physical Therapy After the Initial Episode of Care Is Completed

It is appropriate for people with neurologic conditions to maintain long-term, intermittent relationships and communication with physical therapists. These intermittent relationships and communications may occur in multiple formats, including:

1) additional bouts of care after initial physical therapy discharge,

2) annual or semi-annual reassessments, and/or

3) consultation for a second (physical therapy) opinion.

Additional bouts of care may be initiated (see Figure 1 above) to address specific problems that arise (i.e., pain), or to upgrade the person’s functional activities and/or exercise programs based on changes in the person’s abilities. Insurance coverage for these types of visits may vary and should be verified on an individual basis. People with neurologic conditions and their rehabilitation team, including PTs and PTAs, should discuss a plan for future interactions and follow-ups prior to discharge from the initial episode of care, including potential indications or benchmarks for additional bouts of care or reassessments in the future. With open discussion of this nature, people with neurological conditions can have a better understanding of when they should consider re-initiating contact and/or care from their rehabilitation team in the future.

At times, changes in function or one’s abilities may make it necessary for someone with a neurologic condition to undergo an additional episode of skilled PT. For instance, some people may have a high incidence of shoulder pain due to heavy shoulder overuse, and PT may be appropriate to address this shoulder condition. Another person with a neurologic condition may experience a decline in function; for instance, someone who has more difficulty with walking or transfers after a period of inactivity or deconditioning. In general, the need for a return to PT
should be considered whenever someone with a neurologic condition experiences changes in
motor function or functional mobility, whether improvement or decline, or if other problems
arise.

It may also be appropriate for people with neurologic conditions to follow-up with rehabilitation
professionals for reassessment related to their condition. These reassessments can occur
quarterly, annually, or as frequently as deemed appropriate or necessary. A reassessment with a
PT should be individualized to each person’s needs and may include:

- Reassessment to determine progression or decline
- Reassessment to determine need for further PT care
- Modification to functional mobility strategies
- Equipment assessment and modification
- Review/modification to physical activity and exercise programs.

Some people with neurologic conditions may elect to pursue a consultation for a second opinion
about their rehabilitation plan of care at a facility that specializes in rehabilitation for their
neurological condition. Such a consultation typically consists of a single visit with one or more
rehabilitation team members, including a PT, occupational therapist (OT), and/or a physiatrist (a
physician who specializes in physical medicine and rehabilitation). Such visits are typically most
successful when the person with the neurological condition is prepared with specific questions
and concerns. Areas that could be addressed in such a consultation include, but not are not
limited to:

- Appropriateness of current rehabilitation plan of care in terms of content, duration, and
  frequency
- Any additional interventions that may be beneficial
- Equipment recommendations
- Prognosis for further recovery
- Recommendations related to return to daily life functions such as driving, school, work,
  family responsibilities, and/or household management.

Ultimately, it is the responsibility of each person with the neurologic condition (and their
family/caregiver) to determine their goals and needs for rehabilitation throughout their lifetime.
It is the responsibility of the rehabilitation team to assist the person with a neurologic condition
to determine and implement an appropriate plan related to those goals and needs.
Objective 3: Describe the reasons for lifelong physical activity and exercise after physical therapy; this includes continued recovery of physical function as well as maintenance of physical function.

It is important for people with neurologic conditions to continue to engage in regular lifelong physical activity and exercise to maximize health and wellness. Physical therapists can help with the transition to community-based fitness and wellness programs\(^3\) (see Figure 1) by helping clients understand the reasons and set goals.

Reasons people with neurologic conditions may choose to participate in post-rehabilitation programs/community fitness and wellness centers may include the following:

- Promote functional independence through continued practice of compensatory and restorative based interventions.
- Promote recovery of function and neurologic status.
- Optimize physical and mental health and wellness throughout the lifespan\(^4-6\)
  - Maintain adequate range of motion and strength,\(^7,8\) with consideration of secondary medical conditions associated with their neurologic condition.
  - Decrease cardiovascular risk factors.\(^9-11\) Regular exercise may help to improve cholesterol levels,\(^12,13\) exercise capacity,\(^13-17\) and blood pressure control,\(^18\) as well as prevent obesity.\(^19,20\)
  - Slow the decline in bone density.\(^21\) Following many neurologic conditions, bone density decreases rapidly\(^22\), increasing the risk of fracture and osteoporosis.\(^23,24\)
  - Promote adequate insulin uptake and release to reduce the risk and consequences of diabetes mellitus.\(^25\)
  - Prevent secondary injury and health compromise
    - Participating in a wellness program can enable participants who are wheelchair users to be out of their wheelchairs more hours of the day. Remaining active and reducing sedentary behaviors can reduce risk of skin breakdown\(^26,27\) and joint contractures or tightness.\(^28\) More specific strengthening and stretching may also prevent overuse injuries such as bicep tendinopathy or other shoulder pathologies associated with full-time wheelchair use.\(^29,30\)
  - Develop and maintain social support through building community with peers and professionals. Regular participation in a community fitness and wellness center provides
unique opportunities to learn from and share with peers with similar injuries and ability levels.

- Peer mentorship-sharing successful tips, exercises, methods.
- Improve one's quality of life and reduce the reliance or level of physical assistance needed from others.\(^5,6,18,31\)
- Maintain mental health and/or reduce the risk of anxiety and depression.\(^32,33\) Consider referral to a mental health professional.

**Objective 4: Provide recommendations for setting and achieving goals, including providing criteria and considerations for evaluating resources and modifying physical activity plans.**

Recommendations for Setting and Achieving “After Initial Physical Therapy” Goals:

When setting goals and physical activity plans, it is important for the PT to determine any medical guidelines or limits, including vital sign targets and limits, weight-bearing precautions, appropriate or inappropriate types of exercise, and responses to medical emergencies such as extreme hypertension (e.g. autonomic dysreflexia).

Recommendations related to specific parameters for exercise for persons with various neurologic conditions are available. (See Appendix E: Condition Specific Resources for Exercise Prescription, Health and Wellness.)

To optimize goal setting and goal achievement and ultimately establish an action plan for lifelong physical activity and exercise, the following three steps are recommended for persons with neurologic conditions: (Please refer to Appendices B & C to work through this process.)

1. **Know values.**
   Clarify what matters most to the individual. What are their values, e.g., family, health, spirituality, independence, friendship, growth, wealth? When values and goals match, action and success follow. Ensure that goals match values.
   For example, if family is a value, can daily walks be a family activity?
   Appendix C; Value Clarification Resource, can be used to help the client select and prioritize values.

2. **Set S.M.A.R.T. goals.**
   When establishing specific behavioral goals, ensure they align with client values, support their general reasons for being physical active and exercising, and make them S.M.A.R.T.
   **S.M.A.R.T. goals** are Specific, Measurable, Achievable, Realistic, and Time-based.
For example, if the client values health and family and their reasons for engaging in physical activity and exercise include: increasing independence, strength and endurance, improving overall physical or mental health, and engage with family, their S.M.A.R.T. goals may be:

- In six months, I will propel my wheelchair for 1 mile in 20 minutes without a rest break and with no shoulder muscle soreness so I can engage in family community activities, such bike rides in the park.

- In one month, I will complete my functional electrical stimulation (FES) cycling 3 days/week consistently to slow muscle atrophy and improve circulation to help improve my overall physical health.

- In six months, I will average 6000 steps/day or more, 5 days/week to improve my overall physical activity level and health and reduce sedentarism.

- In one month, I will complete my 15-minute leg strengthening routine at least 3 days/week consistently to help me climb stairs easier at my daughter’s house.

For more information about setting S.M.A.R.T. goals, see https://www.cdc.gov/healthyyouth/evaluation/pdf/brief3b.pdf

3. Make an action plan.

The action plan should match the S.M.A.R.T. goals and include:

- **What** the client will do. Be specific. Address FITT: Frequency (how often, including number of times per day, per week and number of weeks), Intensity (how hard/strenuous), Timing (duration) and Type (what activity).

- **When** they will do it (time of day, day of the week).

- **Where** they will do it (location).

- **How they will monitor** what they do, overcome obstacles, and celebrate success.

For example, a client’s action plan might be to:

- Practice walking 5 days per week at home for 5 minutes at a moderate effort, 3 – 5/10 on the rate of perceived exertion 0 – 10 scale.

- Ride an arm bike for aerobic exercise 3 days per week at the gym for 45 minutes at a moderate to heavy effort, 5 - 8/10 on the rate of perceived exertion 0 – 10 scale.

- Log walking and biking in a fitness App or paper calendar or log book
• Go to PT for a check-up in 6 months to test aerobic exercise capacity, heart rate, blood pressure, and a 6-minute walk test.

Additionally, it is important to explore what resources are available to the client (e.g., people, facilities, and services), revise and finalize the plan considering potential challenges, ways to overcome, and rewards. These considerations may include:

a. Using other aerobic training equipment (e.g., an arm bike, recumbent cross-trainer, recumbent bike) to work toward the goal of improved cardiovascular fitness.

b. Addressing motivation and engagement. People thrive in different environments and situations – so consider where and how the client will be most successful. For example, a gym setting may work best for one client and another may appreciate the accountability that comes with signing up for an exercise class. Additionally, if a client needs an extra push to meet their goals, consider their support system, whether caregivers, peers or family can help stay engaged and meet their fitness goals.

c. **Assessing the resources** available including people, facilities, and services. Consider programs such as local gyms, YMCAs, and community programs as well as support personnel at those locations. People needed to help may include caregivers, personal assistants, family members, or personal trainers.

See the **Appendices** for specific resources to assist in this process.

• **Appendix A** is a summary of this detailed recommendation and objective section.
• **Appendix B** is a worksheet to identify values, set S.M.A.R.T goals and develop an action plan.
• **Appendix C** includes resources to clarify and identify values.
• **Appendix D** includes General Resources for Physical Activity, Health and Wellness such as listings of facilities and programs.
• **Appendix E** includes Diagnosis specific resources on exercise and physical activity prescription and overall health and wellness.
• **Appendix F** includes Questions to Ask of Post-Rehabilitation Facilities.
• **Appendix G** includes the Sargent Health Fitness Plan which can be used as an example of how design an appropriate exercise program at a community fitness center.
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Appendices – Recommendations for use of Supplemental Handouts and Resources (return to table of contents)

A. How to Bridge the Gap Between Physical Therapy and Lifelong Physical Activity/ Exercise Summary: Client Handout
   a. **Target Audience: Consumer/Client**
   b. To be used as a summary of the Detailed PT Recommendations and Objectives section for the consumer/client

B. Values, Goals, and Action Planning for Physical Activity and Exercise: PT Client Handout
   a. **Target Audience: Consumer/Client and PT together**
   b. To be used as a worksheet to determine values, set goals and create an action plan.

C. Value Clarification Resource: PT-Client Handout
   a. **Target Audience: Consumer/Client and PT together**
   b. To be used to help identify and prioritize values. Understanding values, will assist in setting meaningful goals that align with values and enhance success.

D. General Resources for Physical Activity, Health and Wellness: PT Resource
   a. **Target Audience: PTs**
   b. To be used as a resource guide for locating appropriate facilities and programs for lifelong physical activity and fitness.

E. Condition Specific Resources for Exercise Prescription, Health and Wellness: PT Resource
   a. **Target Audience: PTs**
   b. To be used as a resource guide for decision-making on best practice exercise recommendations

F. Questions to Ask of Post-Rehabilitation Facilities: Client Handout
   a. **Target Audience: Consumers/Client**
   b. To be used as a tool when calling or visiting facilities and programs to determine appropriateness, best fit and potential advocacy needs.

G. Example: Sargent Health Fitness Plan for Community Fitness Activities: PT-Client Handout
   a. **Target Audience: PT with Consumers/Clients**
   b. To be used to facilitate communication and success with transition from physical therapy to fitness in a community center
Appendix A: How to Bridge the Gap Between Physical Therapy and Lifelong Physical Activity: Client Handout

What can I expect from Physical Therapy?

Physical therapy (PT) helps you move better, move more, and be healthy so you can do the work and play activities that matter the most to you. You may have PT in the acute care, inpatient, outpatient or home health setting (see Figure 1). PT is there to help you improve your daily function, manage your condition and improve your overall fitness and wellness.

Reasons for stopping skilled PT care and starting community fitness and wellness may include meeting personal and PT goals, other personal priorities and time commitments, and/or insurance benefits and regulations.

Figure 1: Continuum of Physical Therapy for Individuals with Neurological Conditions

Exercise and physical activity are important tools to help you achieve your goals in PT. After an initial episode of PT ends, it is important for you to continue to be physically active and exercise. Physical activity and exercise can help you:

- Enhance recovery, stimulate brain health, and may slow disease progression.
- Promote independence and reduce physical assistance needed from others.
- Optimize physical health and wellness by improving, or maintaining, flexibility, strength, endurance, balance, bone mineral density, insulin regulation, and reducing risk of secondary medical conditions.
- Develop and maintain social support
- Increase positive mental health and decrease the risk of anxiety and depression.
- Improve overall quality of life
How can I stay active after Physical Therapy?

You have many options for continuing physical activity, recovering and maintaining function and being well after PT through community fitness and wellness. These options range from being physically active and exercising on your own at home to hiring a trainer knowledgeable on adaptive fitness and going to a local accessible gym/fitness center. The **Values, Goals, and Physical Activity/Exercise Action Plan PT-Client Worksheet** includes 3 steps to developing your own personalized plan for lifelong physical activity and exercise. This involves knowing your values, setting meaningful goals, and developing an action plan.

- For example, if you value family, health and independence…
  - Your goal may be: In six months, I will propel my wheelchair for 1 mile in 20 minutes without a rest break and with no shoulder muscle soreness so I can accompany my daughter on a walk.
  - Your action plan may then include: Riding an arm bike for aerobic exercise 3 days per week at the gym for 45 minutes at a moderate to heavy effort, 5 – 8/10 on the rate of perceived exertion 0 – 10 scale. To help you monitor your progress, you decide to go to PT for a check-up in 6 months to test aerobic exercise capacity, heart rate, blood pressure, and a 6-minute wheelchair push test.

When should I return to Physical Therapy?

Your needs may change over time. You can, and should, consider seeing your physical therapist from time to time to get input and help addressing your needs.

These additional visits with PT may be periodic assessments or check-ins every 3, 6 or 12 months. They may be weekly or bimonthly visits to help you maintain function or slow decline. Work with your PT and healthcare team to determine what is best for you.

**Additional resources to help you be active:** Resources include people, facilities, and services.

- **General Resources for Physical Activity, Health and Wellness Client Handout:** includes links to programs and facilities across the United States.
- **Questions to Ask of Post-Rehabilitation Facilities Client Handout:** includes questions that you may want to ask of these programs and facilities.

Ask your PT or healthcare team about other resources in your area.
Appendix B: Values, Goals, and Action Planning for Physical Activity and Exercise: Physical Therapist - Client Handout

Regular physical activity and exercise can improve overall health and well-being, enhance brain health and neurologic recovery, and may slow disease progression.

Be Active Your Way

You have many options for physical activity and exercise to help with recovery and wellness. Physical Therapy can help ensure your plan is safe, effective, and enjoyable.

3 Steps towards Lifelong Physical Activity and Exercise

1. Know your values

When values and goals match, actions and success follow. It is important to think about what matters most to you – your values. For example, if you value family, can daily walks be a family activity?

- You can use a value card sort to help (see the Value Clarification Resource PT-Client Handout).

What matters most to you? List 3 values.

1.

2.

3.

2. Set S.M.A.R.T. goals

How will being active help you live your values and achieve your personal health, wellness and unique condition goals? Here is one example. In six months, I will average 6000 steps/day or more on my fitness tracker, 5 days/week to improve my overall physical activity level and health and help me walk with my family.

- S.M.A.R.T. goals are Specific, Measurable, Achievable, Realistic, and Time-bound. It is okay to start small. Every movement counts.

What are your goals? Make them S.M.A.R.T.

1.

2.
3. Make an Action Plan

Your action plan should match your **SMART goals** and include:

- **What** you will do. Be specific. Address **FITT**: Frequency (how often), Intensity (how hard), Timing (how much), and Type (type of activity).
- **When** you will do it (time of day, day of the week).
- **Where** you will do it (location).
- **How you will monitor** what you do, overcome obstacles, and celebrate success.

For example, your plan may be to practice walking 5 days per week, at home, in the morning, for 5 mins, at a moderate effort, 3 –5/10 on the rate of perceived exertion 0 – 10 scale. You will monitor your plan by logging the exercise session on your fitness tracker (or a calendar). You will check in on your progress with your spouse on Sunday and celebrate success by taking a drive together in the country.

**Your Action Plan for Physical Activity and Exercise**

**Name:**

- **What** you will do (FITT: Frequency, Intensity, Timing, Type)

- **When** you will do it (time of day, day of the week).

- **Where** you will do it (location).

- **How you will monitor** what you do, overcome obstacles, and celebrate success.

**Signature(s):** ________________________________

**Date:** ________________________________
Appendix C: Value Clarification Resource: Physical Therapist – Client Handout

This activity helps the client identify what s/he values most by reflecting on common values and then selecting through a card sort activity what is of most personal value.

Value sort instructions listed here are also available at:

Personal Values Card Instructions:

1. Place five anchor cards in order from 1-5 in front of the participant (Least important should be on the left; Most important on the right).
2. Shuffle the 50 value cards; keep the 2 blank cards separate.
3. Instruct the participant to sort the cards using the following script:
   a. “I placed five title cards in front of you—Least important, not very important, neither important nor unimportant, somewhat important, and most important. I’m going to give you a stack of 50 cards. Each card describes something that may represent a personal value for you. I would like you to look at each card and place each card under one of the five title cards. There are also two blank cards. If there is a value you would like to include, write it on the card and put it in whichever pile you would like. I would like you to sort all 50 cards, but whether you use the two additional cards is optional. The only rule is that you can have no more than 10 cards under the Most Important stack. After you are finished with this part, I will ask you to do one other small task. Do you have any questions?”
4. When participant indicates s/he is finished with the sorting, look at the Most Important deck to make sure there are no more than 10 cards under this deck.
5. Read the following:
   a. “For the second task, I’d like you to focus on the top values you chose and sort them from 1 to n (total number participant has in the most important pile—no more than 10) using the ranking sheet. In this spot (point to #1) you will put the card that is your top value. Then you will put your second top value here (point to #2). Do you have any questions?”
6. When participant indicates s/he is finished rank ordering the most important pile, check to make sure you understand how the cards were sorted (ascending or descending).
   a. Point to the #1 spot and say, “I just want to make sure I have this right--Is this your number one value”.
   b. Record values on scoring sheet using either card number or value name. Indicate which stack each value was put under and for stack #5 (most important), indicate rank order. 1= number one value.
Personal value card sort full document available through public domain at:

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<th>PERSONAL VALUES Card Sort</th>
<th>IMPORTANT TO ME</th>
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<td>IMPORTANT TO ME</td>
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<td>University of New Mexico, 2001</td>
<td>IMPORTANT TO ME</td>
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<td>to be in charge of and responsible for others</td>
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Appendix D: General Resources for Physical Activity, Health and Wellness: Physical Therapist Resource

Adaptive Exercise Equipment:

- [http://scihealth.org/RRTC/publications/PDF/Adaptive_Exercise_Information.pdf](http://scihealth.org/RRTC/publications/PDF/Adaptive_Exercise_Information.pdf)

American College of Sports Medicine (ACSM’s) Exercise is Medicine:


American Physical Therapy Associated (APTA):

- Academy of Neurologic Physical Therapy Health Promotion and Wellness resource page: [http://www.neuropt.org/professional-resources/practice-resources/health-promotion-and-wellness](http://www.neuropt.org/professional-resources/practice-resources/health-promotion-and-wellness)
- APTA: Physical Fitness for Special Populations Pocket Guides, including fall risk, pulmonary pathology, spinal cord injury, stroke, and type II diabetes: [http://www.apta.org/PFSP/](http://www.apta.org/PFSP/)

Certified Inclusive Fitness Trainers (CIFT):

- Certified Inclusive Fitness Trainers (CIFTs) who have undergone certification through the American College of Sports Medicine (ACSM) and NCHPAD can provide personal training services to people with health conditions and disabilities. This is not training exclusive to one neurologic condition, as these trainers are more likely to have experience and training in exercise for people with a variety of disabilities. A directory is available here: [https://certification.acsm.org/pro-finder](https://certification.acsm.org/pro-finder)
- Certification Information: [http://incfit.org/node/802](http://incfit.org/node/802)

National Center for Health, Physical Activity and Disability (NCHPAD): National Center on Health, Physical Activity and Disability (NCHPAD) has a national directory of programs, facilities, and organizations that are available for people with health conditions and disabilities: [http://www.nchpad.org/Directories](http://www.nchpad.org/Directories)

Examples of NCHPAD program and resources:

- Exercise Guidelines for People with Disabilities: [http://www.nchpad.org/14/73/Exercise~Guidelines~for~People~with~Disabilities](http://www.nchpad.org/14/73/Exercise~Guidelines~for~People~with~Disabilities)
● Discover Accessible Fitness: booklet that serves as a guide for individuals using wheelchairs for using fitness equipment. 
http://www.nchpad.org/discoverfitness/index.html

● Life on Wheels: “a guide for living a healthy, active life with a spinal cord injury”
http://www.nchpad.org/1200/5830/Life~on~Wheels

● 14 weeks to a healthier you (a 14-week physical activity and nutrition program for people who are sedentary): https://www.nchpad.org/14weeks/

● Get the Facts: https://www.nchpad.org/Get-the~Facts/

● Champion’s Rx (a daily exercise program that provides a daily suggested workout for people who are active): https://www.nchpad.org/CRx

● List of Trainers: https://www.nchpad.org/Directories/Personal~Trainers

National Institute on Aging (NCOA):

● Physical Activity and Nutrition Resources: https://go4life.nia.nih.gov/

● Evidence-based programs listings: https://www.ncoa.org/resources/ebpchart/. Examples include Matter of Balance, Enhancing Fitness and many more.
  ○ These programs are evidence-based and have standardized procedures for community implementation in local organization such as Y-USA.

The Y-USA (YMCA)

● Health Wellbeing and Fitness offerings: http://www.ymca.net/health-wb-fitness

U.S. Department of Health and Human Services (DHHS):


VA Whole Health Library:

https://www.va.gov/PATIENTCENTEREDCARE/features/Whole_Health_Virtual_Library.asp

Multiple Sclerosis:

Exercise Prescription Articles:


Health Promotion and Wellness Articles:


Patient Advocacy Organizations with Health Promotion and Wellness Resources/Programs:

- National Multiple Sclerosis Society [https://www.nationalmssociety.org/Living-Well-With-MS](https://www.nationalmssociety.org/Living-Well-With-MS)

- Multiple Sclerosis Foundation [https://msfocus.org](https://msfocus.org)

- CanDoMS [https://www.cando-ms.org/](https://www.cando-ms.org/)
Parkinson’s Disease:

Exercise Prescription Articles:


Health Promotion and Wellness Articles:


Patient Advocacy Organizations with Health Promotion and Wellness Resources:

- Parkinson’s Foundation booklets on fitness, mood, and sleep: https://www.parkinson.org/pd-library

- Michael J. Fox Foundation (hover over “Understanding Parkinson’s” for information on diet, exercise, sleep, anxiety, and fatigue): https://www.michaeljfox.org/

- American Parkinson’s Disease Association Education and Support Page: https://www.apdaparkinson.org/resources-support/

- Davis Phinney Foundation - Living Well with Parkinson’s Disease (exercise, sleep, etc.): https://www.davisphinneyfoundation.org/living-well/

- Brian Grant Foundation - Training for Exercise Professionals: https://briangrant.org/training-for-professionals/
Traumatic Brain Injury:

Exercise Prescription Articles:


Health Promotion and Wellness Articles:


Patient Advocacy Organizations with Health Promotion and Wellness Resources:

- US Brain Injury Alliance: http://usbia.org/

- Brain Injury Association of America: https://www.biausa.org/
Spinal Cord Injury:

Exercise Prescription Articles:


Health Promotion and Wellness Articles:


Patient Advocacy Organizations with Health Promotion and Wellness Resources:


● Paralyzed Veterans of America - Adapted Sports: [https://www.pva.org/adaptive-sports](https://www.pva.org/adaptive-sports)

● Craig H Neilsen Foundation - Psychosocial Research (resource for clinical researchers): [http://chnfoundation.org/psychosocial-research/](http://chnfoundation.org/psychosocial-research/)

● Christopher and Dana Reeve Foundation: [https://www.christopherreeve.org/living-with-paralysis](https://www.christopherreeve.org/living-with-paralysis)

● SCI Action Canada Lab: [https://sciactioncanada.ok.ubc.ca/resources/proactive-sci-toolkit/](https://sciactioncanada.ok.ubc.ca/resources/proactive-sci-toolkit/)
Stroke/ Cerebral Vascular Accident (CVA):

**Exercise Prescription Articles:**


**Health Promotion and Wellness Articles:**

- Khot and Morgenstern. Sleep and Stroke. Stroke. 2019. 50:1612-1617. DOI: 10.1161/STROKEAHA.118.023553. [https://www.ahajournals.org/doi/10.1161/STROKEAHA.118.023553](https://www.ahajournals.org/doi/10.1161/STROKEAHA.118.023553)


Patient Advocacy Organizations with Health Promotion and Wellness Resources:

● National Stroke Association http://www.stroke.org/

● Heart and Stroke Foundation of Canada http://www.heartandstroke.ca/heart

● American Heart/Stroke Association http://www.strokeassociation.org/STROKEORG/

● Dr. Janice Eng’s Post-Stroke Community Fitness Program. https://fameexercise.com/
Other Conditions:

Huntington’s Disease

*Exercise Prescription Articles:*


*Patient Advocacy Organizations with Health Promotion and Wellness Resources*

- Huntington’s Disease Society of America [https://hdsa.org/](https://hdsa.org/)

Amyotrophic Lateral Sclerosis

*Exercise Prescription Articles:*

- Bello-Haas VD. Physical therapy for individuals with amyotrophic lateral sclerosis: current insights. *Degenerative neurological and neuromuscular disease.* 2018; 8:45-54. [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6065609/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6065609/)

*Patient Advocacy Organizations with Health Promotion and Wellness Resources*


- Muscular Dystrophy Association [https://www.mda.org/](https://www.mda.org/)
Appendix F: Questions to Ask of Post-Rehabilitation Facilities:
Client Handout

What are the goals for your participants? Purpose of facility?

☒ Health & Wellness
☒ Weight training or strengthening intact muscles
☒ Recovery or strengthening of involved muscles
☒ Improve cardiopulmonary function
☒ Improve endurance
☒ Improve flexibility
☒ Weight management
☒ Practice functional activities (mat/bed activities, transfers, balance, etc.)
☒ Multi-purpose

Facility: Is this facility accessible?

☒ Access to medical assistance (on site or call 911)
☒ Enough room between equipment to maneuver wheelchairs
☒ Water (hydration is important!)
☒ Towels
☒ Wheelchair accessible exercise equipment (e.g., weight training equipment with movable seats)
☒ Wheelchair accessible restrooms
☒ Wheelchair accessible locker rooms
  ☐ Is there an available mat in the locker room for dressing, if needed?
  ☐ Is there assistance available for dressing or undressing?
☒ Wheelchair accessible showers
☒ Grab bars in restrooms and showers
☒ Clean and well-maintained facilities
☒ Handicap parking
☒ Distance from parking to facility entrance
☒ Ramp – entry in/out of building
☒ Working elevators if multiple floors
☒ Is the facility near your home? You are more likely to go exercise if the location is convenient.
☒ What are the open hours? Some facilities are open 24 hours, while others have limited hours? When is the facility busiest?
☒ Are participants required to have medical clearance or a health history?
☒ Can you take a tour?
☒ Accommodate people with hemiplegia, paraplegia, tetraplegia: Do you have equipment to adapt exercise equipment as needed for limitations in hand or leg function, such as adaptive gloves or ace wraps.
☒ Other:
Staff Background and Training

Who is available onsite to assist an individual with a neurologic condition?

- Personal trainer with or without certification, such as:
  - Certified Inclusive Fitness Trainers (CIFT):
    - [https://certification.acsm.org/acsm-inclusive-fitness-trainer](https://certification.acsm.org/acsm-inclusive-fitness-trainer)
  - Certified Special Populations Specialist (CSPS):
    - [https://www.nsca.com/Certification/CSPS/](https://www.nsca.com/Certification/CSPS/)
  - Athletic Trainer (ATC)
  - Exercise Physiologist
  - Physical Therapist (PT)
  - Occupational Therapist (OT)
  - Pre-PT/OT or PT/OT students
  - Nutritionist or dietitian
  - Pilates or other specialized training
  - Other _______________________

What training does the staff have?

- Does the center have you fill out a health questionnaire to determine your risk factors and the most suitable activities to meet your needs and interests?
- How does the facility handle emergency situations? Has staff been trained in cardiopulmonary resuscitation (CPR) and first aid?
- If the staff are not licensed in the area of working with people with neurologic conditions (e.g., are not PTs or OTs), are they trained to:
  - Work with people with disabilities (such as with Certified Inclusive Fitness Trainers)
  - Work with individuals with SCI, CVA, PD, MS etc.
  - Pass competencies to be able to work with individuals with neurologic dysfunction
  - Monitor blood pressure and/or heart rate
  - Monitor pulse oximetry/oxygen levels
  - Recognize and address orthostatic hypotension (low pressure upon standing) and severe hypertension in any position (autonomic dysreflexia)
  - Implement an exercise prescription
  - Appropriately progress exercises or decrease frequency/intensity when Needed
  - Perform skin checks after exercise, when appropriate

Extent of assistance

- One-time tour of facility
- One-time orientation to equipment
- One-on-one personal trainer
❏ One trainer for ___ (number of people)
❏ Group workouts or classes? (what type?)
❏ Monitor every session, weekly, monthly
❏ Assist with set-up on each piece of equipment
❏ Assist with transfers on/off equipment
❏ If no assistance…
    ❏ Can a family member, or personal assistant attend to help me?
    ❏ Can the above individual also exercise? If so, what is the cost?

**List the equipment that is available at your facility.** *(While having all of the “latest and greatest” equipment available may not be needed to obtain your personal goals, you will want to find out if equipment that you need is available).*

❏ Automated External Defibrillator (AED)
❏ Weight-training equipment (chest press, biceps curls, triceps, etc.)
    ❏ With or without ability to move seat out of the way for wheelchair access
❏ Free weights
❏ Elastic bands or tubing
❏ Arm ergometers /arm bikes
❏ Recumbent bikes/ bikes with a seat that have a back rest
❏ Inclined plane bodyweight devices
❏ Standing frames
❏ Treadmills
    ❏ With or without overhead harness system or other support system for safety and/or body weight support during training
❏ Overhead harness suspension systems
❏ Sturdy rolling walkers [Second Step, Rifton Pacer (adult, and tall/heavy duty), platform walkers, etc.]
❏ Parallel bars
❏ Pool
    ❏ Lift for entry/exit
    ❏ Ramp for entry/exit
❏ Underwater treadmill
❏ Equipment for balance training (foam, Swiss balls, bolsters, etc.)
❏ Pedometers and/or accelerometers
❏ Slings with overhead suspension
❏ Functional electric stimulation (FES) cycling
❏ Electric stimulation for individual muscles
❏ Whole body vibration
❏ Robotic or powered exoskeletons

**Finances**

❏ Approximate cost ______________ (per session, per week, per month, annual)
❏ Private pay or accept any insurances
❏ Scholarships
❏ Reduced rates for fitness centers that have equipment with limited access for individuals with disabilities
❏ Can I obtain a temporary pass for a small daily fee or at no cost to try out the facility?
Communication with Healthcare Providers

Open communication amongst your team is critical for developing, implementing and progressing your training program in a way that is safe and effective. Questions to ask a post-rehabilitation program or provider include:

- Is the program or provider willing to communicate with your rehabilitation team or PT?
- How will they communicate with your rehabilitation team or PT?
  - One or more meetings face-to-face with therapist for communication and training
  - Email
  - Phone
  - Other: ____________________________

- When will they communicate with your rehabilitation team or PT?
  - To alert therapists of potential or actual medical status changes (e.g., fractures, major illness) and seek input for appropriate physical activity modifications
  - To seek assistance of therapist if need to update program
  - To alert therapist to when a patient increases or decrease function to the point of need of re-entry into therapy
  - At regularly scheduled intervals
  - Other: ____________________________

Other Resources to Consider: Choosing a Fitness Center from National Center on Health, Physical Activity and Disability (NCHPAD):

http://www.nchpad.org/308/1909/Choosing~a~Fitness~Center
Appendix G: Example: Sargent Health Fitness Plan: Physical Therapist - Client Handout

For Community Fitness Upon Discharge From Physical/Occupational Therapy

Name of Participant: ________________________________________________________
Name of Therapist: _________________________________________________________

Thank you for your interest in the Sargent Health Fitness Plan. This form was created by Boston University College of Health and Rehabilitation Sciences: Sargent College (Sargent College) and is intended to be used by physical therapists (PTs) or occupational therapists (OTs) to outline appropriate exercises for their clients. This form serves two purposes:

It can be used to indicate appropriate exercises for individuals upon discharge from PT/OT services
It can help facilitate communication between the PT/OT and the individual’s health fitness professional.

You may copy and use this form as long as you do not make any modifications to it, and properly attribute the form to the copyright holder (BU and Sargent College). Any other use of this form requires written permission from Sargent College.

INSTRUCTIONS
TO THE CLIENT: This form is intended to be utilized to outline appropriate exercises based on your current health status. If you experience a change in your health status, these recommendations may no longer be valid and you should take appropriate action. That means it is up to you to seek out further medical attention either from your primary care physician or any other specialist that is needed. We recommend that you sit down with your physical or occupational therapist and outline an appropriate fitness plan designed specifically for you by checking off the relevant boxes on the form. Please note, this form will be used to report and share with an appropriate health and fitness facility any pertinent medical issues that may affect your participation in an exercise program or activity. If you have any questions or concerns, please discuss them with your therapist.

TO THE THERAPIST: Please fill out this form in consultation with your client by checking only the relevant boxes for the participant. Consider educating your client with regard to indications for returning to a PT/OT professional. Examples may include 6-month brace re-evaluation, anticipated wheelchair modifications for seating clinic, increased activity tolerance, etc. A medical clearance should be received from a medical doctor to clear the individual to participate in FES and/or a Standing Frame program. If you know of any medical or other reasons why participation in an exercise program by the applicant would be unwise/unsafe, please indicate so on this form. For your convenience, equipment that does not require a transfer have been marked as depicted.

Participant is responsible for entering the gym independently OR with one’s own personal assistant (PCA, family)

By using this form, you (Client and Therapist) agree to release Boston University (including Sargent College), its officers, directors, employees and agents from any liability arising out of, or in connection with, your use of this form. In no event will Boston University, its officers, directors, employees or agents be liable for indirect, special, consequential, or punitive damages, even if those damages are otherwise foreseeable or even if any of them have been advised of the possibility of such damages.

Participant or Caregiver should bring completed form to appropriate exercise facility

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Sargent Health Fitness Plan

Name: ___________________________

Mobility Level: Ambulatory: Y / N (Distance: _____) Wheelchair User: Y / N Community Assistance Level: ______

Estimated or Actual Height and Weight: ___________________ Household assistance level: ______

Participant educated on HR and BP assessment for exercise: Y / N Waist Circumference: Sitting: ___________

Other Relevant Information/Contraindications:

Potential Participant Health/Fitness Goals:

- □ Increase Endurance
- □ Increase Strength
- □ Skin Integrity
- □ Weight Loss
- □ Increase Flexibility
- □ Other

Indications for Return to Healthcare Provider:

- □ Safety:
- □ ↑↓ in status (pain, strength, function, etc.):

- □ Brace Re-eval:
- □ Other

Additional Equipment

- □ Functional Trainer
- □ Arm Ergometer
- □ Cybex Bravo Functional Trainer
- □ Rope Climber
- □ Vita glide
- □ Reck MOTOmed
- □ RT 300-5
- □ FES Bike
- □ Muscle Stimulated:
  - □ Glutes
  - □ Hamstrings
  - □ Quadriceps
  - □ Gastroc/Soleus
  - □ Anterior Tibialis

- □ Shoulder Flex/Ext
- □ Elbow Flex/Ext
- □ Shoulder Abd/Add
- □ Hip Flex/Ext

- □ Cuffs, Hooks, Gloves, Chest Strap, Velcro Straps, Adaptive Bike Peddle, Theraband, Free Weights, Cuff Weights, Leg guides

PT/OT Signature indicates ONLY non-transfer activity appropriate: ___________________________

Date: ___________________________

Equipment listed below and on next page require transfers

- □ Easy Stand 6000 Glider* Stander
- □ NuStep TSKR Recumbent Cross Trainer
- □ Concept 2 Model E Rower
- □ Self-stretching Mat Table Exercises

Level of Assist with Transfers:

Participant or Caregiver should bring completed form to appropriate exercise facility

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Sargent Health Fitness Plan

Level of Assist with Transfers: ________________________________

- Keiser bilateral Upperback
- Incline Press
- Keiser Bilateral Chest press
- Overhead Press
- Pec Fly
- Preacher Curl
- Triceps Press
- Super Forearm
- Leg Press
- Hip Abduction/Adduction
- Leg Extension
- Seated Leg Curl
- Lateral Raise
- Abdominal
- Lower Back

Other Relevant Information (BP/HR Targets, Recommendations for Brace/Assistive device use while in the gym, Brace or Assistive Device Re-evaluations, Additional Equipment considerations, etc.):

PT/OT Signature: ________________________________ Date: ________________________________

All Photos Taken at the Quincy Branch South Shore YMCA

Participant or Caregiver should bring completed form to appropriate exercise facility

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