

Spina Bifida:

*Your Guide to
a Healthy Life*



Physical Activity

For ages 0-18+

*Adapted from Guidelines for the Care of People
with Spina Bifida, 2018*



SPINA BIFIDA
ASSOCIATION

Introduction

You may ask yourself, “What is physical activity? Isn’t it the same thing as exercise?” Physical activity is simply movement. Examples of physical activity include things like sweeping the floor, doing yard work, or walking the dog. Exercise, on the other hand, is planned, structured, goal-oriented movement that someone does with the intention of building muscle or improving physical fitness. Examples of exercise include lifting weights at home, going to a gym to use arm bikes and weights, or participating in a physical education class.

Exercise is a type of physical activity, but physical activities are not always exercise. Yet both are very important to maintaining and improving health. We will be using the term ‘physical activity’ in the following guidelines — which includes both planned and unplanned activity.

Physical activity has benefits for everyone but is especially important for people living with Spina Bifida. It can lower rates of heart disease, depression, type II diabetes, for mental health, including a greater sense of self-worth and higher quality of life. Inactivity, in particular for people with Spina Bifida, can lead to a loss of strength and fitness, which can lower independence in day-to-day activities.

There are nationally recommended guidelines for physical activity that if followed, can lead to a healthier life. Unfortunately, the majority of Americans fail to meet these physical activity guidelines. Additionally, children and adults with Spina Bifida, as well as people with other disabilities, are even less active when compared to the general population. The National Physical Activity Guidelines should be followed by everyone, including children and adults with Spina Bifida, unless told otherwise by a healthcare professional. The National Physical Activity Guidelines for Americans are listed in the Appendix.

There are many reasons why children and adults with Spina Bifida do not get enough physical activity. Some people don’t know what to do, how much to do, or where they can do it. Others may need expensive, adapted equipment for activities that they want to do. There are a lot of people who do not have access to an accessible community park, gym, or other places to be physically active.

Why are these Physical Activity Guidelines important?

We have provided the following guidance, categorized by age, in order to help you, your family member or friend maintain their level of physical activity or to start physical activity. Physical activity should be done throughout the lifespan; therefore, it should be an enjoyable experience.

The Appendix at the end of the document includes physical activity and disability resources. These resources are not an exhaustive list and depending on where you live, you may have access to local organizations that can help you or your family member with Spina Bifida to become physically active!

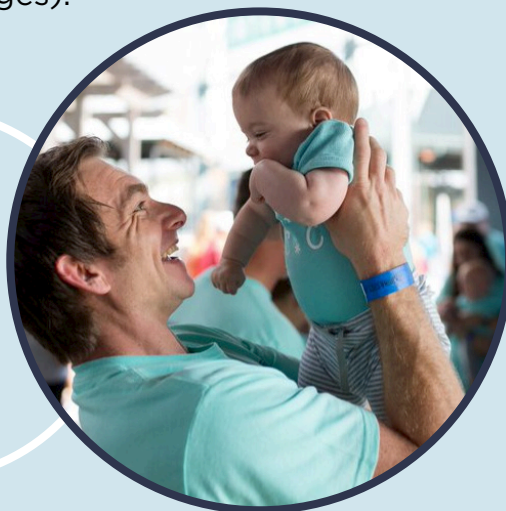
Guidelines for Physical Activity

0-11 Months

1. Ask your healthcare provider about your baby's movements. Providers can help identify what services your baby needs in regard to movement and connect you with them (e.g., physical therapy).
2. Ask your doctor, physical therapists, and other providers how to encourage your baby's movement and activity.
3. Ask your providers to connect you with Early Intervention services in your area. These services can include movement/physical therapy.

1-2 Years

1. If you aren't already connected with Early Intervention services, ask your providers to connect you with these services in your area. Early Intervention services include movement/physical therapy.
2. Ask your therapists how to incorporate physical activity or motor development into everyday activities. Remember that you can serve as a role model for your child's physical activity- even at a young age!
3. Seek out information about adapted activities so that your child can participate more with other children. Physical activity and participation with others may help encourage movement. (e.g., Mommy and Me classes through local parks and recreation departments or community colleges).





3-5 Years

1. Ask your Early Childhood Special Education service providers about adapted physical education/activity or motor development goals in preschool. This can be included on your child's Individualized Family Service Plan (IFSP), Individualized Education Plan (IEP) or 504 Plan.
 - If you are not connected with Early Childhood Special Education Services at this point, contact your local school district or other local education agency in order to receive services.
2. Ask your providers if there are any activity precautions or management tips related to things like a shunt, bowel/bladder care, and assistive devices.
3. Seek out information about adapted and inclusive activities so that your child can participate more with other children. Physical activity and participation with others can help your child build strong bones and muscles, improve balance and coordination, develop social skills and maintain a healthy weight.
4. Seek out opportunities for your child to participate in activities with other children who have a disability and those who do not.
5. Your child has a growing need for independence. Ask your providers, talk to other parents/caregivers, or contact disability organizations to get tips about how to balance your role as a caregiver in your child's physical activities and ways to promote independence.
6. Ask your providers about getting the right mobility equipment for your child to participate more fully in activities (e.g., wheelchair, dynamic stander, walker, adapted sports equipment).

6-12 Years

1. Keep your child active, including through activities with other children who have a disability and those who do not. Seek out information to help you make a plan for your child to be active.
 - Adapted or inclusive sports programs or community programs in your area can be great ways to be physically active – contact local disability organizations or the Parks and Recreation Department.
2. Encourage activities that promote movement and limit activities that promote little movement.
3. Unless advised that it is unsafe, your child should stick to the National Physical Activity Guidelines as closely as possible (See Appendix).
4. Ask your providers if there are any activity precautions or management tips related to things like a shunt, bowel/bladder care, and assistive devices.
5. Ask your providers about getting the right mobility equipment for your child to participate more fully in activities (wheelchair, dynamic stander, walker, etc.). Seek out advice and tips from other disabled athletes or disability organizations about how to pick out quality adapted equipment and figure out the right size equipment your child might need.
 - The proper sports equipment or mobility equipment can help your child to participate and keep up with peers during activities and games. There are many grants available to help pay for adapted equipment. Some communities have loaner programs to borrow adapted equipment. See Appendix for more information.
6. Make sure that there are physical education goals in your child's Individualized Education Plan (IEP). Adapted PE can also be added to a Section 504 plan.
 - Physical education is specifically listed as a part of special education in the federal law. The physical education teacher must include students with disabilities in the regular physical education class whenever it is appropriate. If it is not possible to include the student in regular physical education, then the physical educator must document their efforts to involve the student, including supplementary aids and services, before moving the student to a more segregated setting.

13-17 Years

1. Keep your child active, including through activities with other children who have a disability and those who do not. Seek out information to help you make a plan for your child to be active.
 - Adapted or inclusive sports programs or community programs in your area can be great ways to be physically active – contact local disability organizations or the Parks and Recreation Department.
2. Encourage activities that promote movement and limit activities that promote little movement.
3. Unless advised that it is unsafe, your child should stick to the National Physical Activity Guidelines as closely as possible (See Appendix).
4. Ask your providers if there are any activity precautions or management tips related to things like a shunt, bowel/bladder care, and assistive devices.
5. Ask your providers about getting the right mobility equipment for your child to participate more fully in activities (wheelchair, dynamic stander, walker, etc.). Seek out advice and tips from other disabled athletes or disability organizations about how to pick out quality adapted equipment and figure out the right size equipment your child might need.
 - The proper sports equipment or mobility equipment can help your child to participate and keep up with peers during activities and games. There are many grants available to help pay for adapted equipment. Some communities have loaner programs to borrow adapted equipment. See Appendix for more information.
6. Make sure that there are physical education goals in your child’s Individualized Education Plan (IEP). Adapted PE can also be added to a Section 504 plan.
 - Physical education is specifically listed as a part of special education in the federal law. The physical education teacher must include students with disabilities in the regular physical education class whenever it is appropriate. If it is not possible to include the student in regular physical education, then the physical educator must document their efforts to involve the student, including supplementary aids and services, before moving the student to a more segregated setting.
7. If your teen is considering continuing education after high school, ask your providers for help in looking at how different educational institutions support physical activity for people with mobility limitations. (e.g., does the university have an accessible gym and adapted or accessible exercise equipment; accessible outdoor track or walking and biking paths, recreation clubs).

18+ Years

1. Unless advised that it is unsafe, it is recommended that you stick to the National Physical Activity Guidelines for adults as closely as possible (*See Appendix*).
2. Ask your providers or fitness professionals to help you set goals to keep you motivated.
3. Do muscle-strengthening activities that include all major muscle groups if able (chest, back, arms, shoulders, abdomen, leg and hips) on 2 or more days a week.
4. Avoid inactivity. Any movement is beneficial!
5. Ask your providers about any precautions or management tips that should be taken in physical activity if you have limited mobility or a shunt. Also, seek out tips from peers with disabilities on management tips.
6. If you are a student, check with your college's disability student support office or the campus recreation center about how your institution supports physical activity for people with mobility limitations.
7. Work with your physical or occupational therapists about getting the right mobility equipment to participate more fully in activities. Seek out advice and tips from other disabled athletes or disability organizations about how to pick out and figure out the right size of adapted equipment you might need.
 - Adapted equipment, such as a handcycle, are very expensive. However, there are grants that you can apply for in order to buy a handcycle. Also, some communities have loaner programs - where you can check out and borrow a handcycle.



Appendix

Physical Activity and Disability Resources

The Spina Bifida Association does not endorse any brand of equipment, company, or website. Use them at your own risk.

National Organizations

- National Center on Health, Physical Activity, and Disability (NCHPAD) – www.nchpad.org – a resource center on health promotion for people with disabilities
- Spina Bifida Association Fitness Resource Links - <https://www.spinabifidaassociation.org/resource/sb-you-get-fit-and-stay-healthy/>
- Disabled Sports USA: <https://www.disabledsportsusa.org>

Equipment Resources

Apply for Equipment Grants

- Challenged Athletes Foundation (training and equipment grants): <https://www.challengedathletes.org>
- I Am Able Foundation grants (mid-Atlantic region): <https://imablefoundation.org/grant-application/>

Purchase Adapted Equipment

- How iRoll Sports: <https://howirollsports.com/product-category/adaptive-sports/>
- Sport Aid: <https://www.sportaid.com/>
- Spin Life: spinlife.com
- Craig Hospital Marketplace (secondhand equipment): <https://craighospital.org/resources/craig-marketplace>
- Sports Abilities Classified Ads (secondhand equipment): <https://www.sportsabilities.com/sa-classified>
- Ebay has adapted sports equipment (secondhand and new): ebay.com

Physical Activity and Exercise Videos

- Spina Bifida's Get Fit and Stay Healthy [Webinar](#)
- "[How to Choose a Fitness Center](#)"
- [Exercises for People with Spina Bifida](#)
- [Discover Accessible Fitness – A Wheelchair User's Guide for Using Fitness Equipment](#)
- [NCHPAD Physical Activity Resources](#)
- [Inclusive Fitness Tips - Seated Wall Balls \(video\)](#)
- [Inclusive Fitness Tips - Wheelchair Burpees \(video\)](#)
- [How to Choose a Fitness Center \(video\)](#)
- [RubberBanditz](#)
- [Adam Guerrero's Exercise Routine I](#)
- [Adam Guerrero's Exercise Routine II](#)

Physical Education Resources

- The Adapted Physical Education Resource Manual:
<https://www.shapeamerica.org//publications/resources/pa/upload/Adapted-Physical-Education-Resource-Manual.pdf>
- Wrights Law-Physical Education for Students with Disabilities:
<https://www.wrightslaw.com/info/pe.index.htm>
- PACER Center: IFSP: <https://www.pacer.org/ec/early-intervention/ifsp.asp>
- PACER Center: IEP: <https://www.pacer.org/parent/iep/>
- PACER Center- Section 504 of the Rehabilitation Act: https://www.pacer.org/parent/504/?gclid=Cj0KcQjw7qn1BRDqARIsAKMbHDZcyBD7nltfEOMuD2BhKTS32pIb77hAUDyAgyj0O5_0WDCG5VjrAWsaAusSEALw_wcB

National Physical Activity Guidelines for Americans (disability or not)

https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf

For Preschool-Aged Children:

- Preschool-aged children (ages 3 through 5 years) should be physically active throughout the day to enhance growth and development.
- Adult caregivers of preschool-aged children should encourage active play that includes a variety of activity types.

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National Physical Activity Guidelines for Americans (*contd.*)

For Children Ages 6-17:

- Engage in 60 minutes or more of physical activity each day.
- Aerobic activity should make up most of the youth's activity each day; vigorous intensity aerobic activity should be done at least 3 days/week (e.g., running or pushing a wheelchair, dancing, cycling or handcycling).
- Muscle strengthening activities should be done at least 3 days/week as part of the 60 or more minutes (e.g., resistance band exercises, body weight exercises-modified push-ups, yoga, climbing/swinging on playground equipment).
- Bone-strengthening activities should be done at least 3 days/week as part of the 60 or more minutes (e.g., weight lifting, dancing, tennis).

For Adults:

- Engage in physical activity according to your abilities. Avoid inactivity. Some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits.
- For substantial health benefits, adults should do at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity (e.g., brisk walking or pushing a wheelchair), or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity (e.g., jogging, running, or pushing a wheelchair fast), or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.
- For additional and more extensive health benefits, adults should increase their aerobic physical activity to 300 minutes (5 hours) a week of moderate-intensity, or 150 minutes a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity activity. Additional health benefits are gained by engaging in physical activity beyond this amount.
- Adults should also include muscle-strengthening activities (e.g., weightlifting, resistance bands, modified push-ups, heavy gardening) that involve all major muscle groups on two or more days a week.