



*Educational Webinar Series for Adults with
Spina Bifida*

Audience Questions: Your Health After Forty

December 2020

Should diet and nutrition be different for older adults with SB who are less mobile?

Information about diet and nutrition is found in our [Guidelines for the Care of People with Spina Bifida](#). Many of the guidelines are the same for all adults aged 18+. However, some Guidelines may be especially important for older adults. For example, some medications can interact with nutrition in foods. It is also recommended that blood pressure be monitored regularly.

Screening for blood sugar is indicated in adults aged 40 to 70 years who have a Body Mass Index > 25 kg/m².

Screening for cholesterol/ lipids is recommended for men 40+ and women 50+ or women who are postmenopausal.

Additional recommendations might also be important to older adults with high body mass index, and those within certain racial or ethnic groups.

For more, refer to [SBA's Mobile App](#) or the [Nutrition, Metabolic Syndrome, and Obesity Guideline](#)

My spinal cord is tethered. I was told it is too risky to untether again (it's been untethered once before). Is it accurate to not want to untether a cord because of concerns it will cause more pain, or is it better to untether?

The decision whether to untether a spinal cord is a complex one and best made by an experienced neurosurgeon. That decision will be based upon the possible risks of surgery, the possible benefits from the surgery, and the symptoms you are experiencing.

What do we do if we get to the point where we can't take care of ourselves anymore? Will we need specialized providers?

It is best to have a plan in place ahead of time, before that happens.

Talk to family and friends to understand whether they can be part of your care team. Call a local advocacy agency for information about attendant care services, skilled nursing, assisted living and group home options so that you can understand the differences between them, costs, and how you qualify for each one.

Attendant care programs can provide caregiver support to some people to allow them to continue to live in their homes.

Examples of local advocacy organizations that could provide information would be Agencies on Aging or Centers for Independent Living.

You may also want to talk to your insurance company to understand your benefits for long-term care and in-home support.

What is the percentage of people with SB that have severe osteoporosis?

SBA is currently working on a new guideline about osteoporosis. About one third of young adults with SB have osteoporosis, but we do not know the percentage of people with SB who have severe osteoporosis.

I'm 41, able to walk but with weakness in bladder, arms, and lower legs and ankles, with chronic back pain. What is the likelihood of losing my full mobility if I've lived with tethered cord and hydromyelia my whole life?

In my mid-20s/early 30s, I was diagnosed with hyper mobility, fibromyalgia, ME, overactive bladder, and Irritable Bowel Syndrome. A spine MRI showed tethered cord, hydromyelia, degenerative discs and spondylolisthesis.

Loss of mobility can be due to the cumulative effects of normal aging, plus complications that are related to SB. What you describe is a combination of both. You should see a neurosurgeon in order to determine whether one or more of your back problems are causing this loss of function, and whether some are treatable. If surgery is not an option, a physiatrist (rehabilitation physician) may have some good advice about how to preserve your mobility and manage symptoms.

I would like to know where I can find neurologists, physical therapists and psychologists for adults with spina bifida.

SBA's National Resource Center is happy to help. We continue to build a list of providers who understand how to help adults with SB. Please write to Juanita Panlener at jpanlener@sbaa.org.

What is the longevity of people with MMC without shunts?

We don't know the exact lifespan of people with MMC who do not have shunts, but many people who do have shunts have more complications over their lifetime than those who do not.

What is the recommendation of how physically active we should be? Will being as physically active as possible earlier in life catch up to us after age 40 and cause orthopedic problems?

The *Guidelines for the Care of People with Spina Bifida* recommend for adults:

- At least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity, 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.
- The types of exercise you do may need to be adapted so it is safer for your particular situation. You can find these recommendations in the [SBA app](#).

The *Guidelines for the Care of People with Spina Bifida* have exercise recommendations for adults over 18. Does the recommendations change for people over a certain age?

You can find detailed information about physical activity recommendations for individuals of different ages at the link below. This information is also available in our SBA App. Currently the recommendations are the same for all ages 18 and up

<https://www.spinabifidaassociation.org/wp-content/uploads/Physical-Activity.pdf>