

PREVENTIVE CARE CHECKLIST FOR ADULTS WITH CEREBRAL PALSY



WHAT IS PREVENTIVE HEALTHCARE?

Preventive healthcare includes health care services like physical exams, screenings, tests, vaccines, and even talking with your doctor about healthy habits. Keeping tabs on preventive care can help you stay healthy, avoid or delay getting sick, and catch problems early when treatment is likely to work best.

An adult with cerebral palsy may have additional health considerations to keep in mind and discuss with healthcare providers.

The Cerebral Palsy Foundation has created a checklist to help guide you in living the healthiest life possible. This checklist has been created for adults with cerebral palsy to provide basic guidance surrounding routine and additional screenings that should occur as part of your primary and preventative care. All adults should follow the same general health screening guidelines to stay healthy, but individuals with CP may need to do other things as well to ensure long term health and wellness.

WHICH BASIC PREVENTIVE CARE SERVICES DO ADULTS NEED?

There are health care services that all adults need whether or not they have cerebral palsy.

At least once per year:

- Physical exam with your primary care doctor
- Blood tests for glucose, cholesterol, and lipids
- Dental cleaning and exam twice a year
- Regular eye exams

Every few years:

- Cancer screenings for breast, cervical, or colorectal cancer
- Vaccines to help keep you and those around you healthy - get the CDC Recommended Immunization Schedule for Adults
- Tests for contagious diseases

AT YOUR VISITS, TALK WITH YOUR DOCTOR ABOUT:

- Changes to your medications and family history
- Concerns about your mental health, including depression and anxiety
- Getting help with tobacco cessation or weight-management

ADULTS WITH CP HAVE SOME ADDITIONAL HEALTH CONSIDERATIONS

What blood tests and screenings should I discuss with my PCP and why?

- Adults with cerebral palsy may have some additional risk issues that should be monitored over time and addressed early if necessary. Your PCP should conduct and manage routine screenings to monitor changes over time.
- Your doctor may include other standard tests as part of the initial physical exam as well. Among them may be blood tests to check electrolytes, liver function, toxicology screening, and kidney function. Because the kidneys and liver are responsible for the elimination of depression medications, impairment to either of these two organs may cause the drugs to accumulate in the body. Additionally, blood work can show if there might be other indicators that could be contributing to feelings of fatigue and depression including thyroid function, vitamin/hormone deficiencies and anemia.
- Your provider will want to make sure that your immunizations are up to date.

SCREENINGS MAY INCLUDE:

- **Blood Pressure** – If blood pressure is high (hypertension) this can cause conditions such as heart disease or stroke. Adults with cerebral palsy are at higher risk at younger ages than peers without cerebral palsy.
- **Bone Mineral Density** – This is a type of x-ray that looks at bone density to check for bone health which can be impacted for people with cerebral palsy. There are two types of bone density tests: The DXA, dual x-ray absorptiometry, tests bone density in the hip, spine and total body. The second type of test, QCT, quantitative computed tomography, measures the spine. For individuals with cerebral palsy, these tests should be done at age 21 to provide a baseline for changes over time.
- **Metabolic Panel** – This is a blood test that measures blood sugar (glucose), electrolyte and fluid balance, kidney function and liver function. Waist to hip ratio is another simple way to evaluate risk for metabolic disease.
- **Mental Health** – It is important for your PCP screen for mood disorders such as depression, anxiety, and thought, personality or behavioral disorders. Your provider can help refer you to the best mental health



care resources if indicated. You should request a mental health screen, these can range from simple questionnaires that your doctor will ask you to fill out to more in depth standardized measures that help identify mental health issues.

- **Lipid Panel** – This is a blood test that looks at your Cholesterol Level and can help determine your risk for fatty build up or fatty deposits in your arteries that can put you at risk for heart attack, stroke or disease of the blood vessels.
- **Pap Smear & Mammogram for Women**- These annual routine checks are important for all women to screen for breast or cervical cancer. Ask your PCP for a referral to the appropriate healthcare professional for well woman screenings and ask if there are clinicians who have experience with women with cerebral palsy and/or physical disabilities.
- **Colonoscopy** – This is a routine check for all adults to screen for colon cancer (beginning at age 45 – then every 5 to 10 years thereafter, or earlier if your health and family history indicate the need for earlier screening). Ask your PCP for a referral to the appropriate healthcare professional.

AS AN ADULT WITH CEREBRAL PALSY, IT'S IMPORTANT TO KNOW THAT SOME SCREENINGS MAY BE MISINTERPRETED BY YOUR PRACTITIONERS. THESE SCREENINGS MAY INCLUDE:

- **Body Mass Index (BMI):** This screening tool calculates a formula of weight/height to estimate your total body fat. BMI may be underestimated in individuals with CP, especially for those with more severe forms of CP. This is because individuals with CP tend to have less muscle and more fat infiltration in the muscle architecture. Providers must be sure to properly assess for obesity using waist-to-hip ratio.
- **Chronic Kidney Disease:** People with cerebral palsy may be at higher risk for kidney disease, and the tests used to measure this misinterpreted. Persons with cerebral palsy often have less muscle, which can lead to lower levels of creatinine - a waste product in the body that comes from normal wear and tear on the muscles. Everyone has creatine in their bloodstream, and in addition to muscle mass, it is affected by a person's age, gender, race and body size.

Make sure your practitioner reviews the results of your metabolic panel with an understanding that the results of one value (GFR) may not be accurate because you have CP. GFR stands for glomerular filtration rate and is a routine lab test reported on the group of tests called metabolic panel. The GFR is used by your healthcare provider to look to see if you have kidney disease, but it may be normal, even if you are developing kidney

disease, because it is calculated using a creatinine level that starts lower due to the CP.

- **Bone Fragility:** Fractures can be common in cerebral palsy and can lead to further complications and functional declines. Both Bone Mineral Density and Bone Size are important to measure when assessing fracture risk. Individuals with CP can be at risk for poor bone mineral density, leading to progressive deformity regardless if they walk independently or not. However, individuals who primarily use wheelchairs have more challenges with bone fragility and fractures.
- **Pain:** Chronic pain is a common issue for adults with cerebral palsy and can impact all aspects of one's life, as well as increase the risk of mental health issues. Pain for cerebral palsy should be treated by a specialist familiar with the different types of pain (pain as a result of growing up with cerebral palsy and/or having many surgeries, poor biomechanics; or more generalized pain that may be associated with conditions like fibromyalgia; or neuropathic pain). Far too frequently, pain in individuals with CP is treated with opioids, which may not be appropriate for the type of pain that someone experiences and may increase the risk of addiction.



COMMONLY ASKED QUESTIONS

Is My Cerebral Palsy Getting Worse?

- No, your cerebral palsy is not getting worse, although it may sometimes feel like it! For individuals with CP, the initial injury to the brain that caused CP is not getting worse, but the effects on the body of aging with cerebral palsy may have caused differences in the way your muscles and bones developed.
- Additionally, if you have limited mobility and have a primarily sedentary lifestyle, it's important to keep a close eye on possible spinal complications, osteoarthritis, cardiac, kidney, and other diseases at an earlier age. With age, you may also want to have conversations with your healthcare provider if you experience declines in mobility, increased pain, and other concerns.

Am I experiencing changes in function?

- **Changes in Function:** Decline in mobility, changes in bowel or bladder, sensation, balance, and fine motor skills such as hand writing can be signs of spinal compression or other conditions and it is very important to discuss these symptoms with your provider.
- There are screening tools that can be used to help your healthcare provider assess changes in function you might be experiencing. These include:
 - **Screening for Cervical Stenosis and/or Lumbar Stenosis** – This is done with an MRI, and should be done beginning as early as age 40 if indicated.
 - **Urodynamics/bladder function-** The management of urinary function is important and there are many ways to address issues with bladder control and continence. It is important to manage bladder function to prevent kidney disease, as well as social issues and quality of life.
 - **Cardiovascular disease-** Changes in cardiac capacity impact the health and function of all adults. People with cerebral palsy often don't get enough aerobic exercise to keep their heart and cardiovascular system healthy. Simple measures of aerobic capacity can help your healthcare provider make recommendations for all ability levels that can improve cardiovascular function.

Is my diet healthy and suited to my nutritional needs?

- **Diet and Nutrition:** Be sure to talk to your provider about your nutrition and healthy eating to ensure that

you are getting enough of the appropriate vitamins and nutrients for your physical needs. If necessary, ask to be referred to a nutritionist and/or a weight management program.

Can an exercise program improve my fitness and overall health?

- **Fitness and physical activity:** Exercise is well known to prevent and treat many of the chronic diseases that all adults face as they age. Exercise and physical fitness are vitally important for people with cerebral palsy to improve quality of life and help prevent declines in mobility, cardiovascular health and mental health. Talk with your healthcare provider about how to get started or continue to incorporate exercise and fitness into your life. There are many adaptive exercise and fitness resources both online and in your local community to help you get and stay active throughout your life.

Do I need to take medication or supplements?

- **Medications and any supplements:** Talk to your PCP about the medications and supplements that you currently take, any new ones that you may need to consider. Discuss how those medications and supplements may interact with each other and what you need to know. If you take medications to treat mental health issues, make sure to discuss the side effects of these medication. Some medications can impact movement or sleep, which is especially important for a person with cerebral palsy to be aware of.

What is the best way to manage my pain?

- **Pain Management:** A majority of adults with cerebral palsy report they have pain. Pain, especially chronic pain, can arise for different reasons. Pain can be caused by injury, previous surgeries, movement pattern issues or a variety of other reasons. It's important for your pain to be diagnosed and treated correctly by a trained healthcare provider who specializes in pain management and has experience with adults with permanent conditions like cerebral palsy.

How can I improve my sleep and energy levels?

- **Fatigue and sleep quality:** People with cerebral palsy often have questions regarding their energy levels and sleep quality. Be sure to discuss your sleep habits and any concerns you have with your primary healthcare provider including difficulty falling or staying asleep, leg spasms, and breathing issues. Additionally, you should let your provider know if you are fatigued throughout

the day, and/or if your energy levels interfere with your ability to work or impact your quality of life. There may be ways to help including Sleep Therapy which includes an evaluation and treatment plan by a trained specialist.

I have Mental Health concerns. Is that something I should discuss with my primary care provider?

- Mental Health: Many adults with and without cerebral palsy report mental health concerns and concerns with depression, anxiety and social isolation - now more

than ever. Having cerebral palsy can increase this risk and it is important to share your concerns with your primary healthcare provider. **You are not alone and there are many treatment options that include talk therapy, medication and other options.** Often mental health is impacted when there are changes in function, or pain and fatigue issues, so it is important to have honest conversations with your healthcare provider in order to optimize your mental health. Mental health services are available and accessible more than ever with telehealth options.

HOW DO I SELECT A PRIMARY CARE PROVIDER?

It is important to find a Primary Care Provider who understands you and your unique needs. While not every provider will have experience with Cerebral Palsy, there are many who do and/or have experience with patients who have physical disabilities. Importantly, you will want to be comfortable that your doctor will listen to you and your specific needs, as well as have the qualifications and knowledge you want. Depending on your healthcare insurance plan, there may be a variety of resources to help you select a primary care physician in your area.

If you have a mobility challenge, it's important to remember that the accessibility of the office and the exam room will be important to you and you want to ask about that before making an appointment.

QUESTIONS TO ASK A POTENTIAL PRIMARY CARE PROVIDER

- Do you have experience treating individuals with Cerebral Palsy?
- Are you and your office staff comfortable treating individuals with Cerebral Palsy and related disabilities?
- Are you able to see me for longer appointments if needed, to ensure that all my healthcare needs are addressed?
- Can your office accommodate my physical needs (i.e. is there accessible parking, additional space in the exam room for my care giver if needed, movable exam table etc.)
- Are you able to coordinate my care across providers if needed?
- Do you have a network of specialists you refer to?
- Does your office have capability to do bloodwork and other procedures "in house", or will I need to visit multiple locations?

RESOURCES

- Cerebral Palsy Resource: <https://cpresource.org/>
- CDC Immunization Schedule: <https://www.cdc.gov/vaccines/schedules/hcp/imz/adult.html>
- U.S. Preventative Services Task Force Adult Preventative Health Checklist: <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation-topics/information-for-consumers>