### **Screening**

It is important to get regular screening (checks) for cancers. If you are a woman with CP, then you should go for routine cervical and breast screening.

If you have physical or communication difficulties, you should talk to your doctor about how they can best support you to have the screening.

As is the case for all men it is important that you talk to your doctor if you notice any changes to your urination or testicles so they can be checked.

### **Menstruation and menopause**

Some women with CP may experience difficulty managing menstruation because of muscle spasms, wheelchair use, heavy bleeding or pain. Others may have irregular periods because of medications taken for CP-related problems. If you have any concerns about how to manage your periods, you can speak to your doctor or community nurse.

If you are going through menopause (when your period stops) or have hot flushes or changes in your mood, it is important to speak to your community nurse or doctor.

### **Pregnancy care**

It is important to talk to your doctor, obstetrician or gynecologist if you are thinking of becoming pregnant or if you do not want to become pregnant. Your doctor will give you advice on the pregnancy care or contraception that is available for you. It is also important to discuss any support, or you may need when attending your anti-natal appointments or with your birth plan.



### Your mental health and well-being

Anxiety and depression are common problems with CP. They can happen when people have a lot of worries. Some of the things people worry about are health, relationships, money, housing, losing someone you are close to and current/future care.

Sometimes, having worries like these can:

- Change the way you feel and think (e.g. you may be nervous, frightened, emotional)
- Change the way your body works (e.g. feeling headache, tiredness, sleep problems)
- Get in the way of your life (e.g. losing confidence, having difficulty making decisions, avoiding friends and family)

There are many things you can do to help:

- Meet with friends, family, and other people with CP or members of the disability community.
- Make lifestyle changes to your diet, your activities and exercise.
- · Practice good sleep hygiene.
- Keep a diary of how you feel and discuss with your doctor.

Your doctor can explore the reasons for your worries and discuss what can be done to help. This may include seeing a mental health team (e.g. psychotherapist, and talking therapist), a physiotherapist or a dietician. Medical treatments may also be available.

Further sources of information:

- · UP, The Adult Cerebral Palsy Movement
- van Gorp M et al. 2020
- Ryan et al. 2018
- · NICE guidelines for adults with cerebral palsy 2019
- Cerebral Palsy Foundation. Preventive care checklist for adults with cerebral palsy



# Information Leaflet for Adults with Cerebral Palsy

#### What this leaflet is about?

This leaflet will help you understand more about common conditions that adults with Cerebral Palsy (CP) have. It will also help you look after your health as you age. You can use the information in this leaflet to talk to your doctor.

Adults with CP commonly experience issues with:

- Pain
- Tiredness and sleep
- Mobility decline
- Reduced balance and falls
- Communication
- Swallowing and nutrition
- Mental health
- Chronic health conditions

# Your physical health and well being

### **Managing pain**

We know that people with CP often experience pain. It can be caused by unusual stress on muscles, bones and joints. Pain may be related to your CP or because of other persistent conditions (e.g. constipation). Pain can often make fatigue and poor sleep worse. Pain can reduce what you are able to do in daily activities.

There are things that you can do to help reduce the effects of pain in your life such as

- Try to keep moving and find what movements that ease your pain.
- Ensure that you have the correct equipment to support your seating and posture
- Explore activities to relax your mind and body (e.g. enjoy the outdoors, mindfulness, creative activities)
- Think about ways to relax your muscles e.g. swimming, stretching, massage
- Practice good sleep hygiene
- Use ice or heat and take medications if needed.

It is important that you keep a record of your pain, sleep quality, and daily activities. If you notice changes, you should let your doctor know. Your doctor can check and find out the cause of your pain.

Your doctor may be able to refer you to a pain management service. They may also be able to refer you to services that will help you with sleep, your posture, and helpful assistive technology. These services are run by a team of health professionals like physiotherapists, or occupational therapists with specialist training.



Physical activity is important for physical and mental wellbeing in CP.

### Prevention and early detection of under-lying health conditions

As you get older, you might start to feel unsteady on your feet or just feel you are slowing down a little. For some people, changes in muscle strength are more noticeable than others. We know that people with CP fall more often than others and are at increased risk of osteoporosis (weak bones) and arthritis (pain and swelling in joints). This might increase the risk of serious injuries.

There are many reasons for losing muscle strength, feeling unsteady, or falling more often. But keeping physically active helps you to:

- Improve muscle strength
- Prevent some long-term conditions like arthritis from getting worse
- Reduce the risk of falls and bone fractures
- Maintain a healthy weight
- · Improve heart health
- Reduce the risk of diseases like diabetes and cancer
- Improve sleep
- · Support your mental health.

It is important to tell your doctor if you have had a fall or are falling more often. You should also tell you doctor if you have started to feel unsteady on your feet.

Your doctor can check your balance and how you walk to see if improvements can be made. They may be able to refer you for a falls risk assessment or to a falls prevention service. This is run by specialist health professionals who give people advice and support to improve and maintain their strength and balance.

Your doctor may also run additional tests to check your calcium, vitamin D and bone density (DEXA scan) to check for osteoporosis.

We know that adults with CP are at increased risk of some health conditions and that there is a risk that they can be overlooked if all symptoms are attributed to your CP. This is often referred to as diagnostic overshadowing. Adults with CP can be at more risk of:

- High blood pressure
- Heart problems
- Stroke
- Diabetes
- Lung conditions
- · Liver disease
- · Kidney disease
- Stomach problems

You can reduce your chances of getting these condition by some lifestyle changes and with regular monitoring. It is important that you talk to your doctor about any of the health concerns you have. You can also ask about health check-ups and at what age you should have them.

Your doctor may suggest having blood tests to check your blood glucose, your cholesterol level, thyroid function, and how your kidneys and liver | are working.

You may also be screened for bowel and bladder problems (e.g. urine test, stool tests, colonoscopy). If needed, your doctor will refer you to health professionals for further discussion about lifestyle changes.



Regular monitoring and screening of health conditions is important in CP.