

Medical Issues  
and

**Cerebral Palsy**





# **Medical Issues and Cerebral Palsy**

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## About this Booklet

People with cerebral palsy (CP) have no doubt had some experience with the medical profession already. If those experiences haven't been good ones, this booklet is about making future experiences better.

If you're a health practitioner, a parent or other care provider who is able-bodied this booklet will help you understand some of the issues and concerns that people with CP face when considering health care.

No two people are affected by the disability in the same ways. For this reason the information is general, and can (hopefully) be adapted to any specific needs you may have.



## Cerebral Palsy: The Basics

Cerebral Palsy (CP) is a hard condition to pin down, but there are some common issues

- CP is usually diagnosed within the first few years of life.
- Motor function and muscle coordination are affected, often leading to such things as involuntary movement of arms, legs and head, and muscle tension.
- Balance and posture are affected, often leading to an unsteady walk, or the need to use a wheelchair or other mobility aid to get around.

People with CP have full sensation in their limbs. CP cannot be passed on to a child from her mother, at birth.

They may also have varying degrees of hearing impairment, visual impairment, difficulty in learning, or other sensory deficits (e.g. no depth perception). These may or may not be caused by CP.

A small percentage of people with CP may have an intellectual delay. They're of average, or above average intelligence, capable of holding jobs, having families and leading active lives.

*Remember: People with cerebral palsy aren't sick. They may have certain physical limitations, but are able to live fully within them.*

### **“Not Another Appointment!”**

There's a good chance that people with CP have had dozens of medical professionals involved in their lives by the time they reach adulthood. Like any baby, they had little control over what happened to them, or how it happened. But memories of childhood may include things not usually experienced by able-bodied children: seemingly endless visits to physiotherapists, occupational therapists, social workers, surgeons and doctors. All necessary for adult health, but time-consuming, boring, perhaps even painful and exhausting.

If no one fussed over your care as a child, you may feel as if your bodies aren't worth much. But how you feel matters, and if you're not feeling well, your body is trying to tell you something.

**Go to your doctor (once or twice a year) for regular checkups.** People with disabilities tend to forget about, or postpone medical care for themselves, for any number of reasons

- it'll take too long.
- it'll be too stressful.
- because they don't want to put anyone to any trouble helping them make the appointments, or get to the offices.

But everyone needs their health concerns checked out, at some point in their lives. Knowing you're healthy is a good stress-reducer: one less thing for you to worry about.

Be wary of practitioners who describe out-of-the-ordinary symptoms as “part of your cerebral palsy.” What you are feeling, or the reaction your body is having to something, may have very little (or nothing at all) to do with your CP.





## Take Your Health Seriously

Your Number One ally in building a health care team you can trust, is resourcefulness. It will help you get the care you need, when you need it. Being proactive about your own care gives you control over your body and the care it needs.

You can choose to take control of your medical care, even if you need others (such as personal care attendants) to help you do so. Assuming that your physical growth has stopped, CP will not offer a big shock to your body. You know how your body normally feels: you've developed movement patterns in your limbs, and ways of coping with the world that (hopefully) work for you and minimize the effects and stress of CP on your body and mind.

- Acknowledge the way you're feeling. Pinpoint when your symptoms occur, how often symptoms occur and when they occur. They may be resolved quickly, with little difficulty.
- Find a basic health guide, read up on symptoms and advice and compare them to your own.

- Ask someone for help or advice. You may not even need to visit a health professional to solve your health care issues.

To begin with, you might ask yourself:

- What does my body do in this situation, normally? Is what's happening to my body now, different from what usually happens?
- What are some coping strategies I use to deal with similar situations? Can I use them now?
- Is there any information available from books that might help pinpoint a problem and a solution?
- Can I come up with a new coping strategy to help deal with my health issue?

If pain or symptoms you're experiencing are unexplained and not resolved with self-care, seek appropriate professional health care.

## **Know Your Body**

Find books, magazines or other materials about CP. Learn about the disability, and compare what you read to how you feel, and what you can and can't do in a particular situation.

When you get to know your body in this way, it's easier for you to understand your needs, as well as for any health practitioner to do so.

Build a relationship with health care practitioners before you're in crisis - that way they know you, know your disability and can focus on the appropriate issue when the time comes.

## **Finding a Health Practitioner**

Before booking an appointment, get some basic information, such as

- What is the health practitioner's background and specialty? Does it fit with your needs right now?
- Is the office physically accessible? Are there ramps or elevators? How many stairs are too many to manage?
- Does s/he see many people with disabilities? What kinds of disabilities? This may give you an idea of how the professional will deal with you as a patient.

- What are their fees and billing practices? Are reduced rates available? This may be especially important if you do not have a steady source of income.

If you're satisfied with the answers you get to these questions, go ahead and book an interview with the health practitioner you wish to see. Keep your energy levels in mind. Schedule the appointment for your most energetic time and plan for a 30 minute visit.

- Get clear directions to the office. Be a little early. This way you won't be rushed in talking to the receptionist, taking your coat off, or wheeling around, etc.
- Gather your medical or other relevant records. Doing this beforehand will prepare you and give you confidence when talking to the health professional.
- Know your health history and be prepared to tell the professional how CP affects you. If you can't express these things, maybe someone can help you do this. This will make any care you receive more comfortable for both you and the professional.

- Bring a notebook: take notes so that you're able to make an informed decision about your care. Ask for lists, pictures, pamphlets, or books that'll help you understand the treatment you're considering.
- If it's more helpful for you, ask the doctor if you can tape-record your visits. Take the notes later.
- Bring a friend: they can help you communicate with the professional, if you need it, and give you their impression of the practitioner after the meeting.

Ask any questions you may have: this is a good time to deal with any initial concerns you may have.

**After the first appointment,** ask yourself

- Do I feel the health practitioner spent enough time with me?
- Did I feel respected by them? Was I treated as an intelligent adult?
- Does the professional seem like they'll take my specific needs into account?
- Does the s/he seem open to learning about my disability, and to trying different treatment options?

If you answered “Yes” to some or all of these questions you may have found a good match! If not, keep searching. You'll find a good fit eventually.

If you experience rudeness or inappropriate behaviour by nursing staff or health practitioners at any time during your visit, let them know how you feel. They may change their behaviours toward you in following visits. If the behaviour continues, don't go back! Find a more respectful practitioner.

A good health practitioner will

- listen to you, and acknowledge what you say.
- make an effort to find out how your disability affects you.
- respect you and your feelings.
- take initiative to provide you with complete care.
- say things in ways that you understand, or clarify them if you don't.
- treat you as an intelligent adult, not a child.

*Remember: Be aware of your own energy levels. When are they highest? Lowest? How they affect your body and mind? Time your appointments and your preparations for them to your high-energy times.*

*If you cannot keep a scheduled appointment, notify the health practitioner's office and reschedule it for a different day or time.*

*If you've been with a doctor or health practitioner for awhile, and decide to change, find a new one before leaving your present one. This way, you'll still have medical care available when you need it.*



## Information For Practitioners

People with CP don't need or expect sympathy, nor do they want to be talked down to, in a medical office. Health professionals should resist the temptation to tell people with disabilities how "lucky" they are to "not be worse off." More often than not, regardless of the severity of their disability, they've had to struggle to achieve good health and other goals throughout their lives.

Take time to get know your patient: communicating appropriately is especially important when dealing with their health and their bodies. Misunderstandings can cause confusion and possibly injury. If your patient is non-verbal, they may use

- communication boards or books (boards or books of pages with symbols, letters and whole words on them, which help express ideas.
- talkers (speech synthesizers that talk); or
- speech.
- sign language, or
- other means of communicating.

Whether or not they use these devices to communicate, they may use other body movements to help them along the way. Be sensitive to

- eye-blinks: find out what means “yes” and what means “no”.
- head movements: up/down, side-to-side? Find out what different movements mean.
- speech: we may have different rhythms and rates of speech. Patience is key here.
- facial expressions: can be key to understanding meaning.
- arm or hand movements.

Be alert to combinations of the above, and take whatever time you need to understand people using these means to communicate. People with CP would rather repeat themselves until you know what they're saying, than have you misunderstand them.

Different strategies are needed when communicating with someone who has CP. For example, unless you can read upside down, you may need to stand behind (or to the side) of the talker. This can sometimes feel unnatural, as it mostly eliminates body language as a cue to

interacting with someone, and leaves no eye contact to be made with the speaker. But it is often what is needed in order to communicate effectively.

If you have unanswered questions about how CP affects individuals, ask them, but be prepared for the fact that (unless medically necessary) people may not be forthcoming with answers.

**If a friend, family member, or other care provider is helping you communicate:**

Describe to them the kind of help you want, and agree on a signal to let them know when to “jump in” to help you. Don't be afraid to let them know what is inappropriate, but be respectful when you do so.



Understand our communication styles. More than likely, we aren't being aggressive when we're noisy, or waving our arms and legs around. We're simply trying to get a need understood, or met adequately.

Please don't focus on a person's mobility aid. That's inappropriate if they've come to you for reasons other than those related to their disability.

### **It's About Time!**

Lifts and transfers (to or from examination tables, beds, and other medical equipment) and communicating (by ourselves or through someone else) will take time.

**If you're seeing a doctor:** count on 20 minutes for a doctor's visit (instead of the usual 12 minutes) and up to 40 minutes for an examination.

### **Mobility**

When coming into a health professional's office, people with CP may be using a variety of mobility aids to do so.

- Canes
- Walkers

- Wheelchairs
- Leg braces
- Crutches

They may be slower movers, compared to your average patient. Waiting rooms are often cramped and small, so people with CP may need extra time to get into the examination room. That doesn't mean you can shorten the time they spend with you. They need the same level of care and concern that you've shown other patients.

**Asserting yourself** means being “direct, calm and firm in communicating needs and desires.” Make sure that any practitioner you see is aware of your communication needs.

Ask (firmly but politely) for what you want or need. You can't control other people's responses to you, but you may be able to negotiate to get your needs met.

If you're not getting proper care and attention from a practitioner, get your arms, legs, and voice involved. Hand gestures, leg movements and your voice can help alert practitioners to the fact that you want help, or that something may be unsatisfactory.



## Your Health Concerns

### In the professional's office

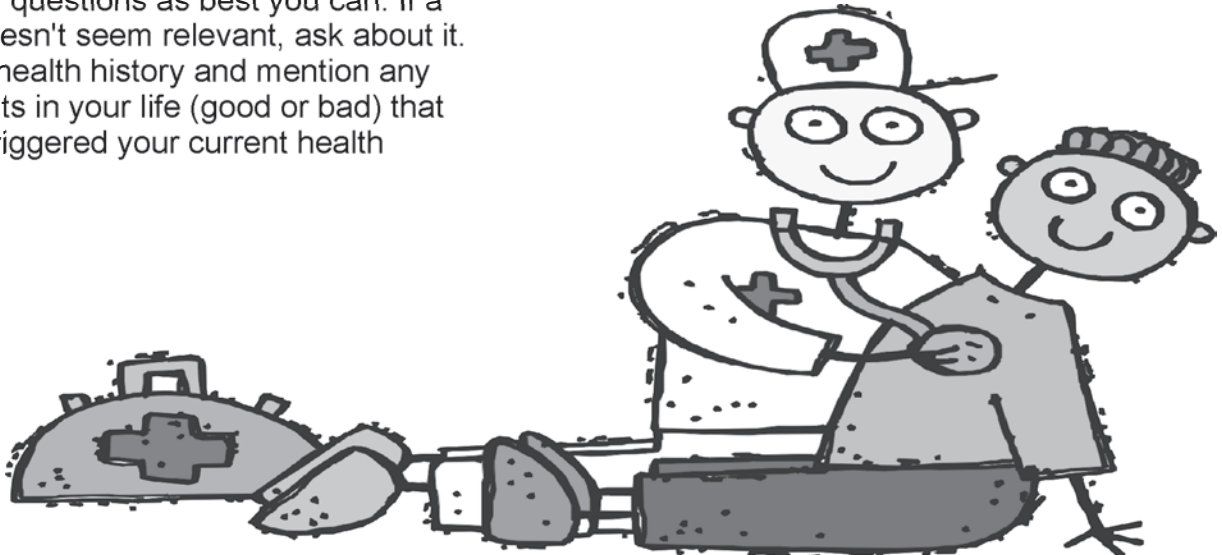
- Know what your health concern is, and know how you want to describe it to the professional. Write it down beforehand, if that helps you.

If you don't know how to describe your concerns, it may be enough to tell the doctor what the general problem is. They'll ask questions and help you pinpoint your concerns.

- Answer any questions as best you can. If a question doesn't seem relevant, ask about it. Know your health history and mention any recent events in your life (good or bad) that may have triggered your current health issue.

**Ask any questions you may have.** Before you leave, be certain you're satisfied with the course of action the doctor suggests. If you aren't satisfied, ask about the availability and feasibility of alternative methods of treatment.

Your doctor may prescribe medications to help relieve stress or tension. You may need medication for a temporary medical issue or for management of your cerebral palsy. Make sure your practitioners are aware of your feelings about medication, and aware of your priorities and your lifestyle. This helps them to personalize your care.



**If your doctor prescribes medication for any reason, be sure to ask these important questions:**

- What's the name of the medication?
- How long does it take to work?
- How long will I need to take it?
- Are there any non-drug alternatives?
- What kinds of side-effects can I expect?  
How long will they last?

**Note to Professionals**

Even if you're in a hurry, don't brush aside the concerns or questions of people with disabilities. Health issues may disrupt their lives to a greater degree than an able bodied person's. Make an effort to arrive at an accurate diagnosis and treatment. If you don't know the answer, let your patient know; make an effort to research the answer for them in a reasonable time.

Visiting health professionals may be difficult for people with CP. Be sensitive to how the information will be received:

- Treat them as adults, and address them as such. They may not be able to communicate verbally, but it doesn't mean they're unintelligent.
- If you're talking to a person with CP about their disability, don't make unfounded conclusions about how their condition may affect them in the future.

Even if the person with CP is accompanied by an advocate and they are speaking through them, talk to your patient. Don't talk to their advocate about them, as if they are not there.

*Remember: Don't focus on the cerebral palsy, unless the situation warrants it. The disability is not the cause of all physical illnesses. Deal with the presenting issue.*

## Going for Medical Tests

At some point in their lives, most people will have to go for medical testing of one kind or another, whether or not it's related to any disability.

### Find out

- if the cost is fully or partially-covered by health plans you may have.
- what the name of the test(s) are, why do you need them?
- how much the test(s) will cost you.
- where the test is to be done. Is it accessible to you? If not, are there alternative, accessible locations you can go to?
- what you need to do to prepare for the test.
- what happens if I don't have the test?
- if the test is painful.
- what can go wrong (if anything.)

Tell your doctor about any concerns/issues you may have when taking medical tests, such as

- being able to lie still on an exam table,
- swallowing anything,
- needing extra time (for transfers etc.)

S/he may be able to inform the technician of concerns ahead of time, so that any difficulties or necessary accommodations to the test are planned for, before it takes place.

*Remember: Ask health practitioners to explain the benefits and risks of a particular test or procedure, in language you can understand. If you need to, ask for a step-by-step description of the procedure, so that you're aware of what's involved. Knowing what happens will help you relax, and help the practitioner do the work they need to do.*

After the test is over, be sure to ask when the results will be available and how you will be notified: by letter, phone or other means.



## Emergency Response

You may need an ambulance at some point, in order to get your health needs met. Call the paramedics (or have someone do it for you) when you are

- having a heart attack.
- bleeding seriously or experiencing severe blood loss.
- having difficulty breathing, choking or unconscious.
- having severe allergic reactions.
- suspected of having a spinal or neck injury.

In case of medical emergency, tell the ambulance dispatcher

- what town or city you are in.
- where the ambulance is needed (exact address or location.)
- telephone # (caller's and patient's.)
- what the medical problem is.
- how old the patient is.
- whether or not the patient is awake, breathing, or bleeding.

*Remember: If your condition is serious or life-threatening call an ambulance immediately.*

People with CP may need to be hospitalized for a period of time because of disability-related issues, or other unrelated health issues.

- Have an information sheet with you at all times, that describes CP and its effects on you in some detail. Include specific steps on how to deal with you if, you have a health crisis such as seizure, or are unconscious.
- List the phone numbers of a few people in your support network, so that emergency personnel can let them know where you are, and your friends or family can be with you for support or help.
- Wear a Medic-Alert® bracelet if you need to. This will immediately alert medical personnel to any specific drug allergies you may have.
- Have a list close at hand, of the medications you're taking, so hospital personnel can be aware of the potential effects of additional medication on your body.

These lists will be of use to friends, family, passers-by, paramedics and hospital personnel. Make sure the information is easy to find. If you are with someone when you fall ill, these lists will help them discover your care needs, which will help them, help you.

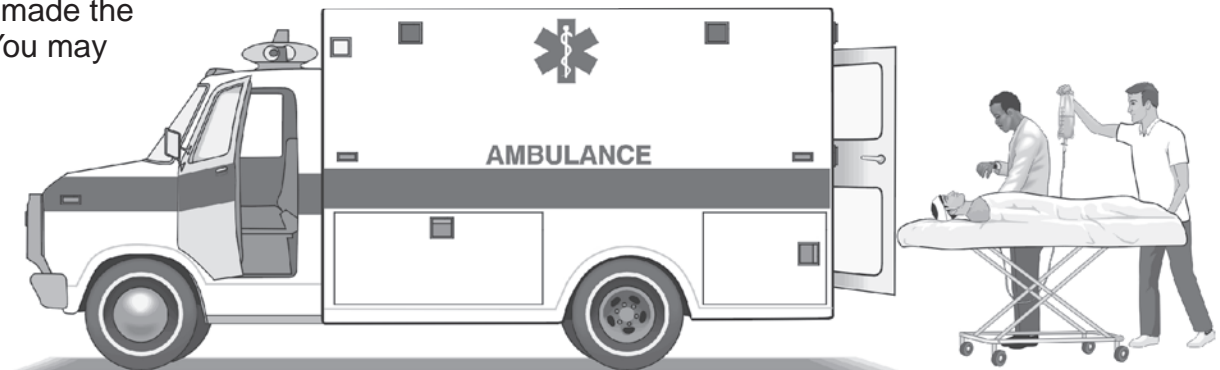
- If you know you are going into the hospital, ask for a tour beforehand. This way, you may meet some of the nurses who will be responsible for your care. You can explain to them your personal care needs, for eating, toileting, and transfers, as well as give them a little bit of background on how CP affects you.

Depending on how you got to hospital (by yourself or by ambulance) you may be stressed out and frightened. Emergency workers may not have had the time, or made the time to listen to you. You may be without your communication boards, and even without your wheelchairs, canes or walkers. Make sure you have a plan to get access

to your communication board(s) and mobility aids as soon as possible. Without these things, it may be difficult for you to obtain appropriate medical care.

Arrange for emergency situations with family, friends or others in your support network. Ask yourself questions such as:

- Who will bring my communication and mobility aids? Who can bring my clothing and a few personal items?
- What medications will I require while in hospital, and who will bring them?
- How soon (after I enter the hospital) can they do the above things?



## Hospital Basics

If you know you are going to the hospital

- pack a “hospital bag” with a few clothes, your toothbrush, comb, toiletries and other necessities. Include reading materials, playing cards, a walkman with music or books on tape along with other things you might enjoy.

When you arrive:

Let the nurses know how your disability affects you and if you need help with feeding, going to the washroom, transfers, etc.

You may also want to tell them that spasticity or medication schedules often interfere with sleep. Ask them to position you so that you do not need to be turned as often, or at all.

You may use medication to relieve muscle spasticity and pain.

- Don't let doctors take away or change medications without knowing for how long, and for what reasons you've used it. The same applies to medication schedules.

## In the Hospital

Being in hospital is a difficult thing for anyone, and regardless of their disability, people expect to get a decent level of care and attention while there.

- Don't treat adults with CP as if they were children. The fact that they drool, need attendant care and may communicate non-verbally is not a measure of intelligence, or chronological age.



## Medical Testing in the Hospital

Be sure to tell X-ray technicians or lab assistants if you have trouble lying still on a medical table or with procedures like giving blood. They may be able to arrange to do any tests you need done in a more comfortable (but not necessarily easier!) way.

You might want to write some of your needs down on paper beforehand. This way you won't find yourself in a scary situations with no way to communicate effectively and quickly.

## Note to professionals

Some procedures, such as having someone swallow a gastric tube, or provide a urine sample may be more involved than others. Be aware that people with CP carry a lot of physical, muscular tension in their bodies, and may not have the necessary coordination to accomplish this on their own. You might have to perform the procedure in a slightly altered way to get the desired result, or a choose a different procedure entirely.

## Getting Enough Sleep

Because they use so much energy during the day (up to three and four times that of an able-bodied person, just to get around) people with CP need as much sleep as they can get. It's important for hospital personnel to schedule any nighttime routines for as little disruption as possible.

Hospital gowns may be awkward. Ask if you're allowed to wear your own PJs in the hospital: Familiar things will offer comfort to you in what could be a stressful time.



## Pregnancy/Fertility Issues

You may encounter doctors who make assumptions about your disability. One of them might be that you can't (or shouldn't) get pregnant because of your CP, or that pregnancy might make your disability "worse." This couldn't be further from the truth.

- Look after your reproductive health. During your routine physical exam, you might ask for tests (such as Pap smears) that can confirm the health of your reproductive system.

Your disability may impact your pregnancy: muscles and tendons will be stretching beyond their normal state. Difficulty with mobility or balance can be caused by such things as muscle weakness or swelling. Increased muscle spasticity may be a concern. Dealing with these issues can prevent harm to you and your baby. Gather a team of people around you, made up of compassionate professionals and loved ones, who will listen to you and your needs and build a plan of care around you.

If a doctor is disrespectful or ignorant of your wish to become pregnant, find a doctor who will

help you understand what kinds of physical changes to expect, how to cope with pregnancy. Make sure they are an available member of your team. Find practitioners that will appreciate your knowledge of your own body.

When pregnant, get someone to help with, or take over the household tasks. Family or friends may be glad to help. If you have the money to do so, hire someone, to deal with major household chores or tasks.

You may wonder how you will care for a baby, or you might even be questioned by strangers as to your ability to take care of a baby.

Tell them that cerebral palsy has no bearing on your ability to love a baby. The practicalities of caring for a son or daughter may require some adaptations to your home or your routine. There are adapted cribs, strollers and other equipment that you can get, via a number of resources, that will make life easier for you.

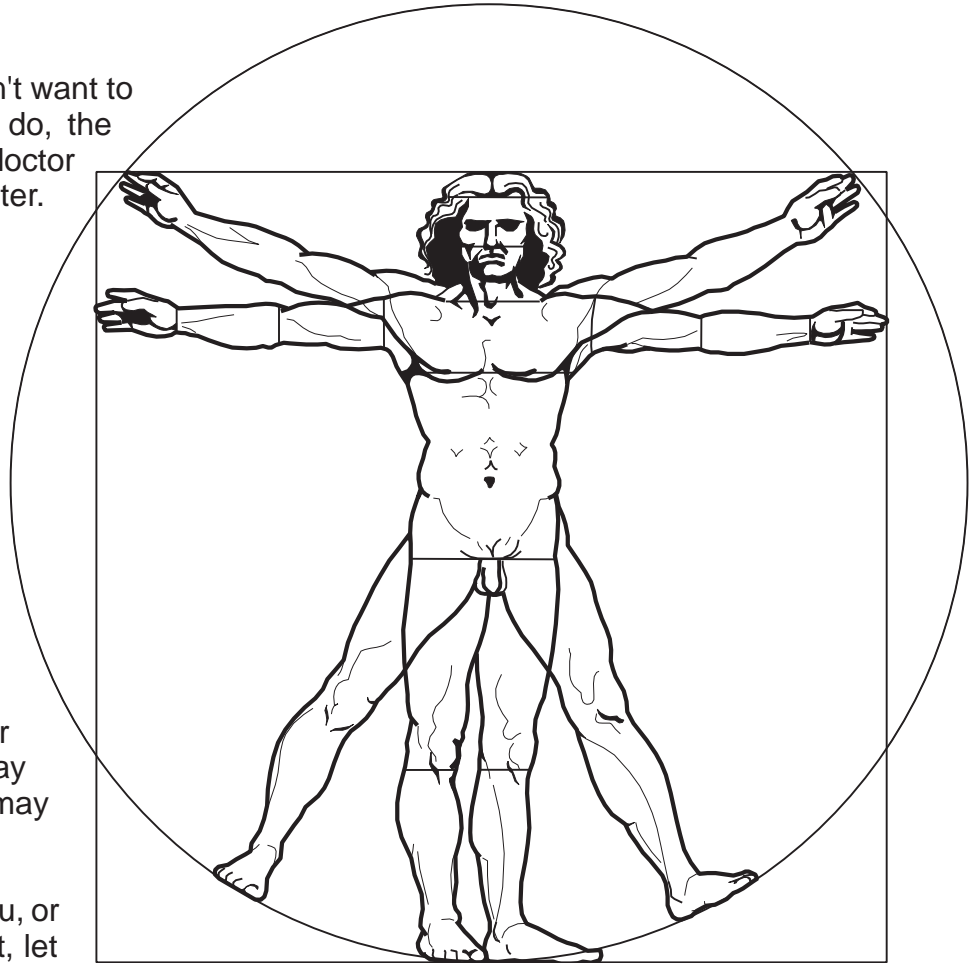
## If you're a man with CP

Your doctor may assume that you don't want to father children. Whether or not you do, the assumption is a rude one. Tell your doctor how you feel, either in person, or by letter. Insist on fair and respectful treatment.

Ask your doctor to perform a testicular exam during your routine physical exam. He'll gently feel your testicles for lumps and bumps. Each one may be sensitive, but it shouldn't hurt.

A prostate exam will tell you if your prostate (which aids in the production of semen, and therefore has an effect on your reproductive health) is enlarged. A doctor will insert a gloved and lubricated finger into your rectum and feel your prostate. It may cause you some discomfort, and it may cause a spastic reaction.

- If you think this might happen to you, or it has happened to you in the past, let your doctor know. You may be able to arrange to have your prostate examined in another way.



## **Testing for Sexually Transmitted Diseases (STDs)**

If you are sexually active, and would like to be tested for STDs such as herpes, chlamydia and AIDS, explain to your doctor what tests you feel would be appropriate. If your doctor questions you, be firm. Acknowledge that you've been sexually active and would like certain tests performed, for your information and peace of mind.

You have a right to feel comfortable and reassured about your sexual health, as does anyone else.

## **Screening for Other Diseases**

If you find it difficult or impossible to perform self-tests such as testicular exams and breast exams (which can help detect cancer) ask a health professional to do these things for you, along with any other routine exams of your body.

But if you feel as if you are being touched or caressed in a sexual way during the exam, you have a right to discontinue the exam, call for help, and leave.

## **Holistic Health**

Holistic health takes into account the wellbeing of our bodies, minds and emotions. People with CP are more than just collections of mismatched body parts that need 'fixing'.

Any health issue you are experiencing may be related to stress or other difficult life experiences. But there is nothing wrong with wanting to rule out any physical causes of your difficulties. Once it's established that you are physically healthy, your stress level may automatically begin to decrease, and you may begin to feel better.

### ***A Final Note***

*The information provided in this booklet provides guidelines and ideas for care and living; by no means does it cover every possible situation you may encounter in the course of daily life.*

*References used in compiling and writing this booklet have been noted at the back.*

## References

1. 2000. **BC Health Guide: Helping you and your family stay healthy.** Province of British Columbia, Ministry of Health; Healthwise Handbook. Healthwise Publications

Basic overview of hundreds of medical conditions and their (sometimes) simple treatments; things to keep in mind when seeking medical treatment.

2. Baladin, Susan, and John Morgan. (1997). **Adults with Cerebral Palsy: What's Happening?** in Journal of Intellectual & Developmental Disabilities. Vol 22. # 2 pp. 109-124

Academic study on CP and aging. Useful for the outline of the varying medical or health issues identified by people with CP as concerns.

3. Lonsdale, Susan. (1990). **Women and Disability: The Experience of Physical Disability Among Women.**

Discusses a variety of topics, raising specific concerns of women with physical disabilities with regard to medical care, sexuality, body image, etc. Academically-focussed, but still accessible to the general reader.

4. McKay, Matthew and Fanning, P. 1992. **Self-Esteem: A Proven Program of Cognitive Techniques for Assessing, Improving, and Maintaining Your Self-Esteem.** (Second Edition.) New Harbinger Publications, Inc. Oakland CA

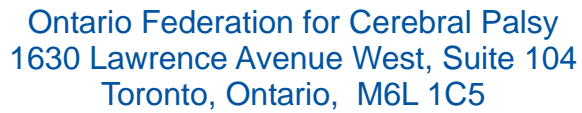
Good overview of self-esteem, identifies many barriers to good self-esteem, and feelings of self-worth. Provides step-by-step exercises to overcoming such things as the inner critic, making accurate assessments of the self, dealing with mistakes, and having compassion for the self.

5. Michaud, Ellen, and Elisabeth Torg. (1995) **Total Health for Women.** Rodale Press Inc. Pennsylvania

## Websites

6. **EnableLink <[enablelink.org](http://enablelink.org)>** excellent source of information brought to you by the Canadian Abilities Foundation, publishers of Abilities magazine. Articles and discussion forums on medical and disability issues, and much more.





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