

Therapy and other supports for people with cerebral palsy

A guide
for adults



What works and how much is needed

Contents

What is cerebral palsy?	1	My physical health and wellbeing	21
Who is Cerebral Palsy Alliance?	1	Accessing adult health services	22
What's in this guide?	1	Finding a general practitioner	23
Using research and other forms of evidence	2	Prevention and early detection	24
Growing up and growing older with cerebral palsy	3	Sexual and reproductive health	28
What's important to adults with cerebral palsy	4	Preparing for a hospital stay	31
Delivery of therapy, services and supports	5	Living well with cerebral palsy	32
Approaches that work well for adults with cerebral palsy	6	My lifelong learning and contribution	51
Highlights	8	Learning, work and volunteering	52
My personal wellbeing	10	Leisure and recreation	55
Friends, connection and belonging	11	My way of living	56
Family	13	Self-care and independence	57
Sexuality and intimate relationships	15	Housing and living options	59
Behaviour, emotions and coping	17	Financial and legal matters	62
Mental health	19	Planning for the future	63
Faith and spirituality	20	Appendix	
		Classification systems	67

What is cerebral palsy?

Cerebral palsy (CP) is an umbrella term for a broad group of physical disorders that affect movement and posture. CP is caused by an injury to the developing brain. Cerebral palsy is a lifelong disability – a person always has CP – but it can change over time. Some people with CP will solely have a motor disorder. Others will also have conditions like epilepsy, intellectual disability and/or sensory impairments.

Who is Cerebral Palsy Alliance?

Cerebral Palsy Alliance is an organisation that provides high quality services for people living with CP and similar disabilities. They have many years of experience and are leaders in what they do. Cerebral Palsy Alliance has a research foundation which supports the best researchers from around the world to learn more about CP. They are always trying to improve supports for people with CP. Their goal is to find ways to prevent and cure cerebral palsy.

What's in this guide?

In this guide you will find information organized in the following topics:

- **My personal wellbeing:** connections and relationships with self and others
- **My physical health and wellbeing:** living well with CP, staying healthy and active
- **My lifelong learning and contribution:** lifelong learning and being part of the community
- **My way of living:** living life your way, now and in the future.



You can use the information in this guide to talk with health professionals, service providers and your family.



- You can use the information to help you:
- Set goals
 - Plan what is important to you
 - Ask for the right services and supports.

This guide provides general information only. It is not meant to replace information given to you by your doctors or other people who help you. To make sure you get information that is right for you, talk to your doctor or other professionals. Information is different around the world and each person has different needs. It's important that you have information that is specific to you.

Using research and other forms of evidence

This guide aims to include evidence-based information about living with cerebral palsy as an adult.

‘Evidence-based’ means bringing together:

- Best research available
- Knowledge and experience of health practitioners
- Your own knowledge, values, preferences and circumstances.

In some areas there is very little or no research evidence about interventions and supports for adults. Sometimes, even when there is research available, there may be limitations in how the research can be used. It can be difficult to make confident decisions based on this evidence.

When there is no published research the best information can come from other sources. It needs to be used together with the knowledge of your practitioners and your own lived experience.

This guide will give you general information. But your decisions need to be specific to you. Always work with your team of health professionals to make the right choices for your needs and circumstances.



Growing up and growing older with cerebral palsy

For much of our life we are an adult. Adulthood starts from the age of 18 years old and continues all the way through to later life. There are different stages within adulthood.

Young adulthood (or sometimes called ‘emerging adulthood’) refers to people aged 18 to 30 years old

This is often a time for exploring who you are and what you want to do in your life. You may be more independent and taking on more responsibility for life tasks. It can sometimes feel like an unstable time. You are trying different things and working out what is right for you. It is also an exciting time full of possibility and opportunity.

Middle adulthood refers to people aged 31 to 65 years old

During this stage many people will find a job, volunteer or pursue other vocational paths. Some people will raise their own family or will care for older family members. This is an important time to set healthy lifestyle habits, be aware of health needs, and start the planning process for later life.

Later adulthood refers to people who are older than 65 years

During this time people who have been working may choose to retire. Hobbies, activities, and social groups can change. Physical, cognitive, social, and emotional changes may become more noticeable. These changes may need to be managed to stay as healthy, independent, safe and connected as possible.

What's important to adults with cerebral palsy

Everyone's life is different, but we do have things in common with each other.

For example, we all need:

- Friends, family and social support
- Fair and timely access to health care
- Opportunity to participate in education, work and giving back to the community
- A safe and suitable place to live.

These are things that are important to everyone.



Recently, researchers asked people with CP to talk about the things that are important to them as they get older.

They talked to people in the young, middle and later stages of adulthood. Many of the things people with CP talked about were the same as what people without CP talk about. But there were also some ideas that were only raised by people with CP.

Whole person, whole life

One of the most important things that adults said was they wanted others to see them as a whole person with all the different parts of their life linked together. They said it was important for people to see beyond the challenges or difficulties that can come with living with CP, to what is unique about an individual and makes them who they are.

Early experiences and expectations set up success

Adults with CP see their early life experiences as critical to who they are as an adult. High expectations that encourage independence during childhood help to build determination and persistence. Being involved in school life, making friends, and learning strategies to cope with relationships (including bullying) is important. Learning how to engage with the health system from an early age can lead to more positive health interactions as an adult.

Doing the same as others do

Adults with CP feel it is important to have the opportunity to do the same things as anyone else. This means opportunity to pursue education goals, work, be part of sporting and cultural events, and contribute to the community. Adults say it is important to be given the opportunity to find their own way to do things, with the right support.

It's a give and take process

For adults with CP, independence does not always mean doing everything for themselves or by themselves. In fact, a lot of people talked about 'interdependence'. A mixture of support from family, friends and colleagues as well as professionals, helps adults with CP to participate and be involved. Having the right and the opportunity to make real choices and decisions is what is important.

Ageing effects are felt earlier

People with CP can experience changes associated with ageing earlier than people without CP. For some people this can be as early as their twenties. Changes can be related to having CP, but they can also be part of a typical ageing process. One of the most challenging things for adults with CP is not knowing what the effects of ageing may be or when they may be felt. Adults with CP want information about what to expect, and how to optimize their health and wellbeing.

Delivery of therapy, services and supports

If you choose to receive allied health services or other supports as an adult, mostly these will be face to face. For some of your goals you may need 1:1 support. Other times a group program may be right for you.

Supports may be offered at home, in a centre or in community settings, such as where you learn, work, or go for leisure and recreation. Some support may be in the form of information that helps you make good decisions.

Growth and improvement of online platforms means that many of the interventions and supports discussed in this guide can now also be delivered in your home via telepractice.



Talk to your health practitioners about the best way to access specific interventions, services and supports.

Approaches that work well for adults with cerebral palsy

Before we introduce each section of the guide, we want to talk about what the research tells us works well for people with CP. It's called task specific training.

This means that you actively work towards real skills, in real life tasks, in real life settings, with lots of practice and feedback.

There are two key approaches:

- Goal directed therapy or training (GDT)
- Cognitive Orientation to Occupational Performance (CO-OP).



These approaches change the way you think about and do things. This in turn changes your brain in positive ways. This process is called neuroplasticity. It is an important process to help people with CP learn and develop new skills, maintain skills and apply them in new ways.

Let's learn more about each approach.

Goal-directed therapy (GDT) involves you setting goals that are needed for everyday life, then practising specific activities to reach those goals. It works best when:

- ✓ You choose the goals, activities, skills or outcomes that are important to you. These could be about physical skills, looking after yourself, communication, relationships, leisure, education or employment.
- ✓ The goal is at just the right challenge level – not too easy, and not too hard. When you start, the goal can be broken down into smaller tasks. As you get more skilled, the task can be made more difficult.
- ✓ You have chosen something that you want to work on. This therapy approach can be done in one-on-one sessions or as a group. What is important is that you want to work on your goal.

Cognitive Orientation to Occupational Performance (CO-OP) is another great approach. The aim of this approach is to help you plan and talk about the steps that are needed to learn new skills and improve the way you can do things. It is a 'thinking program' that helps you solve problems in your day-to-day life. There are four key parts:

- **Goal:** identify a goal that is important to you
- **Plan:** develop a plan for how you will achieve the goal
- **Do:** do the plan
- **Check:** check to see whether your plan worked.

For any therapy and services to work well, it is important that they are built around your goals and priorities. As an adult you will have your own likes and dislikes, needs and preferences. Talk to your team to find out how Goal Directed Training or Cognitive Orientation to Occupational Performance (CO-OP) approaches can work for you.

Highlights

What's important to people with cerebral palsy

- Adults with CP share many experiences in common with people who do not have CP, but they also experience unique challenges.
- It is important for adults with CP to be seen as a whole person and for decisions to consider their whole life.
- Resilience is a key attribute valued by adults with CP throughout adulthood. Encouraging high expectations, involvement in a diverse range of life experiences, and independence supports resilience.
- Ageing effects can be felt earlier for people with CP. Staying healthy, fit, connected, well supported and in control of decisions is part of ageing well with CP.

Best practice therapy approaches

- Therapy should be focused on specific goals. Tasks are best practised in the environment in which they will be used.
- Goal Directed Training (GDT) and Cognitive Orientation to Occupational Performance (CO-OP) are approaches that support you to reach your goals.
- Therapy is usually provided in person, but can be delivered online. Individual, group and community-based services and programs may meet your needs.

My personal wellbeing

- Friendships, sense of belonging, and feeling connected are important for health and wellbeing.
- PEERS® is a social skills program for young adults that can support friendships and positive relationships.
- Staying connected with family is important. Relationships can change over time. Parents, siblings and extended family can offer different types of support.
- Faith-based communities can be great places to build social networks and to get involved in your local community.
- Adulthood is a time to explore sexuality, sexual identity, gender identity, dating, relationships and intimacy. Information, products, services and supports can be tailored to your needs.
- Managing behaviour and mental health is a big part of wellbeing. There are evidence-based interventions and supports known to be effective.

My physical health and wellbeing

- A good transition from paediatric to adult health care services can lead to continued services, with more control.
- It is important to have a general practitioner (GP) you know and trust. A good GP can help guide you around the health system and support links between health and disability specific supports.
- Seeing your doctor regularly for check-ups allows you to raise issues important to you. You will be better able to notice and address potential problems early.
- Physical activity and fitness are long-term health investments. A focus on managing and maintaining your movement and function will help you continue to do things in the best way for you.
- Managing pain is a good thing on its own, and it can also lead to better sleep and better mood.
- Maintaining hand function and fine motor skills can optimise participation and independence.
- Using a range of communication methods will help support your participation, autonomy and control, quality of life and much more.
- Keeping on top of changes in your nutrition, swallowing and the way you eat and drink will help prevent serious complications and future health issues.
- A healthy sleep routine can assist in general health, daily energy levels, mood, sociability, memory, attention and concentration.
- If you have epilepsy, keeping it under control makes for a better life.

My lifelong learning and contribution

- Employment, continued learning and volunteering all increase your community participation. Benefits include gaining new skills, making new friends, contributing, and building your sense of purpose.
- Leisure activities can improve your physical and mental wellbeing, as well as your social participation. They can improve your sense of control, and your feelings of self-esteem and self-fulfilment. They can improve your quality of life. And they can be fun.

My way of living

- Good financial planning can lead to greater stability in your finances and greater independence.
- Researching and planning ahead to secure the home and living situation you want is important. There are many services and supports available in this space but it is good to start early.
- Planning ahead for the future can bring peace of mind for you and for those who care for you. It can also minimise disruptions when life's bumps and hurdles come.

MY PERSONAL WELLBEING

Fostering great connections with self and others



Friends, connection and belonging

Humans are social beings. We feel more connected when we care for others, people care about us, and we are part of community. Feeling connected is an important part of health and wellbeing. It can also help us feel stronger when life is hard or stressful.

For some people with CP, making social connections can be hard. This can be due to:

- Access
- Mobility
- Employment
- Communication
- Social interaction
- Independence.

WHAT WILL HELP?

Talking to people you trust may help. They may have ideas about how you could expand your social network, meet new people (for friendships or a relationships) and stay connected with friends and family.

Specific strategies may include:

- Being employed or involved in volunteer work
- Being involved in personal development activities or hobbies with a group of people with similar interests
- Having reliable access to transport so you can attend group activities, discussions or events
- Having support to attend social activities
- Regularly having informal contact with family and/or friends
- Using social media to make connections with others who have similar interests to you
- Accessing social skills training programs to help you develop skills to make and maintain friendships. One such program is the Program for the Education and Enrichment of Relational Skills (PEERS®).



Program for the Education and Enrichment of Relational Skills

The PEERS® program is an evidence-based social skills program for young people aged 18-35 who are interested in making and keeping friends and/or developing positive relationships. It has been designed for people who have autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), anxiety, depression and other socio-emotional problems.

You attend the program for 16 weeks and join in a 90-minute group session each week. Each person brings along a social coach (e.g. a parent, friend, support worker). They also learn strategies to support you and others to make and keep friends.

You will learn how to:

- Make and keep friends
- Talk to others
- Start a conversation
- End a conversation
- Use humour appropriately
- Communicate using the computer or social media
- Go on a date
- Organise a get together
- Deal with bullying
- Deal with disagreements
- Deal with pressure about dating.

If you think this program may be good for you, speak to someone in your support team.

Having friends and a network of people who are there along the journey of life can help you feel more connected.



Family

Parents and siblings

For a person with CP, parents are often a major source of support. As you and your parents grow older, your relationship may change. The type of support you need and what your parents can offer may also change. Other people may become part of your support network.

Siblings, if you have them, can often become more involved in different areas of your life. Siblings can offer emotional support and also assist with decision-making as your parents age. You and your siblings can be mentors and role models for each another. Sibling relationships can often strengthen with time and become even more important in older adulthood.

WHAT WILL HELP?

Everyone needs time for themselves and time with family. If your parents are your primary carers you may like to encourage them to have regular time for their own interests, socialising and connecting with their social network. This may mean that you need to ask for funding in your support plan. This will ensure your parents have time for a break and that you can access other support options during these times.

Having different ways to communicate with your family and friends opens up possibilities to stay connected. Adults with CP say that staying in touch with loved ones, even when there is distance involved, is so important. Technology or social media can help overcome barriers related to distance and service providers can assist in this area too.

Creating your own family

Research shows that having a long-term partner can have significant social, emotional, health and well-being benefits. It is a key life goal for many adults, including people with CP. Some people also wish to create their own family. This may be a goal for some people with CP too. All families are different and there are many ways to have a family.

WHAT WILL HELP?

If having a family is something that you would like to do one day, start a conversation with someone you trust.

Generally, there are no medical reasons preventing people with CP from having children of their own. But it is always good to have conversations with your doctor about your individual needs. It is important to think about the supports you have around you and what help you may need to raise a family.

It can also help to talk to others with CP or other similar conditions who have children, or who are also thinking of starting a family. You can share your experiences and learn from each other.

If having your own child is not something you would like to do, a pet can be an important part of a family. If you need support caring for a pet, you can discuss this with your support network. Accessing a pet therapy program is another option.



Sexuality and intimate relationships

Exploring and understanding your sexuality, your sexual identity and perhaps your gender identity, are all significant parts of adulthood. This is a time when you may be dating, becoming intimate, and building a long-term relationship with a partner.

It is important that you have the opportunity to discuss these experiences with people you trust. Information, products and services are also available to support you.

WHAT WILL HELP?

- Developing friendships and a strong social network and can increase your chances of meeting a partner or developing intimate relationships.
- Internet dating websites might also help you meet potential partners. As with all social media, use caution when sharing personal information. Make sure you are aware of cyber safety steps you can take. You can speak to someone in your support network if you need help setting up a personal profile.
- Having open discussions with people in your support network about your sexual needs and goals is critical. Including your sexual goals and associated support needs in your disability support plans will ensure this is recognised as something important to you.
- Talk about sexuality and gender identity with appropriate support workers or health professionals that you trust. You can talk about how you might want to explore sexual experiences, how to provide consent and say 'no', and how to protect yourself. They can also help you find ways to explore your sexuality in a safe and trusting environment if you need support.
- Some people may choose to engage a sex worker. Some sex workers have specific experience working with people with disability. One such service based in NSW Australia, is Touching Base: www.touchingbase.org.





Behaviour, emotions and coping

Sometimes people with CP can have behaviour that is difficult to manage. This is known as challenging behaviour or behaviour of concern. You may have experienced this at times in your life; maybe your own behaviour or someone else's.

Behaviour may happen because of pain, frustration, communication issues, unexpected changes, loss or grief, or when big life events occur. Behaviours can change over time. They look different for different people.

Research suggests that if you (or the people around you) understand what causes certain behaviours, they can be managed better.

- Sometimes, physical difficulties that you experience can become more pronounced when you are with a potential sexual partner. For example, issues with muscle tone, speech intelligibility, breathing issues, or comfortable positioning. You can talk to your doctor, a nurse, or another health professional about individualised ways to manage. Inclusive sex toys can be helpful if using your hands is a limitation during masturbation or intimacy with a partner.
 - It is important to be aware that some medications can cause sexual dysfunction. If you experience difficulties with sexual function and take medication, talk to your doctor or pharmacist about what might help.
 - There can be many unknowns when starting a relationship with another person. You may feel unsure of yourself or what to do in these situations. You may like to explore these feelings and experiences with a psychologist or counsellor. This can help you develop and maintain intimate relationships.
 - You may find it interesting to follow the journey and experiences of public figures who have established themselves in the disability and sexology arena. The details of a few people are listed below.
 - **Bianca Laureano**
Sexologist and founder of the Women of colour Sexual Health Network
biancalaureano.com/biancas-bio
 - **Cory Silverberg**
Editor of 'The Ultimate Guide to Sex and Disability'
www.corysilverberg.com/about
www.corysilverberg.com/sex-and-disability
 - **Robin Wilson-Beattie**
Disability and sexuality educator, speaker and writer
www.robinwb.com
- Exploring your own sexuality can bring many rewards. You can experience satisfaction, relief, joy and companionship. You are in charge of when, how and with whom you explore this part of your life.**

WHAT WILL HELP?

Understanding behaviour and emotions

Helpful information can be collected by observing patterns of behaviour and keeping a diary. Observations should include the 'A-B-C's of behaviour:

A

Stands for **antecedent**. This is something that happens just before a behaviour takes place. It may trigger the behaviour.

B

Stands for **behaviour**. This is what the person does, how long it lasts, and how intense it was.

C

Stands for **consequence**. This is what happens just after the behaviour. This includes what was done to manage the behaviour and how the situation was resolved.

A trained mental health professional, such as a psychologist or psychiatrist, can provide you and the people who assist you, with helpful resources to understand behaviour, emotional and mental health concerns.

Managing behaviour

Behaviour support plans

Behaviour support plans are written documents that help people understand the behaviour of a particular individual and what to do. All behaviour plans should include detail about what an individual needs.

Behaviour support plans are a legal requirement in Australia. They must say if any restrictive practices need to be used with a person for their safety or the safety of others. A restrictive practice means anything that stops a person from moving around freely.

Plans should be reviewed and updated frequently. Usually, lots of people work on the plan together. These include the individual where possible, parents and family, carers and support workers and behaviour support professionals.

Behaviour therapy

For adults with CP who have behaviour, emotional or mental health concerns (like anxiety or depression), positive behaviour support and behavioural interventions can help.

- **Positive behaviour supports** aim to make challenging behaviour unnecessary by teaching better ways to reach a goal. It also focuses on taking away triggers of behaviour and giving the right feedback.
- **Cognitive Behavioural Therapy (CBT)** is a form of 'talking' therapy that helps people establish healthier ways of thinking, and positive skills and habits to deal with mental health challenges. A person will need a way of communicating, either verbally or using augmentative and alternative communication (AAC) methods, to do this therapy.
- **Solution focussed brief therapy** is a type of therapy that involves identifying strengths and resources to manage a situation. Solution focused brief therapy can help you and your family to address mental and emotional health and wellbeing, behaviours of concern, or relationship difficulties.



Mental health

Our mental health is important. It affects how we think, feel, and act. Almost half of all adults will experience a mental illness at some time in their life. Anxiety and depression are the most common.

Anxiety

Common symptoms of anxiety include panic attacks, racing heart, feeling wound up, fearing the worst and avoiding situations that make you feel anxious. We all experience anxiety from time to time, but if you experience frequent or persistent anxiety, ask for help.

Depression

If you are feeling down, sad or angry most of the time, you might be experiencing symptoms of depression. Other signs or symptoms include not going out, withdrawing from friends and family, feeling overwhelmed, feeling tired and run down, having trouble sleeping and changes to your appetite.

Research suggests that adults with CP can be more at risk of experiencing anxiety or depression than adults without CP. With the right support, many people with mental health problems recover completely.

WHAT WILL HELP?

Who can you see?

If you think you might be experiencing anxiety and/or depression, please see your health practitioner. They can discuss different combinations of strategies to support you. These could include:

- Lifestyle changes (e.g. eating well and exercising)
- Psychological therapy
- Medical treatments.

Other programs that focus on social support, self-acceptance, sense of coherence and mindfulness can also be of help.



MY PERSONAL WELLBEING

Support services

Sometimes, while people are waiting for a scheduled appointment with a professional, they need to talk to someone sooner.

Some employers have employee assistance programs to provide confidential support to their staff and families. If you are employed, you can ask your organisation if they provide this service and how to access it.

There are some online clinics that can help too. For example, at MindSpot (www.mindspot.org.au) you can take an online assessment and then be linked with some treatments and resources that can help you.

There are also many help lines and websites for people with anxiety, depression and other mental health concerns. You can ring them if you need to talk to someone. They are safe and confidential.

Some of these include:

- **Beyond Blue**
www.beyondblue.org.au
1300 22 4636
- **Lifeline**
www.lifeline.org.au
13 11 14
- **MindSpot Clinic**
mindspot.org.au
1800 61 44 34
- **Black Dog Institute**
www.blackdoginstitute.org.au



Faith and spirituality

Exploring faith and spirituality is an important part of life for some people. It may contribute to feelings of purpose and quality of life. Faith based communities are often great places to build social networks and get involved in your local community.

WHAT WILL HELP?

If exploring your faith and spirituality is a personal goal for you, you should include it in your lifestyle plans and any funding plans you have.

If you need assistance to participate in a faith or spirituality experience, support workers can assist you. For example, they may be able to support the activity, travel, personal care, or physical access.

MY PHYSICAL HEALTH AND WELLBEING

Living well with CP, staying healthy and being active





Accessing adult health services

As a young adult, you will move from receiving paediatric health care services to adult health care services. Although your GP and your community-based therapists may not change, your specialist care and any hospital-based therapists will change.

This can be unsettling. It may take some time to get used to. But it can also be an empowering time when you gain independence and take control of your health care needs and services.

As you get older, your service needs may continue to change. Geriatricians are medical doctors who specialise in healthcare for older people. A range of allied health professionals can also support you as you get older and your physical health and wellbeing needs change.

WHAT WILL HELP?

Young adults

If you are a young person going through this change, your current health professionals should be able to tell you what specialised adult services are available. You can ask your team to recommend specific people to you. They may be able to write you a referral letter and transfer your records to the person you want to see.

You may also be linked with a “transition service”. These services try to empower people living with a lifelong condition to make a smooth shift from children’s services to adult services. They can help you find services that meet your needs.

A good transition can lead to continued services, with more control.

Older adults

As you get older you may be experience changes in your body and what you can do. This is common for people with cerebral palsy. You may find that to get the right support you need to link with more health care professionals and services over time.

Adults with cerebral palsy who have been interviewed about their health experiences say that it is important for health professionals to listen and learn about cerebral palsy and value the knowledge and experience of people with CP as they get older.

Looking after your health can be positive if you can find health professionals that will work together with you, think about the future, and share decision making.



Finding a general practitioner

It is important to have a general practitioner (GP) you know and trust. A GP who understands your life, your disability and your needs can provide advice and support that is tailored to you.

WHAT WILL HELP?

The health system and the disability system are complex. A good GP can help guide you around both systems. They can help you link supports as you need them and get the help you need when you need it. They can also reduce the number of times you need to tell your story.

Many people find it helpful to prepare for appointments with their GP, specialists or other health professionals. You might want to write down your questions. You may also want to have information ready to share with your GP.

You can book two appointments one after another. This may be helpful if you need extra time to communicate, understand information, or you are having an examination. Having a family member or friend with you can also help.



Prevention and early detection

There are many benefits of a healthy lifestyle. Physical benefits include reducing your risk of many diseases, improving and maintaining physical function, and improving your sense of wellness.

Making your general health the best it can be through preventive health care, is important.

Diet and nutrition

A well-balanced diet is vital for the body and all its systems to function properly.

Some people with CP may find it hard to get their nutrition right for their energy needs. Problems with chewing, swallowing, reflux and absorption of nutrients and minerals can mean a person doesn't take in what they need.

The consequences of this may include low energy levels, constipation, digestion problems and poor appetite.

WHAT WILL HELP?

If you find it difficult to eat and drink well, help is available.

It is important to consume the right number of calories and nutrients for your body and lifestyle in order to function well and stay healthy.

It is also important to have your food prepared in a safe way that suits your swallowing abilities. This may mean changing the texture of your food and drinks so it is easier to chew and swallow.

Talk to your GP about your diet and your energy needs. They might refer you to a dietitian to help manage the nutritional side of your diet, and/or a speech pathologist to help you eat and drink in a safe and enjoyable way.

Heart disease

Prevention of heart disease has greatly improved in Australia over the years. But, it is still the most common cause of death in Australia. People with CP can also have heart disease.

There is no single cause of heart disease. There are risk factors that increase the chance of a heart attack or stroke. Some risk factors you can change and others you can't.

The following are risk factors that you can change:

- Poor diet
- Smoking
- High cholesterol
- High blood pressure
- Diabetes that is not well managed
- Being physical inactive
- Being overweight or obese
- Depression that is not well managed.

WHAT WILL HELP?

Regular check-ups by your GP are a good idea. Discuss with your GP any health issues you have, what check-ups you need, and at what age.

You can talk to your GP about whether you have any of the risk factors for heart disease and what you can be doing to stay healthy.

Bowel health and screening

Some people with CP experience difficulties with constipation (blocked up bowel) or faecal incontinence (lack of control of bowels). This can cause pain or discomfort and affect quality of life.

WHAT WILL HELP?

You can talk to your GP or dietitian if you have difficulties. They might suggest:

- A bowel screening to check what is going on
- A bowel management program
- Pelvic floor therapy
- Biofeedback
- Surgery, or
- Medications.

Cervical screening

Cervical screening is also known as the HPV test. It is a strategy for preventing cervical cancer. It is offered to women from 25 years of age (or 2 years after becoming sexually active). The screening is repeated every 2–5 years.

It is important to get screened regularly so that diagnosis of any issues is not delayed or missed. Identifying a problem early offers the best chance of successful management.

WHAT WILL HELP?

Talk to your GP or health professional about how cervical screening will work best for you.

If you have physical, communication or other difficulties which may make cervical screening hard for you, contact your GP or clinic before you attend to see how they can help you.

Breast checks

Breast awareness and breast screening help to identify any changes in shape, size or feel of breast tissue.

Noticing changes and talking to your GP or health professional means you have a better chance of detecting things like breast cancer early.

WHAT WILL HELP?

It is good practice to self-check your breasts regularly. Your GP can show you the best way to do this. If this is difficult, you can arrange an appointment with your GP for them to conduct a breast examination.

Let your GP know as soon as you can if you notice any new or unusual changes or you are worried about your breasts.

More information about breast health can be found at Breast Cancer Network Australia:
www.bcna.org.au/breast-health-awareness.

Testicular and prostate screening

Although it is rare, testicular cancer is one of the most common cancers in men aged between 15 and 45.

At the moment there is no single test for prostate cancer and no regular screening program for young men. The best way to work out the risks and benefits of prostate screening is to talk to your GP.

Be aware of what is normal for you and if you see or feel any changes (like lumps), see your doctor.

WHAT WILL HELP?

- Don't be embarrassed to mention any changes to your doctor; they are there to help you. It is best to get in early if you are concerned.
- Talk to your doctor about having your testicles or prostate checked.
- More information about checks for men can be found on the Cancer Council website:
www.cancer.org.au/cancer-information/causes-and-prevention/early-detection-and-screening/get-checked-men.

Immunisations

Maintaining your immunisations will help keep you healthy. They may include vaccinations for Influenza ('flu shot') or COVID-19, and any other routine or booster vaccinations recommended for you.

WHAT WILL HELP?

- Your GP can work with you to check that you are up to date with your immunisations, especially the annual 'flu vaccine.
- They can also tell you if there are other vaccinations or booster shots that you should have.

Skin health

Sun protection is an important preventive measure to avoid skin damage and skin cancer.

WHAT WILL HELP?

There are simple but very effective ways to protect your skin and prevent sun damage:

- Wear a hat
- Wear sunglasses
- Regularly apply sunscreen
- Stay in the shade
- Cover up with clothing
- Limit time in the sun during the hottest parts of the day.

Talk to your GP about skin checks, how often you need to do them, and what you should be looking for.

You may need to get someone to check your skin for you – they need to know what is normal for you.

Get to know your own skin so you can be aware if something changes.

More information about skin checks can be found on the Cancer Council website:
www.cancer.org.au/cancer-information/causes-and-prevention/sun-safety/check-for-signs-of-skin-cancer.





Sexual and reproductive health

If you are sexually active or are thinking about becoming sexually active, it is important to consider the following areas and to speak to your health care practitioner.

The Family Planning NSW page also has some great resources to help you learn about and enjoy safe sex: www.fpnsw.org.au/factsheets/individuals/disability/all-about-sex.

Menstruation

Menstruation means having your period. It is a normal part of development for people born female. Some people can have heavy bleeding and pain around the time of their period. A person who menstruates can become pregnant.

WHAT TO CONSIDER

There are many ways to manage comfort during menstruation. In addition to finding the right hygiene products for you, some people use natural remedies or medication to manage pain or discomfort. Others use strategies to stop their periods completely. You have the right to choose what is best for you.

People with CP who use a wheelchair and need help with personal care may also require support with managing their menstrual needs. If this applies to you make sure this personal care is part of your funding plans and individual care arrangements.

You can speak to your health care practitioner and support network about the best options for you.

Pregnancy

Generally, people with CP can have children. If you are female and you are getting your period, you can get pregnant if you have sexual intercourse.

If you are thinking about having children and you are on any prescription medications, it is important to check with your health care practitioner about these. Some medications should not be taken when pregnant.

If you are having sexual intercourse and you don't want to fall pregnant then it is important to use one or more forms of contraception.

WHAT WILL HELP?

Each person's CP can affect them differently during pregnancy and when giving birth. Some people may find their muscle spasms increase, while others find their motor symptoms improve.

Research shows that women with CP are more likely to give birth via a caesarean section than the general population.

Speak to your obstetric care practitioner to understand how your CP might impact you. This will help you plan for your pregnancy, birth, and beyond.

Contraception

Contraception is usually used to reduce the likelihood of a pregnancy as a result of sexual intercourse between a man and a woman.

There are many different types of contraception. Some types provide longer term protection. Others need to be used every day or every time you have sexual intercourse. There are contraceptive options for both men and women.

WHAT TO CONSIDER

Some types of contraception may not be appropriate to use if you are taking other medications (including anti-epileptic drugs) or if you have other chronic health conditions.

Some forms of contraception may be easier to use depending on how your CP affects your movement.

It is important to speak to your health care practitioner about the right type of contraception for you and your body.

Menopause

Menopause is when a person stops menstruating (their period stops). This usually occurs between 45 and 55 years of age. When this happens, a woman can no longer have children.

Symptoms can include hot flushes, changes in energy levels, mood swings and physical changes.

WHAT TO CONSIDER

- It is important to continue to do things that make you feel good as you go through menopause.
- You may find practical solutions to your symptoms that help you feel more comfortable. For example, you could wear layers of clothes or scarves that can be easily put on or removed depending on your body temperature.
- If you find it hard to manage the changes in your body, please speak to your health care professional. They may check your certain hormone levels and tell you if there are any treatments that may help.

Sexually transmitted infections

Sexually transmitted infections (STIs) can be passed between people when they have sex. They can also be passed on if sex toys are shared.

The best way to avoid getting a sexually transmitted infection is to use a condom and water-based lubricant when you have sex.

WHAT TO CONSIDER

If you are sexually active or thinking about becoming sexually active, you should speak to your health care practitioner about the risk of sexually transmitted infections and what you can do.

Many sexually transmitted infections can be tested for and treated.

If you need to have a test, please speak with your health care practitioner about your CP and how it affects your movement. They can work with you to complete the test in a comfortable and safe way.



Preparing for a hospital stay

If you need to go to hospital some extra planning will ensure your stay is as smooth as possible.

WHAT WILL HELP?

- Discuss your needs and your planned stay with your doctor and your health care team. This may include a social worker. You may ask whether you can:
- Have a carer or family member stay with you
 - Take in your regular equipment such as a walking frame, modified cup/spoon or wheelchair
 - Access hospital equipment such as a hoist for transfers
 - Use your regular communication method, including communication devices
 - Have your meals made in the way you need to be safe
 - Ensure that your regular medications are available
 - Ensure a pain management plan is set in place.



You can create a one-page summary of key things about yourself. You can display this near your bed to help the nurses and doctors care for you. The summary could include:

- How you move around
- What position you need to be in to eat and drink and whether you need help
- How you communicate
- Critical medical information
- Who to call if you need support when you are in hospital.

It is also good to plan with your team for what happens when you leave hospital. This may change while you are in hospital, depending on your recovery.





Living well with cerebral palsy

Moving around

Your experience of movement and function has probably changed over your life. It may continue to change during adulthood.

Some people with CP find their physical fitness, mobility and balance starts to slow down earlier than for other people. This may even be in early or middle adulthood.

It is an important time to work on managing and maintaining your physical fitness, mobility and balance so you can continue doing things that are important to you.

Mobility and transfers

It is important to say if your movement or mobility changes. This might be when you are walking, moving around or transferring from one position to another.

For example, if you usually walk, you may start to notice some of these things:

- You rely more on mobility aids
- Walking takes more effort
- You feel more tired after walking somewhere
- Your walking is slower
- You feel pain during or after walking; this may be more than usual
- You may feel off balance.

You can talk to your doctor or allied health team about this.



WHAT WILL HELP?

Setting goals to maintain your abilities when transferring between positions and moving around may be important for you.

Your goals may include:

- Continuing to walk with or without mobility aids
- Choosing when and how to use your wheelchair
- Safely changing position from lying in bed to standing
- Transferring from your wheelchair to the car
- Being comfortable when being helped with a hoist transfer.

You might have other specific movement and mobility goals that you can work on with your physiotherapist or exercise physiologist. Maintaining your skills and function as much as possible, is an important focus.

We talked earlier about Goal Directed training as being helpful to achieve goals, including mobility goals. Participating in fitness and sports programs may also help.

MY PHYSICAL HEALTH AND WELLBEING

There are other interventions for people with CP to help with movement and mobility. These include:

Strength training

Strength training programs help with building the strength of specific muscles. They can also help improve mobility. Many programs are an enjoyable way to meet people and socialise too.

Strength programs often run for 8–12 weeks, and include 2–3 sessions per week.

Your physiotherapist or exercise physiologist can design an appropriate program for you.

Gait and balance programs

Gait and balance programs that are goal directed may be helpful. Gait means the way that you walk. These programs should focus on improving your skills in activities that are meaningful to you.

These programs work best when they run for 1–2 sessions per week for at least 10 – 12 weeks.

Sitting balance programs might be helpful if you do not walk.

There are existing falls prevention programs that can be adapted for your needs.

Your physiotherapist or exercise physiologist can design an appropriate gait and balance program for you.

Assistive technology for movement, mobility and transfers

Some people use equipment to help with movement, mobility and transfers. Options include walking frames, crutches, walking sticks, smart walkers, wheelchairs and hoists.

People often use different equipment for different activities, such as crutches inside and a wheelchair for longer distances. Your physiotherapist or occupational therapist can help you choose and trial different types of equipment to find what works best for you.

Your occupational therapist can provide advice about equipment to use at home. This may include something like a handrail in the bathroom or a shower chair. They can also help with changing your home to make tasks easier for you. This is called home modifications.

Ankle foot orthoses (AFOs)

AFOs are splints that improve the position of your foot for standing and walking. They can make small improvements to walking and gross motor abilities.

Talk with your physiotherapist or orthotist to find out if AFOs may be right for you and your goals.

Hydrotherapy

Hydrotherapy is an activity or exercise that is performed in warm water.

For some people with CP hydrotherapy can be helpful as part of a goal directed training program.

For other people it is an enjoyable way to experience freedom of movement not easily achieved elsewhere.

Talk to your physiotherapist or exercise physiologist about whether hydrotherapy can help with your goals.

Treadmill training

Treadmill training involves walking or running on a treadmill. It may be helpful as part of a goal-directed training program.

Treadmill training can help with the way you walk, how much energy you use up when you walk, and your balance.

If a regular treadmill can't be used, you can add a harness that partially supports your weight.

It is important to also do walking training on the ground as well as a treadmill training program. This is so that improvements can be transferred to real life situations.

Talk to your physiotherapist or exercise physiologist about whether a treadmill training program can help with your goals.



Looking after muscles and bones

Muscle tone

Increased muscle tone means muscles are tighter than usual. Many people with CP have increased muscle tone in different parts of their body.

If you experience increased muscle tone it can:

- Affect how you move
- Affect how you control your muscles
- Lead to muscle contractures
- Lead to changes in bones and joints
- Cause pain.

When you were a child or teenager you may have had medical and surgical interventions to help manage your muscles and movement. You may find some of these interventions continue to be useful in adulthood.

WHAT WILL HELP?

Management of muscle tone is done by a team of people. They may include:

- A rehabilitation physician
- An orthopaedic surgeon
- A neurologist
- A neurosurgeon
- A physiotherapist
- An occupational therapist.

They can help you choose the best way to manage your muscle tone. They will listen to your goals and needs and help you choose the most appropriate approach.

Some interventions include:

Botulinum toxin (BoNT)

Botulinum toxin (BoNT) is given by injection into a muscle or muscles. It will temporarily reduce spasticity (increased muscle tone).

The effects of BoNT wear off over 4 months. It is common for people to have a series of botulinum toxin injections, or to use them to achieve specific goals.

There is very little research about use of BoNT in adults. Some people say it helps their walking and reduces muscle tightness. For other people it can help reduce the pain of tight muscles.

Talk to your doctor and health care team to see whether botulinum toxin might help you.

Intrathecal baclofen (ITB)

Baclofen is a medication that can help muscles with spasticity or dystonia to relax.

Intrathecal baclofen (ITB) means the medication is given into the space around the spinal cord. A small thin tube called a catheter is attached to a pump. Surgery is needed to place the pump and catheter.

The good thing about this method is that smaller doses of baclofen can be given more frequently.

Intrathecal baclofen might help you if you have spasticity or dystonia that affects most of your body. It can be helpful if muscle tightness affects your personal care and comfort.

There is little evidence to support the use of ITB in adults, but talk to your doctor and health care team if you are interested in knowing more.

Oral medications

Oral medications are taken by mouth and swallowed. There are a number of different oral medications that may be used for increased muscle tone. However, research in adults is limited.

It is important to discuss the benefits and possible side effects of medications. It is also good to talk about other medications that you are taking (e.g. epilepsy medication). Some medications don't work well together.

Your doctor and health care team can recommend what is best for your needs.



Bones and joints

If you've had issues such as hip displacement, scoliosis and contractures, then continuing to manage them as an adult is important. Good management can reduce pain. It can also help prevent these issues from getting worse as you get older.

As an adult, you might be at risk of *osteopaenia* (low bone density) and *osteoporosis* (more severe low bone density, causing fragile bones) as you age. These are more of a risk if you don't walk very much or not at all. Reduced bone strength can make broken bones more likely.

People with CP are also at higher risk than others of *osteoarthritis*. This condition damages joints and causes pain and stiffness.

There are things you can do to support good bone and joint health.

WHAT WILL HELP?

It is common practice to regularly monitor the hips of children and teenagers with CP. This is done to reduce the risk of hip dislocation and other problems. This is called 'Active Surveillance'.

For many people with CP regular hip surveillance is not needed after childhood. But, orthopaedic review of the hips is recommended for some people with CP, including:

- Young adults who have hip problems (e.g., subluxated hips)
- Anyone who experiences hip pain, or other types of bone or joint pain
- Anyone with scoliosis that is getting worse over time
- Anyone with significant problems with the alignment of their pelvis
- Anyone whose function is getting worse over time.

Your doctor and health professional team can tell you how frequently you should be getting your hips and spine checked.

They will also be able to recommend other strategies to help with your bones and joints, such as nutritional changes, equipment, and any specialist tests that may be needed.



Managing pain

Pain is common in people with CP. You may experience pain in your body related to your CP or another cause. It can help to understand the cause of pain so it can be treated well.

Even if you don't know what is causing your pain there are many ways to manage it.

WHAT WILL HELP?

A team of people are often involved in managing pain. Regular checks are important to make sure that strategies are still working well for you.

Ways to relieve pain include:

- Non-drug treatments like exercise, massage, warm and cold packs, and distraction techniques
- Oral medications
- Sleeping well, with support if you need it
- Making sure your posture is good and using equipment if you need it
- Managing increased muscle tone using oral medications or botulinum toxin
- Checking your specialised equipment and assistive devices, which can cause pain if not properly fitted.

Before you have any major surgery or procedures it is important to have a pain-management plan ready to go. This will help make sure you are comfortable after your procedure and able to recover well.

MY PHYSICAL HEALTH AND WELLBEING

Sleep

Sleep is an important part of general health. It supports daily energy levels, mood, sociability, memory, attention, and concentration. Sleep problems can be common among people with CP.

Poor sleep can be caused by:

- Muscle pain, cramps and spasms
- Breathing problems
- Poor sleep routine
- Difficulty changing body position at night
- Gastro-esophageal reflux
- Anxiety and depression.

There are things you can do to improve your sleep.

WHAT WILL HELP?

A consistent sleep routine can be helpful. This means keeping the same times for going to bed and waking up each day.

Oral medications can improve your ability to fall asleep and the quality of your sleep.

Analgesics can help with pain management. If your pain is managed well, you sleep better. Other medications can help with anxiety and depression. Talk to your doctor or health professional about the right type of medication for you.

Support for your body position can help too. A pressure-relieving mattress, a mattress protector, a bed pole, a stick, and a grasp bar are all equipment options to consider.

Physical exercise, a healthy diet and safe sun exposure can all help with sleep.

You might be referred to a sleep clinic if further investigations are needed.



Staying fit and active

Physical activity is a long-term health investment. Experts recommend adults with CP stay as physically fit as possible. This can help manage changes in your body as a result of CP and also the natural ageing process.

What activities do you enjoy that suit your body? There are different types of exercise that you can do depending on your needs and goals. Start small and gradually increase the duration (how long), frequency (how often) and intensity (how hard) of your exercise over time.

If you can't find an exercise program that suits you, talk to your therapists, doctor or health care professional. Ask if there is a way to modify the exercise to help you achieve your physical activity goals.

Before starting an exercise program, talk to your doctor or someone like an exercise physiologist or physiotherapist. They can help you develop a suitable program that is both fun and safe for you.



Why is physical activity good for you?

- It can improve your heart health
- It can reduce your risk of bone disease
- It can help you maintain physical function
- It can help you maintain a healthy weight
- It can reduce your risk of diseases like diabetes and cancer
- It can improve your balance and coordination
- It can help you reduce tiredness and fatigue
- It can help improve your mental health
- It can help increase your social participation.



WHAT WILL HELP?

A program can be developed to focus on your specific fitness and activity goals. All the suggestions below can be guided by an exercise professional such as an exercise physiologist. They will be tailored to your needs and abilities.

Cardio/aerobic exercise

Swimming, running, walking, cycling, stair climbing, dancing and adaptive exercise programs are examples of cardio/aerobic activities.

These types of exercise need to be hard enough to make your heart rate go up. You can do short sharp bursts, or longer periods of exercise that are slightly less intense.

Resistance training, weight-bearing exercise and flexibility

Weight training, body weight exercises, Pilates, yoga, circuit training and adaptive exercise programs all help.

With resistance and weight-bearing exercises, focus on higher resistance, rather than more repetition. It is recommended to try an exercise for 10 repetitions. Gradually make it more difficult by adding more resistance or weight and by increasing the number of times you do each exercise.

Weight-bearing or impact activities can improve bone health and reduce the risks of falls, and the impact of falls. Stretching alone or through weight training improves the body's range of motion.

Strength training is a type of resistance training that improves strength in different muscle groups. It can help you participate in physical activity.

More research is needed to find out the ideal number of sessions per week of strengths training for adults with CP. Three sessions per week of about 40–50 minutes each is a great start.

Whole body vibration (WBV)

Whole body vibration involves standing, sitting or lying down on a machine with a vibrating platform.

Whole body vibration may help improve tightness in muscles (spasticity), muscle strength, and coordination.

There are very few studies on the use of WBV in adults with CP, but talk to your doctor and health care team if you are interested in knowing more.

Fitness training

Fitness training involves repeated exercises that require you to work your muscles and use up energy. These types of interventions can improve your fitness.

There are lots of different ways to do fitness training. The most helpful ways focus not just on exercise and activity, but also on setting good exercise habits that you can maintain.

MY PHYSICAL HEALTH AND WELLBEING

Motivational coaching

We all need help to stick to our fitness goals sometimes!

Working with a coach encourages you to understand more about yourself and your reasons for exercising (or not). A helpful plan can be worked out, that fits in with your life and choices.

Sport

Apart from the benefits of physical activity, sport can increase your social participation and improve your mental health.

You can join in with sport at a level that is right for you. You may be interested in a casual fun activity. Or maybe you want to join a local sport team. Perhaps sport is a big part of your life and you want to progress at an elite sport level.

Disability Sports Australia is the national body that represents people with a disability, including people with cerebral palsy. They provide information and support about different sports that are available and ways to be involved.

Sports can be adapted to allow people with a disability to participate to the best of their ability. Equipment, modifications and supports can be put in place, to help you achieve your sporting goals. To learn more about what Disability Sports Australia can offer, check their website: www.sports.org.au.

Assistive technology

Some adults with CP benefit from modifications or supports to help them participate in sports, activities and hobbies. Assistive technology can include things like adapted bikes, modified equipment and other devices.

You can learn to use individualised equipment as part of a goal-directed training program.

Hand function and control

As with mobility, it is important to maintain your hand function and fine motor skills to optimise participation and independence.

WHAT WILL HELP?

Hand/arm orthoses/splints

Hand/arm orthoses/splints can be used to help your hand, arm and fingers stay in a good position.

Some people with CP find that orthoses are uncomfortable to wear. You should weigh up the advantages and disadvantages to decide if these are right for you.

Splints can be used in combination with other therapy interventions. They are usually prescribed to achieve specific goals, such as reducing pain.

Assistive technology for hand function

If you have significant difficulty using your hands, there are adaptive options to help you use computers and other devices. These may include a specialised keyboard and mouse, a joystick, eye-gaze technology or a switch.

Mounting arms and systems may also be helpful – they might help position the assistive technology well for you.

If you have severe cerebral palsy, specialised seating systems are important. Good positioning helps you use your hands in the best way.

Talk to your occupational therapist about splints and technology that might be helpful for you.



Communicating with others

Getting your message across clearly, being listened to and understood, and connecting with others is very important.

Many people with CP will communicate using a range of methods. These include speech, symbol boards or books, speech generating devices, and non-verbal communication methods like signs and gestures.

Speech pathologists can help you work towards your unique communication goals. They can help with:

- Speech and voice
- Language and literacy
- Social skills
- Use of communication systems, like visual supports or devices
- Participation in the community.

Speech pathology is not just for children. As an adult, there are lots of things you can be doing to support your communication if that is a goal for you.

WHAT WILL HELP?

Expressive language therapy

You can work on the way you use words to share messages with others. You can do expressive language therapy using any method of communication – speech, signs and gestures, symbol or word boards, communication books, and communication devices.

Expressive language therapy works best when you have a specific goal or activity that you would like to work towards.

Receptive language therapy

Receptive language therapy is about helping you to understand communication. Information comes in many different forms, including information that you hear and see written down.

A speech pathologist can help with listening, understanding and using information in everyday situations.

Motor speech therapy

Motor speech therapy focuses on helping you to speak clearly and be understood by others. You can work on the way you say sounds, control your movements, the pitch and loudness of your voice, and other parts of speech.

Augmentative and Alternative Communication (AAC)

Augmentative and Alternative Communication (AAC) helps people to communicate when they cannot use speech alone. It includes body language, signs and gestures, pictures, symbols, and speech-generating devices.

As an adult you may find your speech and communication change. You may start to explore AAC for the first time as an adult, to help you communicate effectively. Or, you may find as your needs change you use AAC in different ways as you get older.

Communication partner training

Communication partner training involves people around you learning about how you like to communicate.

It's important to have communication partner training included in any of your speech pathology programs. This way, people around you will have the skills to support your communication progress and success.

Literacy interventions

Literacy interventions focus on helping you develop and improve skills for reading, writing and using information in your daily life. Literacy skills are important for independence. Decisions about your health, work, leisure activities, and finances all involve literacy skills.

It is never too late to improve your literacy skills. If this is something that would benefit you in your life, speak to a speech pathologist.



MY PHYSICAL HEALTH AND WELLBEING

Eating, drinking and swallowing

Adults with CP may experience difficulties with eating, drinking and swallowing. These difficulties are known as dysphagia and are common.

Apart from the direct issues it causes, dysphagia can also lead to respiratory infections. There is a free, online checklist that can help identify early warning signs of respiratory disease. You may wish to do this checklist to assess your risk and to help you think about your safety when eating and drinking: www.abilitycentre.com.au/resources/cpchecklist.

You can also have your swallowing function assessed by a speech pathologist. They can recommend specific strategies to help. These can include changes to how you sit during and after meals, teaching you how to protect your airway when swallowing, and working with you choose the foods and drinks that are safest for you.

You can talk to your doctor, dietitian or speech pathologist about your diet.



WHAT WILL HELP?

It is important to meet with your speech pathologist and dietitian at least once a year.

They can monitor your swallowing and diet and help you with safe and effective ways to meet your nutritional needs.

Interventions can be organised into different categories:

Non-surgical interventions

These are strategies that aren't invasive. They include:

- Sitting in a good position for eating and drinking
- Changing the texture of your food to make it easier to swallow
- Using adapted equipment like cups and spoons
- Keeping your teeth and mouth clean and healthy.

A speech pathologist can conduct a mealtime assessment and write up specific recommendations that work for you.

Surgical interventions

These interventions may be needed if swallowing difficulties are very severe. They are more invasive.

- Instead of having to chew and swallow food, it can be put directly into the stomach using a gastrostomy. For some people this can be a safer and easier way to eat.
- There is also a surgical option to help manage severe reflux. This is called a Nissen Fundoplication.

The decision to have surgery will always be talked about with you. A team of people including you, your family and health and medical professionals will likely be involved.

Nutritional interventions

Nutritional interventions help you get the right amount of nutrients meet your energy needs.

A team of people including a dietitian and GP work together to help you stay healthy. They can also check your levels of Vitamin D and Calcium – both are important for bone health as you get older.

Drooling interventions

When saliva falls out of the mouth, this is called sialorrhea or drooling. Drooling interventions help people with CP who have difficulty managing their saliva.

If you have difficulties with drooling there are simple things you can do, like carrying a cloth to wipe your mouth. Some people with CP take medication to reduce the amount of drooling. Botulinum toxin and surgery may also help.

These strategies should always be discussed with your doctor as there can be side effects.

Oral hygiene and dental health

Poor oral health can affect your general health and cause pain and discomfort.

WHAT WILL HELP?

Have a regular dental check-up. This is particularly important if you take anticonvulsant medications (for epilepsy). Some of these medications can cause problems for the teeth and gums.

A dentist or dental hygienist can help you with a plan for keeping your teeth and mouth clean and healthy.

Specialised dental clinics are available if you need support to use dental services. These clinics might be wheelchair accessible and offer alternative seating, and might offer longer appointments.

Epilepsy

Epilepsy is common among people with CP. If you have epilepsy, you will know how important it is to have it under control.

You doctor will be able to advise you about how to manage your epilepsy. You may wish to ask them about whether your epilepsy will impact activities such as driving, swimming and employment.

WHAT WILL HELP?

In adulthood, you should continue to have your epilepsy and epilepsy plan regularly checked by your GP or other health care practitioner.

Medications are the main treatment, and for most people, they are enough. If your epilepsy is not well controlled, you should see a specialist. They can talk to you about other options.

If you want to start taking an oral contraceptive, or are thinking about having a baby, talk to your doctor as some medications don't work well together.

MY LIFELONG LEARNING AND CONTRIBUTION

Lifelong learning and community involvement, your way





Learning, work and volunteering

People who learn, volunteer or work generally experience great pleasure and fulfilment. There are different types of support available to help you achieve your goals in this area.



Further learning

If you are interested in further learning or study as an adult there are a number of different education options available after school. Some options involve completing a formal qualification, whilst others don't.

Tertiary education

In Australia, tertiary education refers to formal education provided after high school. It is generally divided into two sectors: vocational education and training (e.g. TAFE, private colleges) and higher education (e.g. universities).

Vocational education and training

Vocational Education and Training (VET) qualifications help prepare people with skills for work. These qualifications usually have a very practical focus.

Higher education

Higher education providers offer qualifications ranging from undergraduate awards (e.g. bachelor degrees, associate degrees and advanced diplomas) to postgraduate awards (graduate certificates and diplomas, masters and doctoral degrees), across many subject areas.

Community education

Community colleges or community education providers offer both accredited qualifications and non-accredited interest-based courses. If you are not seeking a qualification but want to learn a new skill or explore a new topic, then community education may be for you. There are short courses in areas like art, business, languages, lifestyle, sports and fitness.

Most education providers nowadays offer face to face options, online options, or a mixture of both. Look for a provider that provides flexibility and offers study options that match the way you like to learn.

Part-time or full-time work

Research suggests that people with CP who can do 'vocational training' including on-the-job training and job placement support, are more likely to be in long-term competitive employment.

You may wish to explore opportunities in open or supported work settings, depending on your abilities, needs and preferences.

Many organisations will offer employment focused programs that support transition into the workplace. As an example, Cerebral Palsy Alliance offers the CPA School Leavers Employment Support (SLES) program.

In this program participants can learn a range of employment specific skills, including:

- Writing a resume and cover letter
- Searching and applying for a job
- Communicating at work

- Money handling and budgeting
- Travel training and catching public transport
- Understanding what your employer needs from you
- Starting a new job
- Health and safety.

This program also offers individualised functional assessments dependent on your needs, as well as coaching support, either individually or in groups.

You can also ask for guidance from specialist transition planners, from employment counsellors, from Centrelink and from the Disability Employment Network.

Ongoing career training and counselling can help you look ahead and have access to what you need in the future.

Community participation

There is also the option of joining a community participation or life skills program. The focus of these programs is going out and participating in the community, making friends and connections, and pursuing individual interests. For example, a program could include:

- Music
- Visual arts
- Technology
- Home and living skills
- Personal development
- Yoga
- Cooking
- Sports.

You may also wish to explore workshops or programs offered in the community that build life skills and capacity for independence. Living independently and accessing the community independently means different things for different people. A program can be designed to meet your learning needs and interests.

Volunteering is another great way to get involved in the workforce. There are many benefits of volunteering: from gaining new skills to making new friends, as well as contributing and building your sense of purpose. When looking for volunteer work, you might consider:

- An organisation or field that you are passionate about
- A role that will use your skills or help build skills.

A volunteer organisation such as Volunteering Australia can help you find the right role. You can find out more at www.GoVolunteer.com.au.

Life skills training, mentoring and coaching

A number of life skills training, mentoring and coaching programs exist for adults with CP. These specialized services can be delivered as a one-to-one session, workshop, group class, or camp.

Life skills training and coaching is client-centred and goal directed. Goals are often practical and may focus on securing employment, developing skills to carry out activities of daily living, developing social skills and maintaining friendships.

The focus of these programs is all about you and your needs. This means working with you and your support network to set meaningful goals and build up your skills.



Leisure and recreation

Taking time to rest, relax and have fun is a vital part of a healthy lifestyle. Participation in leisure activities supports community participation and contributes to quality of life.

Benefits of leisure and recreation can include improved:

- Emotional wellbeing
- Mental wellbeing
- Physical wellbeing
- Social wellbeing.

We do know from research that people with a disability are less likely to be part of leisure and recreational activities than others.



WHAT WILL HELP?

If you have leisure and recreation goals it may be helpful to discuss what you would like to achieve, any barriers you experience, and ways to overcome them. Friends, family or support workers may be able to help you with this.

An occupational therapist, physiotherapist or exercise physiologist can help you achieve functional goals you have. For example, they may work with you on physical strength and endurance, transfers and access to help enhance your leisure activities even more.

MY WAY OF LIVING

Living life your way, now and in the future



Adulthood can be a time of change in many aspects of your life. You may be making more decisions, working out the balance of supports you need, and exploring the way you want to live your life.

As you get older, specific areas to think about include:

- How you look after yourself
- What independence looks like for you
- Being a self-advocate for your needs and wishes
- Where you want to live
- Financial and legal planning for the future
- Ageing well with CP.



Self-care and independence

Many people with CP talk about the importance of being able to care for themselves on a day-to-day basis. This may include toileting, bathing, moving between positions, dressing, preparing meals and sleeping.

How well you can care for yourself comes down to a combination of your skills and abilities, the activity you are doing, the environment around you at the time and what support you have access to.

Changes in any of these factors – ageing, illness, a new home, new staff – can change how you do a task.

WHAT WILL HELP?

Managing your health

Changes in your health, or in the way your body works, can have an impact on how you look after yourself and how much you can do for yourself.

Talk to your GP, occupational therapist, physiotherapist and other health professionals about what you are experiencing and what you need.

Goal directed training and CO-OP

Goal directed training and CO-OP are interventions that help you achieve goals. We described these interventions earlier in the booklet.

These approaches can help you learn to complete self-care activities to the best of your ability.

As you do more and more of the task, caregiver support may reduce.

MY WAY OF LIVING

Assistive technology

Assistive technology can help you to be as independent as possible while still doing tasks in a safe and efficient way.

Equipment and devices may help with:

- Bathing and showering
- Going to the toilet
- Dressing and undressing
- Moving between positions
- Preparing meals
- Sleeping safely and comfortably
- Moving around your home and the community.

Occupational therapy

Occupational therapists can assess your self-care needs. They can suggest ideas to improve your skills and help you do as much as you can for yourself. You may not need ongoing therapy at this stage in your life. But an occupational therapist can work with you on a specific goal you have.

Sleep

Establishing a good sleep routine is important. There is much you can do, with support from a therapist. Selecting the right sleep intervention should be part of a multidisciplinary approach by both therapy and medical teams.

You might be offered a referral to a specialised sleep clinic or service, medications to reduce the time taken to fall asleep, analgesics to help manage pain, or breathing equipment for obstructive sleep apnoea.

Assistive technology for sleeping is often an area that adults with CP want to know more about. Various equipment options are available to support sleep based on what you need.

Options include a height-adjustable bed, body position supports, a pressure-relieving mattress, a mattress protector, a night CPAP mask, a bed pole, a stick and a grasp bar.

Driving

People with CP can get a driver's license and drive a car if they are able. Driving can support independence as you don't need to rely on taxis, public transport or other people to drive you places.

Not everyone wants to learn to drive. If it is one of your goals you can speak to an occupational therapist or a representative from your state-based roads and transport service. Each state/territory has its own service and supports available for people with a disability to learn to drive.

For example, the NSW Roads and Maritime service in Australia states:

"If you have a disability, you'll be given a fair opportunity to demonstrate your driving ability in a standard driving test. If required, you can take a disability driving test, which considers your capabilities and any aids or vehicle modifications you need to drive."



Housing and living options

Adults with CP can access a range of different living arrangements. These may include:

- **Living independently:** this is called 'individual living options'. You could live by yourself, with people you choose or with a 'host family'.
- **Living with a group of people:** This is called 'shared supported living'. You may live with a group of 2–5 people, who also have a disability, in the same house.
- **Living with your family:** you and your family may decide that you will continue living in the family home.

It's important that you have choice and control over what type of housing is appropriate for you.

WHAT WILL HELP?

Information about housing options

It can be difficult to find the information you need to plan for where you would like to live.

The process of finding out about options may start in your teenage years and continue for a period of time as you learn about what is available and what is right for you.



MY WAY OF LIVING

You can find information about accommodation in different places:

The National Disability Gateway Website

This is an Australian Government website that connects you with information and services. They have a section of the website dedicated to 'Housing'.

You can click on the link to find out more:
www.disabilitygateway.gov.au/housing.

Disability Accommodation Australia

This is a service that provides information and consultancy about accommodation options. They are registered with the NDIS to provide Specialist Support Coordination in the area of accommodation.

You can visit their website to learn more:
www.disabilityaccommodationaustralia.com.au.

Disability Service Providers

Many disability service providers provide information and/or accommodation options as part of their service offering.

Contact your preferred Disability Service Provider to enquire if they provide accommodation options.

National Disability Insurance Scheme (NDIS)

The NDIS can assist participants to live independently. They don't offer accommodation but they can fund different supports you may need to live the way you want to.

You can talk to your NDIS planner about what options are available to you.

You can also visit the website to find out more:
www.ndis.gov.au/participants/home-and-living.



Support at home

No matter what type of housing you live in, you may want and need support at home. This could include help with:

- Cooking, cleaning and laundry
- Showering, dressing and toileting
- Managing and administering medication
- Building your capacity to live independently, such as behaviour support and social skill development.

You can have supports at different times and frequencies. For example, one person may just need checking in once a day while another person may need 24/7 support. Supports can be arranged to meet your individual needs.

You can talk to a support coordinator, social worker or advocacy organisation to help you look at the various housing options available to you. They can also help to assess and coordinate any supports you may need at home and ways you can fund this.

Home modifications

Wherever you live, you need freedom of movement. Home modifications allow you to move around your home safely and easily. They can include ramps, hoists, extra handrails for stairs, door widening, assistive technology for home automation and alterations to kitchen and bathroom fixtures.

If you live in a private home – which can be a rental, a share house or your own home – you might be able to arrange for modifications.

A suitably qualified occupational therapist can do an assessment to find out what home modifications you might need. They will consider all possible options, including how you might use equipment for different purposes.



Financial and legal matters

Good financial planning can lead to greater stability in your finances, and greater independence. Most adults with CP have financial independence to the same extent as their peers. But it can still be difficult.

There are government and non-government supports available to eligible people. If you need help managing your finances, legal supports can be put in place to assist you.



WHAT WILL HELP?

- Talk to your family, support team and social worker about planning for financial independence.
- Talk to appropriate government and non-government agencies about possible financial support, insurance schemes and pensions.
- If you can't manage your own finances, seek help from qualified professionals.



Planning for the future

Planning for the future is important for all adults. Things happen in life that we can't predict – illness, a change in care needs, a change in finances, or death. These things may not be pleasant to think about. But it is important to have a plan. This is so your loved ones know what you want and what to do.

WHAT WILL HELP?

Guardianship

If you cannot make decisions for yourself, at any point in time, you may need to have a guardian. A guardian is a person who can make decisions about your health, where you live, supports you need, and day-to-day matters. It is important that this is a person you and/or your family trust. They need to make decisions that are best for you.

In most countries there is a Guardianship Act that says how a guardian can be appointed and what they need to do. A tribunal has to agree that a person can be your guardian. If there is no-one in your support network suitable to be your guardian, the tribunal can say who your guardian will be.

Enduring Guardianship

An Enduring Guardian is someone that you say can make decisions for you. They can make decisions about your health, where you live, supports you need, and day-to-day matters.

They will only start to make decisions when you can no longer do this for yourself. For example, if you have an accident or get very sick. If you get better and can make your own decisions again, this person will stop making decisions for you.

Some people will have an Enduring Guardian for their whole life. For some people it will only be a short time. You need to sign legal papers to show you have given permission for someone to be your Enduring Guardian.

The Australian Guardianship and Administration Council supports people with their decision making. You can find out more on their website: www.agac.org.au.

MY WAY OF LIVING

Advance Care Directive

An Advance Care Directive is a way to say what healthcare treatments you do or don't want to have. This plan is only used if you are very sick or injured and can't decide or tell people what you want.

An Advance Care Directive can only be made by people who can understand the consequences of their decisions. So, some people with an intellectual disability may not be able to make this type of plan.

An Advance Care Directive can say:

- Who you would like to make medical decisions for you if you cannot do this
- What is important to you (your values, your goals, what you want to happen)
- The treatments and care you agree to
- The treatments and care you do not agree to.

If you want an Advance Care Directive to be followed you need to have it in place ahead of time. Once it is made, all health professionals and your family have to follow what it says you want.

You may need support in putting together an Advance Care Directive. You can speak to a nurse consultant or social worker about important areas to include. You may also need legal advice to make sure all necessary information is included correctly.

Advance Care Planning Australia provides information about this topic. You can find out more on their website: www.advancecareplanning.org.au.

Will

A will is a legal document that says what will happen to your assets when you die. Assets are important things that have value.

You need to have a will that is clear, legally valid and up to date. This is the best way to make sure your things go where you want them to.

Your will can cover things like:

- How you want your assets shared
- Who will look after your children if they're still young (if you have any)
- Any trusts you want to set up
- How much money you'd like to give to charities
- Plans for your funeral.

It is best to get a will prepared by an expert. There are lots of different areas to consider.

You can learn more about making a will on the Money Smart website: moneysmart.gov.au/wills-and-powers-of-attorney.



Power of Attorney and Enduring Power of Attorney

A Power of Attorney is where you decide to let someone look after your financial and legal decisions. The person is usually someone you know and trust.

There are different types of Power of Attorney:

- General Power of Attorney lets someone make decisions for you for a short period of time.
- Enduring Power of Attorney lets someone make decisions for you if you become sick or injured and you cannot make your own decisions. You must decide who this person is before you become sick or injured. The person needs to agree to take on this role for you.

It is best to get legal advice. You can find out more about estate planning and wills on the MoneySmart website: moneysmart.gov.au/wills-and-powers-of-attorney

Primary Support Network

Many people with CP get support from their parents, siblings and friends. These people are called an ‘informal network’ of support; they don’t get paid to help you.

This type of support is very valuable. But something could happen to the people who give you informal support. You need a plan for how you will keep getting the support you need.

Many people with CP receive most of their support from their parents. As your parents get older they may not be able to give the same support. It is a good idea to develop a transition plan. That way your parents can show your new supporters how you like things done.

It is useful to think of what you do in a usual week or month. Then think about how you do it. This will help you work out your support needs.

You may need a temporary plan – if your supports can’t help you for a short period of time. But you also will need a long-term plan – if your supports cannot continue to support you over the long term.

APPENDIX

Classification systems

The classifications below help to easily and simply describe how you move, use your hands, communicate, speak, eat and drink. They were developed and researched specifically for use with people with cerebral palsy. Most were created for children and teenagers up to 18 years of age. However, in practice they are widely used for adults with cerebral palsy too.

Gross Motor Function Classification System (GMFCS)

The GMFCS is a helpful tool to describe your usual method of moving around at home, work and in the community.

• Level I: you walk without limitations

You walk at home, work, outdoors, and in the community. You are able to climb curbs and stairs without physical assistance or a railing. You perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

• Level II: you walk with limitations

You walk in most settings but environmental factors and personal choice influence mobility choices. At work, you may require a hand-held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community, you may use wheeled mobility when travelling long distances.

• Level III: you walk with a hand-held mobility device

You are capable of walking using a hand-held mobility device. You may climb stairs holding onto a railing with supervision or assistance. At work you may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community you are transported in a wheelchair or use powered mobility.

• Level IV: you self-mobilise with limitations or use powered mobility

You use wheeled mobility devices in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, you may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. You may operate a powered wheelchair, or otherwise you are transported in a manual wheelchair.

• Level V: you are transported in a manual wheelchair

You are transported in a manual wheelchair in all settings. You are limited in your ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

Manual Ability Classification Scale (MACS)

The MACS helps to describe how you use your hands to handle objects in daily activities.

- **Level I:** you handle objects easily and successfully.
- **Level II:** you handle most objects but with some reduced quality and/or speed of achievement.
- **Level III:** you handle objects with difficulty – and need help to prepare and/or modify activities.
- **Level IV:** you handle a limited selection of easily managed objects in adapted situations (with help and/or adapted equipment).
- **Level V:** you don't handle objects and are not able to complete simple actions with your hands.

Communication Function Classification System (CFCS)

The CFCS is helpful to describe how you communicate with people around you. A few points to note:

- It refers to all methods of communication including speech, gestures, behaviours, eye gaze, facial expressions and augmentative and alternative communication.
- It includes both elements of communication: your ability to express (transmit) a message (as the 'sender') as well as to understand a message (as the 'receiver').
- 'Unfamiliar' communication partners are strangers or acquaintances, while 'familiar' communication partners are relatives, caregivers and friends.

-
- **Level I:** You are an effective sender and receiver with unfamiliar and familiar partners.
 - **Level II:** You are an effective but slower sender and/or receiver with unfamiliar and/or familiar partners.
 - **Level III:** You are an effective sender and receiver with familiar partners.
 - **Level IV:** You are an inconsistent sender and/or receiver with familiar partners.
 - **Level V:** You are seldom an effective sender and receiver even with familiar partners.
-



Viking Speech Scale (VSS)

The VSS is used to specifically describe your speech (unlike the CFCS, which includes non-verbal methods of communication too).

- **Level I:** Your speech is not affected by your motor disorder.
- **Level II:** Your speech is imprecise but usually understandable to unfamiliar listeners.
- **Level III:** Your speech is unclear and not usually understandable to unfamiliar listeners out of context.
- **Level IV:** You do not use any understandable speech.

Eating and Drinking Classification System (EDACS)

The EDACS describes how you usually eat and drink.

- **Level I:** You eat and drink safely and efficiently.
- **Level II:** You eat and drink safely but with some limitations to efficiency.
- **Level III:** You eat and drink with some limitations to safety; and you may have limitations with efficiency.
- **Level IV:** You eat and drink with significant limitations to safety.
- **Level V:** You are unable to eat or drink safely and you may receive nutrition through tube feeding.

The information in this booklet has been informed by high quality, published research from the field of cerebral palsy. A complete list of references can be requested from ask@cerebralpalsy.org.au

**For more information,
please get in touch:**



Call us on **1300 888 378**



Email us at
ask@cerebralpalsy.org.au



Visit **cerebralpalsy.org.au**



Cerebral Palsy
ALLIANCE