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Future Thinking



Living well with physical disability

Ability
Centre

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Living with your disability

Living with your physical disability is a lifelong journey, with highs and lows. Everybody feels the impacts of ageing as they get older.

While most people begin to feel the impacts of ageing in their 60s, people with a physical disability often begin to feel tired and sore earlier and may start to slow down much earlier in life, some as early as their 30s.

Many people living with a physical disability comment that they wish they had known what was going to happen and wanted more information to help them prepare.

These resources are useful for many people with physical disabilities and those who support them to know what may happen over their life. While the focus in some of the resources is cerebral palsy and similar physical conditions, they are still useful for many people with other physical disabilities that start as a child or as a young adult.

People with a physical disability often begin to feel tired and sore earlier and may start to slow down much earlier in life.





Being prepared

Paying attention to your body and what you need to do can help you as you get older.

It is never too late to pay attention to what you need and take action. Things take time, thinking about things early means plenty of time to plan, think and do what you want to do.

For people with a physical disability, early planning can be particularly important because some treatment options – particularly surgical ones – are best addressed and actioned before the body stops growing. The human body changes rapidly during the teen years and some of these changes can cause injury, pain or problems later in life. Regular monitoring will help you pick up problems early.

In childhood, the same child health team may look after you for many years. They know you very well. Your parents have looked after all your decisions and you often do not know what has been discussed over your life.

In adulthood, you receive services from the adult health system. You may see many different specialists and teams in the adult health system, sometimes at different hospitals and community settings. If you have the ability to, you can become an expert in your own health and can make the decisions about what will happen.

Steps to Being Prepared

Step 1 Around the age of 14, people with physical disabilities and their parents should begin discussions about long-term planning with their paediatrician, GP and therapy team.

Step 2 Long-term plans should be reviewed and updated every year in consultation with your network and team.

Step 3 A physiotherapy review should take place annually. Depending on your abilities and needs, other annual reviews may be required with health professionals including occupational therapists, speech therapists, dietitians, social workers and psychologists.

Diagnosis

The first step in being prepared is knowing and understanding your diagnosis and what it means for you. Remember though, your diagnosis is not your identity. Everyone is different with some things that are similar.

Important questions to ask:

- **What is the diagnosis? What do the words mean?**
- **What is expected for someone with your diagnosis?**
- **What is possible?**
- **What is not possible?**
- **Are there changes likely to happen over the lifespan?**

Ask your therapy team, GP or specialist to explain your diagnosis and what it means for you.

Cerebral palsy is a developmental disability. It results from damage to the brain. Impairments that are associated with cerebral palsy are non-progressive but permanent. Words like “non-progressive” can be a bit confusing. The definition is talking about the brain injury. It is not talking about how your body works. Your body does change and some things do progress. Some things improve, some things get worse and others change during your life.

Monitoring

Some changes and progressions are known. Exactly when they occur is different. Some changes are quick. For most, the changes happen slowly and are only noticed when they stop you doing something you really enjoy.

If changes are picked up early, the amount they progress can be reduced. Regular monitoring of your abilities and what your body can do helps pick up the changes and provide you with ideas of what you can do to slow the progression.

Important: while most changes happen slowly, if you have a sudden change in what you can do, you need to take action as soon as possible. Speak to your GP or therapy team immediately.



Your normal

Knowing your normal and making sure those who support you also know your normal will assist you to explain any changes in your abilities to health professionals and other people supporting you.

Ask yourself these questions, everyone's answers will be different, they are "your normal".

How do you walk or transfer or move yourself up the bed or roll in bed?

How much can you do by yourself?

If you get help, do you get help because you want to or need to?

What parts of your body can you move?

There may be parts of your body that you have had trouble moving and other areas that you have always been able to move.

What parts of your body can you feel?

There may be parts of your body that you have never been able to feel if they are moved or touched while other areas that you have always been able to feel if moved or touched. It may feel the same on both sides or feel different.

Do you cough when you are eating or drinking?

What foods and drinks are easy to swallow or more difficult?

If you get regular chest infections, know what your resting heart rate and oxygen saturation levels are when you are well. Your physiotherapist, nurse or doctor can help you find these out.

If you have any medical conditions, know what your baseline is and have these reviewed regularly by your doctor e.g. diabetes, asthma.



Everyone's answers will be different, they are **"your normal".**



What does independence mean to you?

Independence means something different to different people. There is no right or wrong answer.

For some, independence is being able to physically do everything by themselves and for others, independence is feeling in control or 'in charge' of things happening in their lives; others feel a sense of independence somewhere in between.

It is interesting to note that:

- People who do everything themselves, without support, often find it harder to cope with changes and experience more soreness and fatigue while people who accept help are less sore and tired and can generally cope better.
- Wear and tear on the body generally appears to be less in those who accept help compared to those who don't.
- People who accept help often have more energy to get out and about doing the things they enjoy and seeing other people.

Have a think about what independence means to you.

Share this with those who support you.



Coping with change

Coping with change is hard for most people. Like many people with physical disabilities, you and your family have probably spent your years as a child trying to walk or transfer and to live as independently as possible. For some, you have tried very hard hoping that you won't need to use equipment while others may have happily embraced equipment to help.

Whatever you have been doing, despite all your efforts you find that you are now struggling to do the things you want to. You may be tired and sore. Those who support you may have as much invested in your independence as you do and may struggle with the changes you are going through as well.

Being prepared for what may happen to your body can help you cope with the changes. Catching changes early can also help slow progression so that you can do the things that you want to. Understanding what your body is going through and looking at different ways to do things can also help you to cope with changes.

Preparing to plan

Preparing to plan can bring different emotions to everyone. It can be an exciting moment of taking control of the supports in your life through to a daunting experience not knowing where to start and worrying if you'll miss or forget something. When funding is being sought, the stress and worry can be heightened.

Your funding planner and those who you choose to support you will assist you to consider what your needs are based on your goals.

Ask those that you trust and know you to help you create a list of goals. Many service providers can help you figure out what you actually need to do to reach your goals. They do this by talking to you and completing assessments and reviews.

When it comes to your health and wellbeing and what may happen as you get older, it can be hard to think ahead especially if you are not really sure what it is that you are supposed to be thinking ahead about. Health professionals can provide recommendations to help you plan.

Asking for help

Many people with physical disabilities state that it is hard to ask for help. If you need help, it is always OK to ask.

Be honest about what you can and can't do. If you can do something by yourself but it causes you pain or makes you very tired or means you can't get out and about, it is always OK to ask for help.

If you have support in the home or equipment to help you but it isn't meeting your needs, it is always OK to ask for help.

There are many service organisations who can provide support in the home and community.

Being prepared for what may happen to your body can help you cope with the changes.

It's always OK to ask for help.





Conserving your energy

Pain, fatigue, having to change or stop work or enjoyable activities are all very common as people get older. For those with physical disabilities, the experiences are greater and happen earlier in life.

Regardless of why pain, fatigue, weakness and having to change how you do things happen, it is important to know that you can do something about it to stop small problems becoming big ones.

Many comment with sentiments such as ...

**“I’m so tired, my tired is tired”
or “I’ve hit a brick wall”**

Conserving your energy is one of the most important things you will ever have to think about when living with a physical disability.

Conserving energy will be a journey. It will be a balancing act. At times you will get it right. At others, you won't. Like others before you, it will test you. It will make you think about everything you have done before now and wonder if it was the right thing to do. It will make you fight for what you have set out to do. Health professionals will recommend things with your best interests at heart, that like most before you, you won't like. It will eventually likely change your mind on firm opinions you have held for many years.

If you are a parent supporting your child with a physical disability, you will likely do the same.

This is all very normal. Everyone takes this journey at their own pace. Everyone copes with what health professionals recommend in different ways.

No one reaching the point of knowing how to conserve energy has ever said, “I did the wrong thing”. Rather, the sentiments are usually, “why didn’t I do this earlier?”, “if I stick to the plan and have balance, I can do more and I’m much happier,” or “there is nothing that could have changed my mind earlier, I just needed someone to tell me many, many times before I was ready”.

To find the best solution for you, discuss your energy with your physiotherapist and occupational therapist.

To wheel or not to wheel...

While some people request equipment from their health professionals or people to support them at home, many view it as a setback in their independence.

Common responses include:

“Well that’s a slap in the face!”

“But I worked so hard to walk and transfer by myself”

“I’m walking until the day I die – I’m not using a wheelchair”

“I can’t have someone else come into my home”



Having equipment and support does not replace what you can do, they can work together. They are never the end of the line.

Sometimes the suggestion is because there is a need to make a big change so that you do not injure yourself or those who support you. Sometimes there are activities you can do to regain your previous skills.

For most people, equipment and support is suggested to help you conserve your energy. If you are still walking and completing transfers independently, there is a very good chance that you'll continue to walk and transfer.

- **Wheelchairs and scooters** can mean you can move over longer distances and have the energy to walk around the home and shorter distances.
- **Walkers** can mean that you have the energy to walk more often.
- **Hoists** can mean you are at less risk of falling and have less stress on your body making you more comfortable. Using hoists also looks after the people who support you so that they are more available to help you do the activities that you want to do.
- **Support from other people** with household tasks can mean you have more energy to do other activities that are enjoyable. Many people spend hours doing household tasks that use up all their energy which leaves them unable to do anything else in their day.

For parents, it can be a similar feeling when equipment or support is suggested. Using equipment or getting support in the home can mean less strain on you as well as your child. It can mean more “parent” than “carer” time and give you more time to get out and about. This is important for everyone's wellbeing and confidence in your child being supported into the future as you get older yourself.

Health professionals and community support coordinators often hear similar comments from people who have embraced equipment or support in the home and community;

**“Thank you for helping me get a scooter or wheelchair, I can now go out for coffee with friends or take my kids to the park”
and “thank you for helping me get someone to cook and clean, I’m finally getting out of the house”.**



**To wheel or not to wheel...
it's worth thinking about.**



Pain and fatigue

Pain, fatigue and weakness are very common for people with physical disabilities regardless of diagnosis, location, culture or support available. While feeling sore and tired is common as the body ages, people with physical disabilities generally feel both of these more frequently and earlier in life.

Interesting points to note about pain, fatigue and physical disability:

Many people with cerebral palsy accept pain as “just part of having cerebral palsy” and only seek support when they can’t do what they want to do any more.

Children with cerebral palsy commonly have pain, it is easy to think it is normal once you are an adult.

Some people experience constant tiredness, it does not matter what they do.

Pain and fatigue stops people doing activities.

Not moving increases pain and fatigue.

People with physical disabilities feel pain in almost all parts of the body.

Many people experience chronic pain which means they feel it all the time.



Pains in the muscles and joints can be due to injury, general wear and tear or how you do an activity.

People with moderate impairment tend to be more tired and sore than those with mild or severe impairments, possibly due to increased strain on the body to keep up with peers and be independent.

People who use multiple ways to manage pain are generally more satisfied than those who only take pain medications.

For example, combinations of physical activities on land and in water, pacing, relaxation techniques, counselling, cognitive therapy, using equipment and assistive technology, adjusting and planning activities.

Important points about pain and fatigue

- **Pain is not normal** and should not be ignored.
- Find out **why you have pain** and seek help.
- While medication has a place in managing pain, it is important that **sources of pain are identified** and treated long-term.
- In most cases, **pain and fatigue can be managed** to ensure it does not completely inhibit lifestyle.
- **Fatigue and tiredness can be managed** and reduced through many different techniques.
- **Regular monitoring** is important to identify problems that may cause pain or fatigue as early as possible, to enable treatment and minimise long-term impacts.

Physical activity

Physical activity is an important aspect of daily life for all people, regardless of ability level: it improves physical and mental health, encourages participation and promotes general wellbeing.

Major benefits of physical activity include:

- **Improved muscle, heart and lung function and increased energy levels.**
- **Improved muscle strength and length, and improved balance.**
- **Assisting weight loss.**
- **Reduced risk of chronic diseases including diabetes and heart-related diseases.**
- **Improved ability to fight infections.**
- **Improved mood and decreased stress.**
- **Improved memory, planning and ability to do multiple tasks.**

It is important that intensity during physical activity is moderate. When taking part, you should feel a little short of breath but still able to comfortably hold a conversation. Adequate rest between sessions is essential.

For maximum benefit, physical activity is recommended three to four times a week, for sessions of 30 minutes or so. Sessions can be broken into shorter pieces if needed – for example, two 15-minute sessions with a break in between.

Before commencing a program of physical activity of any sort, it is important to be assessed by a GP or allied health professional to reduce the risk of injury or ill health. For anyone with any pre-existing conditions or pain, this is particularly important.



Incorporating physical activity into daily life

There are many ways to incorporate physical activity into daily life. Speaking with your health professional team can assist you in identifying the physical activities that best suit your needs and ability level.

Individualised exercise and fitness programs are an excellent addition to recreational physical activity. They can be especially useful for people who cannot access other recreational activities for any reason. Physiotherapists can assess and tailor an individualised program to meet specific needs and interests.

Attending a community gym is popular and regularly recommended to improve strength and fitness. An individualised, tailored program – with exercises suited to an individual’s diagnosis and type of physical disability – is very important to prevent injury or other long-term problems. Physiotherapists can work with a personal trainer to tailor and review a suitable gym-based program.



Physical activity for complex physical disabilities

Physical activity is just as important for those with complex physical disabilities. An individualised program at home or in the local community can be a great way to keep active. Physiotherapists can provide formal exercise ideas, as well as advising on how best to incorporate physical activity and exercise in everyday life (known as ‘incidental exercise’).

A physiotherapist can also offer training and provide recommendations to family and support workers on how best to assist an individual in keeping physically active, as well as providing formal ‘booster programs’ with a therapy team. Many people with physical disabilities need these regular booster programs each year to assist them in maintaining the benefits achieved in therapy programs long term. This need is related to the very specific types of exercise required for people with physical disabilities, which is not easily replicated without the input of a health professional.

Common Concerns for People with Physical Disabilities

Contact your health professional team for support with any of the following.

Shoulders

Pain, joint dislocation, difficulty with activities that require arms to move away from the body.

Respiratory

Regular chest infections that require antibiotics or result in hospitalisation. Also, lower than recommended weight, difficulty swallowing, difficulty with independent movement or pain in the chest region.

Heart

Headaches, dizziness, vertigo, history of blood pressure problems or pain or discomfort in the chest, arm, back, neck or jaw.

Gastrointestinal

Reflux, constipation or any other problems with the bowel.

Scoliosis or kyphosis

Spinal curvatures, different leg lengths, difficulty taking deep breaths, back pain, pins and needles or numbness in the legs.

Lower back

Back pain, pins and needles, numbness, difficulty standing on one leg or staying in positions for long periods of time.

Elbow, forearm and hands

Pain in the hands, forearms or elbows, muscle contractures, difficulty completing activities with hands and arms or trouble maintaining hand hygiene.



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Mental Health

Feeling low, stressed or worried.

Neck

Pain, difficulty moving or changes in feeling in the hands and legs.

Jaw

Pain around the jaw, or a locked jaw.

Teeth and gums

Mouth pain, trouble with biting and chewing or difficulty brushing teeth.

Swallowing

Coughing when eating or drinking or have any difficulty swallowing food or drink.

Communicating

Difficulty communicating with family, friends or support people.

Hips and pelvis

Pain in the hips or pelvis, feelings of joints moving or being out of joint, difficulty keeping legs equally apart when sitting, or changes in transfer or gait when walking.

Knees

Pain in the knees, walking and transferring with hips or knees bent or increased difficulty walking.

Ankles and feet

Pain in the ankles or feet when walking or standing, particular flatness in the feet, or muscle tightness in the feet or legs.



Changes in walking ability

Will I keep my ability to walk or transfer as I grow older? Changes in ability to walk or transfer with age depends on your diagnosis, what you can do and how you and those supporting you have managed your disability. Everyone's journey is different.

Things to consider

People with hemiplegia are less likely to lose their independent walking, while those with spastic diplegia or choreoathetosis are more likely to.

There is a commonly recognised change in walking at around 20 to 25 years of age, generally due to increased bending of the knees when walking and increased difficulties keeping up with peers.

A second commonly recognised change in walking or transfer ability occurs between 40 to 45 years of age, when pain and fatigue make it harder to complete activities, likely due to large stresses on the joints over time.

Increasing weight of the body with age can cause stress during movement.

A lack of physical activity can reduce movement ability and increase pain and fatigue.

Long-term stress on the body can increase pain and fatigue later in life.

Use of equipment and assistive technology is not 'the end of the line' - using a wheelchair, scooter or walker does not always mean a complete loss of independent walking or transfer ability.

Steps to maintain walking or transfer abilities

- Protection of joints from early on in life
- Possible surgery in the teen or early adult years to assist the movement of muscles and joints
- The use of mobility aids to ease joint stress
- Maintenance of a healthy weight range
- Addressing pain early – finding the cause and taking steps to minimise any impact
- Seeking advice and support for consistent tiredness or fatigue
- Regular physiotherapy and occupational therapy reviews to monitor mobility and ability to complete activities. These may assist by:
 - Assisting you to find ways to manage and reduce pain and fatigue
 - Reviewing daily activities and tasks to make things easier and safer, and to prevent further problems
 - Providing an exercise or therapy program
 - Providing walking and transfer training
 - Prescribing equipment such as wheelchairs, transfer aids or walking aids
 - Providing recommendations about support needs based on ability levels.



Health

Health, our most important possession.

Staying healthy is often not as easy as you'd think for many people with physical disabilities. For some, illness is a large part of their life and it is easy to think it is "normal" to cough, splutter and be generally unwell all the time. For others, they find that as they get older, recovering from illness can take much longer.

There is nothing normal about being regularly unwell.

Our bodies need regular "services" and "repairs" when we are ill, just like any piece of machinery. Just as ignoring the service light on the dash board of your car can lead to inconvenient breakdowns or big repair bills, ignoring aches and pains and not having screening health checks and monitoring can lead to being very unwell or struggling to do what you want to do.

Preventative health and screening

Guidelines and recommendations for screening are the same for everyone regardless of abilities. The types of screening tests and how they are taken are changing with technology advances and research finding new and improved ways. There are also different ways the tests can be completed depending on people's abilities or cultural needs.

Some services may have limited physical access for wheelchairs or do not have a hoist for transfers. If this is the case, discuss with your GP whether they can visit you at home or whether there is a local or hospital clinic that you can be referred to or whether an alternative screening method is best for you.

**See your GP
for a yearly
medical review.**

**That way you and
your GP can get to
know "your normal".**



Healthy eating

Good nutrition is very important at all stages of life – in childhood it helps the body to grow and develop, and in adulthood it ensures good long-term health and quality of life. But eating a healthy diet is difficult for many people and can be even more challenging for individuals with a disability.

The key to eating well is to enjoy a variety of foods from each of the five food groups that make up the central plate of the Australian Guide to Healthy Eating. Eating these foods means you are most likely to get the right amount of nutrients and help protect the body from chronic disease.

Having a disability does not change the general goals for eating healthily, however some extra things may need to be considered. A dietitian can help with food ideas and meal plans that consider your health needs and your abilities.

There are many resources online that offer information and ideas around healthy eating including: healthy eating at all stages of life; more information about the five food groups and why they are important; tips for eating well; understanding food labels; and food safety.



Overweight and obesity

The percentage of Australians considered to be either overweight or obese is increasing, and it is a problem common in people with disabilities. Carrying too much weight can make movement difficult and goals like walking and transferring become difficult to continue, reducing independence.

Factors that are linked to increased levels of overweight and obesity include:

- Eating more food than the body needs.
- Modern lifestyles – for example driving instead of walking and excess time seated in front of computers, televisions and other devices.
- Increased availability of food – particularly those that have little nutritional value.

Being obese increases the risk of conditions including type 2 diabetes, coronary heart disease, high blood pressure (which can cause stroke), osteoarthritis, sleep apnoea and pressure injuries.

Many people who are overweight often do not eat huge volumes of food, but the foods being eaten are not of high nutritional value. Regular monitoring of weight is recommended.

**Having a disability
does not change the
general goals for
eating healthily.**

**A dietitian can help
with food ideas and
meal plans.**

Challenges gaining and maintaining weight

Some children with disabilities have difficulty gaining weight and may be underweight for their height and age. This can continue into adulthood, with some people struggling to gain weight and maintain a healthy body weight their entire lives.

Low body weight can lead to:

- Growth failure in children
- Decreased muscle strength
- Reduced ability to cough
- Increased risk of infection
- Constipation
- Osteoporosis
- Pressure injury
- Irritability
- Depression.

There are two general causes of low body weight: a lack of correct nutrition to gain and maintain weight; and more energy being expended than is being taken in.

Reasons for not getting the right amount of food include:

- Difficulties with eating and drinking
- Inability to express hunger or thirst
- Requiring assistance with eating and drinking
- Reflux, vomiting or aspiration (food and drink going into the lungs)
- Requiring food textures to be changed before eating or drinking
- Lack of appetite
- Taking a long time to eat and drink
- Constipation.

Reasons for excessive energy expenditure include:

- Increased muscle tone e.g. spasticity
- Involuntary movements e.g. athetosis.

Depression, anxiety and other illnesses

Mental wellbeing is equally as important as physical wellbeing – mental and physical wellbeing both influence each other.

Many people experience depression, anxiety and other mental illnesses, people with physical disabilities do too. If you feel low, sad, stressed, worried or any combination of these, seek support.

People with physical disabilities may experience mental illnesses for similar reasons to anyone else or they may experience them because of additional hardships related to their disability.

Psychologists, social workers and doctors can help people with disabilities manage their mental illnesses.

If you feel low, sad, stressed, worried or any combination of these, seek support.



Swallowing

Eating and drinking is a very big part of our health and wellbeing but what we pay most attention to is the huge part they play in our culture. We often meet for coffee or a meal with family and friends and big occasions always have food and drink as a centre piece.

Many people with physical disabilities experience some difficulties with swallowing. Many are fearful to share these difficulties, worrying about the changes that may have to be made to accommodate swallowing limitations. Some are unaware they have a problem or how important it is to swallow safely.

Many difficulties with swallowing can be managed with simple solutions – a consultation with a speech pathologist can assess swallowing abilities and provide solutions.

People with cerebral palsy (CP) and similar conditions often experience swallowing difficulties from birth, with swallowing ability changing or deteriorating with age. Changes occur for various reasons however it is known that for people with CP, changes in swallowing most often occur from 30 years of age onward.




A person's health can be seriously impacted if they are not able to swallow safely – concerns include:

- Recurring chest infections, often resulting in many rounds of antibiotics and possible hospitalisation
- Difficulties gaining or maintaining weight and tiredness or generally feeling unwell due to lack of food intake and low energy
- Higher than average risk of infection due to lack of nutrients.

Signs of swallowing difficulties include coughing or a 'gurgly' voice when eating and drinking, constant hunger or thirst due to lack of food and drink, regular chest infections requiring antibiotics or hospitalisation, or feeling uncomfortable eating and drinking in public. It is recommended you see a speech pathologist for a review if you experience any of these issues.

Because swallowing changes can happen quickly and without warning, regular reviews with a speech pathologist are recommended for people with physical disabilities.



**Many difficulties
with swallowing can
be managed with
simple solutions.**

**A speech pathologist
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solutions.**

Communication

There is nothing more important than being able to communicate with those around you.

Many people with physical disabilities have trouble speaking. This is due to problems with the muscles used for speaking.

As people with physical disabilities get older, they may find new problems arise.

What can I do to improve and maintain my communication?

See a speech pathologist for a review of your communication needs. They may help you by:

- Finding ways for you to communicate with those around you
- Finding ways to remember what is happening around you
- Finding ways to improve your strength and coordination of your muscles that help you speak
- Recommending low or high tech Augmentative and Alternative Communication (AAC) tools and methods and support you and those who support you to learn how to use them.

Create a Communication Profile or Dictionary to help those around you to communicate with you in a meaningful and respectful way. A speech pathologist together with your family and support network are the best people to help you create your profile.

See an occupational therapist to help you to access any devices you use.



Communicating with health professionals

Many people with physical disabilities have expressed their frustration with having to repeat their story so many times.

There are several ways to facilitate better communication with health professionals. First, it's important for your health information to be compiled into a concise document that can be shared, for example a Communication Passbook or 'book about me'. Family, support staff, a therapy team and GP can assist in creating this document, which will help health professionals understand medical background, medication history, treatment recommendations, referrals, activities, likes and dislikes and other relevant details.



Tips for health appointments

- A list of medications and health concerns should **be prepared in advance** and taken to appointments. These can be saved on a communication device if needed.
- A **Communication Passport** or '**book about me**' and **communication profile** and **dictionary** should be taken to **every appointment**. These should be handed to the health professional at the start of the appointment.
- Use your **communication board** or **book** or **device** or **prompt cards**.
- A **trusted friend, family member** or **support worker** should be taken to **every appointment**, to help if needed.
- **Notes should be taken at every appointment**
 - if help is needed to take notes, the health professional or support person attending the appointment can assist.

24-hour positioning and movement

Supporting someone with a physical disability with complex needs can be challenging, particularly if the person is not able to move themselves independently or communicate how they're feeling.

The body moves thousands of times every day. Many regular movements are subconscious, and the full extent of stiffness or pain is often not felt until a position has been held for a long time. Think about how often you reposition yourself when in a meeting or while watching a movie.

Now consider the people you support with complex needs, who may not be able to reposition themselves or express discomfort. It is essential for everyone in the individual's support team to tune into their subtle changes and reactions during the day and overnight, to best understand their needs.

Supporting all positions and movement from as early an age as possible can help people's comfort and wellbeing and mean that people can participate in whatever way is best and enjoyable for them.



Positioning

When determining suitable positioning for an individual, it is important to consider their general health, comfort, pain levels, safety within their surroundings and participation in activities.

Everyone feels comfortable in different positions. The aim when providing positioning support is always a neutral body.

Postural supports can be helpful in ensuring a neutral position. Supports range from simple pillows purchased from a department store, through to customised pieces of equipment. While some people tolerate or want lots of pieces of equipment for support, others prefer just one or two pieces.

Regular consultation with the therapy team for postural supports and positioning can greatly enhance participation in activities. A 24-hour positioning plan can be useful for people who are supported by multiple support staff across the week. The therapy team can assist with putting together a plan that best meets the needs of the person.

Movement and repositioning

Experiencing a range of movements and different positions across a 24-hour period is important for comfort and wellbeing.

Suggestions for providing optimum comfort to an individual with complex needs include:

- Make use of the recline and tilt in space functions on wheelchairs
- Regular re-positioning – make sure to re-position someone even when they “look comfortable”
- If they can, offer the opportunity to stand or walk
- For those who do not stand or walk, can they be hoisted into another seat or bed? Ask the therapy team to assess for alternative positions during the day. Always consider safety
- Encourage participation in exercises, stretching or other movement. Ask the therapy team for specific ideas and programs.

Equipment

Equipment is one part of 24-hour positioning and movement. There are many types of equipment available to support people with all types of abilities.

People with physical disabilities often say they didn't realise equipment was available to help them or they spent lots of money on something that wasn't the best for them.

Therapists will help you find what you need to be as independent, safe and comfortable as possible and help you to know what support you are eligible for. Therapists may be able to help you receive funding to purchase required equipment.



Sleep

Sleep is vital for everyone. Having difficulty sleeping is not normal and should always be investigated.

Many people with physical disabilities have difficulty sleeping and may find it difficult to position and move themselves during the night.

The reasons for sleeping difficulties are often the same as the wider community. If however, the reasons you have difficulty sleeping include respiratory (chest) problems, temperature control or pain and discomfort, then it is likely to be linked to your physical disability. Other reasons are unlikely to be linked to your physical disability.

Supporting all positions and movement from an early age can help people's comfort and wellbeing, this supports them to live their best life.

Common problems experienced by people with physical disabilities include:

- Pain and discomfort due to positioning and reduced ability to change position, muscle spasms, other sources of musculoskeletal pain or gastroesophageal reflux
- Reduced ability to control temperature overnight
- Pressure injury due to positioning
- Respiratory ill health further reduced due to positioning
- Obstructive Sleep Apnoea
- Restless leg syndrome
- Reduced melatonin.

Important considerations for people with physical disabilities to understand include:

- Normal hours of sleep across the lifespan
- Sensory needs to allow a restful bedroom
- The impact blue light from screens can have on sleep
- The impact sleep quality can have on your overall mental health
- The impact of physical activity on sleep
- The impact of other health conditions on your sleep e.g. epilepsy and medications.

There are a combination of medical and therapy supports available to help you.



Summary

To do the things you want to do...

- ✓ **Get to know you and know your needs.**
- ✓ **Plan early.**
- ✓ **Share your plans and goals with those who support you.**
- ✓ **Stay engaged with therapy and health services.**
- ✓ **Be monitored across your life.**
- ✓ **Find a GP, see them regularly.**
- ✓ **Have a yearly physiotherapy assessment**
- ✓ **Have a yearly speech pathology swallowing assessment if you are at risk or over 30 years of age.**
- ✓ **Have a yearly occupational therapy assessment of your home, work and community.**
- ✓ **Get your equipment and assistive technology reviewed every year.**
- ✓ **Stay within a healthy weight range, see a dietitian for help**
- ✓ **Keep yourself balanced and well, see a psychologist, social worker or GP for help.**
- ✓ **Ask a speech pathologist for communication strategies if you need help.**
- ✓ **Ask for help at home and in the community.**

**Explore the Future Thinking
website for more information
futurethinking.abilitycentre.com.au**





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