Learning Guide

Physical disability and support needs

Name: 

Workplace: 

16871 Describe physical disability and support needs of a person with a physical disability in a health or wellbeing setting Level 3 4 credits
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Introduction

A person living with a physical disability has the same needs as everyone else in the community. When you are supporting a person with a physical disability you will need to understand their disability, their abilities and their individual needs.

How to use your learning guide

This guide supports your learning and prepares you for the unit standard assessment. The activities and scenarios should be used as a general guide for learning.

This guide relates to the following unit standard:

- 16871 Describe physical disability and support needs of a person with a physical disability in a health or wellbeing setting (level 3, 4 credits).

This guide is yours to keep. Make it your own by writing notes that help you remember things, or where you need to find more information. Follow the tips in the notes column.

You may use highlight pens to show important information and ideas, and think about how this information applies to your work.

You might find it helpful to talk to colleagues or your supervisor.

Finish this learning guide before you start on the assessment.

What you will learn

This topic will help you to:

- understand the causes and effects of physical disabilities.
- recognise how physical disabilities affect daily living.
- support people with physical disabilities.

What you will need

To complete this topic, you will need:

- this learning guide.
- your trainee assessment for this topic.
- forms from your workplace, such as:
  - personal plans.
  - observation forms.
- the people you support.
- you!
What is a disability?

Disability is not something individuals have. What individuals have are impairments. Impairment means a limitation to the way a person is able to function. They may be:

- physical, related to body function.
- sensory, such as vision or hearing.
- neurological, related to the nervous system, such as seizures.
- psychiatric or mental - the state of psychological and emotional wellbeing.
- intellectual or cognitive, such as limitations of thought processes, memory, reasoning and learning ability.
- age related, as multiple impairments are common with older age.

Our society is built in a way that assumes we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions.

Impairments affect daily life and social activities, and can limit access to education, health care and welfare services.

People with disabilities face huge barriers to achieving the life that so many take for granted. Barriers are created as often society takes no account of the impairments other people have. Barriers may hinder a disabled person’s full and effective participation in society on an equal basis with others.

A person’s impairments may be present from birth (congenital) or caused by disease, trauma or a health condition. Each person with a physical disability is unique. They will:

- have different reasons for their impairment.
- experience different symptoms.
- have different limitations on what they can do.
- require different kinds of support.

Some people will also have intellectual or learning disabilities.
The New Zealand Disability Strategy

Making a world of difference

The New Zealand Disability Strategy is vital to the wellbeing of the almost one-in-four New Zealanders who identify that they have a long-term impairment.

The New Zealand Disability Strategy has a vision and presents a long-term plan for changing New Zealand from a disabling to an inclusive society. It has been developed in consultation with disabled people and the wider disability sector, and reflects many individuals' experiences of disability.

New Zealand will be inclusive when people with impairments can say they live in: ‘A society that highly values our lives and continually enhances our full participation.'

Disabled people will be integrated into community life on their own terms, their abilities will be valued, their diversity and interdependence will be recognised, and their human rights will be protected. Achieving this vision will also involve recognising the principles of the Treaty of Waitangi.

Implementing the strategy

The New Zealand Disability Strategy provides a framework to guide government agencies making policy and services impacting on disabled people. In taking the lead, the government will do everything possible to influence the attitudes and behaviour of society as a whole. By all New Zealanders considering issues facing people with disabilities and their aspirations, New Zealand can become a fully inclusive society.

The Minister for Disability Issues must report every year on what the government is doing with the Disability Strategy.

The Disability Strategy operates across all sectors and government agencies. It sits alongside other government policies like the New Zealand Health Strategy and the Positive Ageing Strategy.

The New Zealand Disability Strategy is available for reading online or for downloading at: www.odi.govt.nz/resources/publications/new-zealand-disability-strategy.html

The Disability Strategy is also available in an easy read version, a pictorial version, an audio version, a braille version and a video in New Zealand Sign language.
The New Zealand Disability Strategy includes **15 objectives**, underpinned by detailed actions.

- Encourage and educate the community and society to understand, respect and support disabled people.
- Ensure disabled people’s rights are understood and promoted.
- Provide the best education for disabled people.
- Provide opportunities in employment and make sure disabled people have an adequate income.
- Strengthen the leadership of disabled people.
- Make sure that government organisations and organisations that get money from the government know about and respond to disabled people.
- Have services for disabled people that work for disabled people and are easy to get.
- Support disabled people to have a good life in the community and to have the opportunity to live in their own homes.
- Support disabled people to have choices and help them to have access to recreation and cultural opportunities.
- Collect information about disabled people to help with planning and understanding what disabled people want and need.
- Promote the involvement of disabled Maori so their culture is understood and recognised.
- Promote the involvement of disabled Pacific peoples so their cultures are understood and recognised.
- Help disabled children and young people to have good lives that prepare them to be adults.
- Assist disabled women to improve their lives and be a part of their communities.
- Recognise the importance of families, whānau and people who provide support for disabled people.

The Code of Rights also applies to all consumers.
The Disability Survey

The Disability Survey is a national survey of children and adults and is the most comprehensive source of data on disabled people living in New Zealand. It provides information on the needs of disabled people and the nature of their impairments. In 2013, 1.1 million New Zealanders identified as living with a disability and the survey allows these people to have their voices heard.

The survey collects information about both disabled people and people who do not have a disability. Disabled and non-disabled people are interviewed, and adults living in residential facilities are also interviewed.

The information helps us know:

- how many disabled people live in New Zealand.
- what kinds of disabilities people have.
- how people became disabled.
- what kind of support and how much support people need.

Information collected includes the nature, cause and duration of impairments. The survey also looks at issues such as human rights, social attitudes, education and employment, recreation and lifestyle, public services, and support systems.

Results from the 2013 New Zealand Disability Survey showed that:

- the most common disability type for adults were physical disabilities.
- diseases or illnesses were the most common cause of disability for adults, followed by accidents or injuries, and ageing.
- the most common type of accident or injury causing disability was one that occurred at work.
- just over half of all disabled people (53%) had more than one type of impairment.
- the most common causes of disability for children existed at birth, and 52% of these children had difficulty learning.
- the percentage of people with disability increased with age, from 11% for children under 15 years old, to 59% for adults aged 65 years and over.
- Māori and Pacific people had higher-than-average disability rates.
Definitions of disability

The way that disability is perceived has changed over the years. Disability, for most of the 20th Century, was considered in the medical model concept. This model assumes medical care and management of the condition is required, with disability being ‘something wrong’ and that had to be ‘fixed’. This ‘fix’ was often residential accommodation where the special needs of the person could be met alongside others with similar needs.

The prevailing model is the social model of disability, as has been adopted in the New Zealand Disability Strategy. This view is that disabled people are unable to fully participate in society because of limitations placed upon them.

The United Nations Convention on the Rights of Persons with Disabilities, Article 1 states: ‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’


The International Classification of Functioning, Disability and Health (ICF) define disability as ‘an umbrella term for impairment, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition, eg cerebral palsy, down syndrome and depression, and personal and environmental factors, eg negative attitudes, inaccessible transportation and public buildings, and limited social supports.’

www.who.int/mediacentre/factsheets/fs352/en/

The World Health Organization’s, International Classification of Functioning, Disability and Health (ICF) can be found at www.who.int/classifications/icf/en/index.html

The ICF is also available at www.disabilitaincifre.it/documenti/ICF_18.pdf

The New Zealand Ministry of Health’s definition of disability determines who is eligible for the range of disability support services they fund, ie, ‘a person with a disability is someone who has been assessed as having a physical, intellectual or sensory disability (or a combination of these) that is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.’

As a person moves through different stages of their life, they will need different support. Often the biggest challenge can be trying to find out what is available and getting support in place.
## Examples of physical disabilities

<table>
<thead>
<tr>
<th>Health condition</th>
<th>Age of onset</th>
<th>Examples of impairment (there may be others)</th>
<th>Examples of activity limitation (may be others)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral palsy</td>
<td>Within the first 3 years.</td>
<td>Weak muscles. Uncontrolled movements.</td>
<td>Unable to walk independently.</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>Before birth.</td>
<td>Bladder control.</td>
<td>Unable to maintain continence.</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>Any age, but commonly before teenage years.</td>
<td>Muscle weakness.</td>
<td>Need to use a wheelchair.</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>Usually 20 – 40 years.</td>
<td>Fatigue.</td>
<td>Tires easily.</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>Usually infancy or childhood (depends on cause).</td>
<td>Enlarged head.</td>
<td>No limitations when condition controlled.</td>
</tr>
<tr>
<td>Stroke</td>
<td>Any age.</td>
<td>Damage to the speech area of the brain.</td>
<td>Difficulty speaking and/or finding words.</td>
</tr>
<tr>
<td>Head injury</td>
<td>Any age.</td>
<td>Poor concentration.</td>
<td>Cannot complete tasks.</td>
</tr>
<tr>
<td>Arthritis</td>
<td>Any age.</td>
<td>Inflamed and painful joints.</td>
<td>Unable to open cans, containers, medicine bottles.</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Any age.</td>
<td>Low blood glucose levels can cause shakiness, confusion, and personality changes which can be mistaken for drunkenness.</td>
<td>Dietary and alcohol restrictions can be difficult for social occasions.</td>
</tr>
</tbody>
</table>
Think about a person you are supporting who has a physical disability, and then answer the questions.

What is the disability?

When did it start (age of onset)?

What kind of impairment do they have?

What actions are limited?

What effect does this have on their life?
Common causes of disability

Disabilities are generally present at birth, or caused as a result of a trauma, or a health incident.

Congenital disability

A congenital disability is one that is present from birth as a result of either heredity or environmental influences.

A congenital disability exists at, and usually before birth and may be either hereditary or due to an influence occurring during gestation up to the moment of birth. The person may fully or partly adapt to their impairment. Some examples include cerebral palsy, spina bifida, hydrocephaly, and muscular dystrophy.

Result of trauma

A physical disability can occur following an injury or accident. A trauma can occur at any stage of life and the person’s ability to adapt to their impairment can vary according to the extent of their injury, for example, a head or a spinal injury.

Health incident

Health incidents usually result from the long term effects that occur with a chronic or ongoing health condition. For example:

- degeneration of joints causing arthritis may result in difficulty with mobility.
- a stroke can permanently affect the person’s communication and mobility.
There can be many different things causing disability. The degree of disability will vary from person to person. A disability may be:

- **partial**, affecting a person's capabilities to a limited extent. For example, a person who has reduced mobility following a stroke.
- **total**, for example, a person paralysed following a car accident.
- **temporary**, which lasts for a limited time. For example, a person has limited mobility following an operation.
- **intermittent**, occurring at irregular intervals. This may be as a result of a health condition that fluctuates over time. For example, multiple sclerosis.
- **permanent**, which lasts for life and is unlikely to improve over time. For example, spina bifida.
- **congenital**, existing at birth. For example, cerebral palsy.
- **acquired**, as a result of injury or illness. For example, a trauma or chronic health condition such as arthritis.

People living with a disability are likely to require support with many aspects of daily living.
Common effects of disability

Disabilities are often described by their characteristics and the effects they have on the person. These effects impact on the support needed.

Muscle control

Muscle control is the ability of the person to control the use of their muscles voluntarily. This ability to control muscles can vary from person to person even if they have the same disability.

Reduced muscle control can affect:

- the arms and can range from no control over muscle movement to normal coordination.
- the legs and can range from an inability to stand to mild difficulty moving to a standing position.
- walking - resulting in an unusual or uneven gait.
- the trunk resulting in difficulty sitting up straight or maintaining an upright position.
- the face and throat resulting in difficulty eating and speaking.
- the bladder and bowel and may result in a loss of control.

Body function and hygiene

Physical disabilities often affect the way a person is able to function. This can affect personal care, hygiene requirements and support needed.

For example, a person with muscular dystrophy finds it difficult to raise their hands above their shoulders, making it hard for them to comb or wash their hair. A person with arthritis in the fingers and wrist may find it painful to wash their hair.

Bathrooms may need to be altered to make showering and using the toilet easier. A shower chair is helpful. A person with multiple sclerosis may have difficulty coordinating and balancing in the shower and may get fatigued easily.

Larger size facilities may be needed for people in wheelchairs or using a walking frame, for example people with spina bifida, spinal injuries or a neuromuscular disorder. Hand rails for the shower and toilet are also helpful.

Bathrooms and toilets need to have easy of access and be close by. People with multiple sclerosis or muscular dystrophy may have weak lower limbs and tire easily, so getting to the toilet may take a lot of time and energy.
Control of the bladder and bowel may be affected, with bladder dysfunction and incontinence. Difficulties with bowel and bladder function may also lead to urinary tract infections.

**Cognitive ability**

Cognitive ability relates to intellectual functioning - the way a person gains and processes knowledge, and then retains that knowledge to use in the future. It includes the capacity to reason, remember, understand, and problem solve.

For many people however, the ability to learn is unaffected by a physical disability and it is the physical environment which forms the greatest barrier. People whose disability is more variable and/or degenerative may have to have greater support if they are to achieve their learning goals. A disabled child may have both physical and intellectual disabilities which makes learning more difficult.

Additional factors a person with a physical disability may frequently have to cope with and which can affect their cognitive function and learning include:

- **tiredness** - having a physical disability might mean that the person has to work very hard at activities that others take for granted.
- **balance** and coordination difficulties - carrying books and equipment, or moving around a crowded room can present difficulties.
- needing to **rest or move around** at regular intervals.
- **communication** difficulties, for example, writing or unclear speech, especially when tired.
- problems of **perception**, for example, hand/eye coordination or difficulty judging space, distance and speed.
Mobility

Mobility is about the way a person moves. Impaired mobility is a reduction or loss of independent purposeful physical movement of the body or of a limb. There are many health and disability related conditions which can lead to difficulty with mobility.

The person may need to use equipment to assist them to move, for example, a wheelchair, walking stick or frame. They may need assistance to transfer between mobility aids.

Mobility aids may:

- improve access to buildings, transport or outdoor activities.
- possibly may reduce access due to the bulky nature of some aids.
- draw attention to the impairment.
- require the assistance of another person. For example, using a manual wheelchair.
- be essential for day-to-day life for some people.

Make sure any mobility aids or equipment are nearby and that you know how to use them.

Support to transfer between mobility aids
Supporting a person with a disability

A person living with a disability is just that - a person with a disability. This person has the same needs as everyone else in the community for a place to live, finance to live on, ability to go places, communicating with others, and the activities of daily living like eating and dressing.

The prevailing social model of disability is that disabled people are unable to fully participate in society because of limitations placed upon them. With support, disabled people will be more able to participate in the community.

<table>
<thead>
<tr>
<th>Needs</th>
<th>Implications for a person with a disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing</td>
<td>Their house will need to be convenient and accessible so that the person can live on their own or with others of their choosing. For example:</td>
</tr>
<tr>
<td></td>
<td>• wheelchair ramps instead of stairs;</td>
</tr>
<tr>
<td></td>
<td>• modified bathrooms to make showering and using the toilet easier;</td>
</tr>
<tr>
<td></td>
<td>• kitchens configured for easier meal preparation and clean up.</td>
</tr>
<tr>
<td>Mobility and access</td>
<td>This means access for wheelchairs, private vehicles or an ‘accessible’ taxi service, public transport and easy access to places of work, study, leisure, shopping and social support.</td>
</tr>
<tr>
<td>Finance</td>
<td>Having sufficient income to pay for all their requirements for daily living, including the cost of services they cannot provide themselves.</td>
</tr>
<tr>
<td>Personal assistance</td>
<td>Suitable support and help to do the tasks they cannot do for themselves. People living with a disability are likely to require support with many aspects of daily living.</td>
</tr>
</tbody>
</table>

There may be financial implications for people with a disability who need to reduce their work hours or give up work. They may need significant time to attend health related appointments or require additional support to function independently.

When you are supporting a person with a disability, they will have a detailed personal plan which you will need to follow closely.

You may need specific training for the support your organisation requires you to give. You must work within the boundaries that your organisation requires.
There are also many resources in the community that can support people with a disability. You should make yourself aware of these supports.

**Physical support**

These are supports which help the person in a physical way, such as support with showering, accessing a wheelchair, health-related needs, or administration of medications.

This learning guide focuses on how daily living is affected by disabilities and the role support workers have in activities of daily living.

**Cognitive support**

Cognition is the ability to know, think, perceive, recognise, and remember. Support workers play a role by doing things such as prompting a person when required, teaching new skills in logical ways and helping with problem solving.

Communication support (including speech and language therapy) may be needed because of the effects of some disabilities. Use of technology and aids for communicating and learning may be required.

**Social support**

These are supports which help the person to interact and have contact with their friends, families, and the community. Support workers play a vital role in ensuring that people with physical disabilities are able to have their social needs met.

This could be by facilitating opportunities to build and maintain friendships, helping a person maintain contact with family, assisting with transportation and helping the person to access community facilities.
**Access**

Access can place limitations upon where a disabled person can go, especially independently. The layout of a building, and poor access to buildings and outdoor areas can mean that a person with mobility impairment may not be able to easily enter a building. It may even mean they cannot attend their marae or a restaurant with whānau/family or friends.

When an abled bodied person parks in a signed mobility car park space at the supermarket it can make life more difficult for a person with walking, balance or gait difficulties. It may result in the disabled person not being able to do their shopping.

Some types of public transport and facilities, or services which are too inflexible (times and places), may make it difficult for the person with a disability to easily use them. People who live with a physical disability can experience a variety of day-to-day difficulties and **good access** and **non-slip surfaces** can ease some of these difficulties.

<table>
<thead>
<tr>
<th>Access considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levels</td>
</tr>
<tr>
<td>Parking</td>
</tr>
<tr>
<td>Path of travel</td>
</tr>
<tr>
<td>Lighting</td>
</tr>
<tr>
<td>Entries</td>
</tr>
<tr>
<td>Floor surfaces</td>
</tr>
</tbody>
</table>
Ways to interact in a positive way

Avoid using ‘labels’
When identifying a person with an impairment, the person’s name should come first, and descriptions of the impairment/disability should be used so that the impairment is identified, but is not used to negatively describe the person. For example, Joe has cerebral palsy.

Take time to listen and understand the person
A person with a disability may talk slowly, slur their words, and be difficult to understand at times. This does not mean that they can’t understand you or don’t know what to say. Give them time to respond. As you get to know the person, you will better understand their verbal and non-verbal language.

Use positive language
Equipment should be described as something that assists a person, not as something that limits a person for example the person ‘uses’ a wheelchair rather than the person is ‘confined’ to a wheelchair.

Use age appropriate language
This means using communication methods and language that is relevant to the person’s age. For example, when talking with a teenager you might use colloquial language that might be less acceptable to an older person. Do not use ‘baby talk’ when talking to an adult. Do not talk loudly and slowly to someone who is quite capable of understanding.

Other ways to provide support include:
- Treat the person as you would want to be treated.
- Look, listen, understand the person and their disability.
- Make sure any mobility aids or equipment are nearby and that you know how to use them.
- Be aware of any difficulties the person may experience in the environment, for example, changes of level.
- Observe and report any changes that may indicate medical complications are developing.
Cerebral palsy

Cerebral palsy is a term used to describe a group of specific conditions which affect movement and posture. ‘Cerebral’ refers to the brain and ‘palsy’ to muscle weakness and poor control.

A person with cerebral palsy has damage to areas of the motor areas of the brain, which control movement. This results in permanent difficulty sending messages from the brain to control different muscles.

The type of cerebral palsy will depend on the area of the brain damaged and can cause mild impairment (such as difficulty walking) to significant impairment requiring a high level of support and assistance with mobility.

A characteristic of a cerebral palsy is a person may experience weak and stiff muscles or uncontrolled movements. Movements may appear stiff and jerky because the muscles are contracted and tense, even though they are weak. ‘Spasticity’ describes the tone of muscles or how tight they are. Coordination may be affected which can result in problems with balance and coordinating movement.

You may notice that people with cerebral palsy can have problems such as weakness, stiffness, muscles spasms, unwanted muscle movements, floppiness, an awkwardness of movement, slowness, shakiness and difficulty with balance.

In mild cerebral palsy, the person may be slightly affected in one arm or leg and the problem may be barely noticeable.

When the effects of cerebral palsy are more severe the person may have a lot of difficulties, with the whole body affected. For example, some people with cerebral palsy will have difficulty talking, walking or using their hands. Some will be unable to sit up without support and will require help to do most everyday tasks.

Cerebral palsy can affect the way the person walks, for example, on their toes, with an unsteady or ‘scissored’ gait, or dragging one leg.

Cerebral palsy is usually diagnosed in infancy or early childhood. It can occur before or during birth, or in early childhood. Cerebral palsy does not get worse over time, however, the effects of the disability may become more apparent with age. Although the cause may be unknown, cerebral palsy can be the result of an accident or illness such as:

- a pre-natal rubella infection.
- asphyxia (lack of oxygen to the brain).
- a premature birth.
- childhood diseases, for example, meningitis.
- a car accident causing a head injury.
How cerebral palsy affects daily living

Cerebral palsy can:

- limit mobility requiring the use of aids such as a wheelchair, callipers, braces or other walking aids.
- cause difficulty with everyday activities such as standing, walking, sitting, eating and drinking. Aids can simplify the basic tasks of everyday living such as eating, grooming and dressing.
- cause absent speech, or slurred speech.
- require the use of communication aids such as boards, signing or technological aids.
- lead to some difficulty in reading and writing because of perceptual problems for some people.
- cause coordination difficulties.

Providing support

To assist people with cerebral palsy you need to use the support methods described earlier in this workbook and those listed below.

- Direct your conversation at the person. Do not overlook them by carrying on your conversation with a person who is with them, or assume they are unable to understand.
- Take care when serving hot drinks or food. Make sure the food/fluids are at the desired temperature.
- Provide any eating utensils necessary. Make sure they are readily available at the time and in the place required.
- Find the best way to communicate with the person, for example, using an aid, sitting at their level and maintaining eye contact. Be willing to communicate in different ways and remember each person is an individual.
- Be patient when talking to someone with a communication difficulty. Resist the temptation to interrupt or to answer on their behalf. At first the person’s speech may be difficult to understand, but with practice, you will both get better at communicating.
- Make sure any mobility aids or equipment are ready nearby and that you know how to use them.
Write

Read the following scenario and answer the questions.

Richard has lived with cerebral palsy all his life although it was not diagnosed until he was almost two years old. His physical development milestones were delayed and he could not roll over or sit up on his own until much older than other children. When he did start to walk, his parents noticed that he walked with an unusual scissor like gait with his toes turned inwards which seemed to be the best way for Richard to maintain his balance.

As he got older Richard had some muscle spasms and pain, but this did not stop him completing his education and getting a full time job. Richard flats with a friend and lives independently, apart from some personal care support morning and night from a support worker. He drives an automatic car and enjoys a busy social life.

What impairment and effects does each of the following have on Richard’s life?

Muscle control:

Body function and hygiene:

Mobility:

Cognitive ability:

What supports does Richard need to ensure quality of life and wellbeing?

Hint: Think about the answers to these same questions when you read about other disabilities.
Spina bifida

Spina bifida (meaning ‘split spine’) is a developmental condition known as a neural tube defect. It involves incomplete development of the brain, spinal cord, and/or their protective coverings in the first six weeks of pregnancy.

Some of the vertebrae (the small, ring-like bones that make up the spinal column) which normally protect and cover the nerves of the spinal cord do not close over. Consequently the spinal nerve tissue can protrude through the gap and form an open swelling on the back. This could occur anywhere from the back of the head to the bottom of the spine. Even though surgery at birth can close the gap, the damage to the spinal nerve tissues cannot be repaired.

Spina bifida may be caused by a combination of genetic and environmental factors. Folic acid deficiency has also been linked to spina bifida. Researchers believe that women should take folic acid before they become pregnant to help reduce the risk of neural tube defect.

Spina bifida can take a number of forms, from hidden, to severe, which may involve some paralysis and loss of sensation in the legs and lower trunk. Loss of sensation can make it difficult to recognise pressure, friction or temperature changes.
How spina bifida affects daily living

- The effects of total or partial paraplegia results in the person likely to need some form of mobility aid, for example, callipers, crutches, wheelchair or walking frame.
- Shunts used to drain fluid from the brain (hydrocephalus) may become blocked, infected or disconnect. Problems with shunt malfunction may result in drowsiness, headaches, vomiting, irritability and an increase in head size, which may require frequent oversight from health professionals.
- The person may have vision impairment and/or learning problems.
- They may have bowel and bladder function difficulties and urinary tract infections.
- Poor sensation of the lower limbs requires good skin care to prevent grazes, burns and bruises.

Providing support

Assisting a person with spina bifida is similar to supporting people with other forms of physical disability.

A specific way to assist a person with spina bifida is to change their posture to prevent pressure sores occurring.
Muscular dystrophy

Muscular dystrophy (MD) is a neuromuscular disorder. Neuromuscular disorders affect the nerves that control voluntary muscles (the ones that a person can control, for example, an arm or leg). Nerve cells send the messages from the brain, via the spinal cord to the muscles which then create a movement.

When some part of this communication system is damaged the messages are either reduced or stopped resulting in muscle weakness and wasting. This weakness can lead to twitching, cramps, aches and pains, as well as joint and movement problems. Sometimes it also affects heart function and the ability to breathe if MD involves these particular muscle groups.

There are more than 30 genetic diseases in the muscular dystrophy group. People with MD have incorrect or missing information in their genes, which prevents them from making the proteins they need for healthy muscles.

MD is characterised by progressive weakness and wasting of the skeletal muscles that control movement.

Muscular dystrophy can appear in infancy or childhood, or may not occur until middle age. The group of disorders vary according to the extent of muscle weakness, age of onset, and rate of progression. Impairment may be mild to severe.

How muscular dystrophy affects daily living

People with muscular dystrophy may have:

- the need to use a wheelchair at an early stage.
- limitations in body functions.
- difficulty carrying out activities where there is a need to lift hands above the shoulders, for example, to comb hair.
- difficulties with steps and stairs due to weakened lower limbs.

Providing support

Assisting a person with muscular dystrophy is similar to supporting people with other forms of physical disability. In particular, avoid prolonged activity which can easily tire weakened muscles.
Multiple sclerosis

Multiple sclerosis (MS) is also a neuromuscular disorder. It is a disorder affecting the central nervous system in which communication between the brain and other parts of the body is disrupted. It is the most common disabling neurological disease among young adults and is most often diagnosed in people between the ages of 20 and 40 years old. Women are almost twice as likely to develop MS as men and it is more common in countries further away from the equator.

MS is life long and the cause remains unknown. Researchers believe it may be that the body, through the immune system, attacks its own tissues.

There is a protective covering called myelin which surrounds the nerve fibres in the body. This covering is like insulation around each nerve fibre and helps messages travel quickly and smoothly between the brain and the rest of the body. People who have MS have some disruption to this message system when the nerve-insulating myelin is ‘attacked’ and begins to deteriorate.

MS is unpredictable, causing mild to severe disability. It can progress very slowly, rapidly, or more gradually when it may ‘wax and wane’.

Symptoms vary from person to person. Some symptoms may be:

- blurred or double vision.
- abnormal feelings such as numbness or ‘pins and needles’ in hands and feet.
- muscle weakness especially in lower limbs.
- difficulties with coordination and balance.
- tiredness.
- difficulty concentrating and remembering.
- depression.
- bladder dysfunction.
- speech or swallowing difficulties.
- spasm or tremors.
Some people require no treatment, or may benefit from drug therapy, and/or physiotherapy.

**How multiple sclerosis affects daily living**

MS usually has very little effect on a person’s life span, except in some very severe cases. Staying healthy is particularly important for people with MS. Symptoms and sometimes the medications used to treat the disease can impact on a person’s mobility, energy level, eating habits, and feelings, which can affect general wellbeing. The person needs to plan activity to avoid becoming overtired.

People with MS also have to adjust to fluctuating health and energy levels. Child care and household tasks may no longer be easy for the person with MS. This can place additional stress on a family. People with MS may need to reduce their work hours or give up work as they may need significant time to attend health related appointments.

People with MS may require additional support to function independently. Ensuring that people are aware of the supports available and how to access them, especially during periods of relapse, is also important.

**Providing support**

Supporting the person to maintain good general health is an important part of living with MS. Most people will manage independently for long periods, but you may be required to support some people during periods of relapse or in the advanced stages.

Key health areas include:

- maintaining a healthy diet and including aerobic exercise (exercise that raises the pulse and respiration rate) to improve fitness and energy levels. Some people also find alternative therapies helpful.
- maintaining a healthy immune system and avoiding infections which can lead to relapses.
- trying to keep cool - overheating the body can cause symptoms to get temporarily worse.
- avoiding stress and fatigue - there can be an increase in relapses during or right after periods of extreme stress. Fatigue makes all symptoms of MS more difficult to deal with.
Write

Read the scenario below and answer the questions.

Ginny was a gifted student at school and university. She enjoyed the activities most young people do and was always busy with friends, shopping, travelling, going to movies and listening to her iPod. She had endless energy, and worked long into the night to finish her university assignments. Then Ginny noticed that she became more tired and started to drop things. She seemed to lose sensation in her fingers and sometimes her feet had ‘pins and needles’. However this passed and she had no more problems for three years.

While away on her OE, the symptoms returned so she went to see a doctor. After tests, she was told that she had MS. Although the MS comes and goes, there are times when Ginny is really weak and unable to even use a can opener. She gets so tired that she can barely have a shower and wash her hair without help. Afterwards she has to rest just to get over the exertion, before she begins to dress herself. She also finds it difficult to concentrate and forgets that she has watched a DVD many times before. Ginny has had to think about her goals and how she can achieve them now that she has MS.

What impairment and effects does each of the following have on Ginny’s life?

Muscle control:

Body function and hygiene:

Mobility:

Cognitive ability:

What supports does Ginny need to ensure quality of life and wellbeing?
Hydrocephalus

The term hydrocephalus comes from the Greek words ‘hydro’ meaning water and ‘cephalus’ meaning head, hence the term ‘water on the brain’.

Hydrocephalus occurs when there is a build-up of cerebrospinal fluid (CSF). The build-up in the ventricles (cavities) of the brain causes abnormal enlargement which can affect the whole head. It is related to problems with CSF secretion, flow or absorption.

CSF is a clear water-like fluid that protects the brain and the spinal cord and carries away waste from the brain cells. Any excess CSF usually drains away from the brain and is absorbed by the body. For people with hydrocephalus, this doesn’t happen, and the fluid builds up in the ventricles, producing pressure on the brain.

Hydrocephalus can be congenital, or develop later (acquired) in childhood or adulthood. In infants, the key sign of hydrocephalus is an abnormally large head. In children, hydrocephalus is usually diagnosed before or at the time of birth, or in early childhood. In older children and adults, symptoms of hydrocephalus include headache, nausea, vomiting, and blurred vision.

Normal pressure hydrocephalus (NPH) is a type of hydrocephalus, which usually develops in people over 60, because the drainage of the CSF gradually becomes blocked. It can be an unusual cause of dementia or develop after a brain infection.

How hydrocephalus affects daily living

Hydrocephalus is most often treated with surgery which places a small flexible tube (shunt) in the brain to divert the flow of CSF so that it can be absorbed into the body. Once treated, the impact on daily life is usually related to other health conditions which may be present. For example, some individuals with spina bifida also have hydrocephalus. There may be difficulty with learning, motor skills, vision and seizures. There may be complications associated with the shunt itself.
Providing support

When a person has a shunt, they (and you) need to be aware of the possibility of blockages and infections. Seek advice for symptoms such as fever, sore neck or shoulders and any redness along the line of the shunt.

The person also needs to think about the types of physical activities they do.

Write

Read the following scenario and answer the questions.

My only daughter, Karina, is now 13 years old, and has hydrocephalus. She was diagnosed when I took her in for her 3-month well baby check-up. She had a shunt inserted almost straight away at the Children’s Hospital.

When she was an infant, I would have given anything to know what to expect as she grew up. She had to go back to hospital a number of times because the shunt blocked. Sometimes it seemed that we were always in the hospital, and this was made worse because we lived two hour’s drive away.

My two older boys really missed us when we were away, so Karina’s problems affected everyone. As she got older though, there have been hardly any problems. Karina reached all her milestones, and has had no problems learning, playing sport and keeping up with her friends!

How has this affected Karina’s daily living?

What things does Karina need to be aware of to maintain her health?

What supports does Karina need to ensure quality of life and wellbeing?
Spinal injury

Spinal injury is usually the result of an accident, for example, a car crash, diving incident, pedestrian or sport accident. The vertebra of the spine are displaced or crushed, which injures the spinal cord or the spinal column.

This damage interrupts or stops messages to and from the brain, resulting in paralysis, which is loss of function and feeling in the area below the level of the injury. This usually means that the person will need to use a wheelchair. Muscle spasms in paralysed muscles can occur and make the condition worse. Damage is usually permanent and irreversible and requires a long period of treatment and rehabilitation.

The body also has another system which controls the involuntary functions of internal organs and glands - the autonomic nervous system. These include the automatic functions of breathing, blood circulation and sweating as well as messages to and from the bowel and bladder and male sexual function. Damage to the spinal cord will usually affect the autonomic nervous system to some degree.

Types of spinal injury

Paraplegia

Where the spine is injured below the level of the neck the person will be paralysed to some degree in the legs and abdomen.

Quadriplegia

Where the spine is injured in the neck region, leading to partial or complete paralysis of the arms as well as the lower body and limbs. All four limbs are affected and the person is said to be quadriplegic or tetraplegic. The chest muscles will also be affected and the person may have difficulty with breathing, coughing and clearing their chest.
How a spinal injury affects daily living

People living with a spinal injury are likely to require support with many aspects of daily living to support them to do the tasks they cannot do for themselves, such as personal cares.

Mobility and ease of access are constant challenges.

So that the person can live on their own or with others of their choosing their house will need to be convenient and accessible. For example, modified bathrooms to make showering and using the toilet easier and kitchens configured for easier meal preparation and clean up.

Providing support

If you are supporting a person with a spinal injury, you will need to fully understand their disability, abilities and degree of injury - in other words, the individual needs of the person. This information can be found in the person’s personal plan, which will have been developed with the person and reviewed over time.

Support needs will usually include:

- personal care and hygiene requirements.
- bladder and bowel management.
- skin care.
- food and fluids.
- exercise programmes.

Support may include leisure and social activities.

It is likely that you will need to have additional and specific training in the support requirements for the person.
Head injury

Head injuries can take many forms. These include skull fractures, blood clots between the brain and the skull, and concussion, which may cause loss of consciousness without other visible damage to the skull.

**Brain damage** can occur, even if the skull itself is undamaged, because the brain may move around inside the skull with enough force to cause bruising and bleeding. A brain injury is a head injury affecting the internal part of the head underneath the skull bones.

The most common causes of head injuries are road crashes, sports injuries, falls, workplace accidents, assaults and bullet wounds. The head may be damaged both from direct physical injury to the brain and from secondary factors including lack of oxygen, swelling of the brain and loss of blood flow to the brain. Swelling may cause the brain to push against the skull, blocking the flow of blood and oxygen to the brain.

A person with a **mild head injury** often recovers completely. Some symptoms however, may last for up to a year after the accident. These symptoms include headache, dizziness and an inability to think clearly and this can affect a person’s ability to work and to deal with other people.

**Severe head injuries** can often produce permanent physical or mental disabilities. Other complications such as epilepsy can develop.

Recovery from a severe head injury can take many years, with the length of recovery linked to age, the length of time the person was unconscious following the injury, and the extent and location of injuries.

**How a head injury affects daily living**

After a head injury a person may experience a period when their brain does not function normally. The person may become confused, have partial memory loss and lose the ability to learn or remember normally. Some people have memory loss (amnesia) that can last for a few weeks or months, with their memory only returning slowly over time.

The person may also experience vomiting, dizziness, partial paralysis or numbness, shock or anxiety.
Symptoms of brain damage and providing support

The recovery process for head and brain damage is different for everyone. No two head injuries are alike and recovery can typically take months or years because the brain takes a long time to heal.

The person will need lots of rest and may need to write things down to help with memory problems. The effect of the injury can lead to temporary or permanent changes in personality, memory and behaviour.

Personality changes

These are often an exaggeration of the person’s pre-injury personality in which personality traits become intensified. Some changes can be quite striking. It may be, for example, the person used to be easy going, energetic and thoughtful, but now seems easily angered, self-absorbed and unable to show enthusiasm for anything. Try not to compare them with ‘how they were before’ the injury.

Memory loss

Memory loss can be an issue. Usually new learning is the most difficult for the person, while longer term memory is less affected.

Helping the person focus and concentrate are the keys to short-term memory problems. Keep distractions to a minimum and try to focus on one task at a time.

Be patient when supporting a person to learn or relearn daily activities. Keep to a sequence.

Using a list to outline a routine, along with repetition, makes it easier to remember what is expected and what to do next.

Keep to routines, and keep household objects in the same place.

Have the person repeat the name of a person or object. Get them to write down key information, for example, appointments, phone messages, and a list of chores.

If getting lost is a problem, label or colour code doors.

Accompany the person when they start going out. Use a simple map. Always use the same route. Make sure the person carries their address and emergency phone numbers written down.
Behaviour changes

A change in behaviour, personality changes, poor memory, poor judgement, lack of control, impulsiveness, and poor concentration are all common.

A person may lack emotional responses, especially during the earlier stages of recovery. You can help by modelling the expected behaviour, for instance, smiling at a joke. They may have intense mood swings or extreme reactions to everyday situations, which is called lability. Reactions may be sudden, so it is helpful if you show calm behaviour. Help the person recognise when their emotional responses are under control and reinforce techniques that work.

Difficult behaviour is stressful, frustrating and challenging for families and support workers alike. Being realistic and learning to recognise the best way to communicate and support the person are important things in their recovery.

Difficult behaviour

Sometimes an injury to the brain can cause some changes in behaviour which can be unpredictable and difficult to control. This can put the person you support, other people and yourself at risk. Knowing how to respond in these situations is an important part of the support you give.

A person may become aggressive. Remain as calm as you can and where possible try to ignore the behaviour.

When supporting a person with aggressive behaviour:

- avoid arguments.
- try to reduce the underlying frustration and acknowledge that loss of functional and/or cognitive abilities is normal.
- avoid challenging or confronting the person. Rather try to negotiate.
- help the person regain a sense of control by involving them in decisions that affect them and giving choices that are manageable.
- if necessary isolate the person and consider your own and their safety.
- offer alternative ways to express anger. For example, a punching bag, a gripe list.
Stroke

Strokes occur when blood flow to an area of the brain is interrupted resulting in death of brain tissue. It is a major cause of permanent disability. Blood brings oxygen and nutrients to the brain cells and also removes waste products from cells. Without blood, brain cells quickly begin to die.

Two-thirds of all strokes occur in people over the age of sixty-five, but can occur in infants, children and younger people. 25% of people who recover from a stroke have another stroke within five years.

A stroke is also called a cerebrovascular accident or CVA.

There are two main types of stroke:

**Ischemic** – caused by a blockage in an artery that supplies blood to the brain, resulting in reduced blood flow and small clots forming in the brain or elsewhere in the body.

**Haemorrhagic** – caused by the bleeding of ruptured blood vessels in or around the brain. Sometimes this type of stroke can be treated by surgery to seal the bleeding blood vessels.

How a stroke affects daily living

The effects of a stroke depend on the part of the brain affected and can result in:

- hemiplegia (paralysis on one side of the body) or hemiparesis (weakness on one side). This affects independence and quality of life.
- problems with thinking, awareness, attention, learning, judgment, and memory.
- problems understanding or forming speech.
- difficulty controlling emotions or expresses inappropriate emotions, eg, tearfulness.
- depression and fear of further strokes.
- numbness and pain – often worse in the hands and feet and is made worse with movement and temperature changes, especially cold temperatures.
- damage to throat muscles causing difficulty swallowing normally. Food may get into the lungs, causing pneumonia or other infections. This may mean changing the texture of food or thickening fluids.
Rehabilitation can be a slow process because brain cells damaged by a stroke do not grow back. Surviving brain cells can sometimes learn new functions and some recovery is possible. For example, areas of the brain that were not previously responsible for the ability to speak may ‘learn’ how to control speech.

Rehabilitation is aimed at recovery of normal functions to the extent possible. The person may also need to relearn some functions to take the place of those lost by the stroke.

Of people who have a stroke, 10% recover completely; 10% experience severe disability; 80% regain a good level of independence following therapy and with support services.

Providing support

Supporting a person following a stroke is critical for their recovery. The personal plan will guide you on their level of independence and the focus of their rehabilitation programme.

You may need to:

- assist with physical exercise which is aimed at improving mobility, strength and balance.
- place mobility aids and assistive devices within reach of the person.
- keep the environment safe, with easy access to toilets and bathrooms. Remember, the person may have reduced ability to gauge distances, doorways and obstructions because of changed side vision and perception problems.
- encourage the person to do speech exercises and to swallow correctly.
- encourage self-care and independence wherever possible and assist the person to seek support, for example, from the stroke foundation.
Imagine you if you had a stroke, and think about how this would affect the way you currently live.

What do you do now that you may not be able to do if you had a stroke?

How would this make you feel?

What would you need support with?
Arthritis

Arthritis means ‘inflammation of a joint’. Arthritis affects joints, making them stiff, painful and swollen. Damage to joints can lead to long term disability and may be complicated by pain restricting mobility.

More than half a million New Zealanders will be affected by arthritis at some time in their life. Although many older people do have arthritis, some forms of arthritis affect young children and adults. There are 1000 children and young people under the age of 20 with arthritis in NZ.

There are more than 100 types of arthritis. The common factor for all these types is joint and musculoskeletal pain. Sports and other similar injuries can lead to arthritis. There is no known cure.

Common types of arthritis

- **Osteoarthritis** is commonly associated with older age. The person experiences pain and joint stiffness associated with the breakdown of the protective cushion of the cartilage over the ends of bones at a joint. Most often, it affects the big weight-bearing joints, for example, the spine, hips and knees or the hands.

- **Rheumatoid arthritis** tends to occur in younger people, especially women. The inflammation progressively damages joints, causing deformity usually at the wrists, knees, fingers and feet.

- **Gout** causes attacks of pain and swelling. It’s caused by the build-up of a waste product called uric acid in the blood. It’s most common in men. Most gout attacks will end of their own accord, but healthy lifestyle, diet changes and treatments can help.

How arthritis affects daily living

The physical effects vary according to the specific type of arthritis. It can involve pain from joint damage, poor bone alignment, or pressure on nerves from surrounding bone or tissue. Arthritis can also increase joint degeneration.

The treatment for arthritis is aimed at treating the symptoms. The goals of treatment are to reduce pain, reduce inflammation, minimise and/or prevent joint damage, and maximise joint movement. To achieve these goals a combination of treatments is usually recommended. These include medication, surgery, heat, exercise, or rest.

Providing support

Stiff and painful joints make activities of daily living difficult. For instance a person with arthritis in their wrist, hand or finger joints may have difficulty opening containers, such as tins of food, and preparing food and will need help with this.
Diabetes

People develop diabetes when the body cannot make (or properly use) insulin — a hormone that is released from the pancreas in response to the level of glucose (sugar) in the blood. If not enough insulin is being produced, the level of glucose in the blood will rise and this is harmful.

If diabetes is not adequately controlled the person will have a significantly higher risk of developing complications like hypoglycaemia and coma.

There are two types of diabetes that make it a chronic illness:

Type 1 diabetes means that the pancreas is not producing any insulin. The person will need to inject insulin, usually two times a day, to control the level of glucose in the blood. Food needs to be eaten within a certain period of time after injecting insulin otherwise the blood glucose level will become too low and the person will become hypoglycaemic.

Type 2 diabetes occurs when not enough insulin is being produced to cope with the amount of sugar in a person’s diet. It is usually caused by being overweight. Some people with this type of diabetes may need to inject insulin, but control is often achieved by a weight reduction diet and oral medication to manage blood glucose levels.

How diabetes affects daily living

A person with diabetes cannot simply eat whatever they like or whenever they feel like it. Dietary and alcohol restrictions can make social occasions less enjoyable. There is a need for a strict routine of monitoring and self-care may seem restrictive.

Wearing a “medic-alert” bracelet in case of emergencies can be seen as undesirable if it changes other people’s perception of the person.
Providing support

Controlling blood glucose levels can be done through a combination of medication, diet and exercise. Medication may be through injected insulin and/or tablets. The diet will need to be based around regular, small meals that limit carbohydrates and fats but include plenty of fresh fruit and vegetables. Physical exercise can help regulate blood sugar levels and circulation, and may also be a vital component of a weight loss diet.

Recognising and reporting on changes in physical condition and knowing how to deal with an emergency are important for a support worker to know about.

It is crucial to monitor blood glucose levels. If a person’s blood glucose level becomes too low, they are hypoglycaemic. The person may get shaky and confused, pale and sweaty or show personality changes. These signs can often be mistaken for the person being “drunk”.

It is important to raise blood glucose levels rapidly. A cheese sandwich is ideal. Some people will lose consciousness when they are hypoglycaemic and urgent medical attention will be needed.

Medication

Insulin injections may be required.