This Guide has been made possible through the generous support of the Ian Potter Foundation.
Independence Australia

Statement of Purpose

Independence Australia is a social enterprise that provides choices for people; living with a disability or other personal need, supporting them to regain and retain their independence.
# Care Now Carer’s Guide

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Care Now Carer’s Guide

Introduction

People caring for a loved one with a disability can lack confidence when undertaking a range of very complex tasks. Unpaid home carers often need immediate information and support whilst delivering care. In conjunction with our project partner, Carers Victoria, Independence Australia has developed this resource to provide user friendly and best practice information for unpaid carers.

We have provided this Care Now Carer’s Guide in order to provide:

- Background information about how to ensure health and safety at home while caring for a person with a disability;
- Insight into your key responsibilities and duty of care;
- Knowledge and skills in manual handling techniques used to transfer people;
- Knowledge and skills in tube feeding and bowel care;
- Useful ways to improve your health and well-being; and
- Information about how to empower, encourage and support the person to whom you are providing care.
Statement of Purpose

Independence Australia is a social enterprise that provides choices for people living with a disability or other personal need, supporting them to regain and retain their independence.

Values & Guiding Principles

We value equity, integrity, respect and quality. To demonstrate our commitment to these values, we adhere to the following guiding principles:

- Consumer Centred
  Ensuring that consumer choice and control is paramount in our decision making

- Committed People
  Encouraging and rewarding innovation and excellence, recognition and feedback

- One Organisation
  Sharing a common purpose supported by positive contributions, clear responsibilities and accountability

- Right First Time
  Promoting efficiency and effectiveness in everything we do
Our mission

Carers Victoria will provide advice, information and support for carers to improve their health, wellbeing, capacity, financial security and resilience.

Our values

Carers Victoria's values provide a touchstone against which individual, team and organisational behaviour can be aligned:

- Respect and dignity;
- Equity and diversity;
- Honesty and confidentiality;
- Integrity and accountability;
- Empathy and compassion; and
- Courage and fortitude.
Our core business

Carers Victoria will continue to build on our carer knowledge and expertise to provide evidence-based advocacy and services.

We will take a leadership role in:

- Listening to what carers tell us needs to change;
- Identifying and researching issues that affect caring families;
- Sourcing innovative and timely solutions for carers; and
- Representing the needs and issues of carers to businesses, Ministers, Government Departments and services providers.

Our core business will therefore focus on providing:

- Evidence-based research, policy and advocacy;
- Emotional support, counselling and peer group support;
- Practical support and respite;
- Information and advice;
- Guidance and referral when navigating the complex systems of care; and
- Engagement, education and development opportunities.

Source: www.carersvictoria.org.au
Chapter 1
Introducing the disability sector and legislation
The disability sector and legislation

As a carer it is important for you to have an understanding of the disability framework in Australia and the various stakeholders. It is also important to be aware of the legislation, regulations and charters which you are required to follow.
International Declarations and Charters

The UN Declaration of Human Rights

The Universal Declaration begins by recognising that ‘the inherent dignity of all members of the human family is the foundation of freedom, justice and peace in the world’.

It declares that human rights are universal – to be enjoyed by all people, no matter who they are or where they live.

The Universal Declaration includes civil and political rights, like the right to life, liberty, free speech and privacy. It also includes economic, social and cultural rights, like the right to social security, health and education.

The UN Convention of the Rights of Persons with a Disability

The Convention of the Rights of Persons with a Disability is an international human rights treaty of the UN intended to protect the rights and dignity of persons with disabilities. Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure they enjoy full equality under the law.

The Convention has served as the major catalyst in the global movement from viewing persons with disabilities as objects of charity, medical treatment and social protection towards viewing them as full and equal members of society, with human rights.

Australian and Victorian Legislation

Federal – Disability Discrimination Act 1992

The Federal Disability Discrimination Act 1992 (DDA) provides protection for everyone in Australia against discrimination based on disability. It encourages everyone to be involved in implementing the Act and to share in the overall benefits to the community and the economy that flow from participation by the widest range of people.

Disability discrimination happens when people with a disability are treated less fairly than people without a disability. Disability discrimination also occurs when people are treated less fairly because they are relatives, friends, carers, co-workers or associates of a person with a disability.
Victorian State Legislation

**Victorian Charter of Human Rights and Responsibilities**

The Charter is a Victorian law that sets out the basic rights, freedoms and responsibilities of all people in Victoria. It is about the relationship between government and the people it serves.

**Equal Opportunity Act 2010**

The objectives of the Equal Opportunity Act 2010 are to encourage the identification and elimination of discrimination, sexual harassment and victimisation and their causes, and to promote and facilitate the progressive realisation of equality.

**The Disability Act 2006**

The Disability Act provides for:

- A stronger whole-of-government, whole-of-community response to the rights and needs of people with a disability
- A framework for the provision of high quality service and support for people with a disability.

The Act sets out principles for people with a disability and for disability service providers. Disability service providers are the Department of Human Services and organisations that are registered under the Act to provide disability services.

**Occupational Health and Safety Act 2004**

There are 4 main objectives of the OHS Act:

- Prevent injury and disease to persons in the workplace;
- Protect the public from health and safety risks;
- Eliminate workplace risks at the source; and
- Involve employers, employees, and the organisations that represent them in the development and implementation of OHS standards.

OHS Regulations include issue resolution, manual handling, prevention of falls, plant, hazardous substance, consultation (asbestos, noise, confined spaces, licensing).

**Information Privacy Act 2000**

The objectives of this act are to:

- Balance the public interest in the free flow of information with the public interest in respecting privacy and protecting personal information in the public sector; and
- Promote the responsible and transparent handling of personal information in the public sector and promote awareness of these practices.
Health Records Act 2001
The Health Records Act 2001 created a framework to protect the privacy of individuals' health information. It regulates the collection and handling of health information and:

- Gives individuals a legally enforceable right of access to health information about them that is contained in records held in Victoria by the private sector; and
- Establishes Health Privacy Principles (HPPs) that will apply to health information collected and handled in Victoria by the Victorian public sector and the private sector.

Carers Recognition Act 2012
The Carers Recognition Act 2012 (the Act) formally recognises and values the role of carers and the importance of care relationships in the Victorian community.

The Act includes a set of principles about the significance of care relationships, and specifies obligations for state government agencies, local councils, and other organisations that interact with people in care relationships.

Federal Disability Insurance Scheme

National Disability Insurance Scheme (NDIS)
The National Disability Insurance Scheme (NDIS) is a new way of providing individualised support for people with permanent and significant disability, their families and carers.
Chapter 2
Health and Safety at Home
Introduction to Health and Safety at home

Every environment we perform tasks in can be considered a place of work, which has its own hazards and needs its own safety considerations.

Injuries that an unpaid carer may sustain during the course of their caring duties may be musculoskeletal disorders caused by unsafe manual handling tasks such as lifting and moving people, as well as pushing and pulling trolleys and equipment. Other significant risks include slips and trips, stress, bullying and violence.

For carers, this can mean pain and discomfort which sometimes lasts for years, affecting not only their ability to provide care but their everyday lives, families and relationships.

WorkSafe Victoria provides a Disability Services Occupational Health and Safety Compliance Kit, which provides practical advice about controlling the risks associated with the most common hazardous tasks in disability services.


Health and safety considerations at home and your duty of care

Based on the Health and Safety Act, here are some considerations relevant to caring for a person with a disability, and yourself, at home.

OHS Act Section 21

- You should maintain an environment that is safe and without risks to health.
OHS Act Section 21 (2)

- Maintain equipment and practices that are safe and do not pose health risks, e.g. having a safe process for transferring the person for whom you are caring.
- Have safe systems in regards to equipment and substances i.e. usage, handling, storage and transport of harmful substances (e.g. toxic chemicals).
- Provide a safe environment (e.g. controlling noise and lighting levels).
- Ensure you are well-informed; seek out further training as required to enable you to provide care safely and without risks to your, or your family member’s health.

OHS Act Section 25

Take reasonable care for your own health and safety, and that of others by:

- Using all safety devices and equipment correctly;
- Consulting on health, safety and environmental concerns;
- Taking action to control hazards and risks; and
- Ensure other family-carers are given appropriate training and advice.

Duty of Care

What is Duty of Care?

Duty of Care is a responsibility to act in a manner that does not cause any harm or loss to that person. Support workers have a Duty of Care to the person they are working with, other staff members in the workplace and in some instances the public. Duty of Care is established by a support worker’s position description.

Parents owe a duty of care to their children. If you stop to offer assistance to an injured person you then owe a Duty of Care to that person.

What standard of care is expected?

The standard of care expected is measured by what a reasonable person would do in similar circumstances. The standard of care also varies according to how reliant a person is on your care. The more reliant they are the higher the standard of care.
Managing Hazards and Risks at Home

What is a Hazard?
“A hazard is anything in the workplace that has the potential to harm people.”
Source: WorkSafe Victoria

What is a Risk?
“A risk arises when it's possible that a hazard will actually cause harm.”
Source: WorkSafe Victoria

What is a Control?
A control is put in place to eliminate or minimise the risk.

*Examples from the home environment:*

<table>
<thead>
<tr>
<th>Hazard</th>
<th>Risk</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Water on bathroom floor</td>
<td>Carer, person you are caring for, or other person in the home may</td>
<td>• Use bathroom mat</td>
</tr>
<tr>
<td></td>
<td>slip and fall and injure themselves.</td>
<td>• Put towels on floor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mop up floor</td>
</tr>
<tr>
<td>Faulty or broken equipment</td>
<td>Equipment may not work correctly, causing injury to the person</td>
<td>• Service equipment regularly</td>
</tr>
<tr>
<td></td>
<td>being cared for or injury to the carer.</td>
<td>• Do not use faulty equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Hire or buy new equipment where required</td>
</tr>
<tr>
<td>No hoist equipment available to use to move a person with a disability who requires this assistance</td>
<td>Carer may strain their back or other areas.</td>
<td>• Hire or purchase equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Use more than one person to lift person being provided with care</td>
</tr>
</tbody>
</table>
Hazard and Risk Management at Home

Identify Hazard

Review Control

Assess Risk

Evaluate Control

Implement Control
Why are risk assessments important?

As a carer you have the responsibility under the OHS Act to ensure that your home is safe without risks to health, as far as is reasonably practicable.

Risk assessment is an important part of fulfilling this responsibility and preventing others in the home, or the environment where you may be providing care, from being injured.

Risk assessment is a process to assess the threat a hazard poses. It is used to determine which hazards should be controlled first and determines the amount of control required.

Risk Assessments consist of two elements:

- The **consequence** if the hazard resulted in injury; and
- The **likelihood** or probability that the incident will occur.

The following tables are a helpful guide to determining the level of threat a hazard poses.

### Potential consequences of a risk occurring

What are the consequences of this incident occurring? Consider the most likely scenario.

<table>
<thead>
<tr>
<th>Catastrophic*</th>
<th>Severity 1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Fatality/Hospitalisation/Security Breach/Property Damage)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Major</th>
<th>Severity 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Lost Time Injury/Property Damage)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Moderate</th>
<th>Severity 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Medical Injury)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Minor</th>
<th>Severity 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Minor Injury)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insignificant</th>
<th>Severity 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minor Injury (First Aid)</td>
</tr>
</tbody>
</table>

*We don’t want you to panic; “Catastrophic” is a situation that occurs very infrequently.

A “Lost Time Injury” occurs when the injured person has to take time off work as a result of their injury.
Likelihood

What is the likelihood of the consequence identified happening?

<table>
<thead>
<tr>
<th>Likelihood</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost Certain</td>
<td>Almost certain that the consequence will happen once exposure occurs.</td>
</tr>
<tr>
<td>Likely</td>
<td>Will probably occur. Has happened several times in the past.</td>
</tr>
<tr>
<td>Moderate</td>
<td>Might occur at some time. Has occurred in the past.</td>
</tr>
<tr>
<td>Unlikely</td>
<td>Has been known to have happened somewhere.</td>
</tr>
<tr>
<td>Rare</td>
<td>Only in exceptional situations.</td>
</tr>
</tbody>
</table>

Risk Matrix

<table>
<thead>
<tr>
<th>CONSEQUENCES</th>
<th>Insignificant</th>
<th>Minor</th>
<th>Moderate</th>
<th>Major</th>
<th>Catastrophic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost Certain</td>
<td>Moderate</td>
<td>Significant</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Likely</td>
<td>Moderate</td>
<td>Significant</td>
<td>Significant</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Moderate</td>
<td>Low</td>
<td>Moderate</td>
<td>Significant</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Unlikely</td>
<td>Low</td>
<td>Low</td>
<td>Moderate</td>
<td>Significant</td>
<td>High</td>
</tr>
<tr>
<td>Rare</td>
<td>Low</td>
<td>Low</td>
<td>Moderate</td>
<td>Significant</td>
<td>Significant</td>
</tr>
</tbody>
</table>

As an example: If something is “Likely” to happen and it would have “Minor” consequences, then the risk would have “Significant” risk.

Assessing the level of threat a hazard poses helps us to understand what level of protection should be implemented, to eliminate the risks associated with the hazard so far as is reasonable practicable, to prevent the injuries from occurring.
Risk Control

Risk Control looks at how you can make changes to reduce the risk.

<table>
<thead>
<tr>
<th><strong>Elimination</strong></th>
<th><strong>Remove the risk completely</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>e.g. removing electrical cables from a walk way, or run then against the wall to prevent tripping over them</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Engineering</strong></th>
<th><strong>Change something about the way you use equipment in order to reduce the risk</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>e.g. use lifting aids, or adjust the lifting aid to minimise the risk of you straining yourself (reduce manual handling risk)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Administrative</strong></th>
<th><strong>Use a process or procedure to reduce risks</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>e.g. use a process or procedure such as a “medication chart” to track how you are administering medicine</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Personal Protection Equipment (PPE)</strong></th>
<th><strong>Use personal protective equipment to reduce the risk</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>e.g. use gloves, face mask etc.</td>
</tr>
</tbody>
</table>
Chapter 3

Manual handling at home
Manual handling

Manual handling is defined as any activity requiring the use of force exerted by a person to lift, push, pull, carry or otherwise move or restrain any animate or inanimate object.

Manual handling may involve equipment - or other people - when performing a task.

Manual handling covers a wide range of activities such as lifting and restraining and also includes repetitive tasks such as packing, cleaning and sorting.

Because most tasks involve some sort of manual handling most carers are at risk of manual handling injury. Unsafe manual handling may cause a variety of injuries such as back strain, muscle and ligament strains.

Correct manual handling techniques are essential for carers.

Preventing Injury

To prevent injury, always warm up your body before undertaking manual tasks.

Even a simple movement can sometimes cause injury if your muscles are not warmed up.

The simple exercises you will practice here were designed by an Occupational Therapist and will help prevent injury – and help your muscles get ready for action.

The exercises may seem quite simple; however they involve controlled stretching and using your own body’s momentum to loosen up your muscles and tendons.

We recommend you take a couple of moments before you start your work each day to stretch and do a warm up for your back, legs, neck, arms and shoulders.
Manutention

What is Manutention?

Manutention involves the use of the human body to lift, lower, fill, empty, or carry loads. The load can be animate (a person or animal) or inanimate (an object).

The aim is to use just the right amount of effort and your own body weight when undertaking transfers.

Why Manutention?

- To reduce the severity of manual handling injuries
- Builds skill progressively
- Competency becomes life-long habit.

Manutention Philosophy

- Minimal carer effort
- Maximum co-operation by the person with a disability
- Use of natural movement patterns
- Safety and comfort for both.

It is important to commence any lift from the right level – take your body to the item without twisting, stooping or increasing the stress on your back.

Manutention is originally a French word literally meaning ‘manual handling’.

It describes a system of training developed by Paul Dotte, a French physiotherapist, who specialised in finding ways to prevent manual handling injuries.

Manutention provides a structure for assessing situations and using the best method of manual handling for a circumstance: e.g. undertaking safe transfers of a person with a disability from a bed to a wheelchair.
Good manual handling is about good forward planning.

Carers need to assess facts, and think of options to ensure they do not hurt themselves when helping the person with a disability or doing a task.

The aim is to use just the *right amount of effort and your own body weight* when undertaking transfers.

**Consideration needs to be given to:**

- The weight of the person being transferred vs carer’s weight
- The ability of the person being transferred to contribute to the move
- Identifying risk of injury
- Equipment that will help the move
- Starting point
- Location of the bed/chair/equipment.

**Core Categories in Manutention**

1. **Passive**
   - No participation from the person being transferred

2. **Controlled**
   - Minimal involvement from the person being transferred

3. **Aided**
   - High degree of involvement from the person being transferred

It is important to have the person being transferred assist with the move if they are able to do so, to help you and also to respect their own abilities.
Considerations for transfers are:

- Safety for the person being transferred and the carer
- What type of transfer do I need to do?
- What is the person being transferred like (upset, heavy, frail?)
- Would equipment make it easier?
- Do I need assistance?
- Is the area safe?

The next step is about protection for you:

- What postures and actions will protect me during a transfer?
- How can I use my body weight in the transfer?
- How can I ensure the dominant action comes from my thighs?
- How can I find support for my spine and protection for my shoulders and wrists?
- Check the equipment has the right maximum capacity for the person being transferred.
- Decide on the placement of holding straps (loops) for the sling that is right for the person being transferred.
- Double hooking of loops to ensure security if one failed.
- Check you know how the controls work and that there is sufficient space for clearance.

Some key postures, movements and holds include:

- **Spoons:**
  To guide the person with a disability by keeping your thumb against your palm. This prevents the individual from being forced or grabbed and reduces possible injury to them. It also reduces injury to you when assisting others e.g. falls, resistance.

- **Bracket:**
  When leaning over anything, try to support your upper body weight, by bracketing on a surface.

- **Cross Brace:**
  Keep your arms close to your body and brace your muscles for protection.

- **Bench Position:**
  To maintain a neutral spine, bend your knees with your bottom out.
• **Knights Position:**
  To remain stable and safe when working at low heights, place one knee on the floor.

• **Side Lunge:**
  Shift your weight from one leg to another to avoid twisting the spine. Move as a block.

Use either the **Knight’s position** or **squatting for low tasks**, e.g. tying a person’s shoelaces.

Some people requiring a transfer will have adjustable beds – either operated manually or electronically.

It is important to lift or lower the bed to the right height for your work.

Use your body weight and thigh muscles to take the strain when gaining momentum to move a hoist to a new position.

Note the person being transferred is centrally placed with support evenly distributed around shoulders and hips.

There is a good level of support achieved under their neck, back, buttocks, thighs and knees through accurate laying out of the sling prior to the lift.

• Gently bend the person’s leg upward and using the lunge, roll them towards your body.

• Ensure your fingers won’t scratch exposed skin.

• Stop and check their position is secured and lower their leg ready for the positioning of the slide sheet.

• Commence tucking the folded slide sheet in behind their shoulders, waist and buttocks, shielding their body from contact with your nails or jewellery by ensuring sufficient slide sheet is folded inward over your hands.

• After sufficient sheet has been pushed well in under the person, gently roll them onto their back.

• If they have slipped down the bed it is possible to reposition them using the slide sheet, keeping the legs and feet together and using a lunge to move them gently up the length of the bed.

• The sheet can be adjusted around their body, and their leg positioned for you to complete their turning and repositioning.

• In each hand, grasp as much of the bunched up material as possible, evenly spacing your grip to balance the next movement.

  **Note:** palms face downwards preventing an upwards pulling motion.
• Lean in over them to assist the backward lunge momentum, then lunge backwards in one motion. The person will roll comfortably and easily onto their side.

• Once they are in their new resting position, you can commence removing the slide sheet.

• Work from the buttocks upward towards the bed head – this way they will not feel they are slipping down in the bed.

  **Note: straight arms and lunge position with your legs doing the work.**

• All that remains is to cover up the person being transferred and ensure they are comfortable for the evening and the room is neat and tidy.

**Things to remember:**

• Health and Safety related to warming up exercises and doing transfers

• Planning movement and using manutention concepts – how to use your body effectively

• How to use specific equipment to make your actions safe for you and the person being cared for.
Chapter 4
Tube feeding
As a carer you need to have an understanding of the digestive system and the feeding process. Tube feeding is sometimes used as a method of providing nutrients to the body.

The digestive system of the human body is made up of various digestive organs. Digestion starts in the mouth and ends in the anus.

Digestion involves various organs that breakdown the chemical components of food, with digestive juices, into tiny nutrients, which are absorbed to generate energy for the body.

The digestion process takes several hours to be completed, from the time food is consumed to the time it is expelled from the body.

### Key functions of the digestive system

- **Ingestion**: Eating food
- **Digestion**: Breakdown of food by the body i.e. stomach and intestines
- **Absorption**: Extraction of nutrients from the food by the body for energy i.e. by the intestines
- **Defecation**: Removal of waste products through urine and feces

As a Carer of a person with a disability, you may experience that the person you are caring for has difficulty swallowing, is unable to swallow or has pain when swallowing.

The difficulty or inability to swallow is called **dysphagia**.
What causes dysphagia?

Dysphagia occurs when food or liquid does not go into the food pipe (i.e. the esophagus), but instead goes into the wind pipe (i.e. the trachea). The trachea is used for breathing.

If the person you are caring for cannot feel that the food is in their trachea and is unable to cough up the food if it goes the wrong way, this leads to silent aspiration. Dysphagia can have serious health-related consequences, including malnutrition, dehydration, and aspiration pneumonia.

Penetration is when food or liquid goes into the trachea and stays above the vocal cords.

Aspiration is when food or liquid goes into the trachea and goes below the vocal cords.

What is a Tube Feeding?

Tube feeding is used for individuals with a functioning gastrointestinal tract whose oral nutrient intake is insufficient to meet estimated needs.

Enteral nutrition is the provision of nutrients, containing protein, carbohydrate, fat, water, minerals and vitamins, directly into the stomach, duodenum (the first part of the small intestine immediately beyond the stomach, leading to the jejunum), or jejunum (the part of the small intestine between the duodenum and ileum) of individuals.

Enteral feeding is suitable for:

- Critically ill patients;
- Postoperative patients with limited oral intake; and
- Some patients with severe pancreatitis.
- Short-term access is usually achieved using nasogastric (NG) or nasojejunal (NJ) tubes at an initial continuous feeding rate of 30 ml per hour.
- Percutaneous endoscopic gastrostomy (PEG) or jejunostomy placement should be considered if feeding is planned for longer than one month

Nasogastric (NG) tube

- A nasogastric (NG) tube is a flexible plastic tube that goes through the patient's mouth or nose into the stomach. Sometimes this tube will go through the patient's mouth into the stomach, then it is called an 'orogastric' tube.
Nasojejunal tube (NJ-tube)

- The NJ tube passes through the stomach into one of the upper parts of the intestine called the jejunum.

- These types of tubes are used for individuals who are unable to tolerate feeding into the stomach, due to dysfunction of the stomach, impaired gastric motility, severe reflux or vomiting.

- These types of tubes must be placed in a hospital setting.

Percutaneous Endoscopic Jejunostomy (PEJ) Tube

- Feeding goes directly to the intestine instead of through the stomach first.

- A tube, called a jejunostomy tube or j-tube, can be inserted into the gastrostomy tube and moved past the stomach into the top of the small intestine.

- A PEJ is considered harder to maintain, long term, and used less often than a PEG

Percutaneous Endoscopic Gastrostomy (PEG)

- A Percutaneous Endoscopic Gastrostomy (PEG) feeding tube can improve a person's nutritional intake and contribute to a greater quality of life where there are severe swallowing difficulties.

- PEGs are used in people of all ages, including babies and children, who are unable to swallow or unable to eat enough and need long term artificial feeding.

- Common causes include stroke (CVA), head injuries, neurological diseases such as multiple sclerosis or motor neurone disease, or surgery to the head or neck.

- A qualified dietitian will advise on the most suitable method for the individual.

- Various formulas of nutrients are used in PEG feeding tubes.

- Water and medicines may also be administered through PEG tubes. DO NOT mix medications together.

- Speak with your Doctor for further information about providing medication through PEG feeding.

- PEG feeding care (care of equipment used, hygiene and cleaning routines) must be followed.
## Potential Complications from tube feeding

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Infection**                         | • Bacterial contamination of enteral feed can cause serious infection.  
• Administration sets and feed containers should be discarded every 24 hours to minimise the risk of infection.  
• Feeds should never be decanted and equipment should not be handled. |
| **Gastro-oesophageal reflux and aspiration** | • Reflux occurs frequently with enteral feeding, particularly in patients with impaired consciousness, poor gag reflex and when fed in the supine position.  
• Patients should be propped up by at least 30° whilst feeding and should remain in that position for a further 30 minutes to minimise the risk of aspiration. |
| **Gastrointestinal symptoms**         | • Gut motility and absorption are promoted by hormones released during mastication, with co-ordinated stomach emptying and the in presence of intraluminal nutrients.                                         |
| **Refeeding syndrome**                | • This occurs in previously malnourished patients who are fed with high carbohydrate loads.                                                                                                                    |
Chapter 5
Bladder and bowel care
Bladder Care

Depending on the type of disability, some individuals with a disability need to have a bladder management program and bowel routine program, as they are unable to control one or both of these functions due to their disability.

What is bladder care?

A good bladder management program must maintain the health of the individual’s urinary system – kidneys, bladder, urethra and urethral opening, be acceptable to the individual and be socially acceptable.

The function of the kidneys is not directly affected by disability, but long term damage to the kidneys may occur as a result of changes to the person’s ability to store and excrete urine.

Individuals may be unaware of the need to/unable to tighten their external urethral sphincter or contract pelvic floor muscles.

Without appropriate pharmaceutical and mechanical intervention, this person would be continuously wet and have an increased likelihood of experiencing complications.

Mechanical management techniques in order of recommendation

All these procedures may involve manual handling or hazardous substances such as urine, blood and could therefore increase the potential for injury.

Please ensure you are aware of how to undertake the required infection control and back care, hoisting and transferring procedures.

What is a catheter?

A catheter is a tube that is inserted in the body to remove fluid.

Catheter Care

Help with the day-to-day management of the catheter by:

- Making sure the catheter is not tugged or pulled while providing assistance to the person for whom you are caring.
• Making sure the catheter is always appropriately secured to the thigh with a catheter strap or other appropriate means particularly when transferring from bed to commode and back to bed.

• Following strict hand washing procedures and wearing gloves when providing catheter care.

• Cleaning the catheter site-entry point to the body- with warm soapy water morning and night.

• Bathing the area with downward strokes away from the area of entry.

• Making sure the leg bag is always attached appropriately and lower than the catheter to ensure adequate drainage.

<table>
<thead>
<tr>
<th>Types of Catheters</th>
<th>What is this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clean intermittent self-catheterisation (CISC)</td>
<td>A type of catheter that measures the amount of urine and is attached to a plastic bag. In women it is attached to the urinary opening. In males it is attached to the opening of the penis.</td>
</tr>
<tr>
<td>Supra-pubic catheter (SPC)</td>
<td>A catheter which is inserted in the body above the abdomen and below the belly button.</td>
</tr>
<tr>
<td>Urethral indwelling catheter (IDC)</td>
<td>A catheter, generally silicon, which is inserted by a qualified health professional into the bladder via the urethra. The catheter is held in place with a balloon filled with sterile water and is usually changed every 6-10 weeks. It is generally connected to a leg bag, night bag or night bottle.</td>
</tr>
<tr>
<td>Tapping and reflex voiding</td>
<td></td>
</tr>
<tr>
<td>Condom drainage</td>
<td>Essentially a condom with a tube at the end to which the leg tubing attached. It is rolled onto the penis. Some men are independent in putting on condom drainage and some are dependent on a worker to put it on.</td>
</tr>
</tbody>
</table>
What is Bowel Care?

After food has been broken down in the stomach it moves into the intestines. The intestines are made up of the large intestines and the small intestines. 

The **bowels** are made up of the colon, the rectum and the anus.

Some disabilities affect the bodies autonomic and central nervous systems, which prevent messages being communicated from the brain to the bowels, which results in loss of voluntary control over bowel activity.

What is a Bowel Management Program?

A Bowel Management Program is designed to train the bowel to defecate at a set time.

- The aim is to encourage the person to consistently pass a moderate amount of soft formed stool spontaneously within 30-60 minutes.
- The program should be designed in consultation with the person and a specialist nurse.
- A good bowel management program must be effective, practical, reliable and socially acceptable.
- A poorly designed bowel program can have implications for bowel management and negatively impact outcomes for the person with a disability.
- A poorly designed bowel program can have negative implications for bowel management.
- An enema or suppository (laxative inserted in the anus), may be used to stimulate the lower bowel to contract and to soften and lubricate the stool.
- An anal examination may be required to ensure the rectum is completely emptied. Laxatives should not be overused.
Potential bowel complications

- Constipation (a sign of possible impaction)
- Diarrhoea
- Accidents
- Autonomic dysreflexia (excessively high blood pressure)
- Haemorrhoids (swollen veins in the anus)

Causes of bowel complications

- Dietary issues (an unbalanced diet, changes to the diet or a low fibre diet)
- Incomplete emptying
- Changes to bowel management routine, including posture
- Missed meals
- Change of lifestyle including illness, mobility and stress
- Change of medications, including introduction of antibiotics
- Insufficient fluid intake

To prevent bowel complications arising

- Ensure that the bowel program is suited to the individual’s needs and level of injury/ disability.
- Look for and address the cause e.g. change in lifestyle, diet, routine etc.
Chapter 6
Care plans and teams
Care Plans and Care Teams

Regardless of your funding arrangements, the person with a disability you are caring for should have an assessment of their needs so that an effective care plan can be developed. This plan will specify the resources that are available to assist the specific requirements of the person with a disability.

Regardless of your funding arrangements, the person with a disability you are caring for should have an assessment of their needs so that an effective care plan can be developed. This plan will specify the resources that are available to assist the specific requirements of the person with a disability.

It is important to ensure that your role as carer is outlined in the plan, as well as any paid support workers. You will probably know needs of the person with a disability better than the case manager or support worker, hence you play a crucial role in the development of the individualised plan.

When planning activities, it is important to discuss how you and the support worker might cooperate to ensure that the preferences of the person with a disability are reflected in the care plan.

Disability Support Workers

Every family and every Disability Support Worker (DSW) is unique. Each relationship will have its own dynamics, roles, and rules. Relationships will be created over time through collaborative effort on the part of both the DSW and the family. There is no one way to do this.

In the past, carers were expected to be passive recipients of the advice and direction of professionals. The relationship between carer and professional was marked by what was called social distance. The relationship was impersonal and in many instances cold.

An impersonal relationship may be appropriate for some professional roles but it is no longer seen as suitable for most direct support work. While establishing appropriate boundaries remains essential in human services, the treatment of carers as inferior is a thing of the past. The carer of today expects and wants to share power, responsibility, and information with the people supporting a person with a disability.

Building trust depends on demonstrating positive character traits and responsible behaviour. To build trust a DSW will demonstrate they are a person who is dependable, accountable, and focused on the person you support.
Individuals who require support need their families and DSWs to work in collaboration. Successful relationships are characterised by a mutual and positive communication, openness to sharing information, and trust.

A DSW works actively with people with a disability, developing and implementing programs to support them to develop skills and abilities so they are more able to make decisions affecting their lives, live as independently as possible and to help them participate in the community.

Encouraging the person with a disability to develop personal, community and social relationships, and help them develop and maintain independence and safety in personal care, health care and hygiene (such as eating, dressing, toileting and bathing).

**A DSW may be required to perform some of the following tasks:**

- implementing individual program plans to enable learning, independence and safe living skills that will improve the person's quality of life
- creating and maintaining an environment that empowers people with a disability
- helping people with a disability to maintain contact with their family, friends and advocates
- identifying and utilising specific communication methods to aid interaction with other people
- undertaking health care procedures relating to the person’s personal hygiene, and well-being
- performing various household tasks including planning menus, cooking and serving meals, cleaning, shopping, and general services
- providing companionship and support during daily activities
- observing safe working practices
- working individually and as part of a team
- completing administrative work (often computer assisted) including maintaining records and household accounts for the person with a disability
- liaising with other professional organisations.

**Significant Others**

People with disabilities require a dynamic and multi-functional care team to ensure that each of their medical, physical and emotional needs is properly addressed. An effective care plan should include details of those people involved in the care of the person with a disability and their specific role.
The care team may include:

- Unpaid carers
- Other family members
- Medical specialists
- Local GPs
- Nurses
- Hospital department staff
- Physiotherapists
- Occupational therapists
- Paid Support Workers

Learning more about what each person contributes to the care plan will enable you to complement their work with your own contribution. Similarly, it will allow you to engage in meaningful discussions about the care of the person with a disability and to negotiate each person’s role in the care plan.

**Paid Support Workers**

Carers interact most regularly with paid support workers who come into their homes on a regular basis to provide specific support that meets the immediate needs of the person with a disability. The degree of support received depends on several factors including the individual needs of the person with a disability, the involvement of carers and the availability of funding (e.g. care packages, support from trusts, etc.)

Some people with a disability have high care needs and require 24 hour nursing aid. Support workers assist with daily needs and activities like feeding, bathing, dressing, toileting, lifting and moving and administering medications.

Others are fairly independent but may need someone to keep an eye on them or help with them with tasks like banking, transport, shopping and housework.

Support workers, like carers, also provide comfort, encouragement and reassurance to the person they support within professional boundaries, oversee their health and wellbeing, monitor their safety and assist them to live as independently as possible.

Together, the care team help the person with a disability to have a good quality of life.

Source: Based on information from Carers Victoria
Boundaries

Providing care to a person with disabilities (whether it is physical, intellectual, mental health, or neurological) raises many challenges when working with paid support carers. The role of the support worker can mean that they are privy to many intimate situations with the person with a disability and their friends and family as they may have access to private or confidential information.

There are some key ethical and boundary issues when looking at the relationships and boundaries between the family, carers and the person with a disability.
Chapter 7
Decisions and difficult conversations
Decisions and Difficult Conversations

A significant number of people with a disability will have many of their life decisions made by yourself or other family members. This is appropriate where a legal determination has been made. If you act as a legal guardian or hold an enduring power of attorney, you may need to negotiate certain decisions on behalf of the person with a disability.

Decision making and Guardianship

Understanding the law:

All adults over the age of 18 years, regardless of disability, are entitled to make their own decisions. This is the case unless, when they were competent, they appointed a person to be their guardian under the enduring power of guardianship and have now lost capacity to make the types of decisions they appointed the enduring guardian to make for them.

Alternatively, a guardianship order can be obtained by making an application for guardianship to the Guardianship List of the Victorian Civil and Administrative Tribunal (VCAT). VCAT then hears the matter and, if necessary, appoints a guardian to make specific types of decisions.

The guardian makes decisions about the represented person's lifestyle, such as where they live and who can have access to them, according to the terms of the order. The guardian's decisions have the same legal force as if the person had made them themselves.

Guardianship is a vital way to protect and promote the rights and interests of people who cannot make their own decisions. Where there is no suitable family member or friend who can act as guardian, VCAT can appoint the Public Advocate as an independent statutory guardian. In some cases the Public Advocate delegates the role to a community guardian.

Enduring Power of Attorney – Medical Treatment or Financial

An enduring power of attorney (medical treatment) or (financial) is a legal document that allows the person with a disability (the donor) to appoint someone (the agent) to make decisions on their behalf. Medical decisions may include agreeing to medication, surgery, and other medical procedures. Financial decisions include matters like banking, property and paying bills.
The agent’s power begins when the person with a disability is no longer able to make their own decisions. The agent’s decisions have the same legal force as if the person with a disability had made the decision themselves.

An enduring power of attorney is easy to make. The person with a disability completes and signs the enduring power of attorney in the presence of a witness who also signs the form. Although it does not have to be prepared by a lawyer, if the financial or legal affairs are complex, the advice of a lawyer is advised.

Once completed, the original document does not have to be registered or sent anywhere. It should keep in a safe place and a certified copy kept for everyday use. A copy should also be given to anyone else involved, such as a doctor, a bank manager or a lawyer.

Source: www.publicadvocate.vic.gov.au

**Wills and Probate**

In a similar way as an enduring power of attorney, a will is a legal document that allows a person to clearly state how they wish their legal assets to be dispersed after their death, and the person or organisation they would like to be responsible for carrying out their wishes.

Probate is a document issued by the court certifying the will’s validity and confirming the appointment of an Executor to administer the deceased estate. The court requires proof that the Executor appointed in the will is alive, willing and competent to undertake the tasks involved. Also, it is important to verify that the document is the last will made by the deceased and that there are no objections to that will.

Without probate the Executor of the estate cannot transfer certain assets (such as real estate) to beneficiaries.

Source: www.statetrustees.com.au

**Everyone should have a Will so please consider discussing this matter with the person with a disability.** If you are assisting a person with a disability to prepare any of the legal documents mentioned above, it might be prudent to involve an objective witness who is not a family member to protect yourself from issues that might arise in regards to conflict of interest.

**Difficult Conversations**

You will no doubt have had to manage some difficult discussions during your time as a carer. This may have been to deliver news to someone, maybe family members or close friends of the person you care for or resolving an issue with a paid support worker. Some conversations can be difficult to approach and emotions often run high. Knowing how to handle difficult conversations can make a tough job a little easier.

**Don’t Delay That Tough Conversation Any Longer**

It’s often difficult to have conversations about sensitive subjects. Whether you need to tell someone you disagree with their approach or are upset by their behaviour, it’s all too easy to put it off in hopes of finding the ‘perfect time’. Chances are, that time will never come.
You'll be better off if you stop procrastinating and make the conversation happen. Request a time to meet.

When having a difficult conversation, it's easy to get wrapped up in what you need. You're angry so you respond with anger. You're frustrated so you respond with frustration. It makes sense, but it's not effective. Instead of reacting, ask yourself a question: what is going on for the other party? Then, ask yourself another: what can I do or say to help? While this may be the last thing you want to do in that moment, it's a much more effective way of getting your needs met.

**Tips for Surviving Difficult Conversations**

It is inevitable that you will have some trying conversations. Here are ways to reach a productive outcome, no matter how tough things get:

- Keep it civil. Don't turn the conversation into a combat with a winner and a loser. Everyone looks bad when the discussion turns toxic.

- Don't rehearse. When you know things are going to be tough, it's tempting to practice what you're going to say ahead of time. But this is a conversation — not a performance. Instead, know where you stand but be open enough to listen and react.

- Resist making assumptions. You don't have access to anyone's intentions but your own. Don't assume that you know where your counterpart is coming from or how she views the problem. Instead, ask for her perspective.

- Provide context. For people to understand a message, they have to know why it's important. Give people enough information so they know where things fall on the priority list.

**How Do I Begin?**

A common question is how do I begin the conversation? Here are a few conversation openers:

- I have something I’d like to discuss with you that I think will help us work together more effectively.

- I’d like to talk about ____________ with you, but first I’d like to get your point of view.

- I need your help with what just happened. Do you have a few minutes to talk?

- I need your help with something. Can we talk about it (soon)? If the person says, “Sure, let me get back to you,” follow up with him.

- I think we have different perceptions about ___________________. I’d like to hear your thinking on this.
• I’d like to talk about ___________________. I think we may have different ideas about how to _____________________.

• I’d like to see if we might reach a better understanding about ___________. I really want to hear your feelings about this and share my perspective as well.

* Values, Integrity and Equity

Ethics are the beliefs that we hold about what constitutes the right conduct in a particular situation or job. Ethical guidelines are formally put in place for the job environment of a support worker and are viewed by most organisations as necessary training for professionals. Knowledge of these concepts will help you to greater understand the guidelines the support worker works within. Some of these concepts most probably will apply to your situation.

There needs to be reliable ethical guidelines in place to ensure the care provided is of a good quality and to protect the rights of individuals with a disability, especially those who may be more vulnerable. Some individuals with a disability will have limited ability to evaluate the quality of care provided to them by carers, to communicate their concerns or complaints. Individuals themselves may also lack awareness that their behaviour and expectations places demands on their family and care workers to do things that are not appropriate or ethical.

Ethical guidelines are important in providing a safe and clear environment for family and carers in assisting to provide the person with a disability with services and support. Guidelines, tell everyone what is expected of them in their role when caring for a person with a disability.

Integrity and equity are to be upheld by support workers, support services and society in general. Families with disabilities can sometimes be marred with people that lack a sense of integrity and may try and take advantage of vulnerable individuals or situations.

There are a number of advisory groups that can assist to support you as a family should you feel that you or a family member have been treated unfairly.

**Maintaining the privacy of a person with a disability and their carers**

Everyone has a right to privacy, including a person with a disability and their carer/s. This can be somewhat challenging in determining how much information to share.

The right to privacy includes personal information that, for some family members, may be necessary.

For most support carers however, there should be little or no need to seek information that is not relevant to the performance of their duties. Support workers also have a right to privacy, and these boundaries will often need to be set with the person with a disability and their family who may seek personal information about you, or want to have a relationship with a worker.
Confidentiality

Similar to our respect to privacy, is the consideration for an individual’s confidentiality. This means that any information obtained or received by the family or the support workers must be kept absolutely confidential, except with the written or verbal consent of the individual with a disability or their legal guardian.

Family and support workers are entrusted to be mindful of the need for confidentiality and therefore must not discuss or disclose confidential and private information with anyone without this permission. It is expected that support workers will sometimes need to discuss matters with their supervisors but this should always be in an appropriate and respectful way.

Treating information of a private nature with discretion

There are many types of information that should be treated with discretion. Be considerate of an individual’s private information and deal with all sensitive information with a sense of discretion and with the same respect that you would your own private and confidential information.

Gifts

There are occasions where carers may offer gifts to paid support workers as a ‘thank-you’ for work done, for example, chocolates, flowers, cards, etc.

While you might think that it is rude that they have declined your generous offer, it is general policy. Support workers/carers do not want to cause offence. Hence, the acceptance of any gift should always be considered with caution, particularly gifts of money or expensive items.

To avoid getting into to such a grey area, don’t be a receiver or a giver of gifts that are to do with the assistance or care of the person with a disability.

Conduct

As you are aware, looking after a person with a disability can sometimes be tiring and hard work even though you care greatly for this person, looking after someone can take its toll.

While this topic has a number of grey areas as you are most probably in your home and looking after the person with a disability there still needs to be considerable accountability and responsibility when it comes to conduct and ensuring that the consumption of alcohol or improper use of drug or other substances does not affect your ability to provide the appropriate care.

Where you are the primary source of care giving you need to have a clear state of mind to ensure that you can act and respond accordingly to ensure the person with a disability is safe and being cared for as needed.

Friendships with Paid Support Workers

The role of a support worker is to build, support and strengthen the existing social, family and community network of a person with a disability. The role of a friend is different from the role of worker and constitutes a conflict of interest in the support worker doing their job.
Support workers may find this difficult as the person with a disability they are providing care for is often isolated, lonely and in need of friends, but it is the role of worker to build friendships, not to be the friendship.

Equally relationships between the support worker and other family members are also not appropriate and risks blurring the boundaries of your professional relationship.

**An inappropriate relationship with a person with a disability or their family members has risks for paid workers including:**

- Increasing or unreasonable demands and expectations from the person with a disability or their family
- High worker stress and burnout
- Inability to provide professional and objective support
- Difficulty setting limits and dealing with behaviour
- Favouring of certain workers over others
- Distress when relationships break down
Chapter 8
Self-care and well being
Self-Care and Well-being

Caring for your own health and wellbeing is equally as important as caring for that of the person with a disability. When you consider the consequences of not looking after yourself, you’ll soon realise that unless you are physically, mentally and emotionally fit, you’ll be unable to effectively care for the person with a disability or the other loved ones in your life.

Person Centred Practice Values

<table>
<thead>
<tr>
<th>Equality</th>
<th>to treat others as equal to myself and vice versa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility</td>
<td>to adjust and adapt readily to changing circumstances</td>
</tr>
<tr>
<td>Kindness</td>
<td>to be kind, compassionate, considerate, nurturing or caring towards myself and others</td>
</tr>
<tr>
<td>Open-mindedness</td>
<td>to think things through, see things from others’ points of view, and weigh evidence fairly</td>
</tr>
<tr>
<td>Respect</td>
<td>to be respectful towards myself and others: to be polite, considerate and show positive regard</td>
</tr>
<tr>
<td>Supportiveness</td>
<td>to be supportive, helpful, encouraging and available to myself and others</td>
</tr>
</tbody>
</table>

Why have values?

Values determine your priorities, and, deep down, they’re probably the measures you use to tell if your life is turning out the way you want it to.

When the things that you do and the way you behave match your values, life is usually good – you’re satisfied and content. But when these don’t align with your values, that’s when things feel... wrong. This can be a real source of unhappiness.

This is why making a conscious effort to identify your values is so important.
Values exist, whether you recognise them or not. Life can be much easier when you acknowledge your values – and when you make plans and decisions that honour them.

If you value family, but you have to work 70-hour weeks in your job, will you feel internal stress and conflict? If you don't value competition and you work in a highly competitive sales environment, you will unlikely be satisfied with your job?

In these types of situations, understanding your values can really help. When you know your own values, you can use them to make decisions about how to live your life.

### Building a Positive Caring Environment

| Make time to connect with others as people | • Take time to engage with others as people and not as a means to an end |
| Acknowledge the positives, not just the problems | • Positive sandwich approach  
• People’s contributions matter |
| Criticise ideas, not people | • Disagree with ideas without marginalising people |
| Stand for something larger than yourself | • Align your behaviour with your values |
| Look for ways to allow your team to contribute | • Be flexible in your thinking and approach  
• Draw your team members into conversations |
| You are not expected to know everything | • Model information and advice seeking behaviour |
| Do what you say you are going to do | • People are energised by a task or goal when they believe in the integrity of the others involved |
| Be visibly and sincerely enthusiastic | • Mentally and physically engage in conversations  
• Show positive regard |
Empowering Families

Family carers need to ensure that they look after themselves both physically and emotionally. Developing strategies that enable you to advocate for the things you need when caring for the person with a disability, will offer you a degree of control. The ability to affect positive change in your own circumstances will lead to a sense of empowerment.

Seeking advice through an advocacy service is one strategy already discussed. Empowering yourself through education and experience is another. The knowledge and skills required to develop effective negotiation techniques can be gained by volunteering your time and efforts to an advocacy service. Being an active part and working alongside experienced advocates will enable you to learn these invaluable skills. It would also expose you to a range of circumstances and concepts where the rights of individuals are asserted and upheld.

Similarly, attending an appropriate course of study will provide a more formal avenue to developing that knowledge and skill.

Things That Improve Wellbeing

1. Get out in nature
2. Exercise
3. Spend time with friends and family
4. Express gratitude
5. Meditate
6. Get enough sleep
7. Challenge yourself
8. Laugh
9. Touch Someone
10. Be optimistic
Accredited courses of study may include the:

- Certificate III in Disability/ Individual Support
- Diploma of Community Development
- Bachelor of Community Health
- Bachelor of Nursing

Other options are to source information from online advocacy groups such as:

- “Our Community” [www.ourcommunity.com.au](http://www.ourcommunity.com.au); or

Regardless of the method you choose to develop strategies to advocate for yourself and your family, the resulting skills will empower you to greatly improve your quality of life and sense of control.

### Support Services

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Website</th>
<th>Email</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifeline</td>
<td><a href="http://www.lifeline.org.au">www.lifeline.org.au</a></td>
<td>Crisis Support Chat Online 7pm - 4am (AEDT), 7 days a week</td>
<td>13 11 14</td>
</tr>
<tr>
<td>Parentline</td>
<td><a href="http://www.parentline.com.au">www.parentline.com.au</a></td>
<td>Parent Counselling <a href="mailto:parentline@boystown.org.au">parentline@boystown.org.au</a></td>
<td>1 300 30 1300 (8am to 10pm, 7 days a week)</td>
</tr>
<tr>
<td>Beyond Blue</td>
<td><a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a></td>
<td>Chat Online 3pm – 12am (AEDT), 7 days a week</td>
<td>1 300 22 4636 (24 hours/7 days per week)</td>
</tr>
<tr>
<td>Reach (Youth)</td>
<td><a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a></td>
<td></td>
<td>(03) 94120900</td>
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<tr>
<td>Suicide Helpline</td>
<td><a href="http://www.suicidehelpline.org.au">www.suicidehelpline.org.au</a></td>
<td></td>
<td>1 300 651 251</td>
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<td>Independence Australia</td>
<td></td>
<td></td>
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<tr>
<td>Counselling Services</td>
<td><a href="http://www.independenceaustralia.com">www.independenceaustralia.com</a></td>
<td><a href="mailto:psychology@independenceaustralia.com">psychology@independenceaustralia.com</a></td>
<td>1 300 704 456 (Ask to speak with a Psychologist)</td>
</tr>
</tbody>
</table>
Chapter 9
Empowerment of people with a disability
Empowerment

Independence support is a way of providing assistance to people that has a focus on making sure the individuals are engaged and participate in their own support, thereby maximising and developing their independence. It recognises the value we all place on being as independent as we can and that even small gains in independence can have many positive benefits.

Empowerment by definition means:

- To invest with power, especially legal power or official authority.
- To equip or supply with an ability; enable: ‘Computers ... empower students to become intellectual explorers’.
- ‘to invest with authority, authorise’.
- ‘to enable or permit’.


Levels of Support

There are certain steps that we can take toward improving one’s degree of empowerment. The extent of success we have taking these steps is often dependent of several factors, which might include time constraints and safety aspects.
Examples of Levels of Support

Prompt /Ask

Questions such as:

‘What needs to be done next?’

‘Isn’t there one more step?’

‘What did you say you wanted to buy when we were out today?’

Comments such as:

‘I believe it is time for you to brush your teeth now, don’t you usually brush your hair once you are dressed.”

Instruct

Explain to the person how to do something one step at a time using a series of verbal/visual prompts.

Show

Demonstrate to a person what to do, either in total, or by steps if needed, with the person then completing the task after you.

Guide

Direct physical assistance for a person to do something such as hand over hand to stir mixture in a bowl, or hand over hand to get their golf swing right.

Do

Do the action for the person.

Although it can be easier to simply do for the person with a disability to save time, this is always a last resort and should only be done when all previous options are not possible.
Barriers to Empowerment

Many situations and things can impede a person’s empowerment including the examples below.

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<td>• Cycle of negative expectations (expectations are low, support is not given, outcomes are low, expectations are lower.)</td>
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<td>• One decision at a time</td>
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<td>• Break it down to one or two choices</td>
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<td>• Avoid leading questions</td>
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<td>• Be patient</td>
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Independent Action and Thinking

Dignity of Risk

The dignity of risk and the right to failure; it is a concept that was first described by people with a physical disability and has since been adapted for people living with a mental illness also.

The concept of the dignity of risk acknowledges the fact that accompanying every endeavour is the element of risk and that every opportunity for growth carries with it the potential for failure. All people learn through a process of trial and error. We learn through taking risks and trying new things and we often learn as much from our mistakes as we do from our successes.

Supporting dignity of risk is a consideration for all people whether they have a disability or not have the right to take risks. Learning by our mistakes is in fact how most of us learn and develop our independence.

Your role is to:

- Help them understand the risks associated with their plans;
- Help them manage the risks associated with their plans; and
- Support them in their informed choice.

Attitudes to Disability

Attitudes to disability can vary greatly there are some carers and family members that will overdo the caring and looking after and there are some carers and family members that may be somewhat neglectful when it comes to the level of care they should be providing.

The balancing of ‘too much or too little’ can be a difficult thing to manage.
Enhance Communication

Encourage Participation

Australia has a wonderful culture that embraces many colourful recreational activities.

People generally experience a range of barriers to participation including; competing priorities, time and the scheduling of activities. For people with a disability there are additional pressures that act as barriers to community participation that include; attitude, transport, support and finances.

“Many people have low expectation of people with a disability, believing that they cannot learn or are not able to do anything useful. They are often denied opportunities to experience life, to explore their potential and achieve success, because it is assumed that their potential is limited. It is often stated that people with a disability are tolerated in the community but tolerance is not acceptance and genuine inclusion”.

Shut Out: The experience of people with disabilities and their families in Australia, 2009

Be mindful of your ability to enable participation to ensure that the voice of the person with a disability is equally represented and can meaningfully influence the agenda rather than being an afterthought. The question is not whether they can participate but rather how we, as family carers, ensure that it happens.

Consider Compensatory Aids

Establishing an environment that empowers someone with a disability may be as simple as identifying a tool or a piece of equipment that allows them to do a certain task for themselves, rather than relying on a support worker or family carer for that same task. There are numerous aids available that promote independence.

Examples of empowerment through compensatory aids:

**Personal Mobility Aids** - for indoor and outdoor use. May include wheelchairs, power wheelchairs and/or power scooters.

**Personal Self-care Aids** - for bedroom, bathroom, dining room, etc.

**Stair Climbing Aids** - for indoor or outdoor use. May include portable ramps or permanently installed ramps, stairway seat transporters or elevators.

**Desk or Work Table** - for home or workplace and wheelchair compatible. For comfortable reading, writing and using a desktop computer.

**Reading Aids** - may include book and magazine holders, hand tools, page turning machines, electric actuators, lights, eyeglasses and/or page magnifiers.
**Telephone Equipment** - which vocal quadriplegics can use alone and unaided. Depending on lifestyle needs, these may include any one or more: (1) desktop telephone, (2) bedside telephone, or (3) wheelchair-mounted, wireless telephone.

**Appliance Controllers** - to enable a quadriplegic to selectively switch ON or OFF specific appliances such as computer, room lights, TV, etc. Such controllers might be at the bed, on the desk or on the wheelchair – depending on the person’s lifestyle needs.

**Personal Computers** - for word processing, bookkeeping, email and internet access, online banking and bill paying, controlling appliances, etc. and for personal use. Also, as a work tool for those who are employed or self-employed.

**Kitchen Aids** - for quadriplegics desiring to prepare and serve their own meals.

**Highway Transportation Vehicles** - are wheelchair compatible vehicles that are adapted so a person with a disability can drive.

**Solve Disability Solutions** (formerly TADVIC) is a not-for-profit organisation that makes and modifies equipment for people with disabilities whose needs cannot be met commercially. Contact: 1300 663 243.
Empowerment through advocacy

Self-Advocacy

Advocacy has been described as:

“... the process of standing alongside an individual who is disadvantaged and speaking out on their behalf in a way that represents the best interests of that person.”

Source: Institute for Family Advocacy and Leadership Development

Self-advocacy is about developing strategies that enable someone to speak out on their own behalf in order to affect positive change, either for themselves as individuals or as a representative of a community of people with disabilities.

It’s common that those who care for a person with a disability will often act, with the best of intentions, as an advocate on their behalf. But, how many have considered having a conversation with the person with a disability, around strategies that might enable them to advocate for themselves?

Conversations may include:

- Identifying what things are important to them, either personally or politically;
- An understanding of their rights and responsibilities;
- The benefit of taking responsibility for decisions that affect their life; and
- Assertiveness training, i.e. learning how to speak-up for things they believe in.

People with a disability who acted as self-advocates said, when interviewed, that a good support worker was one who hands power back to the self-advocate. These people always strive to disempower themselves and make sure that the control of the individual is with the individual.

Fyffe, McCubbery, Frawley, Laurie & Bigby, 2004

It is significantly empowering for the person with a disability to develop strategies that enable them to speak up for themselves, and things they believe in. One of the benefits of such empowerment is a trust in their ability to shape their own future, which in turns improves self-esteem.

Advocacy

In some cases, however, the person with a disability may require an advocate to speak on their behalf. Please ensure before you decide on this approach, that you exhaust all opportunities to identify the wishes of the person with a disability to ensure they remain empowered throughout the process. Although they may require support to achieve their goals, the final decision should be theirs.
Advocacy Groups

When deciding how to appropriately advocate on behalf of the person with a disability, you might decide to seek some advice or support from an organisation that provides an advocacy service to people with a disability.

One such organisation is Physical Disability Australia who believes:

- Self-determination by people with physical disability should be promoted and encouraged, thus empowering them to make their own choices and decisions, particularly where the outcomes directly affect their lives.

- Advocacy is facilitated by Physical Disability Australia, with and on behalf of Australians with a physical disability, on matters that have implications of a national systemic nature.

- Physical Disability Australia raises awareness about systemic issues impacting and affecting people with a physical disability, in a responsive and timely manner, promoting outcomes and actions.

- Members can trust Physical Disability Australia to keep them informed, and communicate with them in a responsive and timely manner on systemic issues.

- Advocacy is the right of all Australians, and must be independent and client centred.

Source: http://www.pda.org.au