

**A Quick Reference Guide to**

**Hospital Care  
for People with a Disability**



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## Please read

This book provides basic information about medical, nursing, personal care and legal issues for people with general health care needs who also have a disability. The nature of the publication means the information is very general. It is not intended to be a substitute for obtaining expert advice in providing services to particular individuals.

Generalisms and assumptions about people who have a disability can be misleading. Each of us is different. Each of us is the expert on our own abilities, likes, dislikes and needs. The best way of understanding the effects of someone's disability is to talk to them. Some people may need more time to express what they want to say. Some may use different ways of communicating. The important thing is to give people the opportunity to speak for themselves.

If for any reason you are not able to communicate with the person directly, others such as family, friends, paid carers or advocates are likely to be good secondary sources of information. For more ideas and strategies about communicating with people, see the section on communication commencing on page 14.

# Contents

<b>How to use this guide</b>	viii
<b>Checklist</b>	ix
<b>1 Introduction</b>	1
What this book is about	1
Legal issues	2
The importance of communication	3
The right to be safe	11
<b>2 Admission</b>	12
Establishing a baseline	12
Additional medical problems	13
Uncommon conditions associated with disability	13
Complex medical problems	13
Personal Health Records	14
Preventive health care	14
People with communication difficulties	14
Anticipating people's needs	15
Patient Information Sheet	17
<b>3 Communication</b>	18
Alternative forms of communication	18
Sign and gesture	19
Communication aids	19
'Yes'/'No' response	19
Finding out how someone communicates	20
Facilitating communication	20
Ensuring the person's rights	22
<b>4 Medication</b>	23
Implications in the hospital setting	24
Preparation for discharge	24

A Quick Reference Guide to Hospital Care for People with a Disability

<b>5 Sensory impairments</b>	26
Sensory impairments and other disabilities	26
Vision	27
Functional assessment of vision	27
Impact of hospital on people with visual impairment	28
Aids for vision	28
Concurrent disabilities and visual impairment	28
Hearing	29
Functional assessment of hearing	30
Hearing aids	30
Impact of hospital on people with hearing impairment	30
Concurrent disabilities and hearing impairment	30
<b>6 Mobility issues</b>	32
Mobility aids	33
Manual handling and transfer	33
<b>7 Psychiatric disorders</b>	35
Mental health problems	35
Attitudes and approaches to mental health issues	35
Admission	36
Medication and its side effects	36
Stress of hospital environment	37
Behaviours and psychiatric disorders	38
<b>8 Behavioural issues</b>	39
Factors affecting behaviour	39
Getting to know the person	39
Understanding a patient's behaviour	40
Managing behaviour	41
Safety	42
<b>9 Seizure disorders</b>	43
Documentation	43
Presentation and classification	44
Generalised seizures	44
Partial seizures	44
Seizure management	46



## *Contents*

Managing generalised seizures	46
Anti-epileptic medication	47
Side effects	48
Safety issues	48
<b>10 Personal care</b>	<b>50</b>
Mealtime assistance	50
Difficulties and strategies with eating and/or drinking	51
Nutritional disorders	52
Consequences of poor/inappropriate nutrition	53
Dental hygiene	54
Common problems	54
Identifying required level of assistance	55
Common problems and strategies when assisting a person with cleaning their teeth	55
Assistance with using the toilet	56
Particular issues related to hospitalisation	56
Constipation	57
<b>11 Preparing for discharge</b>	<b>59</b>
Information	59
Arrangements for care	60
Documentation	61
<b>12 Conclusion</b>	<b>62</b>
<b>Appendixes</b>	<b>63</b>

# How to use this guide

This booklet describes the implications a person's disability may have on their stay in hospital. It outlines the nature of nursing practices for people with particular disabilities, but the information will also be useful to non-nursing staff and other workers.

**Step 1** Complete the following checklist with reference to the person who has a disability.

**Step 2** Use this booklet to access further information.

**Step 3** Photocopy the Patient Information Sheet (pages 63 and 64) and record patient details on it.

**Step 4** Place the completed sheet into a prominent position in the person's hospital file so it will be accessible to, and be seen by, all relevant staff.

*How to use this guide*

## Checklist

The purpose of this checklist is to determine the implications a person's disability may have on the care provided to them during their stay in hospital.

Questions	Y	N
1. Does the person have information available which may be relevant to their stay in hospital? (see pages 12–17)	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the person able to consent to treatment or procedures? (see page 4)	<input type="checkbox"/>	<input type="checkbox"/>
3. Does the person have a guardian or power of attorney appointed? (see pages 4–11)	<input type="checkbox"/>	<input type="checkbox"/>
4. Should the person have a guardian appointed? (see pages 4–11)	<input type="checkbox"/>	<input type="checkbox"/>
5. Does the person have any special needs that require hospital staff to make adjustments? (see pages 2–3 and 12–17)	<input type="checkbox"/>	<input type="checkbox"/>
6. Does the person have any particular medical problems? (see pages 12–14)	<input type="checkbox"/>	<input type="checkbox"/>
7. Does the person have any communication difficulties? (see pages 18–22)	<input type="checkbox"/>	<input type="checkbox"/>
8. Does the person have a sensory impairment? (see pages 26–31)	<input type="checkbox"/>	<input type="checkbox"/>
9. Does the person have any problems with mobility? (see pages 32–34)	<input type="checkbox"/>	<input type="checkbox"/>
10. Does the person have any psychiatric problems? (see pages 35–38)	<input type="checkbox"/>	<input type="checkbox"/>

A Quick Reference Guide to Hospital Care for People with a Disability

11. Does the person have any behavioural problems?  
(see pages 39–42)
12. Does the person suffer from seizures? (see pages 43–49)
13. Are there any personal care or nutritional issues?  
(see pages 50–58)
14. Will the disability have an impact on discharge?  
(see pages 59–61)

# 1 Introduction

## What this book is about

THIS BOOK is about good quality health services.

Most of us at some time in our lives will use health services. Knowing the difference between a good service and a bad service is usually a matter of experience. Things like 'infection rates', 're-admission rates' and 'length of hospital stay' are important standards for people with some knowledge of hospitals, but they are not the only considerations. Other considerations relate to the way the service responds to our individual needs and how health care providers treat us.

We expect a good quality health service to acknowledge and respect our right to:

- be treated with dignity and respect;
- freedom from discrimination;
- be told about what is happening, and to be given a right to choose and make our own decisions;
- be listened to and have what we say taken seriously;
- have our special needs taken into account;
- be safe;
- the best possible service; and
- complain if these expectations are not met.

It is an unfortunate reality, however, that many people with a disability do not have these common expectations met.

The most logical explanation is that many health care providers lack practical understanding about the way a person's disability can impact on them, and especially its relevance in the context of the person's individual health care needs.

## A Quick Reference Guide to Hospital Care for People with a Disability

This booklet aims to address the problem by providing some basic information about different sorts of disabilities and how they impact on a person's health care needs. It is intended as a tool for people interested in improving the quality of the health care service they provide, particularly carers in the general health system who from time to time come in contact with people who have a disability.

### Legal Issues

PEOPLE WITH A DISABILITY have the same rights as people without a disability. They are, however, often treated less favourably than the rest of the population because of their disability. Generalisations are often made about them and attitudes adopted towards them that impact significantly on their stay in hospital. Intended or not, these generalisations often lead to discrimination, impact on quality of the care given, and fail to recognise the person's role in the decision making process.

#### *Freedom from discrimination*

Health care providers who furnish the same level of service to all their patients may be unintentionally discriminating against those who have a disability by not providing for individual needs.

- People with a hearing impairment may not comprehend a general 'Good morning!' addressed to everyone. They should be greeted using a different method, for example a gentle touch on the arm.
- It may be more convenient to wheel the person to a shower, but for people with a mobility disability inactivity can lead to rapid deterioration of fragile muscle power. They should be assisted to walk by themselves to reduce any unnecessary deterioration and to promote self-reliance and independence.
- A meal put on the tray over the bed may not be sufficient. Some people with physical disabilities may need assistance in order to eat their meal.

## *Introduction*

To provide 'equal opportunity' to people who have a disability we may have to make 'adjustments'. These adjustments might include:

- changing the physical environment – e.g., moving equipment out of arm's reach for people who have involuntary movements;
- adapting to sensory impairments – e.g., reducing background noise for people who have a hearing impairment;
- adapting to special needs—for example changing the way we communicate – using clear simple language and visual aides to explain procedures to someone with an intellectual disability.

## *Discrimination is against the law*

The Commonwealth *Disability Discrimination Act 1992* and State anti-discrimination laws make discrimination on the basis of disability unlawful. This includes the provision of health services.

Discrimination does not have to be intended. It can also be based on a misplaced sense of benevolence or 'over-protectiveness'.

- Adults with a disability may be treated as 'child-like' and not given the choices that people without a disability take for granted.
- Treatment options may be discussed without the person being present.

## The importance of communication

COMMUNICATING WITH SOME PEOPLE who have a disability may require more time and effort. You may need to consider communicating in different ways, for instance, by using a communication board or device. Failure to listen to and respect a history given by someone with a history of mental illness, or failing to investigate a change in their behaviour, can lead to misdiagnosis and may constitute malpractice as well as discrimination.

People with communication difficulties do not necessarily have an intellectual disability. It is important not to make assumptions about someone's ability to understand based on whether or not they can speak.

*Elements of informed consent*

**Informed Consent**

It is a civil assault to treat someone without first obtaining informed consent, except in an emergency. Obtaining informed consent to medical procedures ensures the person understands what is to happen and they are empowered in the decision.

There are four elements to informed consent.

**1 Information** Before anyone can agree or not agree to do anything, they must be given information about the risks and benefits of the proposed course of action or treatment. The person should understand the consequences of agreeing to, or refusing, what is proposed and the alternatives available. The information should be communicated in a way the person can understand easily.

**2 Specificity of information** The information must address the particular needs of the person. This means that if a person wants more than routine information about what is being proposed, he or she is entitled to it. For example a particular person may be concerned about inappropriate drug trials and want to know how long a particular drug has been on the market. He or she is entitled to that information.

**3 Coercion** The consent must be freely or voluntarily given. People giving consent must not feel coerced or forced into agreeing. They should understand they have the right to refuse and can withdraw consent at any time.

**4 Legal capacity** The person must have legal capacity. A definition of legal capacity is outlined below.

Informed consent should be obtained from:

- the person themselves;
- the person's parents or guardian, where the person is a child or young person; or
- where the person is over 18 years old and does not have legal capacity, by the person responsible according to the laws of each state. (See Table 1.)



Table 1: Guide to substitute decision makers

State/ Territory	Name of governing Act	Sections	Who consents to:	
			Prescribed matters/ special health matters/ special treatments	Other medical treatment
Australian Capital Territory	Guardianship and Management of Property Act 1991	69-70	Tribunal	Guardian
New South Wales	Guardianship Act 1987	33A	Tribunal	Hierarchy* of persons: 1. Guardian (if appointed) 2. Spouse 3. Person who has the care of the person 4. Close friend or relative
Northern Territory	Adult Guardianship Act	21	Guardianship Panel of Local Court	1. Guardian
Queensland**	Powers of Attorney Act	90 119	Supreme Court of Queensland	Hierarchy* of possibilities: 1. Pursuant to the person's health directive 2. Attorney 3. Statutory health attorney being: a. Spouse b. Person who has the care of the person c. Close friend or relative 4. The Adult Guardian

Table 1: Guide to substitute decision makers (continued)

State/ Territory	Name of governing Act	Sections	Who consents to:	
			Prescribed matters/ special health matters/ special treatments	Other medical treatment
South Australia	Guardianship and Administration Act 1993	59 61	The Guardianship Board	Hierarchy* of persons: 1) The guardian (if appointed) 2) The relative of the person a) Spouse b) Parent c) Person in loco parentis d) Sibling over 18 e) Child over 18 3) The Guardianship Board
Tasmania	Guardianship and Administration Act 1995	39	Guardianship and Administration Board The Guardian with the consent of the Guardianship & Administration Board	Hierarchy* of persons: 1. Guardian 2. Spouse 3. The person who has the care of the person 4. Close friend or relative

Introduction

Table 1 : Guide to substitute decision makers (continued)

State/ Territory	Name of governing Act	Sections	Who consents to:	
			Prescribed matters/ special health matters/ special treatments	Other medical treatment
Victoria	The Guardianship and Administration Act 1986	39	The Guardianship List of Victorian Civil & Administrative Tribunal	<p>Hierarchy* of persons:</p> <ol style="list-style-type: none"> <li>1. Person appointed under the Medical Treatment Act 1988</li> <li>2. Person appointed by the Tribunal to make a decision in relation to the proposed treatment</li> <li>3. Person appointed under a guardianship order with power to make decisions in relation to this treatment</li> <li>4. Person appointed by the person as their enduring guardian</li> <li>5. Person appointed by the person to make decisions in relation to medical or dental treatment</li> <li>6. Spouse;</li> <li>7. Primary carer (not paid)</li> <li>8. Nearest relative</li> </ol>

Table 1: Guide to substitute decision makers (continued)

State/ Territory	Name of governing Act	Sections	Who consents to:	
			Prescribed matters/ special health matters/ special treatments	Other medical treatment
Western Australia	Guardianship & Administration Act 1990	56A 119(2)	The Guardianship and Administration Board	Hierarchy* of persons: 1. Guardian 2. Nearest relative a. Spouse b. Child c. Step child d. Parent e. Foster parent f. Sibling g. Grandparent h. Uncle / aunt i. Niece / nephew

\* First in this list indicates who or what should take precedence.

\*\* Special provisions apply in case of minor uncontroversial treatment such as podiatry, treatment of bedsores etc. The health provider may proceed with treatment if the person does not object, the statutory health attorney cannot be contacted, the treatment is minor and uncontroversial, the treatment will further the person's health and welfare and the health provider is not aware of any dispute regarding the care (section 91)

## *Introduction*

Informed consent can be:

- spoken,
- written, or
- implied.

Consent should be in writing if a serious increase in risk is associated with the consequences of a decision. While a signed consent form is not proof that there was informed consent, it shows that the issue warranted some consideration.

### *Legal capacity and the right to be involved in decisions*

Every adult is presumed to have legal capacity unless there is objective evidence to suggest otherwise. Legal capacity is the ability to understand the general nature and effect of the proposed procedure or treatment and being able to indicate agreement or otherwise. It involves

- being able to understand information,
- weigh-up risks and benefits, and
- make a decision that is personally right and for which she or he accepts responsibility

Because a person has an intellectual disability or a mental illness, or communicates other than with speech, does not mean the person is without legal capacity.

Even when a person has a cognitive impairment (whether due to intellectual disability, acquired brain injury, psychiatric illness or other cause), and is therefore unable to make informed choices, they have *the right to participate* to the fullest extent possible in decisions affecting them.

In hospital settings legal capacity can fluctuate with illness, the influence of drugs and trauma affecting a person's ability to make informed choices.

### *Adults with cognitive impairment*

If a decision needs to be made and there is doubt about the person's current ability to make an informed choice, most States have

legislation enabling a formal assessment of legal capacity to be made relatively quickly.

*Authority to determine a person's legal capacity*

Generally only a court or tribunal with legally binding authority can determine if a person does not have legal capacity. Where this happens, a substitute decision-maker is appointed with the authority to make decisions on behalf of the person.

In all states and territories the law distinguishes between types of treatment to determine who is responsible to consent to treatment. For emergency treatment, the treating physician is responsible. For special procedures such as sterilisation, abortion or transplantation the consent of a tribunal or court is usually required. For other medical or dental treatment each state and territory has different laws to determine who is able to consent to the treatment. A basic guide is set out for each state at the end of this book with reference to the legislation and relevant sections. This guide is no substitute for professional advice should this be necessary.

In practice there are sometimes occasions where health care is provided to an adult (usually an older person) without legal capacity and without the formal appointment of a guardian. This is usually in circumstances where the treatment is straightforward, and there is consensus between doctors, nurses and family members about what is in the best interests of the person. In these circumstances even a guardianship tribunal may be reluctant to formalise an arrangement that is working well.

Whenever you are in doubt about a person's legal capacity and the proposed course of action involves some risk or controversy, or there is disagreement amongst friends, family members, or service providers, it is prudent to apply to the relevant tribunal. Such a course may avoid you having to defend allegations of professional misconduct (or worse) in the event something goes wrong with the treatment.

## *Introduction*

### The right to be safe

#### *Duty of care*

Health care providers owe their patients a duty of care. Ways of discharging an appropriate duty of care, however, will vary. For example people with a disability may have a particular vulnerability that gives rise to the need for a higher level of care than people without that disability. For example, more intensive monitoring may be required for a person recovering from an anaesthetic, if the person also has cerebral palsy and involuntary muscle movements.

#### *Restraint*

Exercising an appropriate standard of care is about acting reasonably in the circumstances. In hospital settings, practices involving physical or chemical restraint are sometimes rationalised as providing for a person's safety. Health care providers using restraint, however, *irrespective of whether the person has a disability*, should be aware that any restraint constitutes a *technical assault*. In order to justify the use of restraint, the provider must be able to demonstrate that the restraint was necessary and the least restrictive course of action likely to prevent foreseeable harm to the person.

Some States have legislation legitimising the use of restraint in mental health or intellectual disability services. The legislation commonly only applies to specific services and where prescribed protocols are strictly adhered to.

# Admission

## 2

PEOPLE WITH DISABILITIES make up approximately 18 per cent of the population and are frequent users of hospital and medical services. Medical problems and preventive health issues for people with disabilities are much the same as they are for the general population. Likewise, the approach to health care management for people with disabilities should be the same as it is for people in the general population. Basic care includes the establishment of rapport, gathering the history and a competent examination.

### Establishing a baseline

THE PERSON WILL HAVE COME TO HOSPITAL in relation to one or more specific health problems. The admission may take place in a variety of contexts.

- The person may be well, and the admission is for elective surgery.
- The person may have had a deteriorating condition for some time and be admitted for intensive investigations and/or management.
- The person may be admitted in an emergency or crisis situation.

The particular presenting health problems may or may not be related to the person's disability. An important first step, therefore, will be to establish a 'base line' of observations and information that includes:

- An understanding of the usual health status of the person;
- an understanding of the way the person's disability affects them;
- an assessment of the potential impact of the person's health problem on the person's life;



### Admission

- an assessment of the relationship between the health problem and the person's disability.

This base line will provide a measure against which any improvement or deterioration in the person's condition can be assessed. A suggested format for documenting initial observations and information about the person is discussed below under the heading '*Patient Information Sheet*'.

### Additional medical problems

The person's disability may be associated with special medical problems or other disabilities. Some of these problems can be anticipated by clinical knowledge of the condition. For example, most nursing staff would be aware of the association of diabetes with blindness, and epilepsy with cerebral palsy. Other problems, however, may relate to the disability itself. For example immobility may lead to osteoporosis, swallowing difficulties to aspiration pneumonia, hemiplegia to arthritis, and hearing problems to articulation difficulties.

### Uncommon conditions associated with disability

Some conditions associated with a disability present so rarely that hospital staff might be unfamiliar with their clinical causes. Resources for anticipating such underlying conditions prior to admission or to the use of hospital services include on-line databases, the Internet and medical texts.

### Complex medical problems

The careful maintenance of medical records is an essential part of management for people with long-standing and complex medical problems. The chronic nature of some conditions makes it likely that the person will have used a number of services, and that the records are spread over these services. It may take time to bring the histories together, but the task is an important part of overall patient management.

## Personal Health Records

Some people may have a Personal Health Record that summarises their medical history. This Record contains information about past medical history, current conditions, current and past medication and health professionals involved in that person's care. (Personal Health Record pro formas are available from the Centre for Developmental Disability Health Victoria, or can be downloaded from the centre's web site at:

[www.med.monash.edu.au/general-practice/units/cddh](http://www.med.monash.edu.au/general-practice/units/cddh))

## Preventive health care

A disability may cause transport, mobility or communication difficulties limiting access to generic medical services. For example the person may have been denied the opportunity for involvement in community education programs and have had limited access to primary care services. The person's initial visit should therefore include a thorough medical examination and an assessment of:

- blood pressure,
- weight,
- blood sugar,
- immunisation,
- urine,
- cholesterol,
- smoking,
- alcohol intake,

and, where appropriate

- breasts,
- prostate,
- pap smear status etc.

Exposure to the hospital system may be one of the few opportunities to promote preventive health care.

## People with communication difficulties

The best source of information is usually the person himself or herself. In most cases management can be discussed directly with him or her.

### *Admission*

When the person has a communicative or cognitive impairment that interferes with this process, it is even more important to accurately assess the person prior to admission or early in their stay. Where applicable, hospital staff should ensure that the carer accompanying the person has knowledge of the person's history, as well as access to all available medical records.

### *Patients with severe communication difficulties*

Severe communication difficulties create particular challenges for the patient and the physician. For many conditions the healthcare professional relies on the person's description of the symptoms to make an informed diagnosis. Conditions with no outward physical signs, usually diagnosed after a person complains of a specific symptom, are a special challenge. These may include such common (but fairly benign) conditions as indigestion, migraine, tension headache, sinusitis, abdominal cramp, neuralgia, back pain, arthritis, toothache or hay fever. Because of the communication difficulties, more serious conditions such as angina, duodenal ulcer, long standing urinary tract infections or bone pain from secondary carcinoma may present at a more advanced stage than they would in the general population.

Diagnosis and assessment of progress may depend on picking up subtle changes in the person's behaviour. To do this, hospital staff need to be familiar with the person's usual health and behaviour. The local doctor or carers may be able to tell staff what constitutes 'usual behaviour' for that person. When there are changes that cause concern, staff may find that carers and family are able to offer valuable insights.

### **Anticipating people's needs**

WHEN A PERSON WITH A DISABILITY first arrives at hospital, it is important to establish how the disability will impact on their stay. A person with a disability may have a range of special needs (for example personal care, communication, and mobility) or they may not have any special requirements at all.

## A Quick Reference Guide to Hospital Care for People with a Disability

Hospital staff need to anticipate a persons' post-procedural requirements, to pre-empt and address their needs. Anticipation helps to minimise potential problems. For instance, someone with an intellectual disability and/or autism may find new situations or experiences difficult and hence if that person is to be admitted for eye surgery, it may be beneficial to practise wearing an eye patch before surgery.

All patients need orienting to the hospital environment, for example the use of buzzers, location of toilets, position of obstacles etc. For those with cognitive impairments this process may take longer, and information may need to be repeated.

The checklist at the beginning of this booklet is designed to identify aspects of the person's disability requiring special attention. The Patient Information Sheet (on pages 63 and 64) is designed to provide a comprehensive guide to the person's disability and particular environment and/or staff requirements that may need arranging.

In addition to the routine orientation staff provide to all patients, some specific questions nursing staff might ask of the person (or a family member, carer or advocate) include:

- Is there anything about the way your disability affects you that you think hospital staff should know?
- What are the adjustments the hospital staff should make to take account of any special needs you have?
- Have you any documentation that would assist hospital staff to better understand your disability?
- Have you any aids, equipment and/or comforts that could help you manage the hospital environment better?

New issues will arise from day to day, and not all problems can be anticipated in advance, but addressing and dealing with probable outcomes early will make the person's stay in hospital a more pleasant experience for everyone. Ask the person if you are unsure about any aspect of their disability – what is obvious to one person might not be obvious to another.

## *Admission*

### Patient Information Sheet

#### *Purpose of the Patient Information Sheet*

THE PURPOSE OF THE PATIENT INFORMATION SHEET is to provide hospital staff with information regarding the person's disability that requires specific attention or documentation during their stay in hospital. While acknowledging the many demands placed on nursing staff for documentation, completion of the Patient Information Sheet, or its equivalent, will provide a valuable source of information. The information will aid in anticipating any special environmental and/or staff requirements necessary to make the person's stay as comfortable as possible. The Patient Information Sheet on pages 63 and 64 could be used as an addendum to your hospital's routine admission documentation or as a basis for amending existing documentation.

The Patient Information Sheet or its equivalent should be photocopied and completed for each new patient on admission and placed in the person's medical file for all relevant staff to access. If you or the person have any difficulties filling out the Patient Information Sheet, refer to the checklist on pages ix and x or the relevant chapters in the book.

# Communication

COMMUNICATION INVOLVES both *comprehension* of what is being said, and the *expression* of a message to be conveyed. Communication difficulties can arise from problems with one or both of these components. Talking is the most common method we use to get a message across to each other, although writing, sign language, body language, gestures and facial expression are also used to communicate. Children and adults who have difficulties with communication (either understanding or making themselves understood) are at a disadvantage in a new situation such as a hospital environment, where staff are unfamiliar with the person's method of communication. It is vital, however, that effective communication be established to ensure the person's comfort, health and safety while they are in hospital. Effective communication ensures the person's legal right to be involved in any decisions regarding their care.

## Alternative forms of communication

ALTHOUGH THE MAJORITY OF PEOPLE communicate with speech, there are many other methods including:

- writing and spelling,
- body language and demonstration,
- facial expression.

Other common methods of communication include:

- sign and gesture,
- communication aids,
- 'yes'/'no' response.

## *Communication*

### Sign and gesture

People, who are hearing impaired, commonly use a form of sign language. Although a person may be fluent in sign language, they may be unable to read or write and may need the assistance of a deaf sign interpreter.

Key word signing commonly uses the Makaton Vocabulary. It is a simplified version of sign that uses a combination of speech and sign. It is designed for people who have both an intellectual disability and communication difficulties. It is easy to recognise and learn to use a few signs, and the person may be able to help by providing a simple sign dictionary.

### Communication aids

Some people have a communication aid to help them to 'talk'. These aids range from sophisticated electronic devices with voice output, to simple-to-use pictorial boards. If the person cannot demonstrate how to use the aid, you may find instructions on the aid or have to consult a family member or carer.

### 'Yes'/'No' response

A person who has difficulty with verbal expressive communication may be able to respond to questions by indicating 'yes' and 'no'. By asking a series of questions in this manner, quite detailed conversations can occur.

#### *Yes/no response procedure*

- 1** Find out (from someone who knows the person), if the person has a reliable 'yes' and 'no' response.
- 2** Find out how they signal 'yes' or 'no' because it may be unusual, e.g., looking right for 'yes' and left for 'no' or using a hand gesture for 'yes' and 'no'. You can ask the person to demonstrate how they 'say' yes or no.
- 3** Ask closed questions, i.e., questions that require only a 'yes' or 'no' reply.
- 4** Take care to only ask one question at a time.

## Finding out how someone communicates

IF YOU SUSPECT THAT THE PERSON has difficulty communicating, try to discover methods that will improve your communication with them. The following are useful strategies:

- 1 Find out what the person can understand, and how they usually communicate. This may be achieved by spending a little time with them and experimenting with methods of understanding. The person may be very good at letting people know the best method of communication.
- 2 If possible, try to observe how the person communicates with people who are familiar with their means of communication.
- 3 The person may also have written information about their needs, which could be kept in their medical file for all staff to access (see Patient Information Sheet and MOIRAs Key Card at end of booklet).
- 4 Find out whether the person has an advocate (e.g., family member, carer) who can help you better understand their communication and other needs.

## Facilitating communication

YOU MAY NEED TO USE a range of strategies and modes of communication to enhance communication with your patient.

### *What the patient can do to enhance communication*

If the person is difficult to understand, ask them to:

- say it again;
- say it again slowly ;
- spell it out;
- try another way of saying it;
- give you the sound it starts with;
- write it down;



### *Communication*

- show the desired object;
- use gestures;
- draw pictures.

If the person has no speech, they may be using a combination of the alternative forms of communication described earlier. Find out how they use their means of communication, and use it with them.

### *What the carer can do to enhance communication*

In a similar way, you may need to use the strategies discussed above to help the person understand you. It may help to put yourself at their eye level, or find a quiet place to communicate. If an interpreter is used, make sure you face the person and talk directly to the person, not the interpreter.

- Do not rush the person: give the person time to respond.
- Always let the person know what you are going to do.
- Beware of talking down to a person, or shouting. When you shout your voice rises and some people can only hear the low registers.
- There are many reasons why someone may be unable to talk – do not assume that it is because they are deaf or have an intellectual disability.
- Stand in front of the person and maintain good eye contact.
- Talk to the person in a manner appropriate to their age.
- Do not talk about the person in the third person or about their condition to others in front of them.
- If you start a conversation and get stuck – ask someone else to help you, or say you do not understand.
- Avoid nodding and smiling when you don't understand. You will be found out!

Remember that in a hospital, many of the words and routines will be unfamiliar to your patient. Always try to put yourself in the position of the person with the communication problem. How would you like to be treated if you could not speak for yourself?

## Ensuring the person's rights

PEOPLE WITH COMMUNICATION DIFFICULTIES have the same right as any other person: to be fully informed about all aspects of their care and of the choices available concerning their care. It is the worker's responsibility to be absolutely sure that the patient is providing informed consent to any procedure, medication or course of treatment, and that the person has the capacity to give consent. Effective communication is integral to this.

# 4 Medication

PEOPLE IN HOSPITAL are often on medication. The medication may have been prescribed during a hospital visit or be a continuing drug therapy. It may be for specific symptoms or for a short or long-term condition.

During the hospital admission procedure it is essential to document the medications the person uses, including dosage, compliance and conditions for which the medications are being used. It is also important to establish whether the person has a history of allergies or adverse reactions. An up-to-date record of exactly what the person is taking and an assessment of compliance are important parts of any assessment.

For every person using medication, there should be:

- a risk-benefit assessment indicating the advantage for the person;
- clearly defined goals or outcomes for the use of the medication;
- a process of monitoring and review;
- an assessment of the potential for interaction with other medications;
- consideration of side effects and their impact on the person;
- a safe system for administering and monitoring the medication;
- patient and/or carer education in the administration of the medication, the importance of the medication to them, its treatment effect, and important side effects and potential interactions.

## Implications in the hospital setting

The person's medication may have implications for the planning of surgery or anaesthetics, e.g., the cessation of aspirin or the maintenance of insulin.

- To minimise problems during surgery, medication may need to be taken with the pre-anaesthetic.
- The medications themselves may interact with the drugs used for the anaesthetic.
- The timing of some medications in relation to meals may have to be adjusted in the light of the hospital routine.

## Preparation for discharge

Preparation for discharge from using hospital services should include measures to ensure that:

- the person or their carers understand the reason for the medication;
- the person or their carers understand the dose, administration and frequency of the medication;
- there is a safe and reliable way of ensuring its administration;
- the person monitoring the ongoing use of the medication (usually the person's general practitioner) is informed in sufficient time;
- the process of monitoring and review is understood by the person or carers;
- sufficient medication is provided to last until the person can acquire their own supply.

Patients should be involved as much as possible in decisions about using their medication. Where a person's disability restricts involvement, the information should be provided to the patient's carer, guardian and general practitioner.

## *Medication*

### *Delegating to carers*

When delegating the monitoring and administration of medication to carers upon discharge, staff should ensure that the carers or family are:

- appropriately trained;
- capable of taking the responsibility;
- prepared to take responsibility.

# Sensory impairments

SENSORY IMPAIRMENTS are impairments where the functions of the major senses of sight, hearing or touch are significantly diminished. Sensory impairments may coexist with other disabilities.

People deal with their disabilities in different ways. How they deal with a sensory impairment reflects the society in which they live, their personality, their social situation and their particular capabilities.

People with sensory impairments have different experiences of the world around them and may have difficulty adapting to a changed environment. Hospitalisation brings with it changes in the personal, physical and social environment for everyone. The routine of every day life is disturbed and coping with outcomes that are not always predictable gives rise to stresses of its own.

## Sensory impairments and other disabilities

When sensory impairments occur with other disabilities, they can create additional problems. When sensory impairments are associated with intellectual disability, for example, the person may be more likely to experience confusion or disorientation. A person's mobility will impact on the management of a sensory impairment in the environment of a hospital. Anticipating the needs and potential problems faced by the individual person is critical to the outcome of the hospital stay.

The following questions should be answered:

- What is the functional vision/hearing of the person?
- In what ways will their sensory impairment significantly affect the ways they use hospital services?

### *Sensory impairments*

- What aids does the person normally use in their day-to-day life?
- What effect do concurrent disabilities have on the visual/hearing impairment?
- What effect do concurrent disabilities have on the initial assessment?
- What effect do concurrent disabilities have on the management within hospital?
- What effect do concurrent disabilities have on the discharge/ follow-up?

## Vision

VISUAL IMPAIRMENT affects people in different ways. Some people, for example, can differentiate between light and dark but can't recognise an object or a person's face. Other people can see during the day but are blind at night. Some can read a book or computer screen but can't see the numbers displayed on a bus. These differences can lead to confusion outside of hospital but will also impact on the hospital stay. People with visual impairment will be required to cope with an unfamiliar environment and will come into contact with a range of people who may not be accustomed to their particular needs.

## Functional assessment of vision

Identifying limitations and special requirements is an important initial step in the assessment of any person using a hospital service. Usually people can indicate their capabilities themselves. When the degree of a person's impairment is not easy to discover, for example where there are communicative or cognitive impairments, the person's limitations may be assessed with the person's carer. Sometimes it may be necessary to make an objective assessment using formal testing procedures or direct observation of the person.

## Impact of hospital on people with visual impairment

Familiar, uncluttered surroundings allow people to move with confidence in their immediate space. An important first step will therefore be to describe the surroundings clearly and to structure the environment according to the person's needs.

### *Structuring the environment*

Access to a radio (rather than a television), and to tapes or books in Braille, may help to relieve the boredom we all face during a prolonged stay in hospital. In cases where blindness restricts mobility, staff should facilitate movement for the person within the hospital. Unnecessary anxiety can be minimised by preparing the person with verbal cues prior to something happening, explaining procedures as they occur and avoiding sudden surprises.

## Aids for vision

To cope with their day-to-day lives, people use aids ranging from glasses to guide dogs. It is important to assess which aids will benefit the patient during their stay in hospital and what adjustments may be needed to accommodate them. Simple things like having access to the menu may be overlooked.

## Concurrent disabilities and visual impairment

Concurrent disabilities can significantly affect our awareness of the impact of the visual impairment and necessitate changes in our management of the patient.

- Visual impairment occurs more commonly in people with intellectual disability but their intellectual condition can make it harder to assess.



### *Sensory impairments*

- A person's mobility may dictate their needs whether or not they have a severe visual impairment.
- A concurrent hearing loss may further restrict person's awareness of the world around them.

At discharge and follow up, management strategies for such issues as the use of medication and wound care will need to accommodate the person's visual impairment.

## Hearing

HEARING IMPAIRMENT may not be as obvious as visual impairment, but the resultant communicative disability can lead to isolation, confusion and alienation, particularly when people around the person are unaware of the person's capabilities or are unable to adjust to them.

### *Variations in hearing impairment*

There is significant variation in the range and impact of hearing impairments.

- Hearing impairments range from difficulty differentiating noise in crowds to total deafness.
- The disability may be of recent onset or present from birth.
- Many people who are profoundly deaf have been able to adapt very well to their condition by lip reading and signing.
- While most people are aware of their deafness, some people with cognitive impairments are not.

In some environments there may be no perceivable handicap to a person with a profound hearing impairment. This is because the impact of the impairment has been ameliorated by the ability of colleagues and carers to adjust and adapt themselves to the disability. Such adjustment and adaptation is equally possible in the hospital environment.

## Functional assessment of hearing

Patients themselves can usually outline their capabilities and requirements. Issues such as the use of signing, the tolerance of noise within the immediate environment, whether or not the person can lip-read or would like an interpreter, and whether written information or communication is helpful, can be covered at the initial assessment. The person should be encouraged to ask questions and to inform staff if they are unsure about a particular problem or issue.

## Hearing aids

Patients themselves will usually be aware of the management of their hearing aids. Ensuring that they are in place and operational at all possible times, including when in theatre and during procedures will facilitate peoples' communication with staff and their awareness of what is going on around them. When the aids are removed, ensure they are labelled to avoid loss.

## Impact of hospital on people with hearing impairment

Staff can have a major influence by ensuring the hearing impairment does not limit the person's involvement in or awareness of the management of their medical problems. Hearing impairments and communication difficulties do not mean people cannot be involved in decisions about their own medical care.

## Concurrent disabilities and hearing impairment

Hearing loss is associated with other conditions and often with older age. People with an intellectual disability also have a higher incidence of hearing impairment. Familiarising the person with hospital surroundings may be harder where there is cognitive impairment,

### *Sensory impairments*

because the ability to use or develop signing and other alternatives to communicate may be limited. The chapter on communication describes practical ways of overcoming these barriers.

#### *Communicating with a person with a hearing impairment*

When communicating with a person with a hearing impairment staff should:

- be an appropriate distance from the person, on their better hearing side;
- have good visual contact to facilitate lip-reading;
- minimise background noise;
- speak clearly, not shout, and avoid patronising tones;
- use gestures and visual cues if indicated;
- use communication aids if provided;
- write things down if appropriate.

# Mobility issues

MOBILITY PROBLEMS may result from conditions affecting movement, muscle strength, balance, flexibility, pain and stiffness, stamina or fitness.

These problems may be:

- long standing and stable,
- temporary,
- improving,
- deteriorating.

Limitations to a person's mobility can adversely affect their self esteem, lead to poor body image, and may even make them feel they are a burden to the people around them. The degree of the limitation may also be difficult to assess, especially when it is a product of a complexity of factors like pain, weight and strength interacting within the individual.

The management and the types of services and support needed during the hospital stay depends on the clinical situation and current progress of the person.

People themselves will usually be aware of the environmental adjustments needed to enhance their mobility, so the best plan is to discuss with them their individual needs and limitations.

Mobility problems may result from general medical conditions. Understanding the cause will generally help in the management:

## *Mobility issues*

### *Examples of medical conditions causing mobility problems*

- problems with balance and gait from an amputation;
- uncontrollable movements from Huntington's Chorea;
- muscle weakness from muscular dystrophy;
- balance problems from Meniere's disease;
- decreased exercise tolerance from cardiovascular disease;
- spasticity resulting from cerebral palsy.

## Mobility aids

A WIDE RANGE OF AIDS are available and people frequently bring their own equipment with them. Mobility aids include:

- electric chairs
- manual chairs
- walking frames
- walking sticks
- sliding boards – for moving from one chair to another;
- splints and body braces – for obtaining optimum posture and limb positioning;
- hoists – for moving from bed to bath, bath to chair;
- positioning straps – for ensuring the people's safety when they are unable to support themselves;
- tilt tables – for improving circulation, strengthening bones, improving breathing and neck control.
- seating systems, including moulded seats to encourage upright posture, or seating that will minimise muscle spasm.

## Manual handling and transfer

### *Safe lifting*

THE GENERAL PRINCIPLES OF SAFE LIFTING apply to lifting people with a disability. In certain circumstances, however, some special issues may need to be considered.

## A Quick Reference Guide to Hospital Care for People with a Disability

- Beware of unpredictable movements or spasms.
- Modify lifting procedures to cater for people who have learned to be inventive or creative in coping with their limitations.
- Some people have written guidelines on the method of transfer they prefer personal carers to use.

### *Rights of patients*

Patients' rights to independence should be respected. For example, people with a long-term disability frequently develop their own methods for transferring from chair to bed, not necessarily following usual approaches. Assistance can be gained from therapists familiar with the person or the type of disability.

- Check the correct procedure and involve the person in the process.
- Provide clear explanations of what is going to happen during the lift so the person understands and is not alarmed by your sudden movements.
- Ensure that the person has a way of communicating pain or discomfort during the lift transfer and feels physically and psychologically secure.
- Allow adequate time, offer reassurance and explanation when the person is anxious
- Listen to the person's explanations of discomfort. Patients with a spinal cord injury may experience strange sensations rather than pain; people with cognitive limitations may find it difficult to express where pain or discomfort is felt.
- Refer to the physiotherapist and/or occupational therapist for guidance when there are unexpected difficulties or further changes in the person's mobility.

# Psychiatric 7 disorders

## Mental health problems

Everyone in our society is in some way affected at some point in their life by mental health issues. Whether through a person's own experience of mental health difficulties, or through the experiences of living with, caring for, or working with others who have a mental health problem.

Having a disability does not protect a person from developing these kinds of problems or being affected by others who have.

Mental health issues include:

- reactions to normal stresses such as the death of a close friend, or going into hospital;
- common mental health problems such as depression and anxiety – problems usually dealt with by the GP or a counsellor;
- serious mental illness, for example, severe depression or psychosis – problems best dealt with by psychiatric services.

People may be in hospital for psychiatric care, or may have mental health issues incidental to the physical illness for which they are in hospital. People may have unrecognised mental health issues, and they may develop mental health issues while in hospital. Hospital staff need to be aware that these issues may arise, and deal with them accordingly.

## Attitudes and approaches to mental health issues

PEOPLE WHO ARE 'DIFFERENT' are frequently excluded from full participation in the community. Socio-cultural factors tend to affect people who have different disabilities. Education is gradually changing social attitudes.

## A Quick Reference Guide to Hospital Care for People with a Disability

Unusual behaviour can be indicative of a psychiatric disorder or simply a means of communication that appears unusual due to the person's disability. Health service providers may be seen as lacking the experience and training to support the needs of such people.

- In practical terms, hospital staff need to start with an open mind and develop an understanding of each person's needs.
- An important first step towards providing inclusive health care is recognising when skills in caring for people who have a psychiatric disorder are lacking.
- The next step is to ask for advice, support and training.

## Admission

IN THE SAME WAY AS ANY PATIENT on admission, people with a past or current psychiatric history and physical or developmental disability should have their mental status and history of psychiatric treatment included in the initial review. A person with a serious or chronic psychiatric disorder may have a mental health case manager who is an important contact and should ideally be involved during the person's admission.

## Medication and its side effects

ADVERSE SIDE EFFECTS or interactions of medication are common causes of distress and disturbed behaviour. It is important to ensure that the exact details of medications taken are recorded on admission.

Some people who have a long-standing history of mental illness may be on very large doses that seem unusual to those who do not practise in the mental health field. Others may not have had an opportunity to have their medication reviewed in a safe environment. A period of hospitalisation may provide the opportunity for a review of medication. But extreme caution should be exercised in changing any medication regime that has been effective in the past. When a change in medication is being considered the decision should include discussion with the person, carers, and the person's treating doctors.



## Stress of hospital environment

### *Particular disabilities and stress*

PEOPLE WITH PARTICULAR DISABILITIES, e.g., intellectual disability, acquired brain injury, dementia and communication disorders, may be at greater risk of becoming emotionally disturbed when they are in hospital. The stress associated with hospitalisation is dependent on the influence of three main groups of factors.

- Environmental factors, i.e., the response of the service to the person's needs. Stress can be reduced, for example, by better communication: making sure that the person understands what is happening, and ensuring that hospital staff have the information and support they need to care for the person.
- Physical and biological risk factors, e.g., the side effects of psychotropic medications (frequently prescribed for agitation, restlessness or confusion) on organic brain damage, genetic influences and epilepsy.
- Psychological factors. Stresses include reduced ability to solve problems, inappropriate expectations of nursing staff, frequent confusing changes to the environment, and no say in what is happening.

Combined with a strange environment and unfamiliar faces, a different routine, pain or other uncomfortable symptoms or procedures, these factors can increase people's anxiety and confusion. This heightens the risk of disturbed behaviour by the person, and inappropriate interventions by staff.

### *Reducing anxiety*

Anxiety and confusion can be reduced with better communication and individualised calming approaches. These may include:

- alterations to the person's environment;
- increasing communication with the person to decrease the risk of anxiety.

A Quick Reference Guide to Hospital Care for People with a Disability

When patients become emotionally disturbed, use information gathered at admission to plan how best to help them.

## Behaviours and psychiatric disorders

BEHAVIOURAL PROBLEMS and psychiatric disorders may overlap, but they are not the same thing. If a person with a psychiatric illness presents with disturbed behaviour, management requires assessment of the cause of distress before intervention. If the situation is serious and acute, safety issues must be addressed first.

# Behavioural issues

PEOPLE WITH A DISABILITY may be more likely to find hospitalisation stressful. They may be concerned that staff may treat them differently, more anxious, more worried about their health outcome, and perhaps preoccupied with distressing memories of previous times spent in hospitals. These factors, in addition to other disability-related issues, may affect a person's behaviour. Staff need to ensure that a person's behaviour doesn't adversely affect the quality of health care delivered and work to overcome any difficulties and ensure the person's comfort and safety.

## Factors affecting behaviour

A VARIETY OF FACTORS AFFECT BEHAVIOUR and some may be related to a person's disability. A person's behaviour may serve a particular function; for example, it may be the only way people with severe communication impairments or cognitive disabilities can let you know how they are feeling. In these cases special care needs to be taken to understand the behaviour.

The side effects of medication (particularly neuroleptic and anti-convulsant medications), epileptic seizures, dementia, delirium and brain injury may also affect a person's behaviour.

How these issues impact on a person's stay in hospital will vary considerably from person to person. To overcome potential difficulties requires additional awareness and sensitivity.

## Getting to know the person

PEOPLE ARE INDIVIDUALS, and a wide range of factors influences how any one person behaves. For this reason the highest priority is getting to know each patient.

## A Quick Reference Guide to Hospital Care for People with a Disability

Some information can be gathered when the person first arrives at the hospital. Spending time with the person, however, is the most effective way. Their life experience has probably been very different from yours, and you will need time to listen and understand.

### Understanding a patient's behaviour

The purpose of a person's behaviour may not always be obvious or easy to understand. In these situations it may be useful to brainstorm the basics.

- Talk to your patient, or talk to a family member.
- Is the person hungry, cold, in pain, delirious, afraid or lonely?
- Involve familiar people as much as possible. They know a lot of information that you need to know.

Don't assume you know what is causing a particular behaviour. The same behaviour may serve many purposes. It may be helpful to ask the following questions.

- Is the behaviour occurring for the first time, or is it part of the person's usual behavioural pattern?
- Could the behaviour be the result of a physical/organic disturbance?
- In what circumstances does the behaviour occur? What occurred prior to the behaviour and what was the consequence?
- How long does a particular behaviour last?
- What factors are known to help, or are known to aggravate the behaviour?
- Does the behaviour interfere with the person's recovery?
- What are the medical implications and complications?

Recording these details in the person's notes will also help other staff better understand the person's behaviour (see *Patient Information Sheet* on pages 63 and 64 in this booklet).

## Managing behaviour

### *Guidelines for everyday management*

When behaviour that impacts on a person's visit to hospital is better understood, methods to overcome problems are likely to be more obvious and straightforward. Some hints and guidelines for everyday management are listed here.

- Try to maintain good communication with the person.
- With the person's help, plan each day so that it is as comfortable and happy as possible.
- Be flexible in your approach, responding to the person's changing moods or needs.
- Be realistic and consistent in your expectations. The daily nurse contact system for people with special nursing needs helps to reduce confusion.
- Be positive and encouraging, and especially vigilant for behaviour that might indicate a person is becoming depressed or feeling hopeless about their situation.

People with significant cognitive disabilities (severe intellectual disability, advanced dementia, and substantial acquired brain injury) are more likely to exhibit behaviour that requires a more thoughtful approach and extra specialist input.

### *Planning staff schedules*

It is probably fair to say that some staff will cope more easily than others with the special needs of people with disabilities. They can adapt their usual nursing practices without interfering with service provision and good outcomes. When possible, schedules should be planned to take advantage of the special abilities of staff. It is not always the person who has to 'fit in'.

## Safety

WHATEVER THE BEHAVIOUR and its cause (which may never be known with certainty) the safety of the person, the staff and co-patients is the highest priority.

The majority of health services provided to people with a disability are provided in an uneventful and straightforward manner, but situations may arise where a person's behaviour impacts on their safety, where they are a danger to themselves or others. These situations vary in severity from a tendency to pull or pick at bandages and wounds, to more aggressive and disruptive behaviour.

### *Management strategies*

There are several strategies for managing these situations:

- Find out where to go for extra help. A psychologist, psychiatrist or disability worker who is familiar with the person or who specialises in the area may be useful.
- Modify the person's environment to decrease danger; for example remove objects with which the person may injure themselves or others.
- Assess whether the person needs a room of his or her own, and one-on-one nursing for a period of time.

### *In an emergency*

In crisis or emergency situations of extreme danger to the person or others, it is important to use common sense. *As a last resort*, physical or chemical restraint may be required. Make sure you are aware of laws and guidelines for the use of restraint.

# Seizure disorders

EPILEPSY IS A COMMON DISORDER, occurring in 1% of the general population and much more frequently in people with neurologically based disabilities. It is a manifestation of the underlying brain injury or difference in brain development. A seizure is an intermittent disturbance of consciousness, motor behaviour, perception, sensation, emotion, or a combination of any of these.

- Most single seizures do not recur or require treatment.
- Seizures may be provoked by acute events including infection, head injury, chemical imbalance, stroke, or brain tumour.
- The term 'epilepsy' refers to recurrent, unprovoked seizures.

## Documentation

THERE ARE MANY DIFFERENT TYPES OF SEIZURE, and the severity of seizures varies from one person to the next. If a person has epilepsy, its characteristics should be documented at admission. Documentation should include information about:

- seizure type and manifestation;
- known triggers;
- seizure management;
- medication and side effects;
- safety issues.

Such documentation contributes to the person's safety and to optimal management of seizures while the person is in hospital. The knowledge and experience of people with epilepsy, and those who know them well, is an invaluable resource and should be respected throughout a person's stay in hospital.

## Presentation and classification

SEIZURES MAY RESULT FROM electrical activity in any part of the brain and can therefore present in many different ways. They are broadly classified as either generalised or partial seizures.

### Generalised seizures

Generalised seizures involve both halves of the brain simultaneously and are associated with loss of consciousness. They include the following types.

- Absence seizures – during which the person stares blankly for a few seconds (old term: *petit mal*).
- Myoclonic seizures – which involve the abrupt jerking of muscle groups. In their severe form Myoclonic seizures can throw the individual to the ground.
- Atonic seizures – in which there is a sudden loss of posture or tone in limbs, or the whole body.
- Tonic-clonic seizures – in which the body stiffens and then jerks repeatedly (old term: *grand mal*).

### Partial seizures

Partial seizures start in a localised part of the brain and produce symptoms relating to that part's function – for example motor, sensory, autonomic or psychic symptoms. Unexplained muscle jerks in a limb, smells, flushing or pallor, or sensations of fear or pleasure may, when they precede a seizure (an *aura*), be clues to the origin in the brain of that seizure.

Partial seizures may remain localised or may spread to produce a secondary generalised seizure. The clue to whether a generalised seizure is primary or secondary lies in the presence or otherwise of focal symptoms, or aura, preceding the onset of a generalised seizure.

Partial seizures may be subdivided into two groups:



### *Seizure disorders*

- simple partial seizures – where consciousness is not impaired;
- complex partial seizures – where consciousness is impaired.

### *Complex partial seizures*

In complex partial seizures people are conscious but may behave in odd ways (such as walking around without apparent purpose and plucking at their clothes). They may not respond appropriately to questions or requests.

### *Evaluation*

Seizures may go unrecognised, particularly in people who find it difficult to describe their experiences or in those whose behaviour during seizures is confused with behaviour arising from other causes. When seizure disorders are suspected, evaluation includes:

- the taking of a detailed history from the person concerned and those who have witnessed the suspected seizure;
- careful observation;
- documentation of suspected seizure activity;
- appropriate investigation.

### *Triggers*

Patients will sometimes know what triggers their seizures, but seizures often occur without warning. The following triggers are of particular importance in the hospital setting:

- missed, or late, dose of medication (e.g., through oversight or during preoperative fasting);
- medication withdrawal (e.g., during change of medication);
- decreased absorption of medication (e.g., because of diarrhoea or vomiting);
- drug interactions (e.g., with psychoactive drugs or anaesthetic agents);
- physiological stress (e.g., high temperature, sleep deprivation, and at particular times in the menstrual cycle).

## Seizure management

### *Managing particular types of seizures*

The appropriate management of a seizure often depends on the type of seizure.

- Simple partial seizures: All that is usually required is to remain with the person during the episode to reassure them.
- Complex partial seizures: Consciousness is impaired, so it is important to stay with the person and provide reassurance and adequate supervision to protect their (and other people's) safety.
- Generalised seizures: Management depends on the type of generalised seizure. The following are the most common types and the strategies used to manage them.

## Managing generalised seizures

### *Absence seizures*

Usually no management is required for absence seizures, although the person may become confused and benefit from reassurance and explanation.

### *Myoclonic and atonic seizures*

If Myoclonic and Atonic seizures occur frequently, protective head gear may be used to prevent injury from falls.

### *Tonic-clonic seizures*

During the first phase (the tonic phase) of tonic-clonic seizures all the muscles are contracting together. Chest muscles are also involved so breathing stops for a time. If cessation of breathing is prolonged the person may become cyanosed (turn blue). This phase is followed by clonic muscle contractions (jerking of limbs). During the seizure:

### *Seizure disorders*

- turn the person on their side so secretions can run out of their mouth (recovery position);
- loosen clothing around the neck;
- clear the area of hard or sharp objects to prevent injuries during the clonic phase;
- place a soft article (pillow/clothing) under the head to prevent the head banging on the floor.

After the seizure the person may be drowsy, confused or anxious. Staying with the person and offering reassurance is important.

### *Emergency drug intervention*

Knowledge of the person's previous pattern of seizures is important in order to determine when drug intervention to stop seizure activity is indicated. Generally, urgent medical intervention is required immediately if the seizure lasts longer than ten minutes or for longer than a time frame specified by the treating doctor.

## Anti-epileptic medication

ANTI-EPILEPTIC MEDICATIONS are used to reduce the frequency of seizures. In some people medication may completely stop seizures. In others, this may not be possible, particularly when there are underlying brain abnormalities (e.g., developmental differences, injury or disease).

### *Choice of medication*

Decisions about whether or not to treat, and the choice of medication, are made during discussions between doctor and patient (and carer if appropriate). Factors taken into account include:

- the seizure type, severity and frequency;
- the implications for the person's health and lifestyle of the seizures and of the medication (e.g., side-effect profile, need for blood monitoring);

- the person's response to treatment (several weeks are required to determine the effect of each drug dose).

## Side effects

Unsteadiness when walking, sleepiness, behaviour change or a reluctance to eat, as well as the more obvious symptoms of rash or vomiting, may all indicate the presence of side effects. Side effects are not always identified as such, and some people may have difficulty communicating their symptoms. Informed questioning and/or observation for evidence of side effects is therefore important.

## Safety issues

### *Preventive strategies*

THE RISK OF INJURY during a seizure must be minimised. There may be no warning of an impending seizure, or the aura may be very brief. Preventive strategies are therefore important. Those of particular relevance to care in hospital include:

- avoiding dangerous activities or places – e.g., proximity to potentially dangerous machinery;
- modifying the environment to prevent injury – e.g., while in hospital-raising the bedsides, placing equipment carefully (e.g., IV stands, monitoring equipment);
- providing appropriate supervision in potentially dangerous places such as the bathroom (a seizure in a bathroom may result in physical injury or even drowning, so appropriate supervision is essential);
- using a protective helmet to prevent head injuries in people with frequent and severe seizures. It may be appropriate for headgear to be used during the person's hospital stay.

*Seizure disorders*

*Reasonable precautions*

During hospital stays, staff must ensure all reasonable precautions have been taken to ensure the individual's physical safety. Potential risk is part of life for someone living with epilepsy and must be balanced with other factors including independence, privacy and individual choice. Discussions around the dilemmas raised by the need for such a balance must involve the person, family and/or carers and hospital staff.

# 10 Personal care

PEOPLE WITH A DISABILITY may have personal care needs that differ from the usual. Staff should clarify what assistance is required, if any. Many people develop creative ways of managing their own needs so they are able to function independently. Independence can be promoted in personal care through good communication and respect for the individual.

## Mealtime assistance

APPROPRIATE NUTRITIONAL INTAKE is essential to aid in healthy recovery. However when someone is in pain, is uncomfortable or anxious, eating may be the last thing he or she wants to do. Many people have allergies to food, require special diets and use special aids or appliances. People with a disability may have particular nutritional needs and may require special assistance when eating or drinking. They may also bring their own aids and appliances to hospital with them.

It is important to communicate with patients when providing mealtime assistance. For example, if a person has a vision impairment, inform them of what the meal is, and where each food type is situated on the plate.

When appropriate, ask the person concerned whether they would like assistance and, if so, how would they like that help provided.

*Personal care*

## Difficulties and strategies with eating and/or drinking

<b>Issues with eating and or drinking</b>	<b>Management</b>	<b>Examples of disabilities associated with eating and or drinking difficulties</b>
A decrease in physical skills to eat or drink independently	Adapted equipment, e.g., cutlery, slings Total assistance with feeding Assessment by speech pathologist	A person with multiple physical disabilities or quadriplegia.
Chewing or swallowing difficulties	Mince or vitamise food Correct position, assistance and verbal directions Smaller meals Use thickening agents if patient has difficulty drinking fluids	Dental problems, sore mouth Medication side effects, e.g., dry mouth Cerebral palsy with spasms Dysphagia Parkinson's disease Neuromuscular disorders
Ropy tenacious secretions present in mouth	Grape juice or medication to break down secretions Ensure adequate hydration	Cerebral palsy
Reflux	Identify usual methods of handling situation, e.g., positioning, food consistency, smaller meals Medication	Cerebral palsy Spastic quadriplegia Scoliosis
Increased risk of choking or aspiration, involving fluid, food or saliva inhalation	Correct positioning Smaller amounts of food/drinks Correct food consistency Refer to speech pathologist and possibly a physiotherapist	Acquired brain injury Parkinson's disease Cerebral palsy Cerebral vascular accident

## Difficulties and strategies with eating and/or drinking (continued)

<b>Issues with eating and or drinking</b>	<b>Management</b>	<b>Examples of disabilities associated with eating and or drinking difficulties</b>
Refusal to eat, spitting out food	Identify cause Seek out information from family or carers	Abnormal tone in facial muscles Respiration difficulties, e.g., mouth breathing Pain, e.g., in mouth, dental, abdomen Anorexia – related to medical condition or medication
Pica – habitual, purposeful and compulsive ingestion of non-food substances	Identify substance and keep it away from the patient, e.g., cigarette butts	Persons with intellectual disability
Satiation control issues. Person will go to great lengths to acquire food	Speak to person, family or carers about the usual management strategy and adapt it to healthcare environment	Prader-Willi syndrome
Stress, anxiety or fear indicated by exaggerated emotional responses	Remain calm, reassure and offer clear explanations	All persons may be at risk in an unfamiliar environment Emergency admission may cause emotional responses

## Nutritional disorders

COMMON NUTRITIONAL DISORDERS in people with disabilities include poor weight gain, obesity, and problems caused by the side effects of certain medications.



### *Personal care*

- Poor weight gain can occur in people who have difficulty eating and people with malabsorption of any cause. The person may require nasogastric tube feeding, or a gastrostomy tube. Guidelines should be made available depending on the type of gastrostomy design.
- Decreased mobility may cause obesity. This may further limit mobility and cause long term problems.

Side effects of various medications include dry mouth, increased salivation, and gastrointestinal problems related to food types. Certain anti-convulsant medications interfere with the absorption and metabolism of vitamin B12 and folate.

The use of alternative medications may reduce the incidence and discomfort associated with side effects. Refer to drug guides for advice.

### Consequences of poor/inappropriate nutrition

People who have physical disabilities commonly experience constipation and weight problems. These problems can be managed by integrating and adapting normal routines into the healthcare environment.

### *Managing feeding and nutritional problems*

To guide you in positioning the person, facilitating oral motor function and monitoring the person's progress, you may need to refer to a health professional.

- Speech pathologists assess and advise on the management of feeding and swallowing disorders that have an affect on language.
- Occupational therapists can improve the functional ability of the person by providing adaptive equipment or alternatively, adapting or modifying the environment.
- Physiotherapists can assess muscle tone, and postural control in relation to patterns of movement and posture necessary for eating.

A Quick Reference Guide to Hospital Care for People with a Disability

- Dieticians give advice about the nutritional needs of people, plan special and therapeutic meals and recommend foods that may make swallowing easier.

In consultation with the person and their families or carers, health professionals can develop guidelines for managing complex eating or nutritional problems.

## Dental hygiene

GOOD DENTAL HYGIENE is essential for the prevention of dental caries and periodontal disease. People with disabilities may experience a range of dental problems requiring assistance or aids, along with additional education in dental hygiene.

## Common problems

Certain dental problems are more common in people with disabilities – for example the incidence of periodontal disease is greater in people with severe intellectual disabilities, particularly if they are on certain anticonvulsants.

Other problems associated with poor dental care result when people are unable to advocate for themselves or are poorly educated in preventive dental health strategies. Poor dental health results in pain, discomfort, eating difficulties, inadequate nutrition and low self esteem.

### *Specific problems*

Common problems include:

- increased risk of tooth decay due to poor hygiene or lack of appropriate assistance;
- missing teeth or extra teeth (genetic syndromes);
- abnormal tooth development, malocclusion and/or periodontal diseases;
- overgrowth of gums due to the use of anti-convulsants;

### *Personal care*

- increased dental trauma in people with poorly controlled epilepsy;
- teeth grinding;
- mouth breathing;
- exaggerated bite reflexes.

## Identifying required level of assistance

Many people will be able to care for their own teeth independently. Others will show you the regime that they follow when they are familiar with the environment and equipped with appropriate aids and equipment.

### *Strategies for identifying the kind of help needed*

Approaches include:

- asking the person, promoting dignity and privacy;
- observing the person's skills and equipment (e.g., an electric toothbrush);
- checking comfort level and positioning (watching for swallowing or choking problems);
- consulting with an occupational therapist and/or speech pathologist;
- offering assistance and feedback as required, while identifying people who may be at risk of poor dental hygiene.

## Common problems and strategies when assisting a person with cleaning their teeth

The patient knows what works for them – so assist in the least restrictive way, allowing the person to be as independent as possible.

- Check time, venue, and equipment first. The bathroom may not be the most appropriate place and the person may require a soft brush for sensitive gums.

## A Quick Reference Guide to Hospital Care for People with a Disability

- If the person is unable to rinse from the tap, offer a glass of water.
- Check whether the person has poor muscle control, altered muscle tone or uncoordinated movements. The person may require supports from behind, or to be tilted back in a wheelchair.
- Be mindful of pain from untreated tooth cavities.

### *Problems with bite reflex*

If the person experiences problems with bite reflex:

- wait for the person to relax and for the spasm to pass, then remove the toothbrush;
- push the chin up slightly to initiate spontaneous release;
- do not try to prize open or pull the mouth down;
- hold the chin gently and firmly with mouth shut whilst you tap lips or teeth – after a few taps push the chin up to release the bite and continue with tapping whilst mouth is open;
- stay calm and use verbal reinforcement.

## Assistance with using the toilet

SOME PEOPLE REQUIRE PERSONAL ASSISTANCE TO USE THE TOILET. Illness or disability may compromise their independence in this task.

The person, their family or carer will often know best what their usual patterns are and be able to assist you to plan for their care.

### Particular issues related to hospitalisation

#### *Common problems*

Lots of people experience problems with bowel and bladder function when they are in hospital, especially when long periods of bed rest are associated with limited movement and reduced intake of food. These bodily functions usually return to normal without any adverse problems.

### *Personal care*

### *Secondary problems*

However, an extended stay in hospital, especially for patients with a disability, may give rise to secondary issues. These issues are frequently related to:

### *Specific problems*

- low fluid and food intake (due to swallowing or feeding difficulties);
- increased immobility;
- positioning making it difficult passing urine or faeces. There may be partial emptying of the bladder, increasing the risk of infection. Ask the person what feels comfortable for them.
- Incontinence. People with a cognitive impairment may be unable to tell others they need to use the toilet and forget they need to go. Regular reminders may assist.
- General bowel and bladder dysfunction. Difficulty adjusting to unfamiliar people and environments can bring on anxiety and stress which can further affect bowel and bladder function.

## Constipation

People with physical disabilities are prone to constipation due to:

- levels of immobility resulting in weakness of the abdominal and perineal muscle, decreasing the urge to defecate;
- reduction in bowel movement;
- insufficient roughage and dietary fibre;
- insufficient fluids;
- specific neurological damage affecting nerve supply to the gastrointestinal tract.

It is not always easy to identify the cause of constipation, however good communication with the person and/or their family, may identify issues specific to the individual. Close monitoring and observation of the person's physical and emotional state may identify further factors.

### *Long term effects*

Constipation may also have long term effects.

- In people with a spinal injury, constipation can lead to increased blood pressure related to autonomic dysreflexia.
- People with cognitive deficits and communication difficulties may not be able to describe the pain and discomfort related to their constipation.

### *Treatment*

Constipation is a serious health problem. Whether people arrive at hospital constipated or develop the condition after arrival, awareness of the individual's approach to constipation will result in the most successful outcome.

Many people with physical disabilities take medication to avoid constipation. It is important that this medication is continued during their hospital stay.

# Preparing for discharge

AFTER-DISCHARGE CARE has an important bearing on a person's continuing well-being. Issues such as wound care, dressing changes and the administration of medication need to take into account the environment in which the person lives, their support networks, and their level of independence. General practitioners and other community-based medical and nursing services should be informed of the patient's requirements for medical management and in particular any important changes that have occurred. In many cases people will be able to manage this communication themselves. When carers are involved, they need to have a clear understanding of their responsibilities and of the ongoing review process.

It is vital for continuity of care that patients discharged from hospital go home well informed, with all necessary arrangements organised, and with comprehensive documentation of their hospital stay.

- Try to anticipate any problems that may occur once the person is at home.
- Ensure that all documentation sent home is self-explanatory.
- Ensure that all documentation is available to the community based medical services prior to – or at the time of – the patient's discharge.

## Information

PEOPLE'S HOME ENVIRONMENTS VARY. Some people with disabilities live alone, totally independent of others; some live alone with assistance from family, friends and/or government services; some live with family or friends; and others live in government or non-government staffed accommodation.

## A Quick Reference Guide to Hospital Care for People with a Disability

In order to judge how elaborate the information and documentation should be, it is important to determine the level of support the person will go home to. Consider also:

- Are there other people, apart from the patient, who should be contacted/educated/informed about their after care?
- Is the person able to anticipate short or long-term requirements at home such as assistance with meals, structural changes at home, etc.?
- Will other health professionals need to be informed/involved with the person's care once they leave hospital?

Explain to the person or a person responsible for the person's care what to expect once they arrive home, how much assistance they are likely to need, how long it might take for them to improve, and who best to contact if they don't improve. It is likely that the person assisting them at home (even if a paid carer) may not have any medical training?

## Arrangements for care

When people are not able to care for themselves after discharge, discuss with the person and/or carer the arrangements that need to be made to ensure adequate short and long-term care. It may be necessary to arrange for a responsible person to:

- transport the person home;
- supervise or assist the person at home;
- arrange alternative accommodation.
- help prepare meals, assistance going to the toilet, and so on while the person is incapacitated;
- monitor seizures, side effects and unexpected reactions to medications;
- assist with the management of wounds and dressings;
- arrange follow-up appointments;
- ensure relevant documentation is provided to the person's general practitioner and/or other health professionals;



### *Preparing for discharge*

- help alter home environs to suit short or long term needs;
- organise for paid carers to be employed where necessary during the day and/or night;
- go shopping for the person.

## Documentation

### *The need for documentation*

Patients leaving the hospital should be provided with some form of documentation about their stay in hospital. This documentation will serve as a hard copy reminder to the person and allow accurate information to be shared with family members, carers, the person's general practitioner, etc.

The documentation should include the following details.

### *What to include*

- Details of the person's stay in hospital, including reasons for hospitalisation, and medical/surgical procedures performed.
- Details of medication including changes to previous medications and the reason for the change. A list of new medications, their dose and expected duration of treatment.
- A management program for wounds and/or dressings.
- Expected period of debilitation.
- An after-care appointment, including time, place and name of doctor.
- Short and long term management programs, if applicable.
- A list of relevant community-based services to contact for help, if necessary.

Ensure all documentation sent home is clearly written and easily understood. The person, members of the person's family, their general practitioner and other health professionals may need to read it or to receive their own copies, (with the permission of the patient).

# 12 Conclusion

Admission to hospital is a potentially stressful event in any person's life. In order to minimise this stress, and to maximise the health benefit for a person who has a disability, careful attention to preparing for admission, in-patient care, and discharge planning are essential. This book is intended to assist in this process by providing information about relevant issues. We hope you have found it helpful.

For further information or to comment on this booklet, please contact staff at the Centre for Developmental Disability Health or MOIRA.

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## Patient Information Sheet

Personal details	Preferred name:
	Carer/guardian/power of attorney (if applicable):
	Carer/guardian's contact telephone number:
Presenting problem (section 2)	<p>Why do you think you have been admitted to hospital?</p> <p>Is there anything hospital staff need to know about your disability that can make your stay in hospital as comfortable as possible?</p>
Medical issues (section 2)	<p>Please write down all your current medical conditions</p> <p>.</p>
Communication (section 3)	<p>Have you any concerns about being able to communicate with staff? If so, please describe your usual means of communication. Describe any prompts or aids that might assist the staff in communicating with you.</p>
	<p>Do you think you will have any problems understanding the staff's requests? Describe any prompts or aids that might assist you in understanding what the staff members are saying to you.</p>
Sensory impairments (section 5)	<p>Please describe any problems you may have with your sight and/or hearing that might affect your stay in hospital.</p>
Mobility, lifting and transferring (section 6)	<p>Describe ways the hospital staff could assist you during your stay in hospital.</p>
<p><b>If more space is required, attach an additional sheet to the checklist and indicate this has been done in the space provided in this checklist.</b></p>	

## Patient Information Sheet (continued)

Personal details Preferred name:

Mental health issues (section 7)	Please describe any current or previous mental health issues that you think the hospital staff should be aware of. How would you prefer staff to manage these issues?
Behavioural issues (section 8)	Please describe any behavioural issues that you think the hospital staff should be aware of. How would you prefer staff to manage these issues?
Seizures (section 9)	If you suffer from seizures, briefly describe your type and frequency of seizure.  What signs might indicate to staff a seizure is occurring or is about to occur? What management procedures would you prefer the staff to follow?
Personal care (section 10)	Do you need assistance with bathing, going to the toilet, cleaning your teeth or any other personal care issues? Please describe the assistance you would prefer the staff to provide.
Nutrition and mealtime assistance (section 10)	Please list any special dietary needs you have.  Please indicate any ways the staff could provide assistance with your meals and/or drinks.
Preparing for discharge (section 11)	Describe any problems you think you might have when you go home. Are there any matters you think the staff could deal with while you are in hospital, in readiness for your return home?
OTHER Issues	Are there any other disability-related issues that may impact on your stay in hospital?
<p><b>If more space is required, attach an additional sheet to the checklist and indicate this has been done in the space provided in this checklist.</b></p>	



# All About MOiRA Key Cards

## Kathy tells us how they work...

"Because I can't always say what I need, I require my Key Cards when I'm with someone else. My Key Cards are the key to me. They help others care for me and meet my needs. They are a permanent record of all the things I like and dislike."

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- how I can communicate
- how much I understand
- if, and how well I can see
- how mobile I am
- how I like to sleep and eat
- if I need help to drink and eat
- if I need bathing and toilet assistance
- all about my medication

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**Order your MOiRA Key Cards online [www.moirra.org.au](http://www.moirra.org.au)**

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