Assessing Adult Capacity for decision-making Social Work Guide & Practice Toolkit



Great state. Great opportunity.

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Assessing Adult Capacity for decision-making: Guide and Practice Toolkit

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INTRODUCTION

Clinical Social Workers interface with human rights issues, the law and ethics within their daily practice. When people are sick or abused, it is not always easy to communicate with them about what is happening or to encourage them to make the 'right' decisions about their health or social life. This guide and practice toolkit will provide you with information about how rights-informed practice can help you navigate the complex world of capacity for decision-making and guardianship.

Social Workers in health contexts often work with people who are very unwell or who have suffered harm. When seeking to intervene to prevent harm or illness, questions about the capacity of the person to consent to assessment, treatment and intervention or make decisions about care options may arise. Within our person-centred health care model, Social Workers have a clear role as an advocate for the person to ensure that the person is prioritised as the decision-maker in relation to their health care and obtains as much assistance as possible to be included in decision-making to the full extent of their ability.

Before Social Workers can assess, treat or refer someone, they must obtain informed consent. Touching a person without their permission in non-emergency health situations is an assault. Being confident about your ability to assess that a person is able to consent to assessment and treatment is very important. If a person cannot consent, then Queensland law provides options regarding who can provide consent. Always remember though that all people are presumed to have capacity to make their own decisions and so it is essential that Social Workers know about the law and its requirements. In relation to issues about informed consent, Queensland Health provides <u>guidance</u> <u>about informed consent for clinicians, students and consumer (in multiple languages)</u>.

People may be subject to abuse in the community. All health professionals must be clear about a person's capacity to make risky decisions versus a need to protect someone who is vulnerable to harm due to impaired capacity. It is a bio-ethical consideration.¹ Confidence in our ability to determine what is a person's dignity of risk versus our duty of care is essential. Social Workers have a strong history of working with people who are vulnerable and we are well-placed to advocate for the patient's right to make their own choices.

CASE EXAMPLE:

A male aged 80 years has recovering from a urinary tract infection at home. He had been admitted to hospital for delirium a month earlier. A health professional who knows him finds him walking in the street late at night in Winter. He says that he is walking to the local shop for a pint of milk. They notice that he is wearing his slippers with a tee-shirt and slacks.

THEY COULD STOP HIM FROM MAKING A DECISION TO CONTINUE HIS WALK BUT IF HE HAS CAPACITY, THEY WOULD BE WRONGLY INTERFERING WITH HIS RIGHTS. ON THE OTHER HAND, THEY DO NOT WANT TO ALLOW HIM TO BE AT RISK OF HARM IF HE IS DELIRIOUS.

ACTION: PROFESSIONALS MUST BE ABLE TO ASSESS WHETHER HE HAS CAPACITY TO MAKE THE DECISION TO WALK IN THE COLD NOW AND THEY WOULD NEED TO JUSTIFY WITH SOUND REASONING AND BASED ON THE LAW, IF THEY FIND HE LACKS CAPACITY, WHY THEY NEED TO PREVENT HIM FROM GOING ANY FURTHER.

¹ A chapter that outlines considerations for all practitioners re capacity assessments: Bowman, D. 'Who decides who decides? Ethical Perspectives on Capacity and Decision-making' in Stoppe. G. *Competence Assessment in Dementia*, (Springer Vienna, 2008) 51-59

Human Rights and Disability

Human rights are a set of universally agreed standards for how people should be treated by each other and by governments. Human rights are the basic rights and freedoms that allow us all to live with dignity and participate fully in civil, political, economic, social and cultural life.

Human rights are inherent and universal, which means they belong to everyone regardless of age, race, sex, disability or other attribute. Australia ratified the United Nations Convention on the Rights of Persons with Disabilities on 17 July 2008, making Australia one of the first Western countries to do so. By ratifying the convention, Australia indicated to the other nations that it intends to be bound by the treaty and make the domestic laws comply with the treaty terms.

The purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity.

Australia acceded to the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities on 21 August 2009. The optional protocol came into force for Australia on 20 September 2009. The optional protocol is a separate instrument to the convention, which gives the Committee on the Rights of Persons with Disabilities the power to receive complaints from individuals and groups who believe that their country has breached the convention after all domestic remedies have been exhausted. Queensland has adopted core principles from human rights and embedded them within the legislation. These are discussed further later in this Toolkit.

The Toolkit adopts a strong Human Rights perspective which not only fits with the Queensland legislation and approach to guardianship but also sits well with the Social Work Code of Ethics.

Social Work and Human Rights

Social Workers are expected to embed human rights and social justice values into their practice. Section 5 of the Australian Association of Social Workers' <u>*Code of Ethics 2010*</u> commits Social Workers to upholding social justice and human rights in their practice. In particular, section 5.1.3 (a) notes that Social Workers will promote policies, practices and social conditions that uphold human rights and seek to ensure access, equity, participation and legal protection for all.

Further, Social Workers are required to prioritise the client's interest so that we maintain the best interests of clients, as a priority, with due regard to the respective rights of others. Social Workers will seek to safeguard the rights, interests and safety of clients who have limited or impaired decision-making capacity when acting on their behalf or when another person, whether legally authorised or not, is acting for the client.²

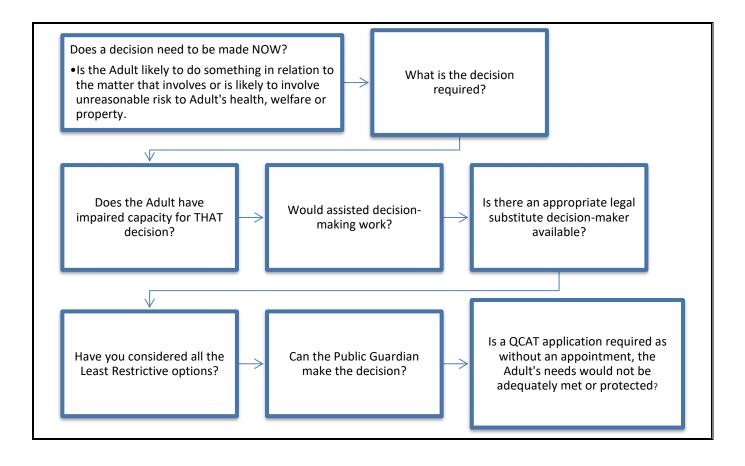
² Australian Association of Social Worker (AASW) Code of Ethics, s. 5.2.1

How to use the Guide and Practice Toolkit

This Guide and Practice Toolkit will lead you through a series of questions that are part of a clinical reasoning framework to use when considering whether an application needs to be made to the Queensland Civil and Administrative Tribunal. Each question is important to answer as it will allow you to 'drop off' the application pathway at any time; however, it is useful as it also allows you to build a case to support any application that may ultimately be necessary. So following all the steps in this process is never a waste of time but it does make sure that you follow a rights focussed approach to capacity assessment.

Of course, as you will learn, it is always best to support the person to make their own decisions if possible and working in Queensland Health provides access to free speech pathologist consultations, interpreters in Auslan as well as interpreters for people from culturally and linguistically different background and a range of assistive devices to assist with communication difficulties.

The reasoning pathway that underpins this guide and toolkit is:



The first question of the reasoning pathway

Does a decision need to be made NOW?

People with disease or disability that may cause a level of impaired capacity for decision-making are often seen in hospitals or health services in the community. Their impairment may be significant or slight, from birth (such as an intellectual disability) or the result of a disease or condition (such as dementia). The inability to make a required decision may be transient such as the inability that arises with delirium.

However, the fact that an Adult has a level of existing or newly acquired decision-making difficulty does NOT automatically warrant or require an assessment of capacity or referral to guardianship.

If the person has a transient illness, consider whether you can wait until they recover for the decision to be made. The time for assessing capacity is when a health or other decision needs to be made NOW and it cannot be delayed.

You should also consider whether the Adult is likely to do something in relation to personal, health or financial matters that involves or is likely to involve unreasonable risk to their health, welfare or property.

The focus of time for the decision to be made is critical. If there is no decision required now and there are no indicators of abuse or risk, then there is no need for a referral to guardianship or administration. It is not appropriate to seek a guardianship or administration appointment 'in case' one is needed in the future. With every QCAT application, you are taking away the patient's rights to make their own decision to the full extent possible and so unless a decision needs to be made NOW and all other aspects of the clinical reasoning pathway are met, then it will need to be left to the future.

In many cases, care of a person with impaired capacity for the decision that needs to be made by have someone who is able under law to make the decision on their behalf – either formally or informally - or who can support them to make the decision instead.

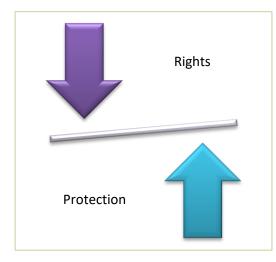
CASE EXAMPLE: A MALE AGED 75 YEARS WITH A DIAGNOSIS OF ADVANCED DEMENTIA IS ADMITTED TO HOSPITAL FOR ELECTIVE SURGERY. HIS DAUGHTER LIVES WITH HIM AND MANAGES HIS SHOPPING AND CLEANING. HE IS IN SOUND NUTRITIONAL HEALTH AND HAS A POSITIVE RELATIONSHIP WITH HIS DAUGHTER. HIS DAUGHTER PROVIDED CONSENT.

A PSYCHO-SOCIAL ASSESSMENT INDICATES THAT THEY DO NOT NEED OR WANT FURTHER SERVICES AT THIS TIME. Although the patient is no longer able to execute an Enduring Power of Attorney, his daughter can make health decisions on his behalf when he is no longer able to do so and his finances are managed as his daughter is his Centrelink nominee.

EVEN IF HE MAY NEED RESIDENTIAL AGED CARE IN THE FUTURE AND MAY NEED AN APPOINTMENT OF AN ADMINISTRATOR AT THAT TIME DUE TO AGED CARE FACILITY REQUIREMENTS, THIS DECISION DOES NOT NEED TO BE MADE NOW AND SO AN APPLICATION FOR ADMINISTRATOR AT THIS TIME WOULD BE INAPPROPRIATE.

Assessment: no decision needs to be made now and the Adult is not likely to do something that involves or will involve unreasonable risk to health, welfare or property.

PART 1: KEY CONCEPTS, ORGANISATIONS AND IMPAIRED CAPACITY CAUSES



1.1 KEY CONCEPTS

The Purpose of Guardianship

The State (government) has traditionally cared for citizens who are unable to make decisions for themselves under its *parens patriae* jurisdiction. The concept arose from English common law and due to Australia's legal heritage; we adopted the concept into our Australian law. The term is a Latin term that means, 'parent of the people'.

Essentially, the concept expects that the State protects

those who are unable to make certain types of decisions. The concept applies to children and to Adults who meet the definition of having impaired capacity for decision-making.

In Australia, our system of government has placed the care of those with impaired decision-making at the state level of government. Each Australian State now has its own different public guardianship and administration legislation and government organizations to support this legislation. In Queensland, an Adult can have someone appointed to make decisions about their health and personal matters (Guardian) and/or someone appointed to make decisions about their financial matters (Administrator). These terms are not the same within all states of Australia. Within the first part of this Toolkit, for ease, we will refer to both guardianship and administration as part of the guardianship system.

Section 6 of the *Guardianship and Administration Act 2000 Qld* notes that the purpose of the Act and hence, guardianship system is to strike a balance:

ractice Point

"Purpose to achieve balance

This Act seeks to strike an appropriate balance between —

a) the right of an Adult with impaired capacity to the greatest possible degree of autonomy in decisionmaking; and

b) the Adult's right to adequate and appropriate support for decision-making."3

This concept of balancing rights and protection is a key ethical tension in practice and is worthy of emphasis.

³ Guardianship & Administration Act (GAAT)2000 (Qld) s.6

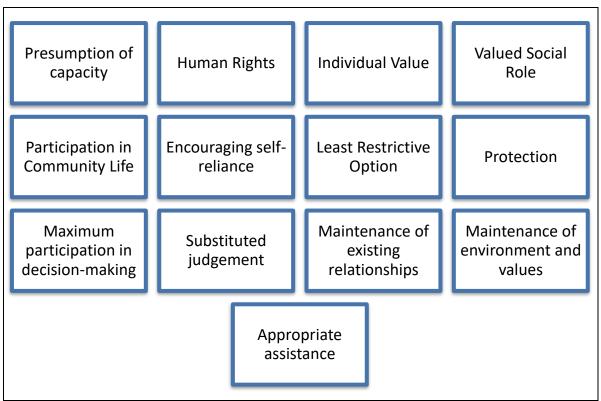
Guardianship in Queensland

In Queensland, guardianship for personal and health and administration for financial matters and capacity for decision-making is governed by legislation. Until the 1990's, jurisdiction for such matters resided with the Supreme Court of Queensland.

However, due largely to grass-roots advocacy from disability organisations⁴ and after extensive consultation by the Queensland Law Reform Commission across a number of sectors, the power for such matters was diverted to the Guardianship and Administration Tribunal (now the *Queensland Civil and Administrative Tribunal [Human Rights Division*]). The purpose of moving the jurisdiction was to improve accessibility due to decreased costs [no lawyers required to make an application] and a less formal and non-adversarial atmosphere [Tribunal, not court] with less restrictive evidence requirements.

Two Acts (*Powers of Attorney Act 1998* Qld and the *Guardianship and Administration Act 2000 Qld*) contain the law in relation to capacity for decision-making matters and guardianship in Queensland. In this program, if we refer to guardianship legislation in Queensland, we mean these two Acts. The Acts refer to people who fit the criteria of the Acts as Adults, so we will use this same terminology throughout the guide and toolkit. At the time of completing this guide, a Guardianship Bill 2017 had been lodged in Parliament but due to the election, this will need to be re-submitted. The changes that this Bill might make, if accepted, have NOT been included in this guide yet.

Key Guardianship General Principles



⁴ Applications to the Supreme Court were slow due to the large court lists and expensive as legal counsel was required.

What are the General Principles?⁵

Most importantly, the guardianship Acts contain general principles. The full description of each general principle can be found in this section below. These general principles are important, as they should ideally guide that way that everyone who uses the guardianship system should interpret and apply the exercise of powers given by the legislation. They are the guide – a 'lens' for you to check and reflect with how you are meeting and complying with the principles when actioning capacity assessments or referrals to guardianship organisations. For example, before making an application for a formal guardianship and/or administration order, you should question and be able to reason how you have met the expectation that you have presumed capacity, used a least restrictive option approach and ensured that the Adult has been assisted to the greatest extent possible to make the decision themselves.

The overarching principle when considering if an Adult has impaired capacity, is that you must:

Presume that the Adult has capacity.

This means that if you are claiming that someone lacks capacity but cannot prove this in some way or there is any doubt or you are unsure, you must presume that the Adult has capacity.

When determining if an Adult lacks capacity or when making a decision for an Adult who lacks capacity, the key considerations are:

- His/her right to respect for his/her human worth and dignity
- His/her right to be a valued member of society and encouraging they to perform valued social roles
- The importance of encouraging they to participate in community life.
- His/her right to participate in decision-making as far as possible and the importance of preserving his/her right to make decisions wherever possible
- The exercise of any power given by the legislation should be done in a way that is least restrictive of the Adult's rights.

These general principles underpin all the guardianship legislation. The President of the Tribunal, other Tribunal members, the Registrar, staff, guardians, administrators and attorneys, as well as health and legal professionals who interface with Adults around capacity for decisions must apply the general principles.

ractice Point:

If as a health professional, you must consider whether you have taken into account all of the above principles when assessing whether an Adult can make their own decision.

For example, did you ensure that you supported their dignity, presume they had capacity, involved them in decision-making as far as possible and act in a least restrictive way by trying assisted decision-making first?

The Act reminds us that the right to make decisions includes the right to make decisions with which you do not agree.⁶ So just because they do not agree with our directions about what they should do in relation to health care or accommodation choices, does not automatically mean that they lack insight or have no capacity for that decision.

Adults of all ages exhibit poor judgement or are reckless every day. For example, they may go bungy-jumping or drink too much alcohol. But no one questions their capacity to make their own choices/decisions.

⁵ Powers of Attorney Act 1998 (Qld), Sch .1 pt. 1; GAAT Act 2000 (Qld) sch1, pt. 1

⁶ GAAT Act 2000 (QLD) s5 (b)

Like all Adults, older people may also exhibit poor judgement such as wanting to return home, despite medical/allied health advice. This decision alone is not evidence of impaired capacity.

Key Points: General principles⁷ to be considered – complete list

- Presumption of capacity. An Adult is presumed to have the capacity to make his/her own decisions unless incapacity for that particular decision is established.
- Human rights. Regardless of decision-making capacity, everyone has the same basic rights, including the protection of individual liberty and access to services. Decision-makers must recognise the importance of encouraging the Adult to exercise his/ her rights.
- Individual value. Each Adult is valued as an individual, and his/her human worth and dignity are respected.
- Valued social role. An Adult's right to be a valued member of society is recognised, as is the importance of encouraging and supporting them in the performance of such social roles as home-owner, bank customer, investor, shopper, worker and volunteer.
- Participation in community life. Decision-makers must acknowledge the importance of encouraging the Adult to take part in general community activities, and of providing the support needed for such participation to occur.
- Encouraging self-reliance. Decision-makers must recognise the importance of encouraging an Adult to be as autonomous and self-reliant as possible—physically, socially, emotionally and intellectually.
- Least restrictive option. Anyone performing a function or exercising a power under the Act must apply the least restrictive option that is consistent with the Adult's proper care and protection.
- Protection .The person or entity must perform the function or power in a way that is consistent with the Adult's proper care and protection.
- Maximum participation in decision-making. The Adult has the right to participate, to the greatest practicable extent, in the decisions affecting his/ her life. (These decisions include the development of policies, programs and services for people with impaired decision-making capacity.) The application of this principle entails:
- Giving the Adult any necessary support and access to information to enable them to participate in such decisions
- Seeking and taking into account, to the greatest extent practicable, the Adult's views and wishes, whether they are expressed orally, in writing or through interpreters or other communication systems.
- Substituted judgment. If it is possible to work out from the Adult's previous actions, what his/her views and wishes would be, then these must be taken into account in any decision.
- Maintenance of existing relationships. The decision-makers must recognise the importance of maintaining the Adult's existing supportive relationships.
- Maintenance of environment and values. The decision-makers must recognise the importance of maintaining the Adult's cultural and linguistic environment, including any religious beliefs and lifestyle choices.
- Appropriate assistance. The assistance given to the Adult in a particular situation must meet his/her current needs and be adapted to his/ her individual characteristics.

^{7,} GAAT Act 2000 QLD, Schedule 1, Principles

Application of the guardianship legislation and its definitions

The legislation has defined key words used within guardianship and capacity for decision-making matters. This section reviews the definitions of who and what is captured within the guardianship legislation.

Who fits the definition of Adult?

Firstly, the legislation establishes jurisdiction over some of the citizens of Queensland. The Acts state that guardianship:

- Applies to 'Adults' defined as someone 18 years or older⁸.
- Applies to people who live in Queensland.
- Applies to Adults who are determined to have' impaired capacity'.
- Refers to the ability of Adults to make a decision about a 'matter'

What is the decision that needs to be made? Personal, Health or Financial?

What type of decisions (matters) are within the scope?

The guardianship system can only determine if a person has capacity to make certain types of decisions. The legal term refers to ability of the Adult to make decisions about a matter. What types of matters are referred to here?

Three types of decisions (matter) are referred to:

- 1. Personal
- 2. Health
- 3. Financial.

Personal matters refer to care and welfare matters of the Adult such as accommodation and whom they live with; day-to-day aspects such as diet and dress, employment and education and non-financial legal and property matters.

Health matters refer to 'health care (other than special health care)'.⁹ Health care is defined as "care or treatment of, or a service or a procedure for a person to diagnose, maintain or treat an

⁸ Acts Interpretation Act 1954 (Qld) s36 ('Adult' defined) Advance appointments for children aged 17 and ½ years may be made to come into effect when the consumer turns 18 years in some cases.

⁹ Powers of Attorney Act 1998 (Qld) s3 Sch3; Sch2 s2; GAAT Act 2000 (Qld) s3 sch4, sch2 s2.

Adult's physical or mental condition; and carried out by or under the direction and supervision of a health provider".¹⁰

In some circumstances, health care can include the withholding and withdrawing of life sustaining measures but it *does not* include first aid, non-intrusive examinations to diagnose or the administration of non-prescribed medications (such as Panadol), if these would usually be self-administered.¹¹

Financial matters refer to financial and property matters such as buying and selling land or other property; paying expenses such as rates, gas, electricity, insurance, tax and debts on behalf of the Adult with impaired capacity; investing money or making financial decisions or signing contracts on behalf of the Adult as well as all legal matters that may arise relating to the Adult's rights or obligations in relation to finances and property¹².

¹⁰ Powers of Attorney Act 1998 (Qld) s3 sch3, sch3 s5; GAAT Act 2000 (Qld) s3 sch4; sch2 s5.

¹¹ Powers of Attorney Act 1998 (Qld) sch2 s5(2)-(3); GAAT Act 2000 (Qld) sch2 s5(2)-(3).

¹² A more detailed outline of the various components involved in financial matters is found in Schedule 2, Section 1, *The Guardianship and Administration Act 2000 (Qld)*

1.2 KEY GUARDIANSHIP ORGANISATIONS IN QUEENSLAND

The Queensland Civil and Administrative Tribunal (QCAT)

For a very basic overview of QCAT see this video produced by Carers Queensland.

The Queensland Civil and Administrative Tribunal (Human rights) replaced the Guardianship and Administration Tribunal that was established in July 2000. The Tribunal has the authority to make, review and revoke guardianship and administration orders. The Tribunal has various functions but its main function is determining and making orders. The Tribunal abides by the General Principles, which are set out in *Guardianship and Administration Act 2000 QLD*. Remember:

- 1. Most people with impaired capacity don't need formal guardianship and administration orders. Their informal system of care and decision-making may be working well.
- 2. Referral to QCAT is a last resort and should only be used an Adult has impaired capacity for decisions that need to be made now and when all other suitable alternative options, such as assisted decision-making, have been exhausted
- 3. QCAT's main duty is focussed upon the welfare and needs of the person with impaired capacity and they are not focussed upon organisational imperatives such as reducing length of stay or targets.

Functions

The functions given to the Tribunal, pursuant to Section 81 of the Act¹³, includes:

- Making declarations about the capacity of an Adult, guardian, administrator or attorney (Attorney' means an attorney under an enduring power of attorney or a statutory health attorney) for a matter;
- Considering applications for the appointment of guardians and administrators
- Appointing guardians and administrators if necessary, and reviewing such appointments;
- Making declarations, orders, recommendations, directions or advising about:
 - (1) guardians and administrators
 - (2) enduring powers of attorney, attorneys
 - (3) related matters
- Ratifying an exercise of power, or approving a proposed exercise of power, for a matter by an informal decision maker for an Adult with impaired capacity for the matter;
- Consenting to the withholding or withdrawal of a life sustaining measure for Adults with impaired capacity for the health matter concerned;
- Subject to section 68, consenting to special health care;
- Consenting the sterilization of an Adult with an impairment;
- Giving approvals under chapter 5B for the use by a relevant service provider of a restrictive practice in relation to an Adult to whom the chapter applies, and reviewing the approvals;
- Registering an order made in another jurisdiction under a provision, Act or law prescribed under regulation for section 167; and

¹³ GAAT Act 2000 (Qld)

• Reviewing a matter in which a decision has been made by the registrar.

urther information: <u>http://www.qcat.qld.gov.au</u>

The Office of the Public Guardian (OPG)¹⁴

An overview video of the Office of the Public Guardian was developed by Carers Queensland and can be watched <u>here</u>. The *Public Guardian Act* 2014 Qld, section 12 outlines the functions of the OPG in detail.

The Public Guardian is an independent statutory position. The Public Guardian is an actual person as well as a title and the incumbent is Natalie Siegel-Brown. The Public Guardian's role is assisted by officers who have delegated statutory powers in the Office of the Public Guardian. The Public Guardian now has child as well as Adult guardian responsibilities & powers; however, this section deals only with the roles and powers in relation to Adults.

The Public Guardian has various roles and functions. This Office is independent from QCAT.

The OPG is comprised of teams that support the different functions of:

- Investigation
- Health decision-making
- Guardian

This explains why you may sometimes encounter a number of different people from the Office of the Public Guardian during the progress of a case and they may approach the case with a different perspective as the roles change. For example, if you referred a matter for investigation of suspected abuse of a person with impaired capacity, you meet someone from the Investigations Team. If the matter is referred to the Tribunal and the Tribunal appointed the Public Guardian as a guardian, then you may be dealing with the Guardian section of the OPG.

Its key roles are:

- 1. Acting as guardian: entails making personal and/or health care decisions for an Adult if the Public Guardian is appointed to do so by the Tribunal;
 - a. If there is evidence that a person with impaired capacity cannot care for themselves and they have no family, relatives or friends who can act as guardian
 - b. Where the person has been abused, neglected or exploited or
 - c. Where there is such serious conflict in the family about the decisions to be made for the Adult that QCAT decides that it is best for someone outside the family or supportive network to act as the Adult's guardian.

When acting in this position as appointed guardian, the role requires the decision-maker guardian to take into account the preferences of the Adult and his/her rights to make his/her own decisions as far as capable.

2. Investigating complaints of abuse, neglect and exploitation or inappropriate or inadequate decision-making in relation to a person with impaired capacity, particularly if there is concern in relation to abuse of an Enduring Power of Attorney. Inappropriate decision-making may include an Attorney's lack of action or attempt to make a decision when a decision needs to be made. Importantly, a little-known power is that the Public Guardian can make application

¹⁴ Information for this section has been drawn directly from the website for the OPG at <u>http://www.publicguardian.qld.gov.au/</u>

to QCAT for a **warrant to enter and remove**¹⁵ when a person with impaired capacity is subject to abuse and is at risk of immediate harm.

3. Health Attorney - Acting as a Statutory Health Attorney [SHA] of Last resort, if a person with impaired capacity does not have an appropriate person available to do so.¹⁶ The OPG may be involved if there is no close friend or family or because there is a dispute about health care decision-making that is not being resolved. The role of the OPG in this case is facilitating a decision to meet a medical need.

This power under s42 of the *Guardianship and Administration Act 2000* can only be used in extreme circumstances and there must be an IMMEDIATE need for a decision to be made as well as family conflict. However, make sure before contacting the OPG that you have determined that there is either no SHA or that every chance to resolve the matter has occurred first. If there is no immediate need, the matter will need to be referred to the Tribunal.

The following are some cases that exemplify the work of the different teams in the Office of the Public Guardian:



CASE EXAMPLE AS INVESTIGATION TEAM:

MRS K IS AN 85 YEAR OLD WOMAN WHO HAS DEMENTIA AND LIVES IN AN AGED CARE FACILITY. PRIOR TO HER MOVING TO THE FACILITY, ONE YEAR AGO, SHE LIVED WITH HER CARER, MR B AND HIS FAMILY. MR B IS NOT A RELATION OF MRS K BUT CARED FOR HER HUSBAND PRIOR TO HIS DEATH TWO YEARS PREVIOUSLY. A

CONCERN WAS RAISED THAT MR B MIGHT BE USING MRS K MONEY FOR HIS OWN BENEFIT AND THAT HE HAD BEEN APPOINTED MRS K'S ATTORNEY. THE INVESTIGATION BY THE PUBLIC GUARDIAN REVEALED THAT MR B HAD BEEN APPOINTED MRS K'S ATTORNEY AT TIME WHEN THE MEDICAL EVIDENCE SUGGESTED SHE DID NOT HAVE THE CAPACITY TO MAKE AN ENDURING POWER OF ATTORNEY.

The investigation revealed that in the past two years approximately \$ 400 000 had been withdrawn from Mrs K's bank Account, with approximately half of that money being deposited into Mr B's bank accounts. Many other large cash withdrawal had been made at various social clubs, hotels and other like venues. Quite alarmingly, the investigation revealed that Mrs K's aged care fees were in arrears to the amount of \$5000 and that she had no money left in her bank accounts to pay these arrears. Further Mrs K's fortnightly income from her pension was not sufficient to pay her nursing home fees.

MR B, THE ATTORNEY WAS NOT ABLE TO PROVIDE A REASONABLE EXPLANATION OF WHERE THE MONEY HAD BEEN SPENT AND MAINTAINED THAT MRS K HAD GIFTED HIM THE MONEY. MR B'S AUTHORITY AS FINANCIAL ATTORNEY FOR MRS K WAS IMMEDIATELY SUSPENDED BY THE PUBLIC GUARDIAN AND AN APPLICATION WAS MADE TO THE TRIBUNAL FOR THE APPOINTMENT OF THE PUBLIC TRUSTEE AS MRS K'S ADMINISTRATOR. AS A RESULT OF THE INVESTIGATION, THE PUBLIC TRUSTEE IS MRS K'S ADMINISTRATOR AND IS ENDEAVOURING TO RECOVER MRS K'S MONEY FROM MR B.

CASE EXAMPLE AS AN APPOINTED GUARDIAN:

A.) MRS Y IS AN ELDERLY LADY WITH DEMENTIA WHO RESIDES IN HER OWN HOME IN A REGIONAL AREA. SHE RECEIVES SUPPORT FROM COMMUNITY-BASED SERVICES; HOWEVER SHE HAD BECOME AGGRESSIVE AND, ON OCCASIONS, THREATENING, TOWARDS THE SUPPORT STAFF. THE GUARDIAN WAS CONTACTED BY THE SUPPORT AGENCY WHO ADVISED THEY BELIEVE SHE SHOULD MOVE TO AN AGED CARE FACILITY. THE GUARDIAN WAS AWARE FROM PREVIOUS VISITS THAT MRS Y HAD LIVED IN HER OWN HOME FOR MOST OF HER LIFE AND WAS STRONGLY OPPOSED TO MOVING TO AN AGED CARE FACILITY. THE GUARDIAN ARRANGED TO MEET THE SERVICE PROVIDER AND MRS Y AGAIN DURING THE NEXT REGIONAL VISIT.

¹⁵ Public Guardian Act 2014 Qld

¹⁶ See section 6 on assisted and substituted decision-making for more information about the SHA role.

DURING THIS VISIT, MRS Y CONTINUED TO STRONGLY OBJECT TO MOVING TO AN AGED CARE FACILITY. THE SERVICE PROVIDER INDICATED THAT MRS Y WAS STILL ACCEPTING HER MEDICATION AND EATING HER MEALS ON WHEELS AND OTHER FOOD PROVIDED. IN FURTHER DISCUSSIONS IT BECAME APPARENT MRS Y'S DEMENTIA HAS WORSENED. HOWEVER SHE DID NOT WANDER AND WAS STILL SAFE AT HOME.

THE PUBLIC GUARDIAN DID NOT AGREE TO MRS Y MOVING TO AN AGED CARE FACILITY AS MRS Y WAS STILL SAFE AT HOME AND DID NOT WISH TO ENTER AN AGED CARE FACILITY. INSTEAD ADDITIONAL SERVICES FOR MRS Y WERE SOUGHT FROM ANOTHER SERVICE PROVIDER WHO HAD STAFF TRAINED SPECIFICALLY IN DEMENTIA CARE. THESE STAFF WERE ABLE TO INTERACT EFFECTIVELY WITH MRS Y AND HER CHALLENGING BEHAVIOUR REDUCED. THE VISIT TO MRS Y ALLOWED THE GUARDIAN TO CLARIFY THE SITUATION AND PROVIDED A STRONG BASIS FOR THE DECISIONS MADE.

B.) MR B IS A YOUNG MALE WITH AN ACQUIRED BRAIN INJURY AND A PERSONALITY DISORDER EXACERBATED BY DRUG AND ALCOHOL ABUSE. MR B LIVED ALONE IN A PROPERTY PURCHASED FROM COMPENSATION FUNDS. MR B WAS ISOLATED WITHIN HIS COMMUNITY AS HE WAS OFTEN THREATENING TOWARDS NEIGHBOURS. MR B HAS A NUMBER OF CRIMINAL CHARGES, INCLUDING POSSESSION OF DRUGS AND DRUG IMPLEMENTS. LOCAL COMMUNITY MEMBERS CONTACTED POLICE ON MANY OCCASIONS TO COMPLAIN ABOUT MR B'S BEHAVIOUR.

IN ATTEMPTING TO MAKE DECISIONS FOR MR B, THE GUARDIAN CONTACTED NON-GOVERNMENT AGENCIES TO PROVIDE SUPPORT TO MR B. HOWEVER MR B WAS VERBALLY ABUSIVE AND PHYSICALLY THREATENING TO SUPPORT WORKERS. HE REFUSED TO ALLOW THEM INTO HIS HOME. THE SERVICES ADVISED THAT DUE TO THE SAFETY CONCERNS THEY WERE NOT ABLE TO WORK WITH MR B. THE PUBLIC GUARDIAN APPROACHED MENTAL HEALTH SERVICES FOR ASSESSMENT. HOWEVER THEY ADVISED THAT MR B DID NOT HAVE A MENTAL ILLNESS AND WERE UNABLE TO OFFER SUPPORT. GUARDIANSHIP STAFF WERE ADVISED THAT DRUG AND ALCOHOL SUPPORT SERVICES REQUIRED MR B TO VOLUNTARILY ACCEPT SUCH SERVICES. WHEN THE GUARDIAN CONTACTED MR B HE BECAME VERBALLY ABUSIVE AND IT WAS NOT POSSIBLE TO DISCUSS MATTERS WITH HIM. HE ALSO BECAME ABUSIVE DURING A VISIT TO HIS HOUSE AND WOULD NOT ALLOW THE GUARDIAN TO ENTER.

THE PUBLIC GUARDIAN SOUGHT A REVOCATION OF THE ORDER ADVISING THE TRIBUNAL THAT WHILST THERE MAY BE A NEED TO DECISIONS BEING MADE FOR MR B, THE PUBLIC GUARDIAN IS UNABLE TO MAKE THESE DECISIONS AS MR B REFUSES SERVICES AND THREATENS SUPPORT STAFF. THE TRIBUNAL SUBSEQUENTLY REVOKED THE APPOINTMENT OF THE PUBLIC GUARDIAN.

The Public Guardian reluctantly sought the revocation, as it was felt that the order was unable to assist the man in the absence of suitable social and legal mechanisms to require that he accept services

<u>CASE EXAMPLE AS HEALTH ATTORNEY:</u> A YOUNG WOMAN WHO HAD A DIAGNOSED MENTAL ILLNESS AND WHO WAS PLACED UNDER AN INVOLUNTARY TREATMENT ORDER WAS REFERRED TO THE PUBLIC GUARDIAN.

The medical team were seeking a hysterectomy for the woman and there was medical evidence suggesting that the woman lacked capacity, based primarily on her mental illness. The woman had previously given birth to 5 children.

In this case, the health attorney of the Public Guardian intervened after a couple of in-depth conversations with the young woman and argued that the woman understood the nature and effect of her decision NOT to have a hysterectomy, although she may have not understood the nature and effect of her mental illness.

ractice Point:

The Office of the Public Guardian is prepared to discuss concerns with health professionals or what information you may need to collect or if you suspect that they may have to investigate but you are not too sure.

Role in Residential aged care placement

<u>The OPG website</u> advises that they may consider residential aged care placement for a person if all community-based options for their proper care and support have been exhausted and if they would be placed at unacceptable risk of harm or neglect if they were to remain living in their current accommodation arrangements. The website outlines what principles are applied and also what the guardian takes into account when deciding whether to make a residential aged care decision. You should review the criteria for requesting this.

The OPG has NO ROLE in

- Intervening if there is already an appropriate guardian or an attorney acting for the Adult in health matters (except where there is evidence of inappropriate behaviour). You should, as a matter of course, ensure that you have checked that there is no Enduring Power of Attorney or Attorney under an Advance Care Directive or any family or friends who may act as SHA.
- **Financial matters** but would liaise with an appointed administrator in making certain decisions. The investigation team can investigate financial abuse.
- Decisions about special health matters such as sterilisation or termination of pregnancy these are made by QCAT.
- Acting as a person's personal carer, case manager or co-ordinator. They will make the decision about where a person should reside but will not organise the accommodation.
- Making referrals to service or in legal aid matters.

urther information: <u>http://www.publicguardian.gld.gov.au/</u>

The Public Trustee Office of Queensland

The Public Trustee is an independent organisation that manages financial matters. It has had a historical role¹⁷ in managing the finances of people are unable to manage their own affairs as a result of health or disability concerns.

Like the Public Guardian, there is an actual person who is appointed The Public Trustee. At the time of writing this, the Public Trustee is Peter Carne. The Office of the Public Trustee supports the Public Trustee in the role. The Public Trustee has offices across the State of Queensland.

Some key roles that you will need to know in relation to the Public Trustee:

See this video on the <u>role of the public trustee</u> for a quick overview – developed by Carers Queensland

- Provides a free Will-making service and free Enduring Power of Attorney service. <u>https://www.qld.gov.au/law/births-deaths-marriages-and-divorces/deaths-wills-and-probate/wills/will-making-service/</u>
- Can be appointed by the Tribunal to act as an **administrator for financial matters** for a person who lacks capacity.

¹⁷ Originated in 1915 as the Public Curator

• Can be appointed as an attorney under an Enduring Power of Attorney to handle the financial decisions.

The Public Trustee has NO ROLE:

- In management of personal or health matters, or
- Arranging personal or health services.

urther information: <u>http://www.pt.qld.gov.au/</u> and offices <u>http://www.pt.qld.gov.au/contact/locations/</u>

The Public Advocate

The Public Advocate provides a systems advocacy lens to guardianship and capacity decisionmaking issues in Queensland. Mary Burgess is the current incumbent. The Public Advocate derives its legal authority from the *Guardianship and Administration Act 2000 QLD*. The body was subsumed for a few years into the Public Guardian's office; however, a recent decision was made to reinvigorate and separate the entity again. The website notes:

Functions

The Public Advocate works on behalf of Adults with impaired decision-making capacity to:

- promote and protect their rights, including protecting them from neglect, exploitation and abuse
- encourage the development of programs to help them reach the greatest degree of autonomy
- promote, monitor and review the provision of services and facilities for them.

Powers

The Public Advocate has the right to all information that is necessary to monitor and review the delivery of services and facilities for Adults with impaired decision-making capacity. This includes information about the services they receive and the policies and procedures of the organisations that provide services. It allows protection from liability for individuals and organisations that provide information to the Public Advocate in accordance with these powers.

Role within government

Statutory systems advocacy provides an important layer of protection for the rights of Queensland Adults with impaired decision-making capacity. The Public Advocate is uniquely positioned to influence government and non-government agencies.

Systemic advocacy reports

Under the Act, the Public Advocate can prepare reports to the Minister about matters relating to the functions of the Public Advocate. The Minister is required to table these reports in Parliament.

urther information: <u>http://www.justice.qld.gov.au/public-advocate</u>

PART 2: THE CAPACITY ASSESSMENT TOOLKIT

Assessing Adult Capacity for decision-making

This document is based in large part on the New South Wales Capacity Toolkit. Queensland Health acknowledges the initial work of the NSW Department of Attorney-General & Justice and the licence provided to adapt the work

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2.1 HOW TO USE THIS TOOLKIT

This Toolkit educates health professionals about guardianship and capacity for decision-making assessments in Queensland and what you need to consider BEFORE actioning a capacity assessment and what you need to do to complete a capacity assessment, as part of the team or as a sole practitioner.

In this Toolkit 'capacity' is a legal word. We use the term to refer to an Adult's ability to make a decision. Under the law, you must presume that every Adult has capacity.

Sometimes you may be the person who decides whether another person has capacity. Generally, when a person has capacity to make a particular decision they can:

- understand the nature and effects of the decision to be made
- make the decision freely and voluntarily, and
- communicate the decision in some way.

However, for some decisions there is a specific legal test for capacity. When you are assessing a person's capacity to make any of these decisions you must consider the particular matters outlined in the legal test. The test you use depends on the legal area to which the decision relates.

Health practitioners assume that every capacity assessment needs to be a major undertaking. Yet, in reality, you make decisions about an Adult's capacity each time you seek their consent to an assessment, intervention or treatment.

What this Toolkit tries to do is bring your unconscious current behaviours to your conscious to ensure that you are mindful of using the correct criteria and principles to determine if someone has capacity to make a decision now.

Who is the Toolkit for?

This Toolkit is for you if you have concerns about the ability of an Adult to make decisions. The person may be someone you:

- work for or with;
- provide services to; and/or
- care for, or support.

You may need to assess, or seek an assessment of, a person's capacity in your personal or professional life. You may be a:

- family member, friend or work colleague
- advocate¹⁸
- government or non-government employee or volunteer, including:
- someone who works for Home Care
- a housing provider
- someone who works for an organisation which provides services to people with a disability, older people or people with a mental illness
- a Social Worker or Case Manager

¹⁸ An advocate is someone who supports a person to say what they want, or speaks on behalf of a person, representing their interests in a way that promotes and protects their rights.

How do I use the Toolkit?

The Adult Capacity Toolkit is not an assessment tool. However, it does provide information about capacity, capacity assessment and the various legal tests of capacity in Queensland, all of which will help you when you need to assess a person's capacity.

This is a guide only. There is no legal responsibility for you to use the Toolkit.

Part 2, the section you are reading now, tells you who will find the Toolkit useful and gives advice on which sections might be of most help to you.

Part 3 is about the general concept of decision-making capacity. It outlines some of the main ideas that are linked to capacity.

Part 4 sets out capacity assessment principles. These are the basic building blocks for any assessment of a person's decision-making capacity. This section also explains when capacity might be assessed and by whom.

Part 5 offers some practical tips on conducting an assessment of capacity.

Part 6 will be helpful for people who need to know what the test for decision-making capacity is in a certain area of life.

Part 7 will be useful when you need to know how to support a person to make a decision for themselves. This section is about enhancing a person's capacity to make decisions. It also provides information on how to resolve disagreements if they arise.

Navigating the Toolkit

The Toolkit is not necessarily meant to be read from cover to cover. If you do, you will find some places where the information is repetitive. Where you are looking for particular information you will be able to find it quickly by using the contents index.

CASE STUDY

The case studies, highlighted in boxes, provide examples of issues raised when a person's decisionmaking capacity is in question.

PART 3: WHAT IS CAPACITY?

Assessing Adult Capacity for decision-making

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3.1 WHAT IS CAPACITY?

Unpacking the definition of impaired capacity

All Adults in Queensland are presumed to have capacity for decision-making. We often take our decision-making for granted. A person who has capacity is able to make decisions about things that affect their daily life, such as:

- Where to live;
- What to buy;
- What support or services they need;
- When to go to the doctor; and
- Matters that have legal consequences, including:
 - Making a will
 - o Getting married
 - Entering into a contract
 - Having medical treatment.

People who have capacity are able to live their lives independently. They can decide what is best for them and can either take or leave the advice of others. They can make unwise decisions such as gambling their money or donating all their money to charity.

"As a legal context, capacity refers to a person's ability to do something that may have legal consequences for that person or for other people. In democratic countries, it is a basic legal principle that Adults have the right to make decisions that affect their lives. For people who may be vulnerable because of impairment of ability to make decisions for themselves, that right to autonomy in decision making has to be balanced against the right to protection.¹⁹

Capacity is also a functional concept, related to a person's ability to select, identify, understand, retain and process relevant information in making a choice between options for the decision and the ability to cause that decision to be put into effect²⁰".

In this Toolkit, when we refer to capacity, we refer to its <u>legal definition</u> under the Queensland legislation. The definition is quite specific to guardianship and it is essential to know when working in health contexts.

Interestingly, the Queensland legislation does not provide a definition of 'impaired capacity'. Instead, the Acts define the meaning of 'capacity'. This is in keeping with the assumption that all people are presumed to have capacity.

To rebut the presumption of capacity, you must be able to prove that the Adult lacks capacity in some way. Similarly, it is not up to the Adult to prove that he/she has capacity.

The legal test of capacity

To determine whether a person has capacity to consent to treatment or other services, health professionals must determine how the law applies to the relevant facts about the Adult.

For example, it is vital to know not only about the Adult's medical history but also how the social,

¹⁹ Adapted from the description used in British Medical Association and The Law Society, 2004, Assessment of Mental Capacity: Guidance for Doctors and Lawyers. 2nd Edition BMJ Books.

²⁰ Entire quote from Walker, R., 2006. Capacity for Decision-making, Queensland Civil and Administration Tribunal internal document, p.2.

emotional, financial or personal history and context of the Adult affects his/her capacity to make decisions and whether there are ways that you can support the Adult to make their own decision with support. That is why a good capacity assessment process involves a holistic assessment and review of the Adult, rather than only a medical or cognitive one.

Unlike a medical report that notes a diagnosis, a complete psycho-social assessment must consider not only the medical aspects and its affect upon capacity but also:

- 1. "The nature and complexity of the decision;
- 2. Awareness of and access of the Adult to adequate knowledge about the matter to make a decision;
- 3. The familiarity of the Adult with the processes for making that kind of decision; including what their pre-morbid decision-making history might have taught them;
- 4. The circumstances that give rise to the need for a decision;
- 5. The extent to which reliable advice and other forms of support are available;
- 6. Likely influence by or interference from other people; and
- 7. The prevalence of other problems and pressures"21

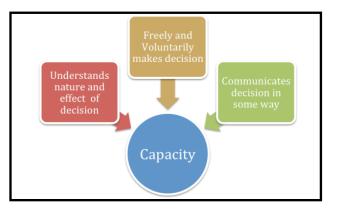
Essentially, an assessment will review the environmental, social, psychological, cognitive as well as medical aspects of the Adult and the effect on his/her capacity to make the decision required. This Toolkit will lead you through this process of assessment.

Capacity defined

The definition²² in the legislation states that an Adult:

"Will have capacity for a matter if he or she is capable of:

- Understanding the nature and effect of decisions about the matter
- Freely and voluntarily making decisions about the matter; and
- Communicating the decisions in some way".



Through the impairment lens, this means that for an Adult to have impaired capacity, he/she must:

- 1. Lack capacity to understand the nature and effect of decisions about a personal, financial or health matter;
- 2. Be unable to make such decision/s freely or voluntarily and/or
- 3. Be unable to communicate that decision in some way.

Let us now unpack these elements.

Understands the nature and effect of decision about the matter

Determining whether the Adult understands a decision is about the Adult's ability to process information about the decision to be made.

²¹ Walker, above n , 3.

²² Powers of Attorney Act 1998 (Qld) s3 sch 3; Guardianship and Administration Act (Qld) s3 sch4.

The test here is whether the decision-making process used was a wise one, not whether the decision itself is wise or conventional²³. The GAAT Act notes that *'This Act acknowledges.... the right to make decisions includes the right to make decisions with which others may not agree"*.²⁴

Broadly speaking, when an Adult has capacity to understand the nature and effect of a decision about a matter, they should be able to:

- 1. Grasp the facts involved
- 2. Retain the information
- 3. Recall the discussion about the concern
- 4. Determine the main choices
- 5. Weigh up the consequences of the choices
- 6. Foresee how the consequences of the choices affect them in terms of his/her personal values
- 7. And of course, communicate his/her decision²⁵.

How is 'understanding' determined?

A health practitioner may need to question gently to determine an Adult's awareness of his/her personal/ health/financial circumstances. For example, to query an understanding of an Adult's personal circumstances, a health practitioner could ask about the Adult's accommodation, care needs and safety.

It is important that the Adult can not only be able understand and weigh up consequences and risks in relation to a decision, but that he/she can also act upon any decision that is made.



CASE STUDY 'UNDERSTANDING NATURE AND EFFECT OF DECISION'

John is a young man in his 30's who has been diagnosed with Korsakoff's dementia. He wants to be discharged to his independent accommodation. He says that he can manage his finances without

ASSISTANCE.

However, on discussion with John, you realise that although he is able to tell you that he receives the 'Pension', is unable to tell you the name of his bank, how much he receives a fortnight or what expenses he may have to pay such as rent, electricity or food.

WITH HIS PERMISSION, YOU CONTACT HIS COMMUNITY CARE PROVIDER AND YOU ARE ADVISED THAT JOHN HAS A NUMBER OF UNPAID BILLS AND THAT HE HAS BEEN THREATENED WITH AN EVICTION NOTICE FOR NON-PAYMENT OF RENT.

When you discuss this with John, he is unable to explain his plan for paying his bills even after you explore some simple options with him. He said that bills would 'take care of themselves'.

Determining when an Adult understands the nature and effect of decisions

Walker²⁶ suggests that you consider the following practical questions when considering whether an Adult understands the nature and effect of decisions:

²³ Walker, above n ,39.

²⁴ The GAA Act 2000 (QLD), section 5(b).

²⁵ The Scottish Government, 2008, p.5.

²⁶ Walker above n 29. 0-11

Understanding of the nature of decisions

- 1. Has the person developed the basic understandings that are necessary for making decisions such as the decision under consideration?
- 2. Has there been an erosion of fundamental knowledge such that there is no longer sufficient knowledge basis for decision-making?
 - a. Does the Adult have sufficient understanding of his/her own financial/health/personal health status to be aware of issues that call for a decision?
 - b. In the case of memory loss, is the Adult's 'knowledge of the world²⁷' now an adequate basis for making decisions of this kind and complexity?
 - c. Is the Adult awareof the existence or possiblity of exploitation for personal gain?
 - d. Is there a working knowledge of issues for which decisions will be needed?
 - e. Is there an awareness of options in regard to decisions and of person, social and legal obligations and restrictions?

Understanding the effect of decisions

- 1. Is there an understanding of the **consequences** for both the decision-maker and others that are likely to flow from decisions that are made of not making a decision at all?
- 2. Is there an ability to compare likely consequences from choosing one option as against another?
- 3. Does the Adult have **adequate insight into his/her own abilities and limitations** for informed decision-making? For example, is there a realisation of memory loss and its effects on ability to make informed decisions?
- 4. Does the Adult possess **power and motivation to initiate action** that will put his her decision into effect?
- 5. **Is appropriate significance assigned to outcomes in general** (e.g. is the person severely depressed, no longer factorng in personal needs/survivial issues?)

Information Processing and reasoning aspects

- 1. Does the Adult have the cognitive ability to grasp and manipulate information as is required for informed decision-making?
- 2. Is there **impairment that precludes retention and rational manipulation of information** such as is necessary to reach informed decisions about the matter?
- 3. Is there a lack of insight or delusional beliefs that are likely to deform the reasoning process?
- 4. Are conclusions reached by the Adult consistent with reality?
- 5. Are decisions made consistent with stated or inferred goals?
- 6. Is there an ability to **remember previous choices**?
- 7. Is there consistency of decisions over time?
- 8. Is there ability to process information regarding options?

²⁷ Knowledge of the world is 'the product of a person's total experience within areas of social and financial functioning, of processes that are conventionally employed within particular areas of activity and any other information that may be predictive of the person's reaction to the matter and circumstances that are under consideration in each case'' Endicott, C. (2009) 'Client capacity and professional standards', delivered QLD Law Society Elder Law Conference

Useful Tribunal case discussing this limb of the definition:



re OB [2010] QCAT 271 at http://www.austlii.edu.au/au/cases/qld/QCAT/2010/271.html

Case relates to an Application seeking appointment of an administrator for an Adult. The Tribunal reviewed the facts and evidence presented and discussed why the Adult does not *"understand the nature and effect of decisions about his financial affairs as he does not appreciate the consequences of his actions, he cannot understand how to budget or why budgeting his limited income is necessary."*

The Tribunal found that it was satisfied that the presumption of capacity has been rebutted and that OB had impaired decision-making capacity about financial matters.

Timing of a decision and issues of capacity

Adults must have capacity to decide at the time that the decision needs to be made. Not the day before or even hours before but at the time.

For example, does the Adult have capacity to make the decision about the amputation of his leg when he is asked to give his consent?

Did he/she have capacity to make the EPOA at the time that he/she had to sign it?

Short-term issues such as general anaesthetic or alcohol may mean that an Adult does not have capacity to consent to treatment for a short time whilst he/she is under the influence of drugs or delirium. But if you have time to wait until this clears, you should.

However, some Adults may have a window of time when they CAN decide. For example, a person with early dementia may be able to retain information long enough to make an informed decision if he/she is asked during a time of lucidity.

In contrast, some matters require a more long-term ability to make decisions. Financial arrangements such as paying for a tenancy, managing investments, taking medications and remembering essential medical appointments may require a more sustained ability to retain information about a decision that needs to be made.

ractice Point: Some Adults will have difficulty with short-term memory recall. This does not automatically mean that he/she will lack capacity. Memory aids such as a writing book or voice journal may enhance recall and assist with capacity issues.

Freely and voluntarily

Adults may lack capacity to make a decision if they are unable to make it freely and voluntarily. One practice example is when an Adult appears influenced by family or other people to make a decision that may be contrary to what they would want if they were making the decision independently. It is particularly insidious if the Adult is swayed to make a decision that is contrary to their best interests e.g. selling their house for less than market value.

Most practitioners would correlate this limb with meaning that the Adult was unable to make a decision due to undue influence, fear of or threat from someone. However, this limb of the definition also refers to the context in which the decision is to be made and the support that is usually available to the Adult to assist them is not present. For example, a person with an acquired brain injury may be able to make decisions independently within an institutional environment because he/she has support, if required. However, if he/she moves outside a supported environment, these circumstances may change. The environmental context is important to consider.

Accordingly, in all cases, it is essential to consider whether the Adult has an existing network that is available to support them²⁸. Or alternatively, you can provide assisted decision-making support.

Good assisted decision-making support is where the assistor:

- 1. Checks that the Adult has enough information to make a decision and obtains more information if required to assist the Adult to make the decision
- 2. Asks for the Adult's perspective or decision
- 3. May check with the Adult about why he/she made that decision
- 4. Does not try to influence the Adult to make/change a decision without discussion
- 5. Does not tell the Adult what he/she should think or dismiss or over-ride his/her decision

Poor assistance with decision-making is

- if there is coaching of the Adult as to how he/she should answer or
- if the decision of the Adult is dismissed as not sensible or wise and the support person substitutes what they think the Adult needs.

Undue influence arises if the Adult is effectively voice-less: he/she is afraid or lacks the confidence to make a decision or complies with a decision because he/she is afraid of being hurt, abused or even left alone and ignored.

The caution about institutional abuse

Medical and other health professionals may unintentionally breach rights if they do not consider the power imbalance that exists between the Adult and family or even the health professional. An older person may comply with a family decision for them to be placed in a nursing home because he/she is afraid of their anger if he/she refuses.

Health professionals should be aware of power issues when supporting decision-making and seeking consent. The consent should always be real; not merely compliance. See the Queensland Health Guide on Informed Consent for more detailed information.

Undue influence is a form of coercion and it may be seen as a spectrum of behaviour: from action arising from actual violence and force applied to the Adult through to talking to the Adult, when he/she is ill, in such a way that he/she agrees to a decision just to stop the pressure.²⁹

ractice Point

Section 87 of the *Powers of Attorney Act* 1998 (Qld) notes that undue influence is presumed when there is a transaction between an Adult and either an attorney under an Enduring Power of Attorney or an Advance Health Directive or a relative, business partner or close friend of these people.

 $^{^{28}\,}$ Guardianship and Administration Act 2000 QLD, s.5 (c) (iii)

²⁹ Gillen, J. Potter v Potter [2003] NIFam 2 5 February 2003



Useful Tribunal case discussing this limb of the definition:

Case example: re SZ [2010] QCAT 64 @ http://www.austlii.edu.au/au/cases/qld/QCAT/2010/64.html

This case is a good example of the Tribunal discussing how it determines 'freely and voluntarily' as well as a discussion about communication and differentiating inability to communicate from a choice to communicate in a particular fashion e.g. culturally appropriate etc. In addition, there is an interesting discussion about conflicting interest by an appointed attorney and when the Tribunal may intervene.

Communicate the decision in some way

An Adult needs to be able to communicate a decision that he/she makes in some way.

'Communication' is NOT limited to verbal communication but can also consider the idiosyncrasies that have been developed by an Adult to communicate his/her decisions with carers or family and friends. For example, an Adult may be unable to move his/her mouth but may have learnt to indicate 'yes' or 'no' or letters of the alphabet through a movement of his/her eyes or they can use story boards to communicate.

It is therefore essential for health practitioners who are considering whether someone has capacity to consent to a decision for treatment to take the time to learn how the Adult communicates, rather than assuming that every decision must be made through an alternative decision-maker.

In such matters, it is also important not to quickly formulate decisions about an Adult's capacity and potential impairment. If communication is impaired due to ill-health or disability, health practitioners should make strenuous efforts to ensure that everything possible is done to assist with communication.

Timing of a capacity assessment might have to be delayed in relation to non-urgent matters until the Adult either improves or stabilizes and/or consultation with a specialist in communication and language, such as a speech therapist, has been undertaken.



Useful Tribunal case discussing this limb of the definition:

Case example: see QCAT case discussing difficulties with communication CSY [2010] QCAT 49 @ http://www.austlii.edu.au/au/cases/qld/QCAT/2010/49.html

Does the Adult have impaired capacity for THAT decision?

Capacity is decision, domain and time-specific

If you care for, or provide services to, an Adult whose decision-making is in question, you may need to decide frequently (each time a decision is made) whether the Adult has capacity to make each and every decision.

<u>Time specific</u> = Capacity fluctuates over time and a person may lack capacity for a particular decision

temporarily. They may lack capacity for a short or long period of time³⁰. Environmental factors such as new places, noise, time of day and who is present may also affect an Adult's responses. Personal stress or anxiety, medication, infection, drugs and alcohol may also give the appearance that the person lacks capacity. An Adult with dementia may have capacity to make decisions in the morning but in the afternoon, he/she may have difficulty due to an effect called 'sundowning'.



CASE STUDY TIMING, PHYSICAL ENVIRONMENT AND CAPACITY

'MY AUNT HAS AN INTELLECTUAL DISABILITY. I WAS APPOINTED AS HER FINANCIAL MANAGER A WHILE AGO. OFTEN, I NEED TO REASSESS WHICH FINANCIAL DECISIONS SHE HAS THE ABILITY TO MAKE BECAUSE I DON'T WANT TO CONTROL ALL HER FINANCES WHEN SHE CAN DO IT HERSELF.

I SPEND TIME WITH HER A COUPLE OF DAYS A WEEK, AND AFTER ASKING QUESTIONS, I CAN SEE WHETHER SHE IS OKAY TO LOOK AFTER HER SHOPPING AND BILLS UNTIL I SEE HER NEXT. IT USUALLY DEPENDS ON IF SHE IS PARTICULARLY TIRED OR STRESSED OUT ABOUT SOMETHING HAPPENING AROUND HER.

LAST WEEK MY AUNT DECIDED THAT SHE WANTED TO GET A MOBILE PHONE. SHE KNEW EXACTLY HOW MUCH SHE WANTED TO SPEND AND WHAT SHE WANTED IT FOR. BUT WHEN WE GOT TO THE SHOPPING CENTRE IT WAS VERY CROWDED AND EXTRA NOISY. AT THE COUNTER PEOPLE WERE EVEN PUSHING US TO GET PAST. MY AUNT COULDN'T CONCENTRATE AND WAS ANXIOUS. SHE COULDN'T MAKE A DECISION ABOUT THE PHONE PLANS THAT THE SALES PERSON WAS EXPLAINING TO HER. SO I MADE THAT DECISION, BASED ON WHAT SHE HAD TOLD ME AT HOME, AND SIGNED THE CONTRACT ON HER BEHALF. WE GOT OUT OF THERE AS FAST AS WE COULD!' AMRITA, NIECE

ractice Point

Capacity varies from Adult to Adult and from situation to situation. Capacity is not something solid that you can hold and measure. Neither is it something that is the same all the time. It is affected by an Adult's abilities and by what is happening around them.

It is very rare for an Adult not to have capacity for any decisions. However, this can happen when an Adult is unconscious or has a severe cognitive disability, for instance.

<u>Domain-specific</u> = More often, people lack capacity only in making one sort of decision, particularly if the decision is complex. For example, an Adult might be able to decide where they want to live (personal decision), but not be able to decide whether to sell their house (financial decision).

<u>Decision-specific</u> = They may lose some capacity in one domain e.g. where to invest money but still retain an ability to manage their pension or part of the allowance. Adults may be able to do simple grocery shopping (make a simple decision about money), but not be able to buy and sell shares (make a more complex decision about money). An Adult with early dementia may be able to consent to an x-ray but not complicated surgery.

ractice Point

It is essential to remember that capacity is decision specific. This means that, the Adult must have capacity to make the decision required <u>at the time that the decision is required</u> and about a particular decision or decisions. It is very unusual – unless the Adult is in a coma or has significant dementia etc. for them to lack capacity for every decision. Even someone with significant dementia may prefer to choose their own clothing colour.

Where there is doubt, health practitioners are obliged to reassess an Adult's capacity every time a decision needs to be made.

³⁰ Office of the Public Advocate (Qld) 2016, *Decision-making support and Queensland's Guardianship System*, 2016, Office of the Public Advocate (Qld), p.19



CASE STUDY DECISION-SPECIFIC CAPACITY

'I HAVE A GRANDFATHER WITH DEMENTIA. SOMETIMES HE SEEMS TO KNOW THAT I'M HIS GRANDSON AND OTHER TIMES HE THINKS I'M HIS SON. HE HAS GOOD DAYS AND BAD DAYS.

At one stage he needed an operation on both eyes because he had cataracts. When the doctor did the first operation, my grandfather didn't know what was going on. He was having one of those bad days and seemed to be stressed out about the hospital. He thought he was at the hospital campsite in the war. He couldn't understand the cataract surgery and the doctor ended up asking my dad to sign the forms to say he could have the operation.

It's funny, really, because when he went back to have the other eye operated on he seemed much better, and when the doctor talked with him he knew what was going on. I think the doctor realised this because he got my grandfather to sign his own forms that time. I don't know why my grandfather understood the second time. Maybe it was because he had done it before, or maybe he was just having one of his better days.'

LACHLAN, GRANDSON

Factors that may affect an Adult's capacity to make a decision

An Adult's decision-making may also fluctuate, depending upon personal strengths, the quality of services they are receiving, and the type and amount of any other support. Malnutrition or extreme dehydration may also impact upon an Adult's ability to make a decision. This creates a challenge for you when undertaking a capacity assessment.⁵ Some people have the lived experience of mental illness or some cognitive disability that affects their capacity at times of an acute episode.

In essence, capacity fluctuates, depending upon the time of the decision. Everyone's abilities vary and everybody reacts in their own way to their environment. For example, some Adults enjoy being in a crowded, noisy place but others find it stressful and difficult.

Delirium

Delirium is a particularly important condition to understand as it can be mistaken for dementia. Early diagnosis and review of people who have risk factors for delirium and then, if diagnosed, treating the delirium quickly may decrease the number of people who are admitted to hospital with this prognosis. Consumers and family are distressed by delirium and inappropriate or lack of treatment may cause pain and even death.

ractice point:

Unless there is an urgent reason for a decision to be made immediately to prevent harm to the consumer or his/her property, there should be no reason to make an application for guardianship or administration whilst the consumer has delirium. Either an attorney or a Statutory Health attorney can make most health decisions until recovery.

Loss of capacity IS NOT global. Just because an Adult lacks capacity in one aspect of decision-making, it does not mean that he/she lacks it in all aspects. An Adult may lack capacity to make decisions in relation to his finances but not in relation to how he dresses or who he wants to visit him in hospital.

An Adult may lose capacity for some things in one matter. For example, an Adult may be unable to handle his investment portfolio but be able to make simple purchases from his pension.

Statistics suggest that consumers with dementia are five times more likely to have an episode of delirium than those without dementia. If in doubt about whether delirium could be the cause of deterioration, check all the physical signs and risk factors above as a process of elimination.

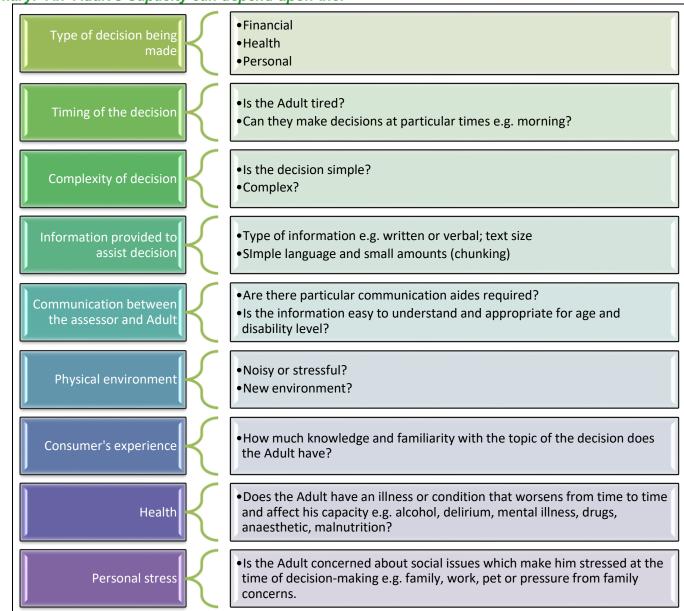
Other risks factors are linked to mistaken diagnosis of impaired capacity.

ractice point:

Risk factors for episode of acute confusion, particularly amongst Adults who are chronically ill or frail may be temporary but produce characteristics that are similar to impaired capacity are:

- More than 3 medications or recent changes in these (poly-pharmacy)
- Being older
- Pain

- Constipation
- Infections
- Use of a catheter
- Immobility
- Malnutrition some vitamin deficiencies and hormonal disorders
- Dehydration
- Institutionalisation effect lack of stimulation.
- Sleep deprivation
- Use of physical restraints
- Visual and hearing impairment
- Existing cognitive impairment such as an intellectual disability



Summary: An Adult's Capacity can depend upon the:

Capacity can be regained

An Adult can regain capacity or increase their capacity. For example, he/she can regain consciousness or learn new skills that will enable them to make certain decisions independently. Adults with a nutritional deficiency may improve capacity with proper nourishment.

Adults with the lived experience of mental illness can have capacity to make decisions at certain times but not be able to make some or all decisions at other times, dependent upon whether he/she is undergoing an acute episode or not. They are described to have fluctuating capacity.



CASE STUDY REGAINING CAPACITY '

MY DAUGHTER HAS A MENTAL ILLNESS WHICH, AT TIMES, MEANS THAT SHE DOES NOT HAVE THE CAPACITY TO MAKE HEALTH DECISIONS FOR HERSELF. GENERALLY, THERE ARE MANY SIGNS AND SYMPTOMS THAT ALERT ME TO THE FACT THAT THE ILLNESS IS BEGINNING TO BECOME MORE SEVERE AND AFFECT HER CAPACITY. WHEN

THIS HAPPENS, I START TO BECOME AWARE OF HER DECISION-MAKING ABILITY, PARTICULARLY AROUND HEALTH ISSUES.

Sometimes she decides not to seek medical advice or rejects medical advice given to her. This is one sign that her capacity is affected because when she is well she doesn't make those same types of decisions. Anyhow, in these acute periods of illness I make her health decisions, and any other decision she is not able to make.

The periods of illness vary in length, but my daughter always regains the capacity to make all decisions herself. Of course, she then starts to make her own decisions without my interference.'

Helen, mother

What happens if an Adult does not have capacity to make his/her own decisions?

If an Adult doesn't have the capacity to make a certain decision, someone called a 'substitute decision-maker' might need to make the decision for them³¹. So it is essential to know how to determine whether an Adult has impaired capacity the decision that you require them to answer now.

³¹ See Section 6 for more information on substitute and assisted/supported decision-making. Note also Section 1: role of Public Guardian and The Public Trustee.

PART 4: CAPACITY ASSESSMENT PRINCIPLES

Assessing Adult Capacity for decision-making

This document is based in large part on the New South Wales Capacity Toolkit. Queensland Health acknowledges the initial work of the NSW Department of Attorney-General & Justice and the licence provided to adapt the work

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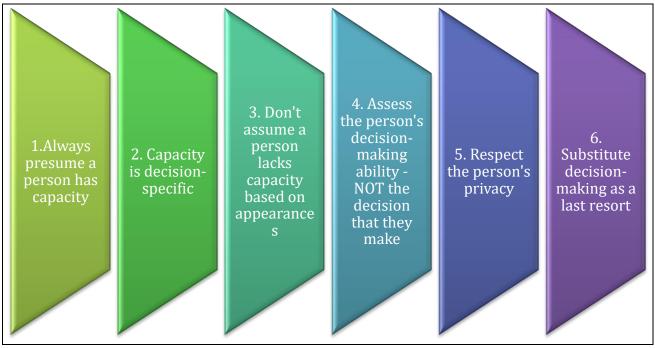
4.1 CAPACITY ASSESSMENT PRINCIPLES

The Guardianship and Administration Act 2000 Qld acknowledges³²:

- An Adult's right to make decisions is fundamental to the Adult's inherent dignity
- The right to make decisions includes the right to make decisions with which others may not agree
- The capacity of the Adult with impaired capacity to make decisions may differ according to
- The nature and extent of impairment and
- The type of decision to be made including complexity of decision
- The support available from members of the Adult's existing support network
- The right of an Adult with impaired capacity to make decisions should be restricted and interfered with to the least possible extent
- An Adult with impaired capacity has a right to adequate and appropriate support for decisionmaking

Accordingly, before commencing an assessment of an Adult's capacity, you use six key assessment principles to guide your clinical reasoning. These six principles are the lens for you to review each case.

Key Point: Six Capacity Assessment principles



This section reviews these principles and how to apply them in your assessment reasoning.

1. Always presume an Adult has capacity

The most basic principle is the presumption that an Adult has the capacity to make all his/her

³² Guardianship and Administration Act 2000 Qld s.5.

decisions. In Queensland, this is embedded within the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998*³³.

Every Adult is free to make their own decisions if they have the capacity. As a family member, friend, carer, or other individual involved with an Adult, you should always presume capacity unless it is established that they don't have the capacity to make a decision. If an Adult needs to decide and is unable to carry out any part of the decision-making process, they have impaired capacity for decision-making for that decision.

Why is this important?

"A finding of impaired capacity for a matter means that a person can no longer exercise their legal capacity for that matter; that is, the law will not recognise the decisions that the person makes in relation to that matter. If a person is found to lack capacity for a matter, a substitute decision-maker such as a guardian or administrator may be appointed to make decisions for them, or an enduring power of attorney may be activated. A finding such as this has an obvious and significant impact on a person's autonomy".

Capacity assessments must consider the Adult's culture, language, ethnicity and religious perspectives. When applying this principle, consider how an Adult's culture, language, ethnicity or religion impacts on their freedom to make decisions. For example, in some communities and in some families, an Adult may regularly allow or prefer the head of a household, a parent or an elder of the community to make all the important decisions. This means individuals with capacity to make their own decisions may freely allow others to make important decisions on their behalf.

Sometimes the decision-making process is collective and involves the whole community in meetings and discussions about the decision, such as in some Indigenous communities.

Also, some religious beliefs may impact on the decision made, or how it is made. For example, some Jehovah's Witnesses and Christian Scientists hold beliefs that might affect their decisions about various medical treatments.

Presumption versus protection – Unwise decisions

Even with a presumption of capacity, it is still important to think about the balance between an Adult's right to decide and the extent to which that Adult's health or safety might be in danger if they can't make a decision. This can be a very difficult balancing exercise.

If you are faced with this situation be mindful not to act in an overly protective way when assessing



whether an Adult has capacity.

Protecting an Adult from making what you think is an unwise decision may seem helpful, but it is often best not to intervene.

It is important to understand that if an Adult isn't allowed to confront a difficult decision or its consequences, their right to be in control of their life is denied. Everyone has the right to take their own chances and make their own mistakes.

³³ GAA Act 2000 (Qld) sch.1, pt 1 principle 1; Powers of Attorney Act 1998 (Qld) sch 1, pt 1. Principle 1

ractice Point:

Remember that making an unwise decision, or one that you don't agree with, does not mean that an Adult lacks capacity.³⁴

The Social Care Institute of Excellence in the UK have developed a vignette that demonstrates what it is like to work with an Adult who appears to make an unwise decision.

View it and reflect on what it feels like to watch this video and how it may change your practice: <u>https://www.youtube.com/watch?v=WbZWRiU9BSc</u>

Challenging the presumption of capacity³⁵

If you are claiming that an Adult doesn't have capacity, you need to provide your reasoning that supports your decision. Use facts to show that it is more likely than not that the Adult lacked the ability to make the decision at the time.

Providing facts and demonstrating an Adult's inability to make a decision can be as simple as doing the following:

- 1. Documenting the assessment process
- 2. Providing a summary of the questions you asked the Adult and his/her answers, and
- 3. Giving an explanation as to the reasons why you made your decision.

As a health professional providing a service to an Adult, you will need to provide written documentation about what informed your assessment and provide a verbal explanation to others such as family members or friends. For example, you may be asked to arrange and attend a family meeting to discuss the treating team's conclusion that your patient does not have capacity to make a decision about complicated surgery.

Keeping detailed notes of an assessment and writing down why you made the decision is therefore essential.

ractice Points: Examples of when good notes are useful

A doctor may decide that their patient has the capacity to consent to a risky operation. If the patient suffers harmful side effects because of the operation, the doctor may need to explain the capacity assessment decision to the family or even the Office of the Health Ombudsman.



CASE STUDY ASSUMING CAPACITY

'I don't like arguing with my sister Eugina, but she thinks that because my brother has been told that he has Alzheimer's, it means he can't make any decisions for himself. I tried to explain to Eugina that you have to have reasons, evidence if you like, to show that someone can't make a

DECISION ABOUT SOMETHING FOR THEMSELVES.

I know that she is just being protective, but she doesn't have to worry. When Eugina actually sees him, I think she will understand. (She doesn't live near us).

He might have been told that he has Alzheimer's, but the idea is not to strip him of his right to live his life like he wants. Eugina and I should monitor the things he can and can't do before taking over any decisions.'

³⁴ See capacity assessment principle 4 'Assess the consumer's decision-making ability - not the decision they make' on page 36.

³⁵ A more detailed discussion about recording in clinical files for legal purposes, as well as health purposes, is provided in Section 7.

NICIAS, BROTHER

2. Capacity is decision specific and it is not static

You must assess, or seek an assessment of, the Adult's capacity for each decision, whenever there is doubt about capacity. This is because an Adult's capacity can vary in different circumstances, locations, at different times, and about different types of decisions.

Just because an Adult has lost capacity to make decisions in one domain e.g. complex financial decisions, this *does not mean* that he/she will automatically lose capacity to make all financial decisions or capacity to make health or personal decisions as well.

If an Adult can make some but not all decisions, then they have a right to make as many decisions as they can.³⁶

Remember, even if an Adult couldn't make a certain decision in the past, they might be able to make one now: or in the future, or other types of decisions now or in the future.

ractice point:

Every time a decision needs to be made, you should ask the question: 'Does the Adult have the capacity to make this decision now?

If the Adult is unable to make a decision about something now, think about whether the decision may be delayed to a later time when the Adult may be able to make the decision alone or with assistance. Delaying the decision will give them the greatest control over their own life.



CASE STUDY DECISION SPECIFIC CAPACITY

'I AM MY HUSBAND, STEPHAN'S, CARER. WHEN STEPHAN CAN'T MAKE DECISIONS FOR HIMSELF ABOUT HIS DAILY ACTIVITIES AND LIFE, I MAKE THEM FOR HIM. EVERY DAY IS DIFFERENT REALLY. SOMETIMES STEPHAN HAS CLARITY AND CAN UNDERSTAND THINGS. THAT'S WHEN HE MAKES HIS OWN DECISIONS.

At other times, he doesn't comprehend things enough to make his own mind up, and then I make decisions for him. I never really know what to expect. I always start by thinking, "Stephan has the right to make any decision he can." I assume that he is able to make his mind up unless it's obvious to me (after I discuss things with him) that he doesn't understand.

IF THINGS ARE URGENT AND IMPORTANT AND I THINK THAT STEPHAN IS HAVING AN 'UNCLEAR' DAY, I WILL JUMP IN AND MAKE THE DECISIONS FOR HIM THEN AND THERE. OTHERWISE I WILL WAIT UNTIL HE CAN MAKE THE DECISION HIMSELF.'

ADA, WIFE AND CARER

3. Don't assume an Adult lacks capacity based on appearances

It is wrong to assume an Adult lacks capacity because of their age, appearance, disability, behaviour, language skills or any other condition or characteristic.

In fact, it may be discrimination under the law if you make unsupported assumptions about an Adult's lack of capacity because of the way they look or behave.

³⁶ However, remember to take into account cultural diversity and religious factors as discussed in capacity assessment principle 1 'Always presume a consumer has capacity'.

Key Point: Incorrect assumptions can often be made about an Adult's lack of capacity, based on any of the following:	
The way an Adult looks	physical characteristics such as scars
	skin colour
	features linked to Downs Syndrome
	muscle spasms caused by Cerebral Palsy
	other characteristics linked to cultural or religious practice
The way an Adult presents	poor attention to hygiene
	tattoos
	body piercing
	a dishevelled appearance
	irregular clothing
The way an Adult communicates	difficulty expressing themselves
	lack of English language skills
	slurring of speech
	using an Alternative and Augmentative Communication (AAC) system ³⁷
An Adult's impairment	physical disabilities
	learning difficulties and disabilities (e.g. Autistic Spectrum Disorder or Attention Deficit Hyperactive Disorder (ADHD))
	illnesses related to age or neurological function (e.g. Multiple Sclerosis, Parkinson's Disease or Motor Neurone Disease)
Temporary conditions	drunk or unconscious
The way an Adult acts or behaves	being an extrovert
	shouting or gesticulating
	behaving in a withdrawn way
	talking to oneself or avoiding eye contact
Actions that are connected to a cultural or religious belief	allowing or preferring another Adult, or the community group, to make a decision on your behalf

CASE STUDY CAPACITY AND APPEARANCE



 $^{\rm 37}$ see Part 1.3 & 7 for more information

'I AM AN ADULT WITH CEREBRAL PALSY. I FIND IT DIFFICULT TO COMMUNICATE. I HAVE PROBLEMS MOVING MY LIPS, TONGUE, JAW AND FACE MUSCLES. WHEN I SPEAK IT IS HARD TO UNDERSTAND ME, BUT IF YOU LISTEN CAREFULLY YOU CAN TELL WHAT I'M SAYING.

I REMEMBER GOING INTO THE BANK ONE DAY WANTING TO WITHDRAW MONEY FROM MY ACCOUNT. I DON'T KNOW WHETHER IT WAS THE COMMUNICATION DIFFICULTY OR THE WAY I LOOKED (SOMETIMES MY MUSCLES MAKE JERKY MOVEMENTS), BUT THE BANK TELLER OBVIOUSLY THOUGHT I COULDN'T UNDERSTAND ANYTHING. HE WAS SPEAKING TO ME AS THOUGH I WERE A TWO-YEAR-OLD AND SHOUTING AS THOUGH I COULDN'T HEAR HIM. HE DIDN'T PROCESS MY TRANSACTION, TELLING ME "I HAD BETTER GET SOME HELP WITH IT".

Well, I reckon he needed the help! I can't believe he didn't sit down with me and make the time to try to understand me. He just took one look, and because of my disability he thought I didn't understand what I was doing. I ended up getting a friend to come with me and explain it to him. How humiliating! For him, me, and the bank. People shouldn't make assumptions based on looks.'

4. Assess the Adult's decision-making ability – not the decision they make

This is an important point. You can't decide that an Adult lacks capacity just because they make a decision you think is unwise, reckless, or wrong. An Adult can make eccentric decisions that do not fit with your life values.

Everyone has his or her own values, morals, beliefs, attitudes, likes and dislikes. You might think a decision is bad yet someone else will think it is good.

Most people take chances or make 'bad' decisions occasionally. The right to make a decision includes the right to take risks and to make decisions with which others disagree. This is known as *dignity of risk*.

However, you may question an Adult's capacity to make a decision if they make a decision that either:

- Puts them at significant risk of harm or mistreatment, or
- Is very different from their usual decisions.

When questioning an Adult's capacity, you may also consider:

- The Adult's past decisions and choices;
- Whether they are easily influenced or pressured by others;
- Whether they have developed a medical condition which might affect their decision-making; and
- Providing more information to assist them to understand what's involved in the decision, and its consequences.



CASE STUDY ASSESS DECISION-MAKING ABILITY

'My mum has Bipolar Disorder. Sometimes when she has episodes of mania she does things I think are reckless, like going out and paying lots of money for a puppy that she won't want or

BE ABLE TO LOOK AFTER LATER. SHE'S DONE THIS A LOT. I TRY TO GET HER TO SEE THE HISTORY AND WHAT WILL HAPPEN BUT SHE DOESN'T LISTEN AT THAT POINT. IT ANNOYS ME BUT IT'S NOT LIFE THREATENING OR HARMFUL TO ANYONE ELSE, SO I GO ALONG WITH IT. I USUALLY FIND A HOME FOR THE DOG LATER. On the other hand, sometimes Mum gets so depressed that she refuses to eat or leave her bed. She refuses to see a doctor. I don't think her decision-making is good then, and I make decisions on her behalf to get help.'

JAN, DAUGHTER

5. Respect an Adult's privacy

Respect an Adult's right to privacy when you are assessing their capacity. When you are assessing an Adult's capacity you are dealing with an Adult's personal information.

The <u>Queensland Health Privacy Plan June 2016</u> is an important source of information.

It states that 'Personal information is any information or opinion about an identifiable living individual. Your identity must be reasonably ascertainable from the information and it does not have to be expressly indicated by the information, nor does it have to be true in order for it to be your personal information. Personal information may be in any form, such as in correspondence, databases, audio recordings, images, alpha-numerical identifiers or any combinations of these. It can also be spoken or communicated in other mediums, including sign language or social media'.³⁸

Privacy laws³⁹ and principles aim to protect the privacy of an Adult being assessed. These principles also balance an Adult's privacy interests against their personal interests, such as health or safety.

The most common privacy principles as outlined in the Privacy Principles:

- 1. Collecting information about an Adult
- 2. Using information about an Adult
- 3. Disclosing (providing) an Adult's information to someone else.

It is important to remember that 'health information' is a type of personal information. It has its own health privacy principles that cover the ideas outlined below.

Collecting information

- Always ask the Adult being assessed for the information you need for a capacity assessment. Explain why you need the information and what you will be doing with it.
- If you need to get information about the Adult from others for the purpose of assessment, explain this to the Adult.
- Ask the Adult if it is okay to speak to the others to get this information. Don't generalise about whom you will talk to.
- Name, or at least clearly identify, the other people for example, 'your sister, Hannah', 'your doctor, Dr Gordon' or 'the woman from Home Care who comes to help you get dressed on Tuesdays'.
- Whether you are talking to the Adult or someone else, ask only for information that is relevant to the assessment.

Using information

³⁸ Page 1

³⁹ See later notes re the Office of the Information Commissioner QLD

• When you have collected personal information to help you assess an Adult's capacity, you can only use it for that purpose. If you need to use it for another purpose, you need to ask the Adult.

Exceptions to this rule:

You can use the information collected to deal with a serious danger to an Adult's health or safety.

This exception only applies when the danger is something that is about to happen. It doesn't apply if the possible danger is in the distant future.

Disclosing information

 If you are going to give the personal information you have collected to anyone other than agreed or advised, you have to get permission. When asking for permission, tell the Adult exactly to whom you are going to give their information, and why you are giving the information.

Exceptions to this rule:

You can give the personal information to others without permission if it is otherwise required or authorised by law; if it will prevent or lessen a serious and imminent threat to an identifiable person's life. It doesn't apply if the possible danger is in the distant future.



CASE STUDY PRIVACY

'A CLIENT CAME IN ASKING ME TO DRAFT A WILL FOR HIM. AFTER I WENT THROUGH THE USUAL LEGAL QUESTIONS I HAD DOUBTS AS TO WHETHER THE ADULT HAD THE CAPACITY TO MAKE A WILL. IT WAS REALLY HARD TO DECIDE, SO I THOUGHT I NEEDED TO ASK THEIR **GP** FOR SOME INFORMATION.

I EXPLAINED THIS TO THE CLIENT, TELLING HIM THAT IT WAS NOT UNUSUAL TO WANT FURTHER INFORMATION IN THESE CIRCUMSTANCES, AND I WENT THROUGH THE BENEFITS FOR HIM TO HAVE THINGS DONE PROPERLY. I ASKED THE CLIENT TO SIGN A FORM GIVING ME PERMISSION TO SEEK PERSONAL HEALTH INFORMATION FROM HIS GP.

I DRAFTED UP A LETTER TO THE GP ASKING FOR SOME SPECIFIC OPINIONS, AND WROTE A PARAGRAPH CONFIRMING THAT THE CLIENT HAD GIVEN ME PERMISSION TO ASK THE GP ABOUT HIS PERSONAL INFORMATION. I ATTACHED A COPY OF THE CLIENT'S PERMISSION FORM.

Although it is sometimes hard to tell a client that I need another opinion about their capacity, most clients can see the logic after I outline the advantages. Asking the client to sign a privacy form giving me permission to access the GP's information also means the GP's disclosure is ethical.'

Nyla, lawyer

More information

Processes relating to access to government information as well as links to the following key pieces of legislation:

The Right to Information Act 2009 Qld Information Privacy Act 2009 Qld Acts Interpretation Act 1954 Qld Queensland Civil and Administrative Tribunal Act 2009 Qld

Remember also that Queensland Health also has processes and policies that should guide you. <u>https://www.health.gld.gov.au/system-governance/records-privacy/health-personal/default.asp</u>

6. Substitute decision-making is a last resort: Consider Assisted decision-making⁴⁰ instead

An Adult may be able to make a decision at a certain time because they have support during the decision-making process. This is called assisted or supported decision-making. They might not have the capacity to make the same decision at another time without that support.

Before deciding that an Adult does not have the capacity to make a decision, you should ensure that everything possible has been done to support them to make their decision. The type of assistance you provide, or get, for an Adult to support them to make a decision for them depends on matters such as an Adult's circumstances, the type of decision, and the time available to make the decision.

When seeking support for an Adult to make a decision, you can try the following:

- Use the most appropriate form of communication for the individual, such as non-verbal communication, visual aids (photographs, symbols, drawings), or other alternative formats. You may need to take advice on an Alternative and Augmentative Communication (AAC) system, or obtain a communication assessment from a speech therapist or other professional
- 2. Provide information in a more accessible form, such as a neutral interpreter or advocate
- 3. Find a particular location or better time of the day so the Adult might feel more at ease to make decisions
- 4. Suggest to, or assist, the Adult to get treatment for a medical condition that may be affecting their capacity
- 5. Support the Adult to resolve, or to get help in resolving, underlying personal or social issues which are causing them stress
- 6. Help the Adult find someone to support them to make choices or express a view, such as an advocate or behavioural support practitioner
- 7. Help the Adult find, or get access to, a structured program to improve their capacity to make particular decisions, such as learning a new skill or improving their communication
- 8. Give the Adult relevant information about the decision and its consequences
- 9.

ractice Point:

Remember, if you are supporting an Adult to make a decision, you must *not* act in a way that might influence their decision.

It is not your role to persuade an Adult to make what you think is the 'correct' decision, or to pressure them into making the decision that you would make. It is best not to talk about your own opinion.

Simply assist the Adult to work through the decision-making process by providing information and support in a way they feel comfortable.



CASE STUDY SUPPORTING SOMEONE TO MAKE HIS OWN DECISION

'I WAS WORKING IN THE EMERGENCY DEPARTMENT OF THE HOSPITAL ONE NIGHT WHEN A MAN, MARK, WAS BROUGHT IN BY THE AMBOS. MARK HAD BEEN IN A CAR ACCIDENT AND WAS CONSCIOUS, BUT IN SHOCK. HE DIDN'T SEEM TO BE ABLE TO SPEAK AND SEEMED REALLY DISTRESSED. HE WAS MAKING NOISES AND WILD GESTURES.

⁴⁰ More information is available about Assisted Decision-making in Section 6.

I THOUGHT MARK LACKED THE CAPACITY TO MAKE DECISIONS ABOUT THE TREATMENT OF HIS INJURIES BECAUSE HE WASN'T TALKING OR LISTENING TO WHAT I WAS TRYING TO EXPLAIN TO HIM TO ME, HE DIDN'T SEEM TO COMPREHEND. I PUT THIS BEHAVIOUR DOWN TO THE SEVERE SHOCK HE WAS SUFFERING, AND DECIDED TO GIVE HIM URGENT TREATMENT WITHOUT CONSENT.

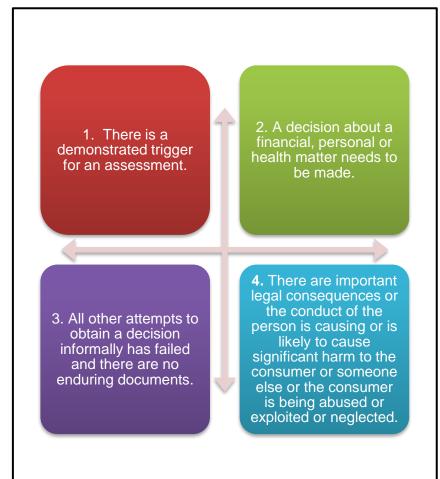
LUCKILY, BEFORE I STARTED ANY TREATMENT A NURSE SAID THAT SHE THOUGHT MARK WAS USING SIGN LANGUAGE. SHE TRIED SIGNING TO HIM AND HE IMMEDIATELY RELAXED AND SIGNED BACK. IT TURNS OUT HE DID HAVE COMPLETE CAPACITY! WHAT I THOUGHT WAS NON-COMMUNICATION AND WILD GESTURING DUE TO SHOCK WAS ACTUALLY MARK'S DESPERATE ATTEMPT TO SHOW ME HE WAS DEAF. I JUST WASN'T GIVING HIM INFORMATION IN THE RIGHT WAY. IN FACT, HE COULD ANSWER MY WRITTEN QUESTIONS, AND I WAS ABLE TO GET MARK TO MAKE ALL HIS OWN MEDICAL DECISIONS.'

MINH, REGISTRAR

Summary

In your practice, whenever considering whether someone has problems with capacity for decisionmaking, remember the key principles and how they work in practice. Learn them by rote so you can use them to advocate for Adults when discussing the case with other team members.

4:2 <u>WHEN</u> SHOULD CAPACITY BE ASSESSED?



Assess an Adult's capacity when:

1. A trigger or event associated with concerns about capacity is evident;

2. A decision about financial, personal or health matters needs to be made now⁴¹;

3. All other attempts to solve the problem have failed⁴², **and**

4. There are important legal consequences or the conduct of the person is causing, or is likely to cause, significant harm to the person or someone else⁴³.

ey Practice points: Balancing protection and rights

It is important to assess a person if you have genuine concerns that they are struggling to understand the nature and effect of a decision or they are under undue influence and the decision needs to be made NOW.

Failing to assess in these circumstances might cause the person to consent but not understand and this may cause them physical or legal harm.

It is equally important to ensure that you carry out the capacity assessment process correctly so that the result is accurate. An incorrect result may deny a person their right to make a specific decision, or force them to make a decision that they are incapable of making.

⁴¹ See Section 1 for further explanation of financial, personal and health matters.

⁴² See Section 6 about assisted decision-making.

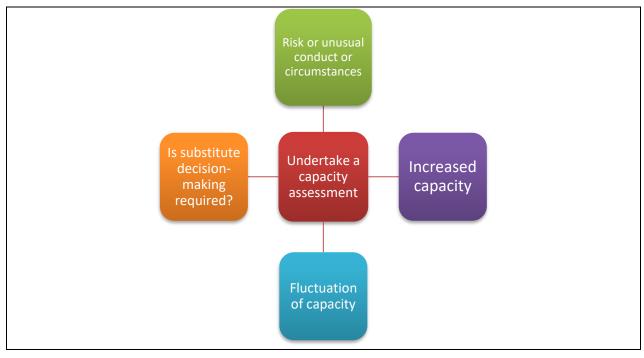
⁴³ See section of abuse and neglect

What types of triggers or events prompt a capacity assessment?

Tips on assessing capacity – what do I need to know before I start?

You should assess or seek an assessment of capacity when:

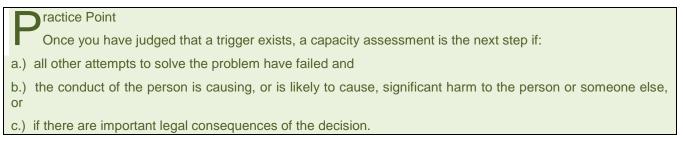
- 1. Risky and unusual conduct or circumstances is observed;
- 2. Determining whether an enduring documents is activated or substituted decision-making is required;
- 3. When a person appears to regain capacity; and
- 4. When there is fluctuating capacity.



Triggers for assessment

Risky and unusual circumstances

It is not always obvious when a person cannot make a specific decision. However, circumstances, events or behaviours might lead you to question a person's capacity at a point in time. These are called **triggers**.



Triggers around behaviours and conduct that may suggest a capacity review:44

- Repeatedly making decisions that put the Adult at significant risk of harm or mistreatment
- Making a decision that is obviously out of character and that may cause harm or mistreatment
- Often being confused about things that were easily understood in the past;
- Often being confused about times or places
- Having noticeable problems with memory, especially recent events, which have an effect on the person's ability to carry out everyday tasks
- Dramatically losing language and social skills:
 - Having difficulty finding a word
 - Not making sense when speaking
 - Not understanding others when they speak
 - Having wandering thought patterns
 - o Interrupting or ignoring a person when they are speaking, or
 - failing to respond to communication
- Having difficulty expressing emotions appropriately:
 - o Inappropriate anger, sexual expression, or humour
 - Tears without actual sadness
 - Displaying sudden changes in personality.
 - Excessive irritability
 - o Anxiety
 - Mood swings
 - Aggression
 - o Overreaction
 - o Impulsiveness
 - Depression
 - o Paranoia
- The onset of repetitive behaviours
- Declining reading and writing skills
- Having difficulty judging distance or direction, for example when driving a car.

Triggers that involve the person's <u>circumstances</u> might include:

 Not looking after themselves or their home the way they usually do and this being bad for their health or putting them at significant risk.

⁴⁴⁴⁴ Some of these triggers are adapted from information provided on the Alzheimer's Australia website: <u>www.alzheimers.org.au</u>

- Neglecting significant personal concerns such as health, hygiene, personal appearance, housing needs or nutritional needs;
- Not paying bills or attending to other financial matters, such as running their business, repaying loans or other debts;
- Making unnecessary and excessive purchases or giving their money away, and this being out of character;
- Noticeably being taken advantage of by others, such as being persuaded into giving away large assets that they still require such as a house, car or savings, or signing contracts that disadvantage them;
- Having been diagnosed with a condition that may affect their capacity; or
- Having lacked capacity to make decisions in the past.

You may notice these triggers or be informed of them by the Adult or his/her family or friends or carers.

Assessing when an enduring document should be activated or substitute decision-making is required

This assessment is triggered by concern about whether the person who made the EPOA still has the capacity to make their own personal or health decisions. If they are found to lack capacity, the appointed attorney for personal and health matters can make the decision for the person.

It may be the individual named as the attorney who will undertake, or seek, an assessment of whether the Adult has lost the capacity to make the personal or health decision. Or it may be a medical or other health practitioner who needs to assess and record the assessment findings in the patient's chart as to whether an Adult can make his/her own decisions or whether their attorney needs to be consulted.

Increased capacity

Another important trigger for assessment is when a person's capacity improves. The person may simply have regained capacity lost through ill health or other circumstances.

They may have learnt skills or accessed support services to increase their capacity. A person who could not make his or her own decisions in the past may now be able to do so if another assessment is conducted.

Fluctuation of capacity

If you are dealing with a person whose capacity fluctuates because of a mental illness or dementia etc., it is crucial to make an assessment when there is an indication of increased ability to make decisions. This will enable the person to have control over as many of their decisions as possible.



CASE STUDY TRIGGERS

'I have an elderly client, Aja, whom I visit regularly. Lately I have noticed that her car is taking quite a few knocks, different scrapes, dents and marks. This by itself doesn't worry me, but I have found that she is also repeating herself often and forgetting where she can find common items, like cups and towels, in her home.

As her caseworker I organised a meeting with Aja, her doctor, and her family (after getting her permission, of course!) and we all discussed whether Aja should undertake a test which would help the doctor advise her (and the Roads and Traffic Authority) about whether she should continue driving. Aja's family said that they had noticed the forgetfulness too, especially that she was not turning up to planned events and was using words from her native language (Hindi) right in the middle of an English sentence.

ON HER DOCTOR'S ADVICE AFTER A CAPACITY ASSESSMENT (AT WHICH THERE WAS ALSO A NEUTRAL INTERPRETER), AJA DECIDED THAT SHE SHOULD NO LONGER DRIVE.'

Shaun, caseworker

Don't forget that.....

Even if a trigger or other reason exists, you should also note:

- 1. Whether a decision about financial, personal or health matters needs to be made now⁴⁵;
- 2. All other attempts to solve the problem have failed⁴⁶, and
- 3. There are important legal consequences or the conduct of the person is causing, or is likely to cause, significant harm to the person or someone.

ractice Point:

It is important to assess an Adult who may not have the capacity to make certain decisions. Failing to assess the Adult means that he/she will continue to make his/her own decisions, which may cause them physical or legal harm.

It is equally important to ensure that you carry out the assessment process correctly so that the result is accurate. An incorrect result may deny an Adult his/her right to make a specific decision or force them to make a decision that he/she is incapable of making or that may cause them harm.

Use this case scenario to reflect. What are the general principles that apply here? What does your knowledge about domestic and family violence tell you about Mary's behaviour? Is this something that warrants a capacity assessment? What are the tensions here?



CASE SCENARIO

YOU ARE ASKED TO REVIEW MARY. MARY IS A 46 YR OLD WOMAN WHO HAS BEEN ADMITTED TO THE EMERGENCY DEPARTMENT (ED) WITH MULTIPLE AND EXTENSIVE BRUISING AND LACERATIONS AS WELL AS A BROKEN ARM. THE STAFF IN ED ARE WELL AWARE OF MARY'S HISTORY OF DOMESTIC VIOLENCE FROM

HER PARTNER AND THEY ARE AWARE THAT THERE ARE DOMESTIC VIOLENCE PROTECTION ORDERS IN PLACE; HOWEVER, MARY NOW REFUSES TO COMPLAIN ABOUT THE BREACH TO THE POLICE. MARY HAS BEEN ADMITTED FOR TREATMENT ABOUT 5 TIMES IN THE LAST TWO YEARS FOR SIMILAR INJURIES. DESPITE STAFF CONCERNS, MARY STATES THAT SHE IS GOING TO LEAVE SO THAT SHE CAN RETURN TO HER PARTNER. THE MEDICAL CONSULTANT IN ED ASKS YOU TO MAKE AN APPLICATION FOR GUARDIANSHIP TO THE TRIBUNAL AS 'CLEARLY MARY DOES NOT HAVE CAPACITY'. WHAT IS YOUR RESPONSE?

⁴⁵ See Section 1 for further explanation of financial, personal and health matters.

⁴⁶ See Section about assisted decision-making.

PART 5: CAPACITY ASSESSMENT PROCESS

Assessing Adult Capacity for decision-making

This document is based in large part on the New South Wales Capacity Toolkit. Queensland Health acknowledges the initial work of the NSW Department of Attorney-General & Justice and the licence provided to adapt the work

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5.1: <u>HOW</u> TO ASSESS CAPACITY?

The Capacity Assessment Process

It is recommended that you download a copy of the Capacity Assessment Pathway Checklist in Appendix 3 to have beside you as you read this section.

Document valid reasons for pursuing a capacity assessment

Prior to commencing a formal assessment of an Adult's capacity, the treating team should record the reasons for

pursuing a capacity assessment upon the Adult's file. If there is no treating team but only a sole practitioner, this is still required.

Social Work Working Party agreed Principle

When a consultant oversees the treating team, either the consultant, or the registrar for that consultant, must indicate on the file that he/she has agreed and authorized in writing that a capacity assessment should be obtained.

How do I complete a capacity assessment?

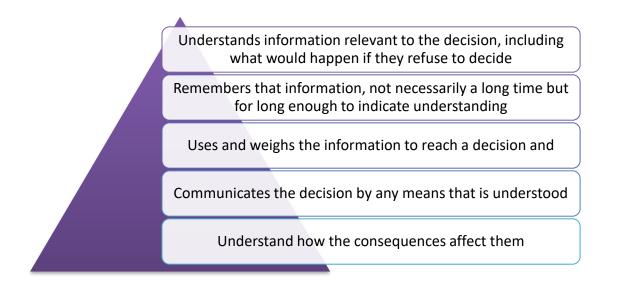
The best way to undertake a capacity assessment is by a conversation with the aim that either the Adult can tell you how they reached a decision or why they would choose a particular decision.

Firstly, you should consider whether making the decision can wait until the Adult regains capacity (if they can). Has the Adult been informed of the choices adequately and at a level that would be easy to understand?

After this, consider how best to approach the Adult and what skills you may need to start the discussion. For example, if the Adult has an acquired brain injury, how might you need to adjust your speech or behaviour to enhance their ability to understand your questions? Refer to all the considerations outlined in Part 1:3.

A good example of a simple capacity assessment is provided by the Social Care Institute of Excellence. View this <u>video</u> and watch carefully how the Social Worker asks questions and adjusts behaviour and speech to enhance capacity. Examine how she explores how the Adult meets the definition of capacity.

With any capacity assessment, you should respectfully and carefully review if the Adult:



You may like to use the *Capacity Assessment Question Tools in Tools 5, 6 & 7* to prompt and assist your first interviews.

1. Tell the Adult about the process

Before beginning an assessment, it is important to effectively communicate to the Adult what you are doing and why. Your aim should be to get the Adult to participate willingly in the process if possible. It also means that they understand that the process is important for them to focus upon.

You might tell them the following:

- There is concern about his/her capacity to make a particular decision or decisions. You might briefly outline the decision and the concern.
- There is the possibility of risk or harm to themself or others if he/she makes a decision or decisions without capacity.
- What is involved in the assessment process.
- Why it is beneficial for them to participate in the process if he/she assists by providing information then you will better be able to safeguard his/her interests. For example, assessing capacity can provide a safeguard later if there are disputes in the future over the Adult's consent to major surgery:
- The result of the assessment will be either of the following:
- · He/she has capacity to decide the particular decision for themselves
- He/she lacks capacity to decide the particular decision and requires someone to make this decision on his/her behalf.

In most cases people are willing to cooperate.

When an Adult remains unwilling to participate and there are serious consequences, you may have to take further steps. If the Adult has an Enduring Power of Attorney or has someone to act as a Statutory Health Attorney but the Adult won't assist you in an assessment then you may need to make an application to the Queensland Civil and Administrative Tribunal.

2. Be flexible when doing assessments

It is important to understand that people are individuals who may come from diverse cultural and linguistic backgrounds, and/or have different skill levels. When conducting an assessment, be flexible and adaptable to the individual's needs and preferences. Each Adult should be given the same opportunity to be correctly assessed. You can do this by making a reasonable adjustment (change)⁴⁷ to the assessment process.

When making a reasonable adjustment, remember the following:

- Never assume what the Adult may need or how best to support them. Always ask them or get specialist advice on what they may require
- Consider that treating everyone the same does not ensure equal outcomes
- Conduct the assessment in a way that best suits the situation and the individual. In most situations you can undertake the assessment in a variety of flexible ways.

3. Consider cultural and linguistic diversity and capacity

Culture, language, ethnicity and religion are integral factors in how people make decisions, as well as the decisions they make. They shape how people think, behave and communicate.

For example, in some communities and in some families, individuals with capacity to make their own decisions freely allow others to make important decisions on their behalf. Sometimes an Adult may allow or prefer the head of a household to make all the important decisions. Or there may be an established pattern where a parent within a family, or an elder of a community, makes certain decisions.

Sometimes the decision-making process is a collective one involving the whole community in meetings and discussions about the decision, such as in some Aboriginal and Torres Strait Islander communities.

Religious beliefs may impact on the decision made, or how it is made. For example, some Jehovah's Witnesses and Christian Scientists hold beliefs that might affect their decisions about various medical treatments.

So, when you are determining capacity, make sure you consider the Adult's language, ethnicity, cultural values and religious beliefs.



CASE STUDY CULTURE AND DIFFERENT MEDICAL UNDERSTANDINGS

"I had to work with an older man from East Europe. He lived alone and had had a difficult life – lost family through war and many losses. He was used to treating himself with home-made remedies and anti-biotics that were cultured from yoghurt left on a sill. He had a great distrust of Western Medicine and it took a long time for him to even begin to

TRUST THE DOCTORS AND ME. AFTER SOME TIME, HE ACCEPTED THAT THE HOMEMADE REMEDIES DID NOT WORK AND ACCEPTED OUR HELP. BUT THIS ALL TOOK TIME AND WE HAD A LOT OF PRESSURES PUT UPON US TO MOVE HIM FROM THE HOSPITAL. I CONCENTRATED ON HIS RIGHTS TO GOOD MEDICAL CARE AND ON RESPECT FOR HIS CULTURAL UNDERSTANDINGS. INITIALLY, THERE WAS SOME CONCERN THAT HE DID NOT HAVE CAPACITY BUT WE SOON REALISED WITH THE ASSISTANCE OF THE INTERPRETER, THAT HIS RESPONSE WAS FAIRLY NORMAL"

MARY, SOCIAL WORKER

⁴⁷ Many of the ideas outlined in 'How can I support a consumer to make their own decision?', in Part 6, can be used as a reasonable adjustment to the assessment process.

You may need to do the following:

- Organise an interpreter if you can't understand the Adult or have difficulty communicating with the Adult in English⁴⁸
- Seek information about the cultural and ethnic background of the Adult as well as the religious beliefs of the Adult and consider it when you are assessing the Adult
- Take into account the effect of a proposed decision on the Adult's relationships within their cultural or religious community.



CASE STUDY CULTURE AND CAPACITY

'Recently I visited with an Aboriginal man to talk about what kind of care or services he might need to help him to remain in his home. Although I had no previous experience with Aboriginal clients, and do not come from an Aboriginal background, I took on this

PARTICULAR CLIENT DUE TO STAFF SHORTAGES.

THE CLIENT AND I SPENT SOME TIME DISCUSSING HIS NEEDS AND WHICH SERVICES HE MAY BENEFIT FROM, BUT HE STILL SEEMED UNABLE OR UNWILLING TO MAKE A DECISION ABOUT WHETHER TO GIVE ME PERMISSION TO GO AHEAD WITH THE REFERRALS.

At first I thought that he might not have the capacity to make a decision about his service options. I decided to come back at another time and discuss the issues with him again.

The second time I visited, his extended family was around too. I was a bit shocked, and suggested that we put the meeting off until another time. He told me that he had asked them around to his place so that they could listen too. It was noticeable that he felt much more comfortable than he was on my first visit. So, I agreed that his family could join us.

It was a learning experience for me. I had misjudged the importance of involving the man's family in the decision-making process. I now understand that it is important to familiarise myself with an Adult's culture before an assessment, and to take it into account during the assessment.'

SARAH, AGED CARE ASSESSMENT TEAM

4. Consider the impact of any medical condition and capacity

Check Part 1.3 for a further information around how medical conditions may affect the ability of Adults to make decisions.

For example, would using Alternative and Augmentative Communication devices or simplified education about the treatment or decision make a difference?

- Do you need to include a speech pathologist's assessment to your considerations?
- Is aphasia or dysphasia an issue?

5. Don't make value judgments

Assessing an Adult's capacity means that you are judging the person's capacity to make a decision and not judging the value behind why they made the decision. You may not agree with drinking alcohol but a decision to drink alcohol to excess alone is not enough to take away an Adult's capacity.

To ensure an accurate assessment it is essential to be objective and impartial about the Adult's beliefs, values, preferences, feelings and emotions.

⁴⁸ Information about interpreters can be obtained from Queensland Health and your local service policies.

6. Determine what you are you looking for

In general, when you assess the capacity of an Adult to make a particular decision, you are considering whether the Adult can do the following:

- 1. Understand the facts involved in the decision
- 2. Retain and Know the main choices that exist
- 3. Weigh up the consequences of the choices
- 4. Understand how the consequences affect them
- 5. Communicate their decision.

For example, some people can tell you the facts about their financial circumstances, but can't solve a problem using those facts. They may know the name of their bank and the value of their assets but not be able to discuss or weigh up options about investing those assets.

There are also situations where an Adult may not have any experience in making certain types of decisions. You might have to assess whether the Adult can learn to start making those decisions.

In rare instances, such as an Adult with 'locked-in syndrome', an Adult may be able to make a decision but is unable to effectively communicate it. The assessment result is that the Adult lacks capacity. However, communication can take many forms and does not have to be verbal.

7. Apply the right test⁴⁹ to the decision in question

For different areas of an Adult's life, different types of decisions need to be made. For some areas there is a specific legal test that applies. When you are assessing an Adult's capacity to make a decision you must consider the particular matters outlined in the test. The test you use depends on the legal area to which the decision relates.

8. Ask questions carefully

Ask open-ended questions rather than questions which require only a 'yes' or 'no' answer. Don't ask leading questions. Leading questions suggest or guide the Adult to a particular answer.

The aim of questioning is to draw the Adult into a discussion about the decision, the options and the consequences. That will give you an opportunity to assess the Adult's ability to understand and weigh up information, choices and consequences.

If the Adult has someone with them for support, <u>remember to direct all your questions to the Adult</u> <u>you are assessing</u>, not to the support Adult. Sometimes, it is a good idea to start the assessment with the support Adult present. When the Adult being assessed feels at ease, they may be comfortable having the support Adult wait outside.

It is important that the Adult being assessed answers the questions. In some circumstances, the Adult being assessed may need support during the assessment from a neutral Adult, such as an interpreter or advocate.

You may want to ask the Adult the following questions:

- How did you reach your decision?
- What things were important to you when you were making your decision?
- How did you balance those things when you were making your decision⁵⁰?

⁴⁹ For further information on each test and how to apply it to an assessment of capacity see Section 5.2 'Assessing capacity in each area of life'

9. Avoid undue influence

Decisions must be made freely and voluntarily. The Adult making the decision must not feel pressured or deceived into making a decision they would not otherwise make. People who have difficulty making decisions, or who are dependent on others financially, physically or emotionally, are more at risk of being unduly influenced.

This is difficult where there may be an established or assumed power difference or where there is an on-going pattern of interaction between two people.

If you suspect undue influence, try communicating with the Adult making the decision, without the other Adult present. Ask questions that will separate the views of the Adult from the views of others.

You may also need to suggest that the Adult obtain some independent advice from a lawyer, accountant or financial advisor depending on the nature of the decision.

ractice Point:

To find out whether the Adult's decision is what they wanted, start by asking them who else was involved in the decision-making process.

Seek to determine whether the involvement amounted to supporting the Adult through the decision-making process, or whether the involvement has been overbearing and has distorted the Adult's real wishes.

Who might assess capacity in health contexts?

In Queensland, assessment of capacity may happen informally and formally for a number of reasons and different people may be involved in assessing a person's capacity. Exactly who, depends on the kind of decision and the time at which it is made. In health contexts, a range of service providers may be required to assess capacity for decision-making. Assessments may be done by:

- Doctors or healthcare professionals may need to assess a person's capacity to decide whether to go ahead with a treatment before they rely on the person's consent;
- Community nurses who have to assess whether a person can consent to getting an injection or having a bandage changed; and/or
- A treating health team that has concerns that the Adult lacks capacity to make decisions and a decision about personal, health or financial matters needs to be made now.

People who engage with the Adult may also need to make capacity assessments at times. For example:

- A member of the community appointed as an attorney under an EPOA for health and personal matters, or appointed for financial matters with a clause stating that it can only commence once a person has lost capacity.
- An advocate seeking consent to support a person to express their views
- A family member, friend or carer making informal decisions for a person with a decisionmaking disability.

The Report by medical and related health professionals

One matter that seems to confuse health service providers is the Health report that must accompany any application to the Queensland Civil and Administrative Tribunal. Many health professionals believe that only a medical practitioner can complete the report. This is incorrect.

Whilst it is true that the Adult has a medical diagnosis to support the claim of impaired capacity, any allied health or nursing professional may complete the report. The only requirement is that the Application and the Report must be completed by two different people.

The most important aspect for the report is that it be comprehensive and up to date. A report that represents information that is collated over a period of time or on more than one occasion is preferred.

The report also requires the person completing it to have an understanding of some medical principles such as receptive or expressive communication as well as key legal principles such as 'freely and voluntarily'.

mportant Practice Point

Capacity assessments are not only the domain of medical practitioners.

A person may have a diagnosis of early dementia, for example, but still be able to make most decisions, if not all of them. They may just need some assistance to do so.⁵¹

Context matters when considering what and when decisions need to be made and Social Workers assess context well.

A medical diagnosis is not enough. Social Workers are well placed within the health system to ensure that a holistic assessment of an Adult's capacity in relation to personal, health and financial matters. This will assist in determining what domains of capacity for decision-making are affected and to what extent and what referrals may be made to support the Adult in the community rather than default to referral to an aged care facility or other supported accommodation.

Social Worker role in capacity assessment

Social Workers in Queensland Health might engage with capacity assessments in a number of ways:

- 1. They may be sole practitioners working in rural or remote Queensland
- 2. They may be working as part of a treating team in a large urban or regional town.
- 3. They may be based in the community in health or mental health contexts.

So what role should Social Workers take in relation to capacity assessment?

This question was discussed at the state-wide Social Work and Welfare Working Party meetings and following principles were accepted:

Social Work and Welfare Working Party agreed Principles



⁵¹ See section of how to support assisted decision-making

- Social Workers will take a lead role in capacity assessments. They often take a lead role now in making the applications but they should also consider their role in capacity assessment processes.
- Social Workers will act as advocate for the Adult's rights if treating team is not considering this in their decision-making.
- As such, all Social Workers are required to know the general principles and rights of the Adult and the law in relation to capacity and be prepared to clarify the application of these principles to the treating team, including medical practitioners, if required.
- Learn the key causes of impaired capacity and how these may present in Adults. You need to be aware of how different disease or disability processes may mimic impaired capacity.
- Think holistically about capacity.
- Are triggers present that might suggest a capacity assessment is required?
- Refer to the section on how to assess capacity. What would be the most appropriate time or location etc. to assess capacity?
- The issue of whom social workers should engage in the capacity assessment process will depend upon who is available.
- A key characteristic of rural and remote practice in Queensland Health is the lack of access to specialist allied health or medical services. In such cases, the social work health practitioner is the person who must identify issues that might trigger concerns about capacity; assess capacity and make an application to the Tribunal if required.
- In regional and urban areas, the difficult task is co-ordinating a capacity assessment and a possible guardianship/administration application that includes a complete and concise picture of the Adult's situation.
- In most cases, within acute care in Queensland Health, the Social Worker, when available, is the default key person who organises the application and co-ordinates the gathering of information about the Adult's circumstances.
- In mental health and community care, the person that performs this is the case manager.

So who can be involved in capacity assessments in different locations?

Rural/remote practitioners

You may not have access to other health professionals should consider reaching out to other workers or relatives/friends of the Adult:

• Are there service providers who may engage with the Adult e.g. Centrelink, Disability, ACAT, Home Care or other providers of home services or respite care etc. ?

- Are there family or friends who can give collateral information about how the Adult is managing in the community?
- If the issue is a financial matter, perhaps the bank manager may be able to assist. They often have concerns but do not know who to contact to discuss.
- In small communities, Adults who are struggling to manage are often noticed more readily.
- In relation to health matters, the Adult may allow you to consult the local general practitioner and if you are worried, you can contact a geriatrician or other specialist in one of the major hospitals to discuss your concerns. Do you have access to key people in your profession who can be consulted about your concerns or uncertainties?
- Use the guardianship organizations as a resource. Contact the Public Guardian, if you have a health concern about an Adult who lacks capacity or if you suspect that the Adult who lacks capacity is being abused or neglected in some way. The Public Guardian may investigate such matters.⁵²

What if there are still doubts about capacity after an assessment has been conducted?

If there are still doubts about a person's capacity after an assessment, you (or another individual) may want to get a second opinion about the person's capacity from a general practitioner, a psychiatrist, a psychologist, a geriatrician or a neuro-psychologist, or other health professional such as a speech pathologist.

These second opinions could be used, for instance, by a:

- General practitioner to determine whether the patient can understand the nature and effect of a proposed treatment, or if a substitute decision-maker should make the decision
- Healthcare worker to help decide whether a person has the capacity to make a decision about their accommodation arrangements
- Family member to decide whether to use an enduring power of attorney or to seek the appointment of an administrator or guardian from the Queensland Civil and Administrative Tribunal.

Should I seek a second opinion?

In some situations, a second opinion may be the only way to ensure a fair assessment of a person's capacity. Factors that may indicate that a second opinion might be necessary are:

- A dispute by the person concerned, who believes they still have capacity
- A disagreement between family members, carers, community workers or other professionals about the person's capacity.
- Additionally, as the serious nature of a decision and its impact /consequences increases, the possible need for a second opinion also increases.

ractice Point

Remember, although getting a second opinion will help, the final decision about capacity is ultimately to be made by whomever it is that needs to know whether the person is capable of making the specific decision. That might be the individual who will be making the decision on behalf of the person (substitute decision-maker), or a community worker or other professional providing a service to the individual.

⁵² See also Part 1.2 for other assistance that the Public Guardian might provide.

Regional/urban

Regional and urban allied health practitioners may have access to a more diverse range of medical and other health practitioners within their team; however, it is still vitally important to carefully match the type of investigation/assessment with the nature of the decision required.

The type of questions that need to be answered by each specialty will differ slightly, depending upon their expertise. But overall, all should inform your final team assessment.

Who could be involved?

Capacity assessments are a multi-disciplinary activity but who is actively engaged in the development of reports will depend upon the concerns or issues arising. Below is a list of professions who are usually engaged in assessments of capacity or can be useful as collateral informants; however, depending on the presenting issues, different professions may also add background and information. For example, in a case of suspected ongoing physical abuse, a radiographer/radiologist may be able to review for a history of fractures.

The Social Worker has a key role to play here. The Social Worker views the Adult holistically and considers the impact of financial and person issues upon health as well as how abuse of people with a disability may make them unable to make decisions freely and voluntarily. Clear understanding of enduring documents such as Enduring Powers of Attorney or Advance Health Directives or alternative substitute decision-making and residential pathways or advocacy are important knowledge that we bring to the team. We also have a key role in working with the Adult and if appropriate, the family, to understand the process and to provide counselling. If a referral is made to QCAT, the Social Worker must know what information QCAT need and what criteria must be met before they can make decisions about the Adult's capacity for a particular decision/s. Similarly, Social Workers must know the boundaries, roles and requirements of the other guardianship entities.

Specialist medical practitioners such as geriatrician or psychiatrists may advise around cognitive or functional loss and the impact of disease progression upon the Adult and decision-making. Psychiatric input is important where a patient's mental health is thought to be impacting upon decision making. Psychiatrist may provide an opinion as to a person's decision making capacity when asked specifically to assess the Adult's capacity to make a decision.

Neuro-psychologists will assess for cognitive capacity as well as neurological impairment whilst physiotherapists and occupational therapists can advise around functional loss. Neuro-psychological input is particularly useful in borderline cases, cases involving conflict or where comprehensive assessment and more sensitive measures of cognition are warranted. Neuro psychologists provide a consultancy service to the medical team(s). Neuro-psychologists formulate a report based on collateral information and results of multiple assessment modalities. The report comments on the patient's decision making capacity but does not provide a legally binding determination about capacity.

Physiotherapists can provide opinions about safety for discharge re falls risk, impulsiveness, ability to improve if provided with functional rehabilitation or community services, ability to use walking aids safely, learn new skills re those aids and transfers and ability to recall information and discussions from the previous sessions. Adults often disclose information about abuse to physiotherapists too whilst they are doing their walking sessions.

Occupational Therapists can provide functional activities of daily living assessments; skills to manage at home; capacity to work assessments; cognitive assessments such as COGNISTATS or RUDAS.

Nursing staff can provide updates about the Adult's daily care needs, degree of independence and

changes in behaviour. It is useful to check the plan for behavioural information, particularly if the Adult is in a high care section. Meet with the nursing staff to ensure that issues such as catheter management, behaviours and care issues are documented, if relevant.

Obtaining a consultation from alcohol and drug teams may also be warranted. These teams may review Adults that have a substance abuse problem and provide recommendations for treatment plan and discharge plan. If called in for assessment, the team may make comments on cognitive and physiological factors that have been influenced by alcohol abuse (such as ataxic gait, impaired insight) and they will record all alcohol history and intake and its impact upon capacity for the decision.

Speech therapists can assess communication skills of the Adult, determine the level of communication skills that the Adult has, particularly the ability to understand or express abstract ideas or thoughts. A communication disorder will impact upon their ability to:

- Express their wants and needs
- Participate in conversations with regard to decision-making.

It would be useful to consult with a Speech Therapist in case you are concerned that someone has a communication disorder that would be maximised by assistive devices or simplifying instructions and language via picture, written word or gestures or summarising points⁵³.

Next steps

Discuss with them what QCAT needs to consider and work with them about how best to achieve this with their tests. Tailor it to each particular decision. See more in Part 7.

You can either use the suggested questions or just provide the professional with a copy of what questions the Tribunal has to answer.

Questioning an Adult's insight is not always an easy thing; however, if there are clear differences between what the Adult is stating (i.e. 'I manage my own bills' or 'I am able to shower and make breakfast without assistance') and the findings of an OT or physiotherapist in a functional assessment, you have added information that may raise concern.

Remember to take into account though, that some Adults are so afraid of losing his/her independence, that he/she will pretend things are okay and he/she is managing whilst knowing that he/she is not managing well. This does not mean they lack capacity without other evidence.

When there is involvement by the Queensland Civil and Administrative Tribunal, this organisation will make the decision as to a person's capacity.

Biopsychosocial assessment

All Social Workers should perform a full biopsychosocial assessment on every Adult as part of the capacity assessment process. Depending on the types of decision to be made, you may find it useful to use the Capacity Assessment Question Tools in the Tools 5,6 & 7 to guide your questions about health, financial or personal capacity.

⁵³ Further reading: Alison Ferguson, Gemma Duffield & Linda Worrall, 'Legal decision-making by people with aphasia: critical incidents for speech pathologists' (2010) 45 (2) *International Journal of Communication Disorders*, 244-258

Louise Hickson, Linda Worrall, Jill Wilson, Cheryl Tilse & Deb Setterlund 'Evaluating communication in resident participation in an aged care facility' (2005) 7 (4) Advances in Speech Pathology, 245-257.

L.C. Brady Wagner, 'Clinical Ethics in the context of language and cognitive impairment: rights and protections, (2003) 24(4) Seminars in Speech and Language, 275-284.

Instruments for assessment use

Health Professionals may use a wide range of assessment tools to assist in capacity assessments. They are just tools though and should not be the sole grounds for arguing that the Adult has impaired capacity. A full assessment that covers all aspects of capacity and the ability of the Adult to make THAT decision is warranted. It is important to know that further training is required before practitioners can use some of the tools. Always check the website for requirements and further details of use. Some examples of tools used are:

MMSE: MINI MENTAL SCALE EXAMINATION

The MMSE is a commonly used cognitive screen that is useful and quick to administer as an early indicator that something is not right with the Adult's cognition. Its limitations are that it fails to adequately account for educational, cultural, age or mild dementia differences⁵⁴. It is not useful in determining whether the cognitive deficit is short or long-term. An appropriate use of the MMSE is if the tool is repeated over a period of time to ascertain change. Alone, however, it is NOT sufficient to rely upon as an indicator of impaired capacity.

KICA

Given the cultural differences that arise between Anglo culture and Indigenous culture, a tool has been developed – called the Kimberley Indigenous Cognitive Assessment tool (KICA)⁵⁵.

RUDAS:

The Rowland Universal Dementia Assessment Scale (<u>RUDAS</u>) is a short cognitive screening tool designed for Adults from culturally and linguistically diverse backgrounds⁵⁶.

When administering the RUDAS it is important that the respondent is encouraged to communicate in the language with which they are most competent and comfortable.

MONTREAL COGNITIVE ASSESSMENT (MOCA)

For the detection of mild cognitive impairment and Alzheimer's Disease.

ACAT ASSESSMENT (IF APPLICABLE)

BARTHEL INDEX OF ACTIVITIES OF DAILY LIVING

GERIATRIC DEPRESSION SCALE

KESSLER PSYCHOLOGICAL DISTRESS SCALE (K10)

DRUG AND ALCOHOL SERVICE ASSESSMENT

CAREGIVER STRAIN INDEX

STAM (SYDNEY TEST OF ACTIVITIES OF DAILY LIVING IN MEMORY DISORDERS)

Different professions will use different tests so talk with them about the purpose of the test and how it meets and answers the questions you need answered to assess someone's capacity.

⁵⁴ Reardon, C.L.(2011) Screening for Cognitive Impairment. Medscape Reference, accessed 1 April 2012 at <u>http://emedicine.medscape.com/article/1941498-overview?src=emailthis</u>

⁵⁵ https://www.perkins.org.au/wacha/our-research/indigenous/kica/

⁵⁶ Storey J, Rowland J, Basic D, Conforti D & Dickson H [2004] International Psychogeriatrics, 16(1) 13-31)



5.2: ASSESSING CAPACITY IN HEALTH, FINANCIAL AND PERSONAL MATTERS

What do you need to consider?

There is no 'one size fits all' legal test for whether a person has capacity in any given situation. This is because people differ, decisions differ and laws differ.

An Adult's capacity for decision-making may be assessed in three areas, depending upon the Adult's need:

Personal life:

- Ability to make and use an Enduring Power of Attorney for personal matters
- Personal decisions including accommodation, who to live with or see and support services.

Health:

- Making and using an Advance Health Directive
- Ability to make and use an Enduring Power of Attorney for health matters
- Statutory Health Attorney
- Medical and dental treatment
- Other health decisions including non-intrusive examinations, over the counter medication and alternative therapies.

Money and property:

- Entering into a contract
- Making and using an Enduring Power of Attorney for financial matters
- Financial decisions
- Making a will.

The main reasons that health professionals assess capacity in health contexts are highlighted in red and will be the focus of review in this section.

The other reasons for capacity assessment are less usual or secondary to our health context and so will be not be reviewed here.

As a health Social Worker, you are likely to be involved in deciding whether the Adult has capacity to make independent health decisions. However, in some circumstances, you may be involved in deciding whether the Adult has capacity for financial or personal matters as well. For example, when a person is dying, you may need to consider whether an Adult has the ability to make an independent decision about executing a Will whilst in hospital or whether an Adult has the capacity to understand the consequences of his/her decision to discharge home against medical advice.

ractice Point: Remember that, generally, when a person has capacity to make a decision they can:

- Understand the facts and the choices involved
- Retain the information and recall the discussion
- Weigh up the consequences
- Make decision freely and voluntarily, and
- Communicate the decision.



Social Work Practice Principles as per SWW Working Party:

- Social Workers and other health practitioners should check with their local HHS Social Work Department about involvement in witnessing an Enduring Power of Attorney or a Will or an Advance Health Directive – called collectively Advance care planning (ACP) documents. It is also useful to review the Australian Law Reform Commission's Elder Abuse Report and its comments upon witnessing and the importance of an independent person in this role.
- Social Workers can explain and should educate Adults, families and other staff about the uses and limitations of advance care planning documents. Providing ACP information is part of our role.
- They can advise Adults and families about who can witness such documents and the avenues that the Adult or family/friends can pursue to obtain such documents.
- In case of emergency, when the Adult has no family to assist them, the Social Worker may refer the Adult to the Public Trustee, the Queensland Law Society for numbers of lawyers involved in this area of practice or the independent Justice of the Peace who visits the hospital.
- Social Workers should generally encourage Adults to complete the enduring documents when he/she is well or not in an acute stage of illness. So unless the situation is an emergency, it makes sense to leave all legal documentation to when the person is in the community or in out-patients.

General Tips on Questioning

Remember, when assessing whether an Adult has the capacity to make a decision/s, It is important that you:

- Ask open-ended questions
- Do not ask leading questions
- Frame your questions to quickly identify any areas of concern in which an Adult may need support or help, or require a substitute decision-maker
- Ensure it is the Adult who answers the questions and not the family or others on behalf of the Adult. In some circumstances the Adult may need support from a independent person such as an advocate or an interpreter. Information about how to access independent Advocates are

in a later chapter and free interpreter service contacts and protocols are available on the QHEPS intranet.

← Question Tool sheets for assessment of capacity (See (See)

Tools 5, 6 & 7 for questions for personal, health and financial matters

- The questions that you ask to determine capacity will change, depending on the type of decisions and matters you are trying to assess.
- The Question Tool sheets in this Toolkit are designed to reflect the focus of the key legal capacity test/question for that type of decision.
- These questions aim to assist you in gathering information from the Adult that will help you to decide if the Adult has capacity to make the decision in that particular area of life.
- These information sheets are called *Tools* so that you can print and take with you to an assessment and then keep as a record of the types of questions that you asked in the assessment.
- They will assist you with any report that you need to write for legal purposes. Tools are supplied for personal, health and financial matters so choose the tools suitable for your purpose.

How to use the question summaries in the Appendices:

Select the area of decision-making that you are trying to assess

Each section provides you with:

The key test to consider, a checklist to apply the test and an example of types of questions that you could use to assess for capacity in relation to that matter

Assessing personal matters

Each day, Adults make many personal decisions, such as when to get out of bed, what to wear, what to eat, and what to do. In many cases, an Adult may lack capacity to make complex personal decisions due to undue influence but still may retain the ability to choose what to wear or eat or if they want to engage in an activity.

Major personal decisions people make throughout life include where to live, what type of support services to apply for or accept, and which people to associate with.

There are several reasons why a person may need an assessment of whether they can continue making certain personal decisions independently.

Reason for an assessment in relation to personal matters

- An assessment may be carried out by a concerned family member, friend or carer who wants to know whether they, or others, should begin making decisions in all or some of these personal areas on an informal basis.
- An attorney under an EPOA may assess, or seek an assessment of, capacity when they think they should start making decisions in areas where the person seems unable to do so.
- An assessment might be the first step on the path to making an application to the Queensland Civil and Administrative Tribunal for a guardian to be appointed.

• Health practitioners may conduct an assessment as part of the preparation of an application to the Tribunal if they are concerned about an Adult being unduly influenced or harmed by someone.

ractice Point

The question about capacity that must be answered in relation to personal matters is:

Does the person have capacity for decision-making in relation to a personal matter THAT NEEDS TO BE DECIDED NOW?

Remember, you are considering whether, in relation to a personal matter that needs to be decided now by the Adult, he/she can:

- 1. Understand the facts involved in the decision;
- 2. Understand the main choices that exist;
- 3. Weigh up the consequences of the choices;
- 4. Understand how the consequences affect them and his/her situation;
- 5. Can make the decision freely and voluntarily, and
- 6. Communicate the decision.

Most often you would carry out an assessment in relation to specific areas of concern, such as accommodation decisions, how they came to a particular decision independently or decisions about support services. If you need a complete picture of the ability of the Adult to manage all personal decisions, you may need to ask a range of questions about personal matters.

Practice Point: If the Adult can't tell you these things, share with them the options and the benefits or disadvantages of each, then ask them the questions again.

You are looking for indications that the Adult can understand the information and weigh up consequences but also retain the information.



CASE STUDY PERSONAL DECISIONS

ONE DAY I SURPRISED MY DAD BY ARRIVING AT HIS PLACE UNANNOUNCED. I HADN'T SEEN HIM FOR NEARLY A WEEK. I FOUND HIM STANDING IN THE YARD DRESSED IN TRACKSUIT PANTS, WOOLLEN SOCKS, A FLEECY JUMPER

AND A BEANIE. THE PROBLEM WAS THAT IT WAS 32 DEGREES THAT DAY! EVEN WITH THE BULKY GEAR ON I COULD SEE THAT HE HAD LOST A LOT OF WEIGHT.

Then I went inside and the place was like a sauna. The heater was on. When I asked Dad about it he kept saying that turning it on was just what you did when you got up in the morning. He repeated this over and over.

When I opened the fridge there was only yoghurt and a couple of bits of mouldy fruit in there. I asked him about what he was eating and whether he was cooking for himself, but he became very aggressive with me, which had never happened before.

I THOUGHT THAT, AS HIS POTENTIAL POWER OF ATTORNEY FOR HEALTH AND PERSONAL MATTERS, I MIGHT NEED TO APPLY FOR MEALS ON WHEELS TO PROVIDE A SERVICE TO HIM. WE TALKED ABOUT THE CHOICES HE HAD, AND WHETHER THE THOUGHT HE WOULD LIKE MEALS ON WHEELS, BUT HE STILL DIDN'T UNDERSTAND THE NEED FOR NUTRITION. HE KEPT SAYING THAT HE'D EATEN ENOUGH THROUGH HIS LIFE TO KEEP HIM GOING NOW! I DECIDED TO APPLY FOR MEALS ON WHEELS FOR HIM AND TO TRY TO WORK OUT IF HE WAS STILL OKAY TO MANAGE THE OTHER THINGS IN HIS LIFE. I DECIDED to take the heater away for the summer because I wasn't confident that he understood that he didn't need to heat the place up.'

BEN, SON AND POTENTIAL POWER OF ATTORNEY FOR HEALTH AND PERSONAL UNDER AN EPOA

Practice Point: An Adult doesn't have to be able to manage all aspects of their life perfectly, but they do need to be able to manage without risk of or causing significant harm to themselves or others.

However, it is also important to remember that there may be simple things that you can do to make their life less risky or harmful without taking away all their choices or independence.

A staged approach may be a good approach. Trying a few things at a time to see and weigh up the outcome.

Medical and dental decisions

It is important that people make their own decisions about medical or dental treatment, when they can, based on their beliefs, preference, wishes and values.

If there is a question about an Adult's medical or dental decision-making capacity, it is usually a medical or dental practitioner, or other health professional, who conducts or seeks a capacity assessment.

Practitioners have a legal and professional responsibility to get consent before treating any Adult. Generally, the Adult gives this consent.

ractice Point:

Before assessing whether an Adult has capacity to make decisions about specific treatment, the practitioner must provide the Adult with all relevant information about treatment options.

There is a need to ensure that informed consent has been granted.

See the guide on informed consent for Queensland Health practitioners at <u>https://www.health.qld.gov.au/consent</u> for a very comprehensive break-down of how to gauge consent in particular circumstances.

If the practitioner assesses an Adult and finds that they lack capacity to make a particular decision, and the treatment is not urgent or life-threatening immediately, they must seek consent from either, in order of priority:

- 1. An attorney for health matters named in an Advance Health directive
- 2. An attorney, appointed under an enduring power of attorney
- 3. A guardian appointed by the Queensland Civil and Administrative Tribunal (if the Adult has impaired capacity and there is no formal or informal decision-maker such as a Statutory Health Attorney (SHA) available)
- 4. A 'Statutory Health attorney⁵⁷

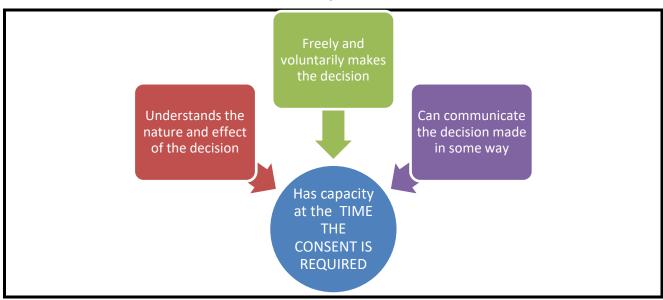
ractice Point

Question to answer when testing for capacity to make medical or dental decisions =

Does the Adult have capacity to make the decision to consent to the treatment or intervention or assessment now?

⁵⁷ See Section 6.2 for more information about this hierarchy

The three areas to consider are outlined in the diagram below:





CASE STUDY MEDICAL DECISIONS

'Jovesa and I were visiting the doctor because he had developed tremors and a very fast heartbeat. The doctor explained that the problem was actually because of a part of his body in his neck called his thyroid. He needed medication and regular blood tests to monitor whether his new medication was working.

The blood tests showed that things were not settling down. The doctor then talked about what he could do next to stop the thyroid from causing these things to happen. He gave Jovesa a pamphlet to explain:

- ↔ WHY THE THYROID WAS PLAYING UP AND WHY THE MEDICATION WASN'T WORKING;
- ✤ THE DIFFERENT THINGS THAT HE COULD DO TO STOP THE THYROID CAUSING PROBLEMS;
- ***** The treatment he recommended for Jovesa, and why;
- THE RISKS OF HAVING OR NOT HAVING THE TREATMENT; AND
- ***** THAT JOVESA HAS A RIGHT TO DECIDE WHETHER OR NOT TO HAVE THE TREATMENT.

The pamphlet used really simple language and photos to explain everything. When I took Jovesa home we went through the pamphlet together on a few occasions. I asked him various questions to work out whether he understood the information or not. Then we went back to the doctor. Jovesa told the doctor that he had decided to have the treatment, even though he was scared about it.

The doctor asked Jovesa some questions about how the treatment worked and why he had decided to have it, and came to the conclusion that he had the capacity to make the decision about the treatment himself.'

Felise, carer

Other health decisions

There may be a need to assess the capacity of an Adult to make other health decisions, such as whether to:

• have minor uncontroversial health care such as having mouth, teeth, nose or eyes reviewed or over the counter medication etc. (see section 64 of the *Guardianship and Administration Act 2000*)

To agree to this simple treatment, the Adult needs to understand the nature and effect of the type of examination, medication or therapy that they are deciding upon.

You can use the capacity test (checklist and questions) from the medical and dental treatment section above, as a guide to capacity assessment for these other health decisions.

Money and property decisions

An Adult must be able to manage his/her money and property. This is an essential part of life. Financial management includes:

- Managing accommodation, for example, maintaining a house, renting or boarding;
- Paying bills for services such as water, electricity, gas and phone;
- Buying food and clothes;
- General banking, balancing income and debt; and
- Deciding what other things to buy and sell, including important items such as cars and investments.

These are the ordinary, regular dealings that continue throughout life.

ractice Point

You may question an Adult's capacity to manage his/her own money and property when his/her decisions are causing them or others harm, or when his/her assets are being lost, or wasted.

Asking questions about money often is uncomfortable for health professionals. You may find it useful to view this video <u>Making decisions about money</u> from the Social Care Institute for Excellence in the UK which shows a Social Worker in the community conducting a simple capacity assessment in relation to finances.

People often plan ahead and appoint someone they trust to act as their enduring power of attorney for financial matters to handle his/her financial matters when he/she lose capacity. If he/she don't do this, the Queensland Civil and Administrative Tribunal can appoint a financial administrator when an Adult lacks the capacity to manage his/her finances and if informal systems that are in place are no longer working. In some cases, people may already have systems in place such as the Centrelink Nominee system.

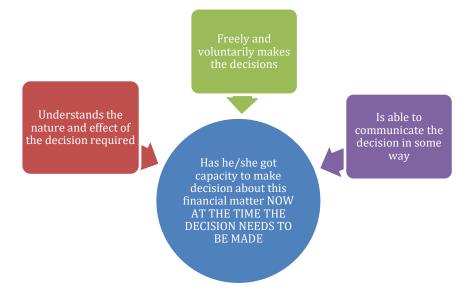
There are several situations in which an Adult may need an assessment of whether he/she can continue making his/her own financial management decisions.

Here are some examples.

- An assessment may be carried out by a concerned family member, friend or carer who wants to know whether he/she or others, should begin making minor or routine decisions about some of the Adult's financial affairs, on an informal basis.
- An Adult with enduring power of attorney may assess an Adult's capacity to manage his/her financial affairs when he/she think he/she may need to start using or continue using the document.
- An assessment might be the first step on the path to making an application to the Queensland Civil and Administrative Tribunal for a financial manager to be appointed for

all or some of the Adult's financial affairs, or it might be being prepared for the Tribunal to look at when deciding an issue of financial management.

The remainder of this section is concerned only with the test for capacity to manage financial affairs, such as in the types of situations outlined above.



ractice Point:

If the Adult is not aware of the financial choices or concerns, provide them with more information about the situation. Then ask the questions again.

You are looking to assess whether the Adult understand the decision and whether he/she has insight into what the potential or existing problems might be. For example, do they understand why it is important to pay unpaid bills, reduce overspending on unwanted goods, giving away large amounts of money or property, accumulating large debts, mishandling of money, or allowing others to influence decisions about money or property. And do they understand how they will pay those bills or what will happen if they continue to buy items beyond what they can afford.

If they are clearly struggling to understand or demonstrate how they will manage without risk, think of less invasive options first. Do they have someone at the bank or have a personal banker set up who can assist them or can a regular payment be sent up with Centrelink to pay rent and other necessities first?

Remember, people have the right to manage his/her affairs. Each individual has the right to take his/her own chances and make his/her own mistakes. Also, making an unwise decision or one that you don't agree with does not necessarily mean that a consumer lacks capacity. The main issue arises is when the Adult clearly cannot manage their finances without risk or harm such as losing their housing or being unable to buy food or pay bills etc. If the consumer can't manage all of his/her affairs, decide whether there are parts that he/she can manage. The Public Trustee often takes this approach by managing the Adult's complex assets such as Trusts or monies from an insurance claim but enabling the person in their care to keep their whole or part of their pension.

Ask the Adult open-ended questions which help them to describe the situation and why he/she thinks it could be a matter for concern such as:

- What other options do you have, or might you want to take?
- What are the pluses and minuses of each option?
- How would you go about this?

ractice Point: If the consumer can't tell you these things, discuss with them the benefits and disadvantages of each option and ask them what he/she think of these choices.

You are looking for indications that the consumer can understand and weigh up information, options and consequences. But also can carry out the decisions in reality.

CASE STUDY FINANCIAL MANAGEMENT

'LAST WEEK I WENT TO MY CLIENT JOAN'S HOUSE. THERE WAS A HUGE PILE OF UNOPENED MAIL IN THE KITCHEN. WHEN I ASKED HER ABOUT IT DURING OUR INTERVIEW, SHE SAID THAT SHE DIDN'T FEEL LIKE OPENING HER MAIL. WE TALKED ABOUT WHAT SHE THOUGHT WAS IN THE MAIL, AND SHE TOLD ME THAT IT WOULD JUST BE JUNK. I SHOWED HER ONE ENVELOPE WHICH WAS DATED MONTHS AGO AND HAD THE NAME OF AN ELECTRICITY COMPANY AND REMINDER WRITTEN ON IT. I SUGGESTED THAT IT MIGHT BE AN ELECTRICITY BILL. WE THEN DISCUSSED WHAT MIGHT HAPPEN IF SHE DIDN'T PAY THE BILL, AND JOAN SEEMED TO UNDERSTAND THAT THE COMPANY WOULD CUT THE ELECTRICITY TO HER HOUSE.

I STARTED TO ASK JOAN QUESTIONS ABOUT HER PROPERTY AND HER BANKING ARRANGEMENTS. HER ANSWERS MADE ME REALISE THAT JUST BEFORE HER HUSBAND HAD DIED JOAN HAD STASHED A WHOLE LOT OF CASH IN THE HOUSE AND HAD BEEN USING IT TO LIVE. HER HUSBAND WAS THE ONE WHO DEALT WITH ALL THE ACCOUNTS AND JOAN DIDN'T KNOW THE BANKING DETAILS.

She was starting to run out of the cash and was too embarrassed to tell anyone about the situation! That's why she tried to make light of the mail situation.

AFTER I HAD WORKED IT OUT, I TOLD JOAN THAT SHE WASN'T ALONE, THAT LOTS OF PEOPLE LET SOMEONE CLOSE TO THEM DEAL WITH THE HOUSEHOLD MONEY. BUT NOW, SHE EITHER HAD TO LEARN NEW SKILLS SO THAT SHE COULD TAKE CARE OF THE FINANCES OR APPOINT A POWER OF ATTORNEY TO DO IT FOR HER.

I AGREED TO ASSIST HER TO GET SOME INFORMATION ON MONEY MATTERS, AND TO TAKE HER TO THE BANK SO THAT SHE COULD FIND OUT MORE ABOUT HER FINANCIAL ARRANGEMENTS.'

REBECCA, SOCIAL WORKER

Contracts

Contracts are a part of daily life. A simple contract is made when an Adult buys a paper, coffee or groceries. All purchases are simple contracts, even though a written agreement is not signed.

More complex contracts are usually written when an Adult buys or rents more expensive items, such as a car or house. For example, if an Adult signs a lease to rent a property or enters into a social housing tenancy agreement, this is making a contract. Written contracts may also be used in relation to the electricity, gas, water or phone. An Adult may have a contract to borrow money with a financial institution such as a credit union, building society or bank.

Contracts also exist at the workplace. It is not unusual to enter into an employment contract with an employer.

If there is any doubt about an Adult's capacity, it is important that you undertake, or seek, an assessment when he/she are entering into a contract. In some circumstances, the law may state that an Adult is still bound by a contract even if he/she did not have capacity when he/she signed the contract.

You might carry out, or seek, an assessment if you are a legal practitioner, family member, friend or carer, community worker, staff member of a financial organisation, government employee or anyone else concerned about the Adult's capacity to enter into a contract.

CASE STUDY CONTRACTS

'I FEEL PRETTY CRANKY ABOUT WHAT HAPPENED TO MY UNCLE AT A LOCAL ELECTRICAL STORE. HE RECENTLY HAD A BRAIN INJURY FROM A STROKE. IT MEANS HE HAS DIFFICULTY PAYING ATTENTION AND IS VERY SLOW TO TAKE IN INFORMATION AND THINK THINGS THROUGH. ALSO, HE DOESN'T COMPREHEND COMPLEX IDEAS.

I dropped by his place the other day and was surprised to see that he has a whole lot of new whitegoods and entertainment equipment – a fancy new fridge/freezer, a washing machine, a new huge screen TV, DVD player and stereo system. He said that he had gone to buy a DVD player and ended up 'renting' the other stuff too. He thought he might try it out because he could always take it back if he didn't need it. This sounded a bit odd, so I asked him if he had any documents to say how much rent he had to pay. It turns out the stuff is actually purchased on an 'interest free' finance deal.

I READ THE DOCUMENTS, WHICH WERE LONG AND TECHNICAL, AND I KNEW THERE WAS NO WAY HE HAD UNDERSTOOD WHAT HE/SHE WERE ABOUT WHEN HE SIGNED THEM. WHEN I ASKED HIM ABOUT IT HE THOUGHT HE COULD TAKE THE STUFF BACK AT ANY TIME AND NOT PAY A CENT MORE! THE CONTRACT ACTUALLY SAID THAT IF HE DIDN'T PAY OFF THE GOODS IN TIME, THE STORE WOULD ARRANGE A LOAN FOR MY UNCLE THROUGH A PARTICULAR FINANCE COMPANY (SO HE COULD PAY OFF THE GOODS), AND THEN HE WOULD HAVE TO PAY THE LOAN BACK AT A HUGE INTEREST RATE!

I FREAKED OUT AND CALLED THE STORE. I HAVE MADE AN APPOINTMENT WITH THE MANAGER, SO I WILL SEE WHAT I CAN DO. IF THAT DOESN'T WORK I MAY HAVE TO TAKE MY UNCLE TO A LAWYER FOR ADVICE.'

George, Nephew

PART 6: OTHER FORMS OF DECISION-MAKING

Would assisted decision-making work?

Assessing Adult Capacity for decision-making

This document is based in large part on the New South Wales Capacity Toolkit. Queensland Health acknowledges the initial work of the NSW Department of Attorney-General & Justice and the licence provided to adapt the work.

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6.1: ASSISTED DECISION-MAKING

Assisted decisionmaking

Assisting, or supporting, an Adult to make a decision means giving them the tools needed to make the decision. It is about supporting them to make their own decision, and in doing so, safeguarding autonomy.

It does not mean making the decision for them. It does not mean acting in his/her 'best interest'. A person's right to make

decisions is fundamental to independence and dignity.

ractice Point

The capacity principles provide that before you assess an Adult as being incapable of making a certain decision independently, you need to do everything you can to support them through the decision-making process.

The support you will be able to give varies, depending on the following:

- What decision is being made?
- For example, a significant one-off decision will require different support from day-to-day decisions.
- What are the circumstances of the person making the decision?
- How much time the person has to make the decision? Is it required urgently?

For example:

- a. A person who has learning difficulties may need a different approach to someone who has dementia;
- b. If the person has a significant intellectual disability then you may need to seek a neutral support person or specialist in behavioural support about usual communication behaviours;
- c. If the person has difficulty communicating, they may need a neutral interpreter or a person with skills in *Alternative and Augmentative Communication (AAC)* systems present when an assessment is taking place;
- d. Where the person has a mental illness that fluctuates, making the decision may be able to be delayed until the mental illness no longer affects their capacity.

The exception to assisted decision-making is where a formal legal substitute decision-maker has already been:

- 1. Called upon as a 'Statutory Health Attorney' (see 6.2 of this Toolkit);
- 2. Activated by an enduring power of attorney;
- 3. Appointed by a Tribunal.

You cannot support the Adult to make his/her own decisions in these situations because it has already been determined that the person lacks the capacity to make the decision for themselves.

But do remember that just because they may lack capacity to make decision in one area or domain or part of this domain, it does not automatically exclude the Adult from being engaged in making any other decisions. Plus, their decision-making capacity may fluctuate and so remember that the General Principle about least restrictive option and engagement to the full extent that they are able comes into play here.

Even in these situations the substitute decision-maker should consult with the Adult about the decision that is required and they are bound to act in accordance with section 61 of the *Guardianship* and Administration Act 2000 Qld.⁵⁸

ractice Point

Remember that impaired capacity is rarely a global loss of capacity in all areas of capacity so although the Adult may require assistance with some decisions, you may be able to ascertain his/her choices in relation to some other queries. For example, although an Adult may lack capacity to make decisions about his finances, he may still know that he wants to live at home.

How can I support a person to make his or her own decision?

This Toolkit provides guidelines to help you to assess whether a person has capacity to make certain decisions. If you have decided that an Adult has capacity but needs help in making a decision, it is up to you to consider what kind of assistance is possible and appropriate.

Assisting, or supporting, someone to make a decision means giving them the tools they need to make the decision to safeguard their autonomy.

It does not mean making the decision for them. A person's right to make decisions is fundamental to their independence and dignity.

Before you assess someone as not being capable of making a certain decision, you need to do everything you can to support them through the decision-making process e.g. communication, timing, assistance devices, interpreter?

You may need to seek the advice of appropriate family, friends, carers, other professionals or specialists. If you don't have time or it is not your role to support the Adult, you may ask them if they would like to talk to one of the Advocate from an Advocacy organisation.

This chapter seeks to strike a balance between—

⁵⁸ 61 Purpose to achieve balance for health care

⁽a) ensuring an Adult is not deprived of necessary health care only because the Adult has impaired capacity for a health matter or special health matter; and

⁽b) ensuring health care given to the Adult is only-

⁽i) health care that is necessary and appropriate to maintain or promote the Adult's health or wellbeing; or

⁽ii) health care that is, in all the circumstances, in the Adult's best interests.

Not all steps outlined in this section will apply in every situation and there may be other ways of supporting a person that are not discussed here.

It is always important to find the most effective way of communicating with the person.

Provide relevant information

- a. Does the person have all the information they need to make an informed decision? If not, provide and explain any information required to help the person make the decision.
- b. Try not to give more detail than the Adult needs. In some cases, a very simple, broad explanation will be enough.
- c. Describe the risks, benefits and any possible consequences of making, or not making, the decision.
- d. You might need to support the Adult to access specialist advice, such as advice from a medical practitioner, or suggest he/she contacts a financial or legal advisor, or to get advice from trusted friends or relatives.
- e. If the Adult has choices, provide the Adult with the facts he/she needs on all the options and present these options in a balanced way. Discuss the risks, benefits, and any possible consequences, of each choice.
- f. Explain the effects that each choice may have on the Adult and those around them, including the people involved in his/her care.

Communicate in an appropriate way

- a. Communicate in the way that the Adult is best able to understand.
- b. Provide information in the Adult's preferred communication mode and format.
- c. It may be necessary to get some support to assist in communication. For example, you might engage an interpreter or have an advocate present.
- d. For people with communication needs, a particular Alternative and Augmentative Communication (AAC) system may be necessary. This may be as simple as obtaining a specific piece of equipment to aid in communication, such as a hearing loop, letter, word or picture board, voice synthesiser or a computer. However, it may mean that the Adult has the assistance of a speech pathologist during the assessment.
- e. Similarly, where a person with communication needs has no AAC system in place, it may be necessary to make a referral to a speech pathologist⁵⁹ for a communication assessment. If this is not practical, then do the following:
- f. If using visual aids ⁶⁰to help explain things, such as pictures or objects, ensure that the Adult understands it the way you want them to. For example, a red bus may represent a form of transport to one Adult and a day trip to another.
- g. For people who use non-verbal methods of communication, behaviour (in particular, changes in behaviour) can tell you how he/she is feeling. You may need to get some advice from a behavioural support practitioner
- h. When you are speaking, use simple language and sentence structure.
- i. Speak at an appropriate volume and speed.

⁵⁹ More about what a speech pathologist can do in assisting better communication can be found <u>here</u>

⁶⁰ Story boards or apps on IPADs or even books that describe medical conditions in story books are available – see https://booksbeyondwords.co.uk/#/resources-dl/

- j. Ask open questions to check that the Adult has understood what you have said or shown.
- k. Separate difficult information into smaller parts to make it easier to understand.

Help the person feel at ease

Location

- a. Find out if there are particular locations where the person might feel more at ease. If there are, use them. It is possible that the Adult may participate in decision-making more readily in a location that he/she is familiar with or alternatively, associated with the decision. For example, it might help the Adult to decide about medical treatment if he/she has the procedure required clearly explained to them in hospital.
- b. Choose a quiet location to prevent interruption of the discussion.
- c. Try to eliminate any background noise or distractions, such as television, radio, or people talking.
- d. Choose a location where the Adult's privacy and dignity is respected. If a ward must be used, draw the curtain with the Adult's permission.

Timing

- a. Find out if there is a particular time of day when it is optimal to communicate with the person. Some people are more alert in the morning; others are better in the early afternoon or evening.
- b. If the Adult's capacity is likely to improve in the near future and the decision is not urgent, then delay the decision until communication is easier for the Adult. For example, you may want to delay a decision until after an episode of depression or psychosis or until a cycle of medication that affects the Adult's capacity is complete.
- c. If there are several decisions to be made and assessed for capacity concerns, it may be necessary to assess each decision at a different time, if possible to minimise the chances of confusion or tiredness.
- d. Do not rush the assessment. Give the Adult time to think and ask questions where necessary.



CASE STUDY HELPING THE PERSON FEEL AT EASE

'THERE IS A YOUNG MAN, VAN, WHO HAS BEEN IN HOSPITAL FOR A FEW MONTHS. HE HAS AN ACQUIRED BRAIN INJURY AND HIS BEHAVIOUR IS, AT TIMES, QUITE DIFFICULT. THIS IS USUALLY WHEN HE ISN'T ABLE TO UNDERSTAND WHAT YOU'RE EXPLAINING TO HIM.

I REMEMBER TRYING TO GET HIM TO AGREE THAT WHEN HE WAS RELEASED FROM HOSPITAL HE WOULD GO TO THE OUTPATIENT CLINIC FOR REGULAR CHECK-UPS. I WAS IN THE MIDDLE OF EXPLAINING IT TO HIM WHEN HE GOT REALLY ANGRY, STARTED SWIPING AT THE BOOK I WAS HOLDING AND YELLING AT ME.

I SPOKE TO VAN'S BEHAVIOURAL PRACTITIONER AND GOT SOME ADVICE. I LEARNT THAT VAN GOT MORE AGITATED AND AGGRESSIVE LATE IN THE EVENING. HE WASN'T ABLE TO CONCENTRATE AS WELL AT THAT TIME OF DAY, AS OFTEN ALL HE COULD THINK ABOUT WAS WHEN DINNER WAS COMING!

The practitioner also advised that it was hard for Van to concentrate in a noisy environment, and the ward was very noisy. This made him increasingly frustrated.

So I decided to talk to Van the next morning, after breakfast. He was much more alert and could concentrate for longer. He was also calm. I took him into one of the empty consultation rooms where it was quiet. As advised, I was very brief with my explanations and didn't rush him at all. Van understood and seemed happy to agree to go to the clinic for check-ups.'

FRANK, NURSE

Consult others

- a. Sometimes an Adult will be much more comfortable making decisions when they have a support person present. Having a relative, friend or advocate present can make the person feel more at ease. PLEASE BE AWARE THOUGH THAT THE PERSON BEING ASSESSED IS THE ADULT SO ENSURE THAT HE/SHE GIVES YOU THE ANSWERS, NOT THE FAMILY OR FRIENDS AND BE AWARE OF THE POTENTIAL FOR UNDUE INFLUENCE AT ALL TIMES.
- b. Others may not like another person present. This may increase anxiety or affect their ability to make a free choice.
- c. Support the Adult to access, or to find help accessing, other services if appropriate. For example, there may be services that will help the Adult build new skills to improve his/her capacity to make particular decisions, or services to assist the Adult to sort out underlying personal or social issues that are affecting capacity.
- d. Get assistance from a neutral interpreter advocate, speech and language therapist, behavioural support practitioner or other professional if required. If you cannot get specialist advice on communication (AAC systems) then ask those who know the person well about the most appropriate form of communication or whether there is someone who can communicate easily with the person. Family members, friends, advocates, carers (paid or unpaid), or health care workers may be able to assist with this knowledge. HOWEVER PLEASE DO NOT RELY UPON FAMILY OR FRIENDS UNLESS NECESSARY. IT IS PREFERABLE TO DELAY THE INTERVIEW UNTIL AN INTERPRETER ARRIVES RATHER THAN RELYING UPON FAMILY DUE TO ISSUES WITH UNDUE INFLUENCE ETC.
- e. Be aware that sometimes people lose verbal skills, for example, due to dementia. While the Adult may have communicated in a second language in the past, he/she may now prefer to use his/her first language, and you may need an interpreter.



CASE STUDY SUPPORTING A PERSON TO MAKE THEIR OWN DECISION

JANE HAS AN INTELLECTUAL DISABILITY. SHE EXPRESSES HERSELF USING SOME WORDS, FACIAL EXPRESSIONS AND BODY LANGUAGE. SHE HAS LIVED IN HER CURRENT GROUP HOME ALL HER LIFE, BUT NOW SHE NEEDS TO

MOVE TO A NEW GROUP HOME.

She finds it difficult to discuss abstract ideas or things she hasn't experienced. Staff concluded that Jane LACKS THE CAPACITY TO DECIDE FOR HERSELF WHICH NEW GROUP HOME SHE SHOULD MOVE TO. THEY THEN ASKED ME, AN ADVOCATE, TO SUPPORT JANE TO EXPRESS ANY VIEWS SHE MAY HAVE SO THEY COULD TAKE THESE INTO ACCOUNT WHEN MAKING A DECISION FOR HER.

I SPENT TIME WITH HER IN DIFFERENT ENVIRONMENTS AND GOT SPECIALIST ADVICE ON THE BEST WAY TO COMMUNICATE WITH JANE, USED PICTURES, SYMBOLS AND A STRUCTURED LANGUAGE PROGRAM FAMILIAR TO JANE IN ORDER TO FIND OUT THE THINGS THAT ARE IMPORTANT TO JANE. I SPOKE TO PEOPLE WHO KNOW HER TO FIND OUT WHAT THEY THINK SHE LIKES. WHEN SOME SUITABLE PLACES WERE FOUND, I VISITED THE HOMES WITH JANE. WE TOOK PHOTOS OF THE HOUSES TO HELP HER TO DISTINGUISH BETWEEN THEM. I THEN USED THE PHOTOS TO SUPPORT JANE TO WORK OUT WHICH HOME SHE PREFERS.

DURING THIS PROCESS IT BECAME CLEAR THAT, WITH THE RIGHT COMMUNICATION, JANE WAS ABLE TO COMPREHEND THE IDEA OF MOVING AND TELL ME WHAT SHE WANTED AND WHY. SHE DID HAVE THE CAPACITY TO MAKE DECISIONS ABOUT HER ACCOMMODATION WHEN SHE HAD THE RIGHT SUPPORT AND COMMUNICATION SYSTEM, AND WILL BE ABLE TO MAKE THE FINAL DECISION ABOUT MOVING.'

Anthea, advocate

Resolving disagreements

At times health professionals and Adult/family/friends will disagree about an Adult's capacity to make a decision.

Tips on resolving disagreements

Disagreements can be resolved in either informal or formal ways.

- Usually, informal ways are better for all involved as the matter is resolved more quickly, with less stress and at less cost than if a formal method is used.
- Addressing disagreements early will often stop the dispute developing into something more serious.
- Listening to, acknowledging and freely discussing an Adult's issues without criticism may be all the Adult is asking for. This could resolve the disagreement.
- Do not be afraid to discuss the 'un-discussable'!
- Where the issue is not urgent, giving a person time to process the information may help them to accept a different point of view.

Informal ways of resolving disagreements

- Setting out the issues clearly in writing or in diagram form will sometimes help those involved focus on the most important issues. Putting the issues in writing may also make them clearer. However, make sure you do not use emotional language or make assumptions. Stick to presenting the facts only.
- Holding a meeting to discuss the issues in detail may also work. It is sometimes a good idea to meet with the person who disagrees with the decision. Adults should be encouraged to invite a support person to the meeting. A colleague, advocate, family member, friend or carer might be suitable.
- It may be helpful to invite someone independent as well. This person could manage the meeting so that everyone gets an opportunity to state his/her views and concerns, while ensuring that the meeting does not become emotionally charged.
- It may be useful for the independent person to guide people through deciding what the rules are at the start of the meeting, as well as getting agreement on the matters for discussion. That person can then ensure that, during the meeting, everyone sticks to the rules and the issues.
- When the meeting is over, you may wish to write to the other person and set out what you think the result of the meeting was and what the next steps are for those involved. NOTE: This method of resolving disputes may be inappropriate where there is an established pattern of behaviour, or a power imbalance, in relation to the people involved.
- Getting an advocate involved can be useful. An advocate may be able to help settle a disagreement in difficult situations simply by presenting a person's views to their family, friends, carers or professionals. Having an advocate can support a person to:
 - Say what they want
 - Protect their rights
 - Represent their interests
 - Get the services they need.

• Getting a second opinion of a person's capacity may resolve a dispute where the second opinion is the same as the original assessment result.42

Formal ways of resolving disagreements

If informal resolution of a disagreement does not work or is so serious that informal resolution is not suitable, it can be referred to the Public Guardian if the matter is an urgent health matter that needs an immediate decision.

If the matter is not so urgent, then refer the matter to the Queensland Civil and Administrative Tribunal. If you are unsure about whether a matter should go to the Tribunal, contact it for guidance and advice.

Resources

Video resources

<u>Bernie's Story</u> developed by the NHS BSC Clinical Commissioning Group – discusses assisted decision-making in hospital settings. It also highlights the importance of timing and place when talking to people about health matters and maximising their decision-making.

Is there an APPROPRIATE substitute decisionmaker available?



6.2 SUBSTITUTE DECISION-MAKERS

When an Adult has impaired capacity for a decision in Queensland and assisted decision-making does not work in reaching a reliable decision, then the guardianship

legislation provides a hierarchy of optional decision-makers. These decision-makers are called substitute decision-makers. Within Queensland, there are a range of formal written as well as an automatic authority options. We will review each in turn. If you want further information about each document or authority, you are directed to the guardianship organisation links. Copies of the documents are available <u>here</u>.

ractice Point

The role of the substitute decision-maker is an important one and is best suited to someone who knows the Adult and their preferences and wishes well. Why? Because the substitute decision-maker does NOT decide what they think is in the best interests for the Adult and decide based upon this.

The role of the substitute decision-maker is to ask the question 'What would {the Adult] have decided to do if they had the capacity to make the decision?'

Written Legal Enduring Documents

The guardianship legislation in Queensland provides people with a couple of formal legal mechanisms that allow people to plan for ill-health and possible impaired capacity for decision-making. This section will explore the Advance Health Directive, Enduring Power of Attorney and Statutory Health Attorney and their uses and differences. Social Workers must know the difference between all three documents and how they are used and activated to ensure that the documents and their appointed attorneys privilege the wishes of the Adult, after the Adult lacks capacity.

Advance Health Directive (AHD)

Illness can cause impaired capacity for decision-making yet paradoxically, this is the time that serious health decisions need to be made, including sometimes, end-of-life-care decisions. Planning by making an advance health directive early when the Adult is well or has just been newly diagnosed with a life-limiting illness or disability, will help Adults have a say in what treatment, health care or life sustaining measures they do/do not wish to have if they do lose capacity.

The AHD stays in force until the Adult dies or is revoked. A person may change or cancel their AHD at any time if they still have the decision-making capacity to do so. It is recommended to review an AHD every 2 years, if there is a life event such as marriage or divorce or diagnosis of a life limiting illness or disability or if health deteriorates generally.

Make all changes in writing and have them witnessed. In Queensland, the AHD is revoked in writing and a form is available to do so. Here is access to the <u>form</u>

The AHD also allows the Adult to appoint someone as their health attorney to make health decisions on their behalf if they lose capacity and need treatment or care. This is not a requirement for completion. If the person has already appointed a personal attorney under an Enduring Power of Attorney, then there is no need to appoint the same person or a different person in the AHD.

ractice Point

In the event of two appointments – one in an AHD and one in an EPOA for a health attorney, the health attorney appointment in the AHD wins!

In Queensland, an AHD usually contains:

- Details of an Adult's health care preferences
- Any values and beliefs that may guide future treatment
- Instructions regarding the future use or restriction of particular medical treatments
- Details of whom an Adult wants to make these decisions for them when he/she is unable to do so.

Things to know about an AHD

The person making an AHD must have capacity.



CASE STUDY ADVANCE HEALTH DIRECTIVES

'I HAVE A CLIENT WHO ASKED ME TO ASSIST HIM IN WRITING AN ADVANCE HEALTH DIRECTIVE. HE HAS MULTIPLE SCLEROSIS (MS) AND IS FEARFUL THAT ONE DAY HE WILL HAVE TROUBLE COMMUNICATING I TOLD HIM THAT THERE REALLY IS ONLY A TINY CHANCE OF THIS, BUT HE SAID THAT YOU CAN NEVER BE TOO

DECISIONS. I TOLD HIM THAT THERE REALLY IS ONLY A TINY CHANCE OF THIS, BUT HE SAID THAT YOU CAN NEVER BE TOO PREPARED. THAT'S TRUE, AND IT'S GENERALLY A GOOD IDEA TO MAKE PLANS FOR THE FUTURE ANYWAY.

We went through the form that he had, and I helped him understand the types of medical scenarios that may come up and the decisions which may need to be made. It was clear to me that he understood what the document was all about, how it related to him, when it would be used, and for what purpose. He signed the advance health directive after we had discussed it thoroughly and I then witnessed it to show that I believed that he had capacity to make it.'

MARGARET, NURSE

Further information about Advance Health Directives can be found on the following link:

http://apps.health.qld.gov.au/acp/new/resources/ACP-Booklet_120320.pdf

QUT also has some answers to common questions that arise around enduring documents. Check the answers out <u>here</u> For Mental health AHD information, review the QH Mental Health website.

Powers of Attorney

There are two types of power of attorney: a general power of attorney and an enduring power of attorney.

A general power of attorney:

- Is limited to financial matters and it is not associated with impaired capacity;
- Ceases to work when the Adult loses capacity to make his/her own financial decisions;

- Was the only power of attorney available prior to the guardianship legislation and was primarily established to allow a person to make financial decisions on behalf of an Adult e.g. when he/she was overseas or physically unable to get to a bank;
- Does not relate to health care.

In contrast, the enduring power of attorney (EPOA):

- Was developed to ensure that the Adult could appoint someone he/she knew and trusted to manage the Adult's affairs if the Adult lost capacity to make his/her own decisions;
- Is an enduring document that is legally recognised and works even when the person loses capacity;
- Enables the appointment of someone to commence or continue, to make decisions for an Adult when the Adult no longer has the capacity to make his/her own decisions;
- Enables appointment of an attorney for health or personal or financial matters or all of these;
- Enables different attorneys to be appointed for different matters e.g. son for financial matters and daughter for health and personal matters;
- Can only be made when the Adult has capacity for decision-making; otherwise, the EPOA is invalid;
- Must be witnessed by a Justice of the Peace/Commissioner of Declarations or Solicitor/Barrister;
- Requires the witness to attest to the capacity of the Adult at the time of signing and not just that they witnessed the signature;
- The person who accepts the appointment must sign his/her acceptance of the task prior to using the document but there is no requirement currently that this signing occur at the same time as the making of the document although this would be optimal so that the attorney knows that they are appointed but also that there are responsibilities associated with the role.

ractice Point:

Review your hospital or health service protocols around accessing and keeping enduring documentation.

On admission or review of the Adult, always check if any document has been changed or revoked and if so, note the new substitute decision-makers. Within QH, some systems still note the next of kin on the admission information but next of kin is only used for decision-making under the *Transplantation and Anatomy Act* when the person dies. When the person is alive and a decision needs to be made about their health, personal or financial matters, the guardianship decision-making hierarchy is the appropriate one to use.

Check:

- Does the document contain any unusual conditions that are worth noting?
- Was the document properly signed and witnessed?
- 4 Are there conflicting documents? Two Enduring Powers of Attorney or an AHD with a health attorney?
- Was it recently completed but it was unlikely that the person had capacity to understand it at the time?
- If the Adult does not have such documents, the Social Worker should provide them with information about the usefulness as well as the limits of such documents and who they can approach to discuss this further if wished. This allows the person to consider this and act on this once they have left the hospital or the health service.

If not sure, always contact your HHS solicitor for guidance or contact either the Public Guardian or QCAT for further information.



Important Practice Point

An issue with the current Enduring Powers of Attorney form is that if the Adult ticks the box on the form that says that the <u>power for finances begins immediately</u>, the attorney <u>may access the finances of the Adult immediately</u>.

This is in direct contrast to the power relating to health and personal matters in an EPOA as these powers only can be used once the Adult lacks capacity.

Many health professionals and people who sign EPOAs are not aware of this issue.

More information about EPOAs is available at: <u>http://www.justice.qld.gov.au/justice-services/guardianship/power-of-attorney/enduring-power-of-attorney</u>

Statutory Health Attorney

Adults often come into hospital without a written formal enduring document such as a completed Advance Health Directive or Enduring Power of Attorney and there has been no reason for the Tribunal to appoint a guardian.

So, if the Adult lacks capacity, who can make health decisions on his/her behalf? The answer is the Statutory Health Attorney [SHA].

The Queensland guardianship legislation embedded this role in the original legislation and it is very important role but often misunderstood. The SHA is NOT appointed formally or via a written document. The SHA is someone who has **automatic authority** to make health care decisions, either permanently or temporarily, on behalf of an Adult who has impaired capacity for health decisions.

The role of the SHA is very useful if the Adult lacks capacity for a short-term or you are awaiting the stabilization of the Adult's health condition to determine whether the impaired capacity will be short or long term.



CASE STUDY USE OF STATUTORY HEALTH ATTORNEY PROVISIONS

MARY WAS ADMITTED TO THE INTERNAL MEDICINE DEPARTMENT OF THE HOSPITAL WITH A DIAGNOSIS OF ACUTE DELIRIUM SECONDARY TO SEPSIS. MARY WAS UNCONSCIOUS AND THE MEDICAL TEAM ASKED THE SOCIAL WORKER TO FIND WHO COULD MAKE DECISIONS FOR MARY ABOUT HER HEALTH CARE. THE HOSPITAL RECORDS CONTAINED NO INDICATION THAT MARY HAD ENDURING DOCUMENTS.

SUE LIAISED WITH MARY'S EMERGENCY CONTACT PERSON, ESTABLISHED THAT MARY WAS SINGLE, AND ESTRANGED FROM HER FAMILY. HER EMERGENCY CONTACT PERSON WAS FREDA, HER LONG-STANDING CLOSE FRIEND. FREDA AND SUE HAD REGULAR HOLIDAYS TOGETHER AND THEY HAD HAD CONVERSATIONS ABOUT WHAT THEY WANTED AROUND HEALTH PREFERENCES IN THE FUTURE SO FREDA KNEW SUE'S PREFERENCES AND LIFE CHOICES. SHE REPORTED THAT MARY HAD NEVER GOT AROUND TO COMPETING AN EPOA OR AHD AND SHE HAD NEVER REQUIRED A GUARDIAN TO BE APPOINTED.

SUE SPOKE TO ANOTHER FRIEND OF MARY WHO SAID THAT MARY HAD ALWAYS SAID IF ANYTHING HAPPENED TO HER, FREDA "KNEW WHAT SHE WANTED". THIS FRIEND ALSO CONFIRMED THAT MARY HAD NOT SEEN HER ONLY SIBLING IN 15 YEARS AND THAT SHE HAD NO PARENTS OR CHILDREN LIVING. SUE ESTABLISHED THAT SUE DID NOT NEED ANY FINANCIAL DECISIONS OR ACTION DONE IMMEDIATELY AS HER BILLS COULD BE PAID FOR HER BY FREDA UNTIL SHE RECOVERED.

SUE ADVISED THE MEDICAL TEAM OF THESE DISCUSSIONS AND ABOUT THE GUARDIANSHIP LEGISLATION'S STATUTORY HEALTH ATTORNEY PROVISIONS. THEY CHOSE FREDA AS MARY'S SHA, UNTIL MARY IMPROVED ENOUGH TO MAKE DECISIONS FOR HERSELF.

THERE WAS NO NEED TO SEEK AN APPOINTMENT THROUGH THE TRIBUNAL.

Who should be the Statutory Health Attorney?

The guardianship legislation lists those who can act as a Statutory Health Attorney. In order of preference (provided they are readily available and culturally appropriate):

- 1. The patient's spouse including a de-facto spouse (if the relationship is close and continuing);
- 2. The patient's primary carer, but not a paid carer (although he/she may receive a carer's pension);
- 3. A close Adult friend or relative; or
- 4. The Public Guardian as a last resort.
- 5. The person must be 18 years or more. The concept of 'paid carer' does not include family or friends who are only in receipt of a Carer's Payment or Pension.

This section suggests that the focus is upon someone who knows the person and their health preferences best – so next of kin may not fit these criteria. If the Adult does not have a spouse or primary carer that fits the criteria, then the next level notes that EITHER close friend or relative may make the decision instead.

Practitioners often worry that this will lead to automatic conflict if you preference a friend over family; however, it is best to treat it as an opportunity to promote discussion and shared understandings rather than seeing it automatically as potential conflict.

Can the Public Guardian act as a SHA substitute decisionmaker?

If there is disagreement about which of 2 or more eligible people should be the statutory health attorney or how the power should be exercised, then section 42 of the *Guardianship and Administration Act 2000 Qld* may come into play. This refers to the role of the Public Guardian as mediator or exerciser of the power for the health matter.

The Public Guardian may also choose to intervene if a person with impaired capacity is being abused by the attorney under an Enduring Power of Attorney. In such a case, the Public Guardian may investigate, suspend the Attorney's power for up to 3 months and file an application to QCAT. More about the Public Guardian powers are noted in SECTION 1.

Formal Tribunal Appointments affecting decision-making

Guardianship

The Queensland Civil and Administrative Tribunal may appoint someone to act as a guardian for an Adult. The role of the guardian is to help Adults with impaired capacity make decisions about health and personal decisions only. Taking into account, the least restrictive general principle, QCAT may choose to only appoint a decision-maker for one aspect of the guardianship.

The Tribunal may appoint a person (such as family or friends of the Adults or professionals) or if there is no one else available or there is conflict, the Tribunal may choose to appoint the Public Guardian to the position.

Time of appointment The Tribunal usually appoints guardians for a time-limited period, depending on the personal and health decision-making needs of the Adult. The type of appointment may be general i.e. all personal matters or it may be limited i.e. to decide whether the Adult is to live and/or with whom.

How many guardians? More than one guardian may be appointed with each guardian appointed to make decisions about a different specific matter or the guardians may be appointed to make joint decisions or separately for the Adult.

Requirements of guardians

Guardians must be over 18 years of age and not a paid carer⁶¹ for the Adult. They must be prepared to:

- Act honestly and with reasonable diligence;
- Act according to the decisions made by QCAT;
- Consult with other guardians and administrators regularly to protect the Adult's interests;
- Respect the rights, capacity, dignity and worth of the Adult;
- Recognise the Adult's right to be a valued member of the community;
- Encourage and support the Adult's efforts to live in the community and participate in community affairs as much as possible;
- Seek to understand the Adult's wishes and take these into account as much as possible ;
- Place as little restriction as possible on the Adult's freedom of choice and action;
- Recognise the importance of the Adult's existing supportive relationships, and his/her cultural and religious beliefs;
- Only make decisions in relation to the matters specified in the order;
- Protect the Adult from abuse, neglect or exploitation.

Who can be appointed if there is no family or friends?

If the Adult has no family or friends willing or able to be a guardian and who are culturally appropriate or there is conflict in the family about decisions, the Tribunal may appoint the Public Guardian to be a health and/or personal decision-maker.

Types of decisions guardian may be appointed to make on behalf of the Adult

- where to live
- what support services
- with whom he/she has contact
- general health matters
- the approval of chemical, physical and mechanical restraints62
- The approval of containment and seclusion in limited circumstances63
- restricting access to objects

⁶¹ Paid carer is defined as a person who performs services for the consumer's care and receives remuneration to do so other than a carer payment or benefit from the Commonwealth or State government.

⁶² This refers to guardians appointed for restrictive practices

⁶³ This refers to guardians appointed for restrictive practices

Entitlements of guardian

- Receipt of a copy of the QCAT Order that can be used to demonstrate their appointment to outside agencies;
- Reimbursement by Adult for reasonable expenses occurred as a guardian (but NOT payment for services) e.g. payment for petrol costs of driving to medical appointments but not for the time taken;
- Access to the same personal and health information that the Adult would have been entitled to if he/she had capacity to make a decision.

Removal of an appointed guardian

The Tribunal may remove a guardian from the appointment if:

- The Adult's health and personal needs are not cared for
- The Adult is being abused or neglected by the guardian or another person due to the guardian's inaction
- The need for a guardian no longer exists e.g. the Adult has been accommodated in a care facility and this was the appointed purpose of the guardian
- The guardian loses capacity themselves
- The guardian no longer wishes to act as guardian
- Another person is more appropriate to be the Adult's guardian

Reviews of guardianship

If a guardian is appointed and there is concern about the appointment due to any of the above reasons prior to the expiry of the term of the appointment, then either the Adult or another interested party may apply to QCAT for a review of appointment.

Just seeking a review is not enough. The applicant will need to provide new information to support the application.

3 things Guardians do not do (including special health care matters)

- 1. Guardians do NOT manage financial or property matters⁶⁴.
- 2. Due to the invasive and human rights implications involved, guardians cannot make decisions about special health care matters including sterilization or tissue donation or termination of a pregnancy of an Adult or participation by the Adult in experimental health care or research
- 3. A Guardian cannot make decisions about special personal matters including making or revoking a Will or consenting to marriage or relinquishing a child for adoption.

Applications for special health care matters must be referred to QCAT in the first instance.

When NOT to seek the appointment of a guardian

- 1. When the Adult has capacity to make decisions about health or personal matters;
- 2. When there is no personal or health decision that needs to be made now e.g. the Adult has sorted out all his/her personal matters such as accommodation in a nursing home or other care service and there is no reason to think that this will end immediately;

⁶⁴ The only time a guardian would be involved in financial or property matters would be if they were also appointed either an administrator or as attorney for financial matters under and enduring power of attorney.

3. When the Adult has a valid Enduring Power of Attorney and is not being abused;

Administration

The Administrator is a formal appointment by QCAT. The role of the Administrator is to support the Adult to make decisions in relation to financial and property matters and sometimes, legal, matters only. Administrators do NOT manage health or personal matters⁶⁵.

When NOT to seek the appointment of an administrator

- 1. When the Adult has capacity to make decisions about financial matters;
- 2. When there is no financial or legal decision that needs to be made now e.g. the Adult has sorted out all his/her financial matters such as direct debit for accommodation in a nursing home or other care service and there is no reason to think that this will end immediately;
- 3. When the Adult has a valid Enduring Power of Attorney for finances and is not being abused;

Requirements of administrators

Administrators must:

- Keep detailed records of dealings and transactions
- Provide the Tribunal with a financial management plan in relation to the Adult's assets and submit accounts and invoices, as required.
- Avoid conflict transactions⁶⁶
- Keep all property of the Adult in separate accounts to the administrator's own
- Maintain any dependants of the Adult
- Know the rules in relation to gift giving
- Ensure investments are made prudently and conservatively.⁶⁷

generally.

(a) the duty of an administrator towards the Adult; and

(b) either-

(i) the interests of the administrator or a person in a

close personal or business relationship with the

administrator; or (ii) another duty of the administrator.

Examples-

2 A conflict transaction does not happen if an administrator is acting under section 55 to maintain the Adult's dependants.

if the transaction were not a conflict transaction.

common.

⁶⁵ The only time an administrator would be involved in health or personal matters would be if they were also appointed as a guardian or as attorney for personal or health matters under an enduring power of attorney or a health attorney under an AHD or as Statutory Health Attorney.

^{66 37} Avoid conflict transaction Guardianship and Administration Act 2000 QLD

⁽¹⁾ An administrator for an Adult may enter into a conflict transaction only if the tribunal authorises the transaction, conflict transactions of that type or conflict transactions

⁽²⁾ A conflict transaction is a transaction in which there may be conflict, or which results in conflict, between-

¹ A conflict transaction happens if an administrator buys the Adult's car.

⁽³⁾ However, a transaction is not a conflict transaction only because by the transaction the administrator in the administrator's own right and on behalf of the Adult—

⁽a) deals with an interest in property jointly held; or

⁽b) acquires a joint interest in property; or

⁽c) obtains a loan or gives a guarantee or indemnity in relation to a transaction mentioned in paragraph (a) or (b).

⁽⁴⁾ A conflict transaction between an administrator and a person who does not know, or have reason to believe, the transaction is a conflict transaction is, in favour of the person, as valid as

⁽⁵⁾ In this section- joint interest includes an interest as a joint tenant or tenant in

⁶⁷ Part 2, section 49-60 Guardianship and Administration Act 2000 QLD

Types of decisions

Administrators may be given authority to make all financial decisions on behalf of the Adult who has impaired capacity or they may be appointed to make only certain types of decisions. For example, an administrator may be appointed to sell the family home or to manage complex investments.

Communication with the Adult to gauge his/her views re the preferred decision is expected. Types of decisions involved are maintaining property, buying or selling property, paying bills or making business or investment decisions for the Adult.

Who can be appointed?

An Adult aged over 18 years of age is eligible for appointment as an administrator. Close family or friends or even professionals may be appointed administrator. A paid carer⁶⁸ of the Adult cannot be an administrator.

If there is no one close to the Adult who can act appropriately as an administrator due to conflict or the complexity of the property or lack of interest, the Tribunal may appoint a statutory organisation such as the Public Trustee to act on the Adult's behalf.

Length of appointment

Generally, five-year appointments are usual. Like guardianship, more than one administrator may be appointed to make either financial decision jointly or severally or for different financial matters. Appointment automatically ends if the Adult dies or the administrator becomes a paid carer for the Adult.

Entitlements of administrator

- Receipt of a copy of the QCAT Order that can be used to demonstrate their appointment to outside agencies;
- Reimbursement by Adult for reasonable expenses occurred as a administrator (but NOT payment for services) e.g. payment for costs of attending financial consultant but not for the time taken;
- Access to the same financial information that the Adult would have been entitled to if he/she had capacity to make a decision.

Removal of an appointed administrator

The Tribunal may remove a guardian from the appointment if:

- The Adult's financial needs are not being met and finances are at risk in some way;
- The Adult is being abused or neglected by the administrator or another person due to the administrator's inaction;
- The need for a administrator no longer exists e.g. the Adult's house has been sold and this was the appointed purpose of the administrator;
- The administrator loses capacity themselves or is not appropriate;
- The administrator no longer wishes to act as administrator;
- Another person is more appropriate to be the Adult's administrator⁶⁹.

⁶⁸ Someone who performs carer services for the consumer and who receives remuneration other than a carer payment from the government

⁶⁹ Guardianship and Administration Act 2000, Chapter 3 Appointment of guardians and administrators, Part 1 Making an appointment order s15 Appropriateness considerations

Reviews of administrator

If a guardian is appointed, then if there is concern about the appointment due to any of the above reasons prior to the expiry of the term of the appointment, then either the Adult or another interested party may apply to QCAT for a review of appointment.

Just seeking a review is not enough. The applicant will need to provide new and relevant information to support the application.

(1) In deciding whether a person is appropriate for appointment as a guardian or administrator for an Adult, the tribunal must consider the following matters (*appropriateness considerations*)—

(a) the general principles and whether the person is likely to apply them;

(b) if the appointment is for a health matter—the health care principle and whether the person is likely to apply it;

- (c) the extent to which the Adult's and person's interests are likely to conflict;
- (d) whether the Adult and person are compatible including, for example, whether the person has appropriate communication
- skills or appropriate cultural or social knowledge or experience, to be compatible with the Adult;
- (e) if more than 1 person is to be appointed—whether the persons are compatible;

(f) whether the person would be available and accessible to the Adult;

(g) the person's appropriateness and competence to perform functions and exercise powers under an appointment order.

(2) The fact a person is a relation of the Adult does not, of itself, mean the Adult's and person's interests are likely to conflict.(3) Also, the fact a person may be a beneficiary of the Adult's estate on the Adult's death does not, of itself, mean the Adult's and person's

interests are likely to conflict.

(4) In considering the person's appropriateness and competence, the tribunal must have regard to the following-

- (a) the nature and circumstances of any criminal history, whether in Queensland or elsewhere, of the person including the
- likelihood the commission of any offence in the criminal history may adversely affect the Adult;

(b) the nature and circumstances of any refusal of, or removal from, appointment, whether in Queensland or elsewhere, as a guardian, administrator, attorney or other person making a decision for someone else;

(c) if the proposed appointment is of an administrator and the person is an individual-

(i) the nature and circumstances of the person having been a bankrupt or taking advantage of the laws of bankruptcy as a debtor under the *Bankruptcy Act*

1966 (C'wlth) or a similar law of a foreign jurisdiction; and

(ii) the nature and circumstances of a proposed, current or previous arrangement with the person's creditors under the *Bankruptcy Act 1966* (C'wlth), part 10 or a similar law of a foreign jurisdiction; and

(iii) the nature and circumstances of a proposed, current or previous external administration of a corporation,

partnership or other entity of which the person is or was a director, secretary or partner or in whose management, direction or control the person is or was involved.

PART 7: REFERRALS TO THE QUEENSLAND CIVIL AND ADMINISTRATIVE TRIBUNAL (HUMAN RIGHTS DIVISION)

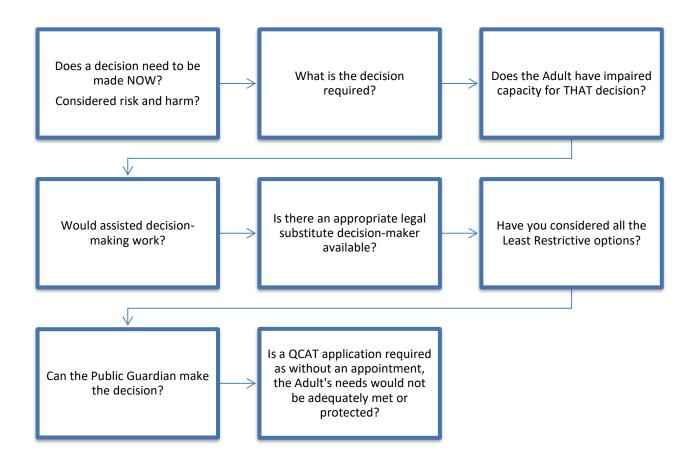
Have you considered the Least Restrictive Alternative to QCAT Applications?

7.1 Before making an application to QCAT.....

Flow chart to Guide Clinical Reasoning when considering whether to make an application to QCAT

The flow-chart below outlines the key questions that should guide your decision-making when making an application to QCAT.

By now, if you have reviewed the Toolkit, you should know how to answer these questions if you apply them in practice. The format of this Toolkit follows the following flowchart that should be used to guide the decision-making process when considering an application to QCAT.



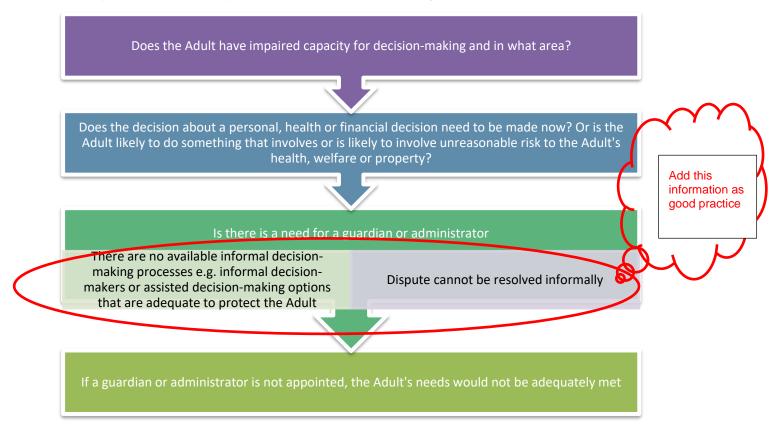
A detailed decision-pathway to guide your thinking is available in **Tool 1**.

7.2 Documenting and Preparing Reports for QCAT

Things to consider before starting to write a report

Seeking appointment of a guardian or and administrator for an Adult is a serious intervention as it removes the rights of the Adult to make decisions related to personal, health and/or financial matters. Responsibility for the decisions is given to someone else. What would you feel like if this happened to you? Before reading this chapter, you may like to review Appendix 1. This appendix is an extract from Walker⁷⁰ and outlines a useful deconstruction of a case in terms of what the Tribunal considers on reviewing the facts and law.

Health professionals must provide clear evidence to satisfy the criteria that QCAT consider:



Who should make the application

Consider whether the family/friend of the Adult could be the application-maker rather than your team. This is the preferred course of action as Tribunal hearings were established to allow family/friends to make applications, rather than having to rely upon service providers to do so. You would still support the application with a report.

Another key reason for not making an application as a service provider is that it is preferable to keep our oversight/intervention in the Adult's life to a minimum. Remember: The Least Restrictive

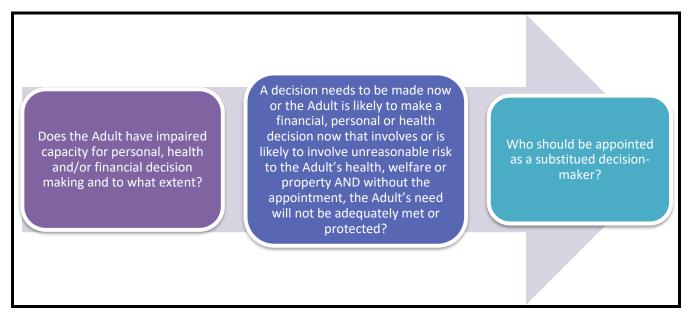
⁷⁰ Walker, above n 29.

Alternative approach. If, however, you are required to write a QCAT Application because family or friends would be inappropriate, you should consider the audience and purpose, structure, timing and language of your application.

Audience

A key issue for any writer is to consider his/her audience and the purpose of the report/record. When writing for medical records, we consider the medical/health audience and the purpose of the record. A similar focus should occur when writing for legal purposes. In relation to applications to QCAT, the audience is the Tribunal and hence, the focus shifts to the question: 'what is required by the Tribunal to make an informed and balanced decision?'.

QCAT's auspice in relation to applications is specifically defined by legislation⁷¹. The legislation notes that, when considering requests for appointment of an administrator or a guardian, the Tribunal must consider and determine 3 questions:



Purpose of report/summary

The person making the application to QCAT for appointment of an Administrator and/or Guardian is required to prove that the Adult has impaired capacity for decision-making in relation to the decision that needs to be made.

The Tribunal requires the completion of two documents:

- An Application Form and
- A Report by Medical and other Related Health Professionals.
- If the person who makes the Application is seeking appointment as an Administrator, they are required to prepare a financial management plan.⁷²

However, as best practice, it is suggested that you should attach these documents to a summary/covering letter that comprehensively summarises your team's case for seeking an Order.

This summary should address:

⁷¹ GAAT Act 2000 Qld, s.12.

⁷² GAAT Act 2000 Qld, s.20.

- The three questions that will be determined by the Tribunal (see above)
- Articulate a succinct summary argument of why you contend that the Adult lacks capacity and why you have to make the application.
- Include the psycho-social factors affecting the Adult's decision-making ability.

Such an overview is essential if you are seeking an Interim Order but is also good practice when seeking any Order. It also serves as a useful summary for the medical record and ensures that any health practitioner who later engages with the Adult can quickly learn what has happened before.

Purpose of Application for an Interim Order

QCAT can grant an interim order if it is satisfied, on reasonable grounds, that there is an immediate risk of harm to the health, welfare or property of the Adult concerned in an application, including concern that there is a risk of abuse, exploitation or neglect of, or self-neglect by, the Adult⁷³. Hence any application for an Interim Order must clearly outline the grounds upon which you argue that there is immediate risk of harm to the Adult.

You can find more information about Interim Orders on the QCAT website here: <u>http://www.qcat.qld.gov.au/matter-types/decision-making-for-Adults/interim-orders</u>

ractice point:

The clause, *immediate risk of harm to the Adult*, is not satisfied if the Adult is in hospital unless there are external factors such as imminent eviction, legal matters etc. to be managed. This clause cannot be relied upon to relieve bed pressures e.g. the Adult needs to be placed in an aged care facility.

The two cases below provide an example of QCAT reasons around evidence for Interim Orders

RE MMR [2012] QCAT 504 (EXTRACT OF REASONS FOR DECISION) – FAMILY MEMBER SEEKING INTERIM

"[1] MRR lives in residential aged care. Her daughter, SJ, wants MRR to live with her. A guardian and an administrator were appointed for MRR by QCAT on 29 September 2011. The guardian has the authority to make decisions about accommodation, health care and services. SJ is neither the appointed guardian nor the appointed administrator.

[2] SJ has applied to QCAT for a review of the appointment of the guardian and administrator. She also applied in the interim for orders directing in effect the removal of MRR from her current accommodation and placement of MRR into SJ's home.

4] IN HER APPLICATION, SJ ASSERTED THAT MRR WAS IN IMMEDIATE DANGER AS HER HEALTH WAS BEING IGNORED, THAT MRR WAS REFUSING NECESSARY SERVICES AND THAT MRR'S SAFETY WAS AT RISK THROUGH THE ACTIONS OF OTHERS. THE EVIDENCE SHE PROVIDED IN SUPPORT OF HER APPLICATION WAS CONTAINED IN HER AFFIDAVIT. NO EVIDENCE WAS PROVIDED ABOUT MRR BEING IN IMMEDIATE DANGER.

[5] IN THE ABSENCE OF EVIDENCE THAT MRR WAS AT IMMEDIATE RISK OF HARM IN HER CURRENT RESIDENTIAL ENVIRONMENT, THERE WERE NO GROUNDS ON WHICH I COULD BE SATISFIED THAT THE DISCRETIONARY INTERIM RELIEF SOUGHT BY SJ SHOULD BE GRANTED.

[6] HER APPLICATION FOR INTERIM ORDERS WAS DISMISSED.

An indication of the urgency of such matters is that an Order can be made without any hearing or representation from the Adult although such Orders are limited to 3 months⁷⁴.

⁷³ Section 129, GAAT Act, 2000 QLD

⁷⁴ It can be extended in exceptional circumstances.

Given the potential for such applications to abrogate the Adult's human rights unless all important details and facts are provided to the Tribunal, it is vital that we send succinct and sound summaries of our concerns to the Tribunal. If we do not, it is likely that our applications will be unsuccessful.

RE SN [2011] QCAT 365 – APPLICATION WHILST ADULT IN HOSPITAL – APPLICATION DISMISSED

[1] TE LODGED AN APPLICATION IN THE TRIBUNAL SEEKING THE APPOINTMENT OF A GUARDIAN AND AN ADMINISTRATOR FOR SN. THE APPLICANT SOUGHT INTERIM APPOINTMENTS OF A GUARDIAN AND ADMINISTRATOR.

[2] The grounds for seeking an interim appointment were contained in a letter from the applicant dated 6 July 2011. The applicant submitted that SN was an inpatient at a hospital. He had had 11

PRESENTATIONS/ADMISSIONS TO HOSPITAL IN THE PAST 12 MONTHS. ON EACH OCCASION HIS HYGIENE WAS POOR AT THE TIME OF PRESENTATION AT THE HOSPITAL.

[3] IT WAS SUBMITTED THAT SN DOES NOT HAVE A PERMANENT ADDRESS. HE HAS BEEN OFFERED SUPPORT TO FIND ACCOMMODATION BUT HE HAD DECLINED THAT SUPPORT. HE HAS DECLINED TRANSFER TO SUPPORTED ACCOMMODATION OPTIONS. HE HAS A SON BUT THERE IS CONFLICT BETWEEN THEM. THE APPLICANT SUBMITTED THAT SN WITHDRAWS HIS ENTIRE PENSION BUT IT IS NOT KNOWN HOW HE SPENDS HIS MONEY.

[4] The Applicant submitted that SN is medically well and he is keen to be discharged from hospital and there is an increasing risk of self discharge. SN is becoming aggressive towards hospital staff and his behaviour is getting difficult to manage. He is likely to be transferred to an outlying facility which the applicant submitted will increase the risk of self discharge......

7] THE TRIBUNAL WAS NOT SATISFIED ON THE EVIDENCE THAT SN WAS AT IMMEDIATE RISK OF HARM. HE WAS AN INPATIENT IN HOSPITAL, HE WAS RECEIVING APPROPRIATE CARE AND HE WAS NOT GOING TO BE DISCHARGED BY THE HOSPITAL WITHOUT ADEQUATE ACCOMMODATION ARRANGEMENTS BEING MADE.

[8] The Applicant submitted that there was a risk of self discharge but there was no evidence that SN had made any attempt to leave the hospital without permission or contrary to medical advice.

[9] THE TRIBUNAL COULD NOT MAKE ANY INTERIM APPOINTMENTS WHEN THE CRITERIA IN SECTION 129 HAD NOT BEEN MET.

[10] LESS THAN TWO WEEKS AFTER THE TRIBUNAL HAD REFUSED THE REQUEST FOR INTERIM APPOINTMENTS, THE APPLICANT LODGED A SECOND REQUEST FOR INTERIM ORDERS. THE EVIDENCE PROVIDED IN SUPPORT OF THE SECOND APPLICATION WAS ESSENTIALLY THE SAME EVIDENCE THAT HAD ALREADY BEEN CONSIDERED BY THE TRIBUNAL. IT WAS STATED THAT THE HOSPITAL WAS OPERATING AT 100% CAPACITY AND COULD NO LONGER SUSTAIN SN REMAINING IN ONE OF ITS BEDS AND THAT HE WAS LIKELY TO BE TRANSFERRED TO AN OUTLYING FACILITY. IT WAS SUBMITTED AS BEFORE THAT THE RISK OF SELF DISCHARGE WOULD INCREASE IN THAT EVENT.

[11] THE SECOND APPLICATION WAS NOT ACCEPTED AS A VALID APPLICATION AS IT SOUGHT THE SAME RELIEF BASED ON ESSENTIALLY THE SAME FACTS AS THE FIRST APPLICATION THAT HAD BEEN DETERMINED AND REFUSED. THE APPLICANT CANNOT MERELY REPEAT HER REQUEST IN THE HOPE THAT THERE WOULD BE A DIFFERENT OUTCOME. THE POSITION WAS THAT NO NEW EVIDENCE HAD SATISFIED THE TRIBUNAL THAT AN IMMEDIATE RISK OF HARM EXISTED AND THAT AN INTERIM APPOINTMENT WAS NECESSARY.

[12] THE TRIBUNAL INFORMED THE APPLICANT THAT THE SECOND REQUEST WOULD NOT BE ACTIONED BUT DID MAKE ARRANGEMENTS FOR AN EARLY HEARING TO BE SCHEDULED FOR HER APPLICATIONS FOR THE APPOINTMENT OF A GUARDIAN AND ADMINISTRATOR. THE TRIBUNAL RECOGNISED THAT IT WOULD BE IN THE INTERESTS OF SN THAT HE HAD THE OPPORTUNITY TO PLACE HIS VIEWS BEFORE THE TRIBUNAL AND THAT A DETERMINATION COULD BE MADE ON THE APPLICATIONS AS EARLY AS POSSIBLE AND INFORMED BY HIS INPUT.

Why is providing a summary letter 'good practice' in all QCAT applications?

• You are forced to write and reflect upon the grounds ('evidence') that you are relying upon to make the application. In effect, you are ordering your thoughts and can consider whether you have balanced the need for protection of the Adult versus his/her rights.

• You are required to consider how your summary/application will answer the 3 QCAT questions (indicated above).

Important points to remember

- Include any examples that do not support your position that a decision-maker needs to be appointed. This demonstrates a balanced approach to your application and ensures that the Tribunal has all necessary facts before it to make a fair decision.
- Record the ways in which you tried to facilitate assisted/supported decision-making for the Adult and how this failed.
- Record if the Adult has fluctuating capacity such as early dementia and how your team incorporated this consideration into their assessment. Such matters demonstrate how you incorporated the general principles⁷⁵ into your assessment.

Example:

The treating medical team sought to optimise Mr Adam's participation in his capacity assessment by:

Informing Mr Adams of the assessment's purpose and the importance of his participation.

Undertaking the capacity assessment at 10am as the nursing indicated that Mr Adam's memory and language skills decreased in the afternoons.

Undertaking the assessment in short sessions of 15 minutes over three days to lessen the likelihood of Mr Adam's performance being affected by his tiredness. It also allowed us to check whether Mr Adam's performance was consistently poor or whether it fluctuated.

Structure of Summary/covering letter

A simple way to structure the letter is to follow these steps:

- 1. Introduction
 - a. Note your role with the Adult and the fact that you are making the application on behalf of the treating team. Succinctly report for how long and in what capacity you know the Adult. Include reasons for admission/referral or occasion of service. State clearly what Order you are seeking.
- 2. Outline the grounds upon which your team is seeking the Order by answering **the 3 questions** that the Tribunal must consider when making its determination. Arrange your report around headings. Place relevant points under each heading so that you can clearly see what evidence you are relying upon to guide your argument.
 - a. See points in next section for ideas about what to report when answering each question.
 - b. To assist you to think about what to add to your report, you may also like to review the Practice Tool in Tool 4 entitled "Gathering evidence for capacity assessment and QCAT application"
 - c. Try to keep the information in chronological order to allow ease of reading.
 - d. Note the points made about 'language' later in this section when writing your summary. The best summary concisely explains the facts upon which your team relies.

⁷⁵ General Principles

- 3. You may be able to attach copies of medical test results or the reports of other health professionals. Be sure that each report writer is clear about what questions the Tribunal considers and ask them to write a report that addresses these issues. If you use information from the file that was added by other health professional in your summary, ensure that you reference the record or attach the report. E.g. "On 29 March 2011, the physiotherapist noted that....".
- 4. Involve a range of professionals who engage in the Adult's care to record aspects that may impact upon or demonstrate issues with decision-making or abuse of the Adult.
- 5. Conclusion concise summation of request.

Breaking it down

How do I answer question 1: Does the Adult have impaired capacity for decision-making? (see Tool 3 for a summary sheet of this discussion to use on the wards)

What evidence do I have to demonstrate that the Adult has impaired capacity?

- Evidence that the Adult does not understand the nature and effect of decision to be made recall, retain, discuss, choose options, weigh consequences and decide
- Cannot make decisions freely and voluntarily?
- Cannot communicate the decision in some way?⁷⁶.

In previous Sections of this program, it was noted that impaired capacity may arise from a number of medical and disability conditions. However, it is not sufficient to rely upon a diagnosis of dementia, stroke, psychosis or an intellectual disability etc. as a reason for a QCAT application.

A diagnosis alone does NOT prove impaired capacity. A diagnosis may suggest some difficulty with decision-making but the difficulty may be fluctuating or transient or, as in the case of dementia, in its early stages, and thus it may not prevent the Adult from making his/her own decisions.

What IS important is your ability to connect and report how and when the disability or diagnosis affects the Adult's ability to make the decision that must be made now or puts them at risk of harm now.

How to demonstrate this:

- Attach a medical report, copies of scans, medical tests etc. that relate to impaired capacity issue.
- What other information is available to suggest impaired capacity? Ensure that you are providing a complete picture to rebut the presumption of capacity.
- What tests/assessments have been done to make sure capacity not available for this decision?
- MMSE⁷⁷ or RUDAS or other?
- Functional assessment by OT and ability to manage independently/safely at home (if this is the issue)?
- Physiotherapy assessment re function and safety to mobilise?

⁷⁶ See Definition of capacity, located in Schedule 4, GAAT Act 2000 QLD.

⁷⁷ An MMSE that is low merely indicates that the Adult has some cognitive issues on that day at that time but it is a flawed test because it is not culturally appropriate and can be misunderstood in value. Use it with care. It may however be a useful baseline that suggests that further investigation is warranted.

- Psycho-social assessment of Social Worker?
- Collateral information from relatives/friends re capacity concerns. Are these people prepared to make the Application instead of you?
- Nursing reports either in community or on the file? How is Adult self-managing his/her cares and making decisions about personal matters. Issues of 'freely and voluntarily'?
- Psychiatrist review and report?
- Other specialist medical that relevant to impaired capacity? ------
- Checked previous admission to see if there has been previous MMSE done and differences? Or similar tests.
- Discuss when and how capacity assessment was done e.g. how you ensured that the precapacity assessment and capacity assessment task was done, taking into account the Adult's rights.
- Interpreter facilitating understanding during an assessment⁷⁸? Other aids or familiar people present but not answering questions for the Adult?
- What questions were asked that led to the suggestion that the Adult lacked capacity for the decision required?
- Were there matters that you deliberately excluded from your assessment e.g. the way the person dressed or previous mental illness - as these do not automatically indicate impaired capacity?
- What pressures are being placed upon the Adult to influence how he/she makes a decision? Could the Adult's medical condition/disability impact upon his/her vulnerability to being influenced by others? E.g. are they highly suggestible, isolated, or dependent.
- How have we demonstrated that our attempts at communication with the Adult have failed?

How do I answer question 2? Does a decision about a personal, health or financial matter need to be made NOW? How is the Adult likely to make a financial, personal or health decision that involves or is likely to involve unreasonable risk to his/her health, welfare or property AND without the appointment, the Adult's need will not be adequately met or protected.

- What is the decision that needs to be made?
 - o Is there more than one decision?
 - Is one decision urgent (requiring an Interim Application) whilst another can wait until a Tribunal Hearing? Consider your options.
- Why does the decision need to be made NOW?
- Is the matter financial or personal or a health matter or all 3? Remember: ONLY apply for substituted decision-making as a last resort.
- Have you checked there is no EPOA or AHD attorney (if a health decision)?
- Have you checked there is no SHA (if a health matter)?
- Have you considered the Office of the Public Guardian as health attorney of last resort, if it is a health decision and the Adult does not have family/friends?

⁷⁸ In some cases, it may appear that the Adult is able to understand spoken English; however, to ensure a deeper level of understanding and to uphold his/her rights, an interpreter should be engaged for capacity assessments.

- Can the OPG act as an informal (i.e. not Tribunal appointed) decision-maker e.g. for consent to aged care placement?
- Would the matter benefit from early intervention by the OPG e.g. are there concerns about abuse or neglect of the Adult?
- Have you tried informal or assisted decision-making and if so, why did this not work?

How do I answer question 3: Who is the most appropriate person to be appointed as decisionmaker?

This is primarily a consideration for the Tribunal. However, due to your exposure with the Adult, you may have insight into his/her relationship with potential decision-makers e.g.

- If you have concerns about financial decision-making, this section may be used to discuss your concerns – make sure these concerns are not just your opinion but that they are based upon facts e.g. statements made to you, discrepancies between money available to Adult vs what should be available, etc.
- If you have concerns about conflict in families and their ability to negotiate around decisionmaking, this could be relevant here.
- If family/friends do not want to be appointed, explain why not and state whether or not they
 support the application.

You may wish to clarify why you chose only to seek appointment of an Administrator rather than also a Guardian here e.g. the person lives in an aged care facility but are unable to access his/her money.

Timing

In most cases, time will lapse between the initial application and the actual QCAT hearing. In such situations, it is good practice to prepare another updated letter and reports to QCAT prior to the hearing date.

Ensure all information is up to date and if necessary, obtain updated reports so that the Tribunal can decide based on current evidence.

Remember that the Adult may have improved since first admission or with appropriate medication and support so an Application may not be required. For example, if the Adult has remained in hospital, there may be improvements noted due to increased hydration and nutrition and medication compliance. Medical reports may also indicate improvements. For example, a psychiatrist may reinterview the Adult to adduce improvements or decreased capacity.

If improvements are noticed, you will need to disclose them to ensure that the Adult's rights are protected and the least restrictive alternative principle is upheld.

Language⁷⁹

Writing for legal purposes is not much different to writing your medical chart notes. The same principles apply – only the questions that must be answered may differ. Essentially, if you follow the following points, you will be able to use your notes not only appropriately for health purposes but it will also be easy to extract the information that you require for legal purposes.

You should:

• Be aware of the Privacy Principles⁸⁰. These state that you should only collect health and other information that is relevant for this particular episode of care – i.e. if it informs your

⁷⁹ More information is available in Cousins, C. & Toussaint, S. (2004) "You wrote what?!...dangers and dilemmas in record-keeping", *Developing Practice* 10:Winter, pp.38-45;

current ability to provide care and that you should make the individual aware of why you are collecting the information about them and who you might give it too, as soon as practicable afterwards.

- Record contemporaneous notes in the chart and ensure they are placed in chronological order.
- Provide succinct and clear detail about what you saw and heard and what was stated. This will allow other practitioners to comprehend what happened in your engagement with the Adult. This is important to ensure continuity of care but also acts as a record of history of care for future readers. Vague or incomplete records "may compromise the quality of services....provided....by colleagues"⁸¹
- Remember that keeping parallel files is not appropriate and that such files are open to subpoena.
- Be factual: state what you saw and what happened and be objective. Do not make assumptions based upon what you saw or what happened. Direct quotes in double inverted commas, observations and facts will lead the reader to a conclusion without you telling them.
- Always make sure that you preface indirect statements with qualifiers such as 'I was advised by X' or 'J states that Mary hit him". Use terms such as reported, stated or advised. Do not claim such statements as fact e.g. John was hit by Mary. Note who you spoke to about the Adult and their relationship to the Adult.
- If an appropriate professional opinion is stated, call it this. "I believe....."
- If you do use professional opinion, be prepared to back up any statement with valid reasons.
- Be accurate, concise and careful of details. If you are unsure of something, state this and indicate when you will find out.
- Organise and structure your thoughts before writing. Outline key points and this may reduce extraneous points.
- Write respectfully. Avoid use of professional jargon. If using an abbreviation, ensure that when first mentioned in the record, clarify its meaning.

Other documentation requested by OPG and PTQ

What information do guardians require to make a residential aged care decision?

Apart from advising when they will make a residential aged care decision on behalf of an Adult with impaired capacity, <u>The Public Guardian</u> requests that the following information be provided to QCAT upon applying for the appointment of a guardian or immediately upon the Public Guardian's appointment:

A guardian has a right to all information necessary to make an informed decision (as per s.44 of the Guardianship and Administration Act 2000 Qld). For residential aged care decisions, the information required usually includes (but is not limited to):

- ACAT assessment
- medical history including any functional, OT or specialist assessments

⁸⁰ National Privacy principles,

⁸¹ Reamer, F.G. (2005) "Documentation in Social Work: Evolving Ethical and Risk-management Standards", *Social Work* 50(4), pp.325 – 334 at p.329.

- social history including any supportive relationships in the person's life, the person's accommodation history, and their views and wishes about their accommodation and care
- current or previous community supports received, either funded or unfunded
- details of any return-to-home trials undertaken and/or other accommodation options explored
- applications/approvals for home care package or other in-home supports
- eligibility for funded disability supports (for people under 65 years)
- confirmation from the person's financial administrator about their ability to pay for the proposed placement.

CHECKLIST⁸²: Has your QCAT application answered these Public Guardian questions too!

The Public Guardian also would like the following information provided to expedite their decisionmaking process. If you have completed the QCAT application and associated documentation appropriately, these issues are likely to be addressed within that!

- What is the Adult's view (currently or previously expressed in relation to their future care and support arrangements?
- Does the Adult have family or friends that can assist with decision-making? If so, provide details of the nature/closeness of relationship with the Adult (e.g. do they provide day to day support)?
- What are the views of interested parties in regard to the Adult's future care and support arrangements?
- If there are no known interested parties, what attempts have been made to locate family and friends?
- If the Adult is unable to return home, what alternative accommodation options have been identified or considered (e.g. residing with family)
- Provide details if any work has been undertaken with the person in relation to Advance Care Planning.
- ACAT Assessment attachment (if applicable)
- Functional OT and other assessments attachments
- Has the Adult had a trial of care at home? Please provide details (if applicable)
- Does the Adult have approval for a home care package or other form of funded in-home supports? Provide details
- Status of Disability assessment and contact details for Disability location and case manager
- Medical history
- Accommodation history length, type, reason for break-down
- Letter from the treating team stating that the Adult is unable to return home (if applicable)

⁸² See Tool 10 for a checklist that you can download and use in practice

✓ CHECKLIST⁸³ for Public Trustee

If your application seeks appointment of the Public Trustee as Administrator, you are requested to provide the following information to the Tribunal at the time of hearing so that Public Trustee decision-making is expedited. If you cannot source all the information, just provide what you can.

This request is under-pinned though with a qualification – remember that until QCAT finds the person lacks capacity for their finances, the PTQ is not automatically entitled to personal financial information from the Adult.

Once appointed, they will want access to:

- Centrelink Customer Reference Number (CRN) and a Centrelink Income and Assets
 Statement
- Copy of Bank ATM and Credit Card
- Copy of Medicare Card and Pension Card
- List of and contact details of any professional advisors such as accountants, solicitors, financial planners etc.
- Tax file number
- Details of assets/liabilities including account numbers or references
- List of expenditure items such as property utilities, regular charges and known debts etc.

This list has been developed by Metro North HHS into a tool to use for every QCAT application: **see Tool 9** for an example.

QCAT Applicant responsibilities

If you are the applicant in a QCAT application, you are required to:

- 1. Keep QCAT updated with the Adult's contact details e.g. new address if Adult is discharged
- 2. Provide contact details for any interested parties to enable QCAT to send written notification advising any interested parties of the Application
- 3. When a matter is listed for a hearing before QCAT, all parties involved in the Application are expected to attend the Tribunal in person
- 4. If the applicant wishes to attend the hearing via phone, they will first need to discuss this with the QCAT case manager prior to the hearing. If approval is given to the applicant to attend by phone, then it is the applicant's responsibility to provide a contact phone number at least 3 business days prior to the hearing.
- 5. It is always important that the applicant complete the attendance advice and return this to QCAT even if they are attending in person
- 6. Prior to the hearing, QCAT may need to discuss the Application with the applicant. The applicant or their proxy should be available in the event that QCAT wish to discuss the application.
- 7. When the Adult is a hospital patient, and the application has been made by the family or others, QCAT may wish to discuss the case with health professionals involved in the care of the patient. Medical practitioners, Social Workers and other health professionals should make themselves available to QCAT should this be necessary.

⁸³ See Tool 9 for this information as a checklist tool.

Prior to the hearing, QCAT may request in writing, additional information about the Adult's decision-making. The tribunal has general powers⁸⁴ to request and obtain relevant information from a health provider treating an Adult.

Withdrawing an application

An applicant may apply to withdraw their Application at any point in the proceeding. However consent is required.⁸⁵

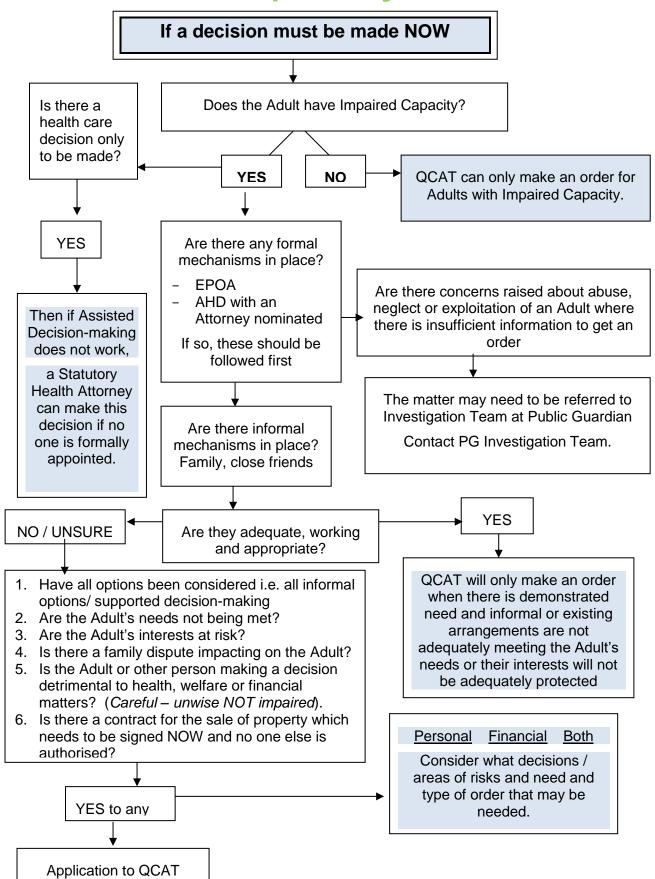
The applicant must complete the approved Form (Form 40 – Application for Miscellaneous Matters). In some instances, QCAT may accept a written request to withdraw either by email or letter.

The applicant should provide reasons why they now believe the Adult no longer requires a substitute decision-maker appointed. This should be supported by evidence of updated capacity information. QCAT will determine whether it will approve the application's withdrawal or not. If not, the matter will proceed to hearing as intended originally.

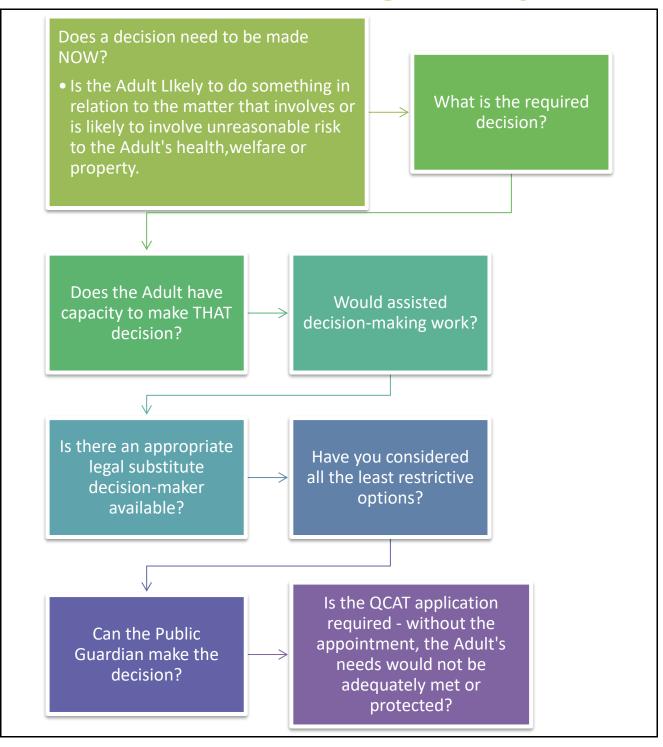
⁸⁴ Guardianship and Administration Act 2000 Qld, s 130(1), 130 (2). 76 (3), 76 (7) and (8) and the national Privacy Principle 2.1 (g)

⁸⁵ Queensland Civil and Administrative Act 2009 Qld, s 46.

Tool 1: Decision pathway



Tool 2: Clinical Reasoning Pathway



Tool 3 : Capacity Assessment Pathway Checklist

Key attribution/ reference for the ideas in this checklist is: Darzins P, Molloy, W & Strang, D (2001) *Who can decide? The six step capacity assessment process.* Adelaide: Memory Australia Press.

PRE-CAPACITY ASSESSMENT PROCESS					
	Yes	No			
Does a decision need to be made by the Adult?					
Personal					
Health					
Financial					
Does this decision need to be made NOW?					
Have you applied the capacity assessment principles?					
Always presume a Adult has capacity.					
Capacity is decision-specific.					
 Don't assume an Adult lacks capacity based only on appearances. 					
Assess the person's decision-making ability; DO NOT judge the decision made.					
Respect the Adult's privacy.					
Substitute decision-making is a last resort.					
Does the Adult have any of the following difficulties with communication?					
Hearing loss/visual loss					
Limitations in communication due to mental illness					
Limitation in communication due to an acquired brain injury					
Limitation in communication due to an intellectual disability					
Has delirium or dehydration or nutritional deficiencies been considered as a tempora cause?	iry				
If yes answered to any of the 2 questions above, have you considered how to best negate any communication difficulties in capacity assessment? E.g. contact a specialist such as a speech therapist if available; otherwise consider the tip sheets in Section 1.3.					

CAPACITY ASSESSMENT CONSIDERATIONS

Step 1: Determine valid reason for a capacity assessment

- Trigger⁸⁶
- Fluctuating capacity
- Increased capacity

Is there evidence or reasonable suspicion of one of the key causes of temporary or permanent cognitive impairment?

A poor score on a Mini-Mental State Exam (MMSE) does not mean that the patient is not capable in relation to the particular question at hand, but it does constitute part of a valid trigger to perform a capacity assessment.

- Dementia
- Delirium
- ABI
- Mental illness

Intellectual disability

Step 2: Engage the consumer

The Adult is presumed to be capable until evidence exists to the contrary. Therefore normal processes for gaining consent to assessment should be pursued where possible.

- Has engagement and normal consent happened?
- Have you sought consent to seek collateral information?

CAPACITY ASSESSMENT PROCESS

When it is impossible to attain a valid consent using normal processes it is critical that valid reasons for carrying out a capacity assessment, as mentioned in Step 1, are established and documented prior to proceeding with the capacity assessment.

- I/ The treating team have/ has documented the reasons for seeking a capacity assessment
- The registrar or consultant of the treating team has agreed and authorized in writing a capacity assessment (if relevant).

Inform the patient that:

- His/her capacity is being assessed in relation to answering a specific question, group of questions or function and because there is concern that there is risk to themself or others.
- The capacity assessment will proceed and he/she is encouraged to participate.

⁸⁶ A valid trigger requires a situation where the patient is / will be required to make a decision, which involves balancing risk and benefit (for themselves or others). Behaviour unusual for the consumer such as impulsiveness, apathy or an apparently unreasonable decision does not prove incapacity however these may trigger a capacity assessment.

- Inform the Adult that he/she does not have to participate but that participation may be of benefit to them because he/she will then have the chance to express their views so that the best judgment can be made. Reassure the Adult that he/she will not receive lesser care if they choose not to participate.
- Describe to them the steps involved.
- If he/she is found to be capable, he/she will be able to continue to make his/her decisions.
- If he/she is found to have impaired capacity and he/she has an attorney appointed under either an Advance Health Directive [AHD] (health decisions) or an Enduring Power of Attorney [EPOA] for (health, personal and /or financial decisions).
- If only health matters are involved and there is no formal appointment of an attorney under either an AHD or an EPOA for the consumer, then under Queensland law, we can ask his/her Statutory Health Attorney to make decisions on his/her behalf.
- If his/her ability to make decisions independently remains uncertain, then further investigations may need to occur.
- The Adult was informed of the process, as outlined above
- The Adult agreed to participate

Step 3: Information Gathering

Gather and record:

- What is the decision required?
- Why has it arisen?
- What are the options?
- What are the reasonably foreseeable consequences of each option?

This step may be time consuming, especially in decisions regarding social issues. A formal assessment may require extensive information gathering and is required for important decisions where there is any uncertainty about capacity.

•	Information gathering com	pleted
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• Summarized and documented on file

Step 4: Educate the patient

The patient should be educated about the information and choices determined in Step 3. Time taken at this stage may enable some people to retain autonomy about decisions.

Remember: It is important that communication difficulties such as deafness, receptive dysphasia, or language barriers do not prevent the patient from learning the relevant information. Seek an interpreter if there is a cultural language barrier.

- Adult received information about the decision required, reasons for the decision arising, options and reasonably foreseeable consequences of each option
- Consideration was given to whether the person required assistance with communication e.g. message board, electronic equipment, interpreter, visual aids, simple language used
- Another staff member was present at the discussion and their name and position is recorded on the file (not required).

- Time spent on educating the Adult
- Name and position of person who educated the Adult is noted on file

Step 5: Checking Patient Understanding

Can the patient tell you in his or her own words about all these 87?

- About the decision to be made
- The options, including doing nothing
- The reasonably foreseeable consequences of each option

If the answer is 'no' and the consumer can only answer some of these questions, there is evidence that the person lacks the capacity to make that particular decision.

Step 6: Taking Action

(a) Unless evidence of incapacity is found, the individual is presumed capable and the individual's decision should be respected and acted upon. An apparently unreasonable decision does not prove incapacity, but it may trigger a capacity assessment.

(b) If the person is found to not have capacity for the decision, then best practice is to inform the person and seek out the formally appointed substitute decision-maker or if the matter is a health matter, the Statutory Health Attorney. See Section 7.

(c) If there is any doubt (especially if there is reason to believe that there are potential communication difficulties) then a second opinion, in the form of other specialists or neuro-psychometric testing, may be helpful in determining capacity.

- Is there evidence of impaired capacity?
- Have you recorded this information in the file?

Being found incapable may lead to decreased self-esteem, grieving and/or depression. Sensitive handling and counselling can assist. Follow-up of the patient is essential.

(Remember that capacity may be present for some decisions such as medical choices, while being absent for others such as financial choices. Also, capacity may return with the resolution of problems like delirium or mental illness).

- Has counselling been considered?
- Has follow-up been organised?

⁸⁷ It is preferable that the consumer can use his/her own words to describe the issue or decision. The use of interpreters may be required. Non-verbal patients should be referred for specialist assessment. Asking the person if they understand – "yes or no" is not sufficient.

Tool 4 : Gathering evidence for capacity assessment & QCAT application

Question 1: Does the Adult have impaired capacity for decision-making?

If yes, the Tribunal can consider the Application. If no, the Tribunal must dismiss the Application.

What evidence do I have to demonstrate that the Adult has impaired capacity?

- Evidence that the Adult does not understand the nature and effect of decision to be made recall, retain, discuss, choose options and decide
- Cannot make decisions freely and voluntarily?
- Cannot communicate the decision in some way?

1. Medical diagnosis that may cause impaired capacity?

 Attach a medical report, copies of scans, medical tests etc. that relate to impaired capacity issue.

2. What other information is available to suggest impaired capacity? Ensure that you are providing a complete picture to rebut the presumption of capacity.

- What tests/assessments have been done to make sure capacity not available for this decision?
 - □ MMSE or RUDAS or other? (check for past as well as current MMSE)
 - □ Functional assessment by OT and ability to manage independently/safely at home (if this is the issue)?
 - □ Physiotherapy assessment re function and safety to mobilise?
 - □ Psycho-social assessment of Social Worker?
 - □ Collateral information from relatives/friends re capacity concerns. Are these people prepared to make the Application instead of you?
 - □ Nursing reports on the file?
 - □ Psychiatrist review and report?
 - □ Other specialist medical that relevant to impaired capacity? ------
 - □ Checked previous admission to see if there has been previous MMSE done and differences? Or similar tests.
 - Discuss when and how capacity assessment was done e.g. how you ensured that the pre-capacity assessment and capacity assessment task was done, taking into account the Adult's rights.
 - □ Interpreter required? Other aids or familiar people present but not answering questions for the Adult?
 - □ What questions were asked that inferred lacked capacity for the decision required?
 - □ Were there matters that you deliberately excluded from your assessment e.g. the way the person dressed or previous mental illness as these do not necessarily equate with

impaired capacity?

- Ensure all information is up to date and if necessary, obtain updated reports so that the Tribunal can make a decision based on current evidence.
- Remember that the Adult may have improved since first admission or with appropriate medication and support so an Application may not be required.

Question 2: Does a decision about a personal, health or financial matter need to be made NOW?

- What is the decision that needs to be made?
 - $\hfill\square$ Is there more than one decision?
 - □ Is one decision urgent (requiring an Interim Application) whilst another can wait until a Tribunal Hearing? Consider your options.
- Why does the decision need to be made NOW?
- Is the matter financial or personal or a health matter or all 3?
- Have you checked there is no EPOA or AHD attorney (if a health decision)?
- Have you checked there is no SHA if a health matter?
- Have you considered the Office of the Public Guardian as health attorney of last resort, if it is a health decision and there are no family/friends?
- Can the OPG act as a decision-maker e.g. consent to aged care placement?
- Would the matter benefit from early intervention by the OPG e.g. are there concerns about abuse or neglect of the Adult?
- Have you tried informal or assisted decision-making and these did not work?

Question 3: Who is the most appropriate person to be appointed as substitute decision*maker***?**

This is primarily a consideration for the Tribunal. However, due to your exposure with the Adult, you may have insight into his/her relationship with potential decision-makers. E.G.

- If you have concerns about financial decision-making, this section may be used to discuss your concerns – make sure these concerns are not just your opinion but that they are based upon facts e.g. statements made to you, discrepancies between money available to Adult vs what should be available, etc.
- If you have concerns about conflict in families and their ability to negotiate around decisionmaking, this could be relevant here.
- You may wish to clarify why you chose only to seek appointment of an Administrator rather than also a Guardian here e.g. the person lives in an aged care facility but are unable to access his/her money.

Tool 5: Personal Decisions - Questions and tips for assessing capacity



uestions for assisting with personal decision-making capacity assessment

Types of issues that you may like to consider here are:

- ? How much does the person know about their living arrangements and how to meet their needs?
- ? Can the person dress appropriately for the weather and take care of their personal hygiene?
- ? Can the person shop for groceries and safely prepare meals, and are they eating properly?
- ? Does the person understand their medication routine and follow it?
- ? What informal or formal support services such as family care, home care, nursing, Meals on Wheels, domestic cleaning or transport services, does the person get or need?
- ? What friends or family does the person see?

Also consider whether there is significant harm, or risk of harm, to the person or others as a result of the person not being able to manage personal decisions.

For example:

- ? Can the Adult manage in their present accommodation without posing any threat to themselves or others? For instance, is there a fireplace that may cause a fire hazard because of improper use?
- ? Is the state of cleanliness a hygiene risk?
- ? Is the Adult at risk due to malnutrition or dehydration, or in danger when cooking such as by cutting themselves or leaving things on the stove, or in danger through dressing inappropriately or due to lack of personal hygiene?
- ? Are they not taking, or taking too much, medication, and could this be a cause of harm?
- ? Are they accepting and accessing relevant services which can assist to prevent risk of harm?
- ? Does the Adult recognise when to seek medical help, know how, and are they able to get medical help when it is needed?
- ? Is the Adult being mistreated, threatened or abused by the people who care for or visit them?

Specific questions you may ask to determine if the Adult has capacity to make every-day personal decisions:

- ? How are you coping with XYZ (the area of concern)?
- ? Do you think you are having any difficulties?

If they don't believe they have any problems, then discuss the concerns that have been raised by the people close to them (or whoever it was that recognized the trigger).

You are looking for understanding of the situation and insight into what the problem might be.

Use the following questions as a basis for discussion:

? Describe your situation. Why do you think it could be a matter for concern?

- ? What do you think could be done to help to address the concern?
- ? Tell me what other options there are, and what option you might want to take?
- $? \ \ \mbox{What}$ are the pluses and minuses of each option, as you see it?

Tool 6: Health decisions – Questions and tips for assessing capacity

uestions to assist with health decision-making capacity

Types of issues that you may wish to explore here are:

? Does the Adult understand the nature and effect at the time that the medical or dental decision is required, not hours or days before or after it is made?

- ? Does the Adult know the 'nature' of the treatment? That means, do they understand broadly and in simple language:
 - o What the medical or dental treatment is?
 - What the procedure involves?
 - Why it is proposed?
 - That there are other options?
- ? If choosing between options, the Adult must understand what each option is, what it involves, the effect of each option, and the risks and benefits and what it means if they don't have the treatment?
- ? Does the Adult understand the 'effect' of the treatment? Are they aware, in simple terms, of the main benefits and risks of the treatment?
- ? Does the Adult have the ability to indicate whether they want the treatment? Can they communicate any decision made, with assistance if necessary?
- ? Has the Adult made the decision freely and voluntarily?

Also accept that an Adult has a right to refuse treatment. What most people would decide to do in the situation is irrelevant.

But asking why they refused is a good idea in case they did not understand or needed more information.

Consider the following:

- ? Is refusal of treatment consistent with the Adult's views and values?
- ? Is this behaviour usual for the Adult?
- ? Has all the relevant information been given to the Adult in a way they can understand?

Here are some specific questions you may ask as part of the assessment process to determine if the Adult has capacity to make medical and dental decisions:

- ? Tell me about your health or teeth and why you need some medical or dental treatment.
- ? What is the medical or dental treatment that you might be having? Can you explain it to me?
- ? Where will you be having the treatment?
- ? How long will it take?
- ? How will the treatment help you? What are the good things about the treatment?
- ? Will there be any bad things about the treatment? What are they?
- ? How do you think you will be able to deal with these?

- ? What are the risks of having the treatment?
- ? Is there any other treatment you might be able to have? Can you tell me about it?
- ? How would this other treatment help you?
- ? What are the risks of having this other treatment?
- ? Which do you think is the best treatment? Why?
- ? What would happen if you didn't have any treatment at all?
- ? What do your family and friends think of the treatment?
- ? What do they want you to do? Why?

Tool 7: Financial Decisions – Questions and tips for assessing capacity⁸⁸

uestions to assist with asking questions about finances

Here are some specific questions you may ask as part of the assessment process to determine if the Adult you are assessing has capacity to make property and financial decisions.

Explain to the Adult why you are asking for the information as part of a capacity assessment. Assure the Adult that the answers are confidential.

Be aware the Adults may be particularly reserved when asked to discuss finances so be sensitive in your approach.

Types of issues you may wish to explore are:

- ? What bank accounts do you have?
- ? How much money do you have in the bank at the moment?
- ? Do you keep any money anywhere else, such as at home? Where?
- ? Do you own any property? How much do you think the property is worth now? Are you the only owner or does someone else own it with you?
- ? Where do you get your money? Do you have a job or a pension? Do you have a business or any other source of income?
- ? How much are your bills each month? What sort of bills do you have to pay?
- ? Do you have any credit cards, and how much do you owe on them? What are your other debts?
- ? Do you have a mortgage or do you pay rent?
- ? Can you tell me who depends on you? Does this Adult or people have any income of his/her own?
- ? What investments do you have? Is there an accountant or financial advisor that you go to? If so, what is his/her name and how often do you see them?
- ? Do your family or friends help you with your finances and, if so, how do he/she help?
- ? Have you ever given money to, or bought things for, your family or friends? What types of things?
- ? Have he/she ever asked you for money or influenced you to spend your money in a certain way?
- ? What sort of major purchases have you made over the last year?
- ? What are the next major purchases you want to make?
- ? What would happen if you didn't pay your bills?
- ? What would happen if you didn't follow a budget and instead spent your money on unnecessary or expensive things?

⁸⁸ Reading re financial capacity: Pinsker, D.M., Pachana, N., Wilson, J., Tilse, C. & Byrne, G.J. (2010) 'Financial Capacity in Older Adults: A Review of Clinical Assessment Approaches and Considerations', *Clinical Gerontologist*, 33:4, 332-346

After you have asked your assessment questions, it is worthwhile to then ask the Adult whether he/she believe he/she can manage his/her financial affairs. You might ask:

- ? Do you have any financial concerns or problems? If so, what he/she are? How will you manage them?
- ? If not, are you aware of any concerns about your ability to manage your financial affairs that have been raised by an Adult or people close to you (or whoever it was that recognised the trigger)?

Is the Adult capable of managing his/her own property and money?

Reminder: An Adult doesn't have to be able to manage his/her affairs in the best possible way; he/she just have to be able to manage them.

- ? Does the Adult have the skills to deal in a fairly capable way with the ordinary, regular dealings in life (such as those described in the first paragraph of this section)?
- ? Does the Adult have money management skills? For example, ask them the name of his/her bank, how he/she budget, and how he/she can work out the market value of his/her property?
- ? Do he/she understand his/her assets, ongoing expenses and financial obligations?
- ? Can he/she manage his/her money to provide for food, clothing, medicine and other necessities for hi-herself and any dependents?
- ? Does he/she have a history of looking after his/her affairs in the past?
 Note: Some people may not have ever been involved in routine financial decisions. You may need to consider how the Adult can get assistance or become familiar with banking and other finances.31
- ? Does the Adult know when to get appropriate professional advice? When considering this you need to take into account the extent of his/her assets and the complexity of his/her financial affairs.

If the Adult's affairs are complex, determine if the Adult:

- ? Knows when he/she can't deal with his/her affairs
- ? Knows that he/she can get professional advice, and from whom can understand and weigh up professional advice.
- ? Can he/she protect his/her own interests? Can the Adult identify and deal appropriately with someone who is unfairly trying to gain benefit from his or her assets?
- ? Can he/she communicate the above, with assistance if necessary?

If the Adult can't manage his/her affairs, is there a risk that he/she may be disadvantaged or harmed, or his/her money or property wasted or lost?

Question the Adult to assess the following:

- ? Is there risk of significant disadvantage or harm caused by his/her inability to manage his/her money or property?
- ? Is the Adult freely and voluntarily making decisions about the management of his/her affairs?

Questions in relation to contracts

Here are some specific questions you may ask as part of the assessment process to determine if the Adult has capacity to make a contract.

? What is the contract about?

- ? Who are you are making this contract with?
- ? If you sign this contract, what happens next?
- ? Do you have to pay anything to, or do anything for, the other Adult?
- ? How will it affect you?
- ? What does the other Adult have to do after the contract is signed?
- ? Do he/she have to pay you anything, or do anything for you?
- ? How will it affect the other person?
- ? Will anyone else be affected by the contract or benefit from the contract? Who? Tell me about some of the important parts of the contract.
- ? Do you need, or did you get, legal advice about the contract?
- ? How long is the contract for?
- ? If you do sign the contract, can you end it later if you want to?
- ? How do you go about ending the contract?
- ? What happens if you don't do what you are supposed to do under the contract?
- ? Did you talk to any friends or family about the contract?
- ? What did he/she think about it?

Tool 8: Completing a QCAT report

Situation

Role and authorized to make application for (what type of e.g. appointment of administrator) on behalf of (what) medical team. Where are you located? Why are you making this application instead of family or friends or as well as?

Background

Adult – basic handover points e.g. male, age, presenting issues + how came to care of health care team – what are the team concerns? Be succinct + how long has Adult been known to the team.

Assessment

- Adult has impaired capacity for what decision and why does the decision needs to be made now?
- Unpack the presenting situation e.g. evidence for stating this behavior, what is said or done that leads you to make this claim; Include dates and relevant information that provides clarity to the case. What was pre-morbid status – when last seen – fast or slow decline – reasons for this?
- What medical tests have been done or are still underway are the results attached summarize what they say that support the claim (refer to capacity assessment checklist).
- What does the Adult have capacity for? (health, financial, personal or part of all or completely). What can they still do? How did you test this?
- Indicate how you have ruled out delirium and other possible short term capacity issues or if the patient has delirium, why the decision cannot wait until delirium resolves (being in hospital is not enough!)
- Why can no one else make the decision on his behalf? Could Public Guardian do so (may negate need for application if yes is answer.
- What is the decision that needs to be made now?
- · If the Adult is at risk, detail your risk assessment process and assessment
- How has the Adult developed impaired capacity for the decision,
- Why have they no other appropriate decision-maker available
- Or is at risk in some way and
- Detail how your team tried supported decision-making and it did not work in relation to the decision required.
- At each step indicate why the least restrictive alternative has not worked
- Note how or who you have contacted to find an alternative decision-maker
- If you are claiming interim (urgent) decision required by QCAT review section in Act and provide evidence how Adult meets this critera + all other criteria
- If you are arguing that there is someone available but they are not appropriate to make the decision, give clear reasons why not. E.g. if suspected financial abuse by EPOA, have you contacted the Public Guardian to discuss and potentially investigate and they have suspended the EPOA for 3 months.

Tool 9: QCAT checklist for Public Trustee

Use this tool when seeking the appointment of the Public Trustee as Administrator – provided with thanks to Metro North HHS Social Work

QCAT – Application Check List- Public Trustee Queensland

If your application nominates the Public Trustee as administrator, you will need to provide the following information to the Tribunal by the time of the hearing. Providing this information will assist the Public Trustee in their decision-making process when an Order is made and this will facilitate timely planning for the Adult. To fit the privacy principles, you would only provide what information comes to your knowledge as a health professional for the purposes of this admission.

Patient Name: Click here to enter text. DOB: Click here to enter a date. Patient's location: Choose an item.

Applicant's Name:Click here to enter text.Phone NoClick here to enter text. Email Click here toenter text.

1. Centrelink Customer Reference Number (CRN)

Click here to enter text.

- 2. Copy of Centrelink Income and Assets Statement attached \Box
- 3. Copy of Bank ATM and/or Credit Card attached \Box
- 4. Copy of Medicare Card attached \Box
- 5. Copy of Pension Card attached \Box
- 6. List of contact details of any professional advisors such as: accountants, solicitors, financial planners etc.

Click here to enter text.

- 7. Tax File Number Click here to enter text.
- 8. Details of assets/liabilities including account numbers or references and copies of outstanding accounts

Click here to enter text. Copies attached \Box

Tool 10: QCAT checklist for Public

Guardian Use this tool when seeking the appointment of the Public Guardian as Guardian – provided with thanks to Metro North HHS Social Work & OPG

Metro North Hospital and Health Service Putting people first

Organisational Development, Strategy & Implementation

QCAT - Application Check List- Office of Public Guardian

If your application nominates the Public Guardian as guardian, you will need to provide the following information to the Tribunal by the time of the hearing. Providing this information will assist the Public Guardian in their decision making process when an Order is made and this will facilitate timely planning for the adult.

 Patient Name:
 Click here to enter text.
 DOB:
 Click here to enter a date.
 Patient's location:
 Choose an item.

 Applicant's Name:
 Click here to enter text.
 Phone NoClick here to enter text.
 Email Click here to enter text.
 Phone NoClick here to enter text.

 What is the adult's view – currently or previously expressed – in relation to their future care and support arrangements?

Click here to enter text.

- What are the views of interested parties in regard to the adult's future care and support arrangements? Click here to enter text.
- Please provide the names and contact details of the interested parties Click here to enter text.
- If there are no know interested parties, outline what attempts have made to locate family or friends. Click here to enter text.
- If the adult is unable to return home, outline what alternative accommodation options have been identified for considered (e.g. residing with family)
 Click here to enter text
- Provide details if any work has been undertaken with the person in regard to Advance Care Planning Click here to enter text.
- 7. If applicable, has an ACAT assessment been conducted? Choose an item. Please attach a copy (i/a)
- 8. Has a functional OT assessment been conducted? Choose an item. Please attach a copy (i/a)
- Has the adult had a trial at home? Choose an item.
 Please provide details if applicable Click here to enter text.
- 10. Does the adult have approval for a home care package or any other form of funded in-home supports? Choose an item. Please provide details Choose an item.
- 11. Status of Disability Services assessment Choose an item.
- Contact details for Disability Services location Click here to enter text.
- Medical historyAccommodation history, including (a) type (b) length of tenancy (c) reason for break-down Click here to enter text.
- 13. Letter from the treating team stating that the adult is unable to return home (if applicable)

The Office of the Public Guardian's policy position on aged care placement is available at: http://www.publicguardian.gld.gov.au/adult-guardian/our-decisions/residential-aged-care-decisions

Please M the completed form to: MNHHS_QCAT@health.gbl.gov.au;



Appendix 1: Analysis of a case

The following is an extract from Walker's⁸⁹ analysis of capacity assessment. The extract analyses a Tribunal decision and demonstrates how medical and social evidence can assist the Tribunal to make decisions. It also illustrates how professionals can dissect decisions.

A declaration about capacity: Re IM90.

The Facts:

Following some years of alcohol abuse and self-neglect, associated with traumatic stress disorder, a depressive disorder, and chronic liver disorder, IM was diagnosed as suffering from Marchiafava-Bignami Disease arising from degeneration of the corpus callosum. The Tribunal received an application on behalf of IM, satisfied itself that IM had impaired capacity, and appointed the Public Guardian to make decisions in regard to accommodation, health care and service provision, and the Public Trustee as administrator to make all financial decisions.

Seven months later, the Tribunal considered a request for a declaration that IM had capacity to make decisions for financial and personal matters, in which case the Tribunal would need to revoke the Orders made at the previous hearing. The following is an abstract of part of the Tribunal's written reasons for its decision in that matter. Bracketed headings have been inserted for ease of reference.

(The factual issues related to the legal question of capacity)

The essential issue for the Tribunal is whether IM has capacity to make financial and health care decisions for himself. As a legal question, the Tribunal must examine three factual issues to come to a legal conclusion: whether IM understands the nature and effect of decisions; whether he can freely and voluntarily make these decisions; and whether he can he communicate his decisions. Careful consideration of all the available evidence is needed and if the answer to any of the questions is in the negative, IM is deemed not to have the requisite capacity.

(Communicating his decisions in some way)

The last of these questions ... can be answered very clearly in the affirmative. On the evidence before the Tribunal we know that whilst IM has difficulty with hearing, he can communicate his decisions without any difficulty and has indeed demonstrated that he is an extremely articulate man ... who can make his decisions known without any difficulty.

(Can he understand the nature and effect of decisions? - The financial issues)

The financial issues IM has to deal with include \$30,000 owing because of non-payment of taxes for the period 1994-2001 There are also complex issues in relation to (the insurance company) refusing to continue to pay (compensation) under the insurance policy. As Mr. IM, also wishes to take out a loan, there are issues that need to be clearly understood in relation to loan repayments and interest rates.

(What evidence does the Tribunal have before it in relation to this issue?)

Evidence on capacity in relation to financial matters

The chief difficulty facing the Tribunal was conflicting opinion on capacity within numerous reports from health professionals. In its discussion of evidence, the Tribunal cited the following:

A neuropsychologist (Dr. D) reported on 12 May 2003 that:

An MRI dated 21 June 2002 indicated "Diffuse cerebral atrophy and a further MRI dated 16 April 2003 indicated "Diffuse cerebral atrophy in keeping with ischemic aetiology;"

⁸⁹ Walker, above n 29. 15-16.

⁹⁰ IM QCAT 2003 16

Significant improvement in areas of IM's cognitive functioning ... no evidence of alcoholic dementia as noted in 2002 and that IM has sufficient cognitive capacity to "independently make decisions about his basic personal welfare and financial affairs".

"IM may struggle with more complex information and material Despite improvements in cognitive functioning, there appeared to be ongoing problems with poor insight into his alcohol dependence and subsequent poor prognosis."

A psychiatrist Dr. G - reported on 9 July 2003 that:

IM had made significant improvement ... he "understands the nature and effect of his estate and is able to manage finances appropriately given recent cognitive impairment". IM understood "benefits, risks, side effects of treatment vs declining treatment and made appropriate judgment accordingly".

The report of a second neuropsychologist (Dr. T), dated 10 August 2002 indicated that:

Mr IM's "insight is poor"

Dr D's report was done after a long period of hospitalization and his findings relate to his level of cognitive deficits at the time of assessment.

It is common for cognitive deficits associated with Marchiafava-Bignami Disease to remit to a large extent following hospitalization and abstinence from alcohol.... However, given his history of alcohol abuse and the pattern of cognitive weaknesses identified ... he is at high risk of relapse and it is likely that he would suffer a relative decline in his level of cognitive functioning if this were to occur.

In relation to Dr D's report, the Tribunal noted that:

Dr. D states that IM. can handle <u>basic</u> financial and personal and health matters. The financial issues before IM however are not basic.... They involve negotiation with the Tax Office, negotiation with (an insurance company) and liaison with a bank in relation to a loan....

In relation to its discussions with IM at the hearing, the Tribunal noted that:

He was unable to give a good explanation of the wisdom of borrowing money to pay off his debts. He was unable to explain how he would pay back the loan or estimate the amount of interest he could be expected to pay. IM believed that a loan would solve all his problems.

His plans to use the loan to have a business class trip overseas and purchase a BMW car seemed to be unrealistic given his financial liabilities. His plan to cancel supports would also appear to be unrealistic given his current drinking problems.

(He) is adamant that he will sue the PTQ because he is angry with them but cannot understand that he will need to establish a cause of action for this to occur.

These plans ... are all examples of impulsive decision making where the consequences of such decisions have not been thoroughly thought through.

In relation to other oral evidence, the Tribunal took into account:

the evidence of Mr. S (IM's case manager) and that of the Public Guardian that reported that IM is drinking again; and the report of Dr. T who states that the cognition of patients with this alcohol syndrome improves whilst in hospital receiving care and whilst they abstain from alcohol, but cognition will diminish if there is a relapse and that Mr. IM has continued to drink.

The Tribunal summarised its reasoning regarding capacity for financial affairs as follows:

it prefers Dr T's report to that of Dr. D; taking into account IM's oral evidence and his disinhibited and at times abusive demeanour at the hearing, it concluded that IM has relapsed; his insight into his financial matters at the hearing was limited; (The Tribunal) is satisfied that IM does not understand the nature and effect of the financial matters he would have to manage.

Evidence on capacity in relation to personal mattersIn relation to IM's capacity to make personal matters, the Tribunal accepted evidence that:

He has had at least 6 admissions to hospital since the appointment of the Public Guardian on 7 November 2002. These health care decisions were made by either the Public Guardian or Mr S (IM's case manager) because IM lacked the required insight.

At the time of the hearing IM had been out of hospital only for a month but had cut many of the supports which are necessary for his continued placement in his own home rather than in an institution.

Summary

The Tribunal concluded that IM did not fully appreciate the nature and effect of the decisions which he had to make in relation to his financial matters and his personal matters. This conclusion was based on the complexity of the decisions that he has to make and the fact that the previous assessments indicating that he had capacity were made at a time when he had been in hospital away from alcohol for a considerable period of time. However, this is no longer the case, On sustained questioning from the Tribunal, IM showed a distinct lack of insight and clear impulsivity in relation to his decision making which led the Tribunal to the view that they should rely on the report of neuro-psychologist Dr T, dated 10 August 2002, this report being a more accurate reflection of IM's understanding as demonstrated at the hearing.

Appendix 2: Key referral pathways to Advocacy Organisations in QLD

The following information is extracted verbatim from the Queensland Legal Aid web site:

Aged and Disability Advocacy (ADA)

ADA has a guardianship advocacy service. ADA was previously known in Queensland as QADA but the website is now <u>https://adaaustralia.com.au/guardianship/guardianship-advocacy/</u>

Their website notes that they support Adults who may have impaired decision-making to resolve guardianship and administration issues that may be related to QCAT orders that are not working or by providing support during QCAT hearings and applications. A short video explaining their role in guardianship advocacy was developed by Carers Queensland and can be viewed <u>here</u>

Services are free and they have access to interpreters if required.

It also states:

We may be able to help if you:

Have an EPOA who you believe is not acting in your best interests

Would like to revoke or change your EPOA

Have people questioning your decision making capacity

Have a QCAT Tribunal hearing coming up and would like support.

Referrals may be by any interested parties including service providers but the team only represent the interests of the Adult and the Adult must agree to the engagement. They are not legal representatives but advocates.

For a full range of ADA services and contacts, review via their website.

They have links to very useful guardianship resources https://adaaustralia.com.au/guardianship/guardianship-resources/

The QPILCH Self Representation Service (QCAT)

Provides free legal advice and assistance to people at the Queensland Civil and Administrative Tribunal under certain circumstances:

http://www.qpilch.org.au/_dbase_upl/Info_brochure_QCAT.pdf

General contact information is available at http://www.qpilch.org.au/cms/page.asp?ID=60872

Seniors Legal and Support Service (SLASS)

"SLASS provides legal and support services for seniors aged 60 years and over (ATSI clients from age 45 years), concerned about elder abuse, mistreatment or financial exploitation. The website also provides some useful factsheets and other resources around older people.

https://caxton.org.au/sails_slass.html

Links to all the SLASS services in Queensland (Cairns, Townsville, Hervey Bay, Toowoomba and Brisbane are available here <u>https://www.qld.gov.au/seniors/legal-finance-concessions/legal-services/</u>

Elder Abuse Prevention Unit

The Elder Abuse Prevention Unit helpline is a free state-wide confidential support and information telephone service for older people, their families and friends. It provides awareness raising and advocacy around abuse of elders and advice and training to organisations about elder abuse and decision-making.

The unit is funded by the Department of Communities to provide a state-wide service to respond to the abuse of older people in Queensland and operates under Uniting Care Community.

The EAPU more generally responds to abuse that occurs within a relationship of trust. They provide directions to people who are seeking advice about elder abuse Contact and access to resources: <u>http://www.eapu.com.au/about</u>

QAI (Queensland Advocacy Inc)

QSI have a <u>Human rights Legal Service</u> that gives priority to assisting persons with impaired capacity who are subject to restrictive practices and involuntary treatment in Queensland.

They also have a <u>Mental health legal service</u> for those before the Mental Health Review Tribunal.

Carers Queensland

Carers Queensland (also known as the Queensland Council of Carers) provides carers with information and services to support them in their caring role as well as working to increase awareness of carers and their issues. The role in relationship to guardianship is around family support and advocacy. They are available to support the family carer and assist to resolve issues prior to or within the QCAT framework. This short <u>video</u> was produced by Carers Queensland to explain their role in guardianship. More information about their Family Support and Advocacy role can be found at <u>http://carersqld.asn.au/services/carer-advice-and-support/family-support-and-advocacy</u>

Appendix 3: Key Causes of Impaired Capacity

Introduction

Certain Illnesses or disability may affect a person's ability to communicate his/her decisions in some way or impair an ability to understand the nature and effect of decisions, whether through an inability to retain or process information.

ractice Point

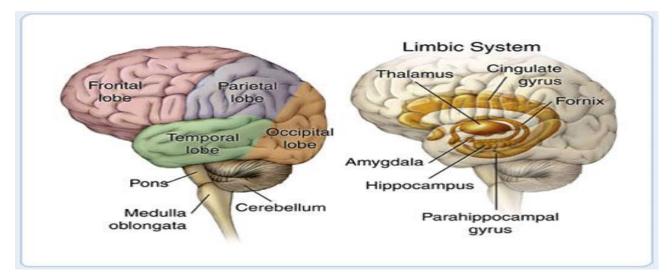
Unless we are educated about it or have regular exposure to an illness or disability, health practitioners may not know the difference between what is indicative of impaired capacity that requires an intervention compared to what is the usual level of capacity for the Adult with this disability or illness.

Certain characteristics of neurological and developmental conditions can present with similar behaviours as impaired capacity, unless properly assessed.

The section provides:

- 1. An overview of disability or illness and capacity issues;
- 2. Factors that affect our perception of an Adult's ability to make decisions; and
- 3. Tips for enhancing assessment and communication, if any assessment is made.

Understanding the brain



© 2000 - 2012 American Health Assistance Foundation, accessed 23 May 2012 - website now <u>https://www.brightfocus.org/news/american-health-assistance-foundation-announces-name-change-brightfocus-foundation</u>

The brain has two hemispheres – left and right. The left side of the brain controls speech and language including talking, reading and writing and comprehension. The right hemisphere relates to visual matters including processing of visual perception and non-verbal information such as spatial analysis and drawing.

Each hemisphere can be divided into four lobes and injury in any of these areas can affect how Adults present in capacity assessments.

Name ⁹¹	Effect	
Frontal lobe	Problem-solving Planning Judgement Abstract thinking Regulating emotional and impulses Left side motor strip controls right side of body movement and vice versa	
Temporal lobe	Processing and receiving auditory information music, language, speech, organisation of information Memory and learning Personality Emotions Sexual behaviour	
Parietal lobe	Monitoring sensation and body position Recognition of objects or spatial awareness e.g. judging the placement of objects in view Understanding time	
Occipital lobe	Reception, integration and interpretation of visual information relating to size, colour, shape and distance	
The cerebellum	Controls balance and muscle co-ordination in large body movements	
The brain stem	Regulates wakefulness, breathing, body temperature and heart activity The cranial nerves regulate functions of swallowing, speech and eye movement	

What is a brain disorder?

A brain disorder⁹² is not an intellectual disability. Intelligence is usually not affected, although there are usually cognitive changes such as problems with memory, concentration and attention. It is also not a mental illness, although it can increase the chances of mental disorders such as depression and anxiety.

The term, acquired brain injury (ABI), refers to all injuries to the brain that occur after birth. This differentiates it from intellectual disability, which is a developmental disorder. Another feature that differentiates ABI from intellectual disability is that an ABI tends to affect a specific cognitive set of skills such as memory, communication and concentration. In contrast, intellectual disability indicates

⁹¹ Derived from information on the Synapse website

⁹² Synapse <u>http://synapse.org.au/about-synapse.aspx</u> accessed 4 January 2017

a more general decline in overall intellectual functioning and understanding.

Synapse, <u>http://synapse.org.au/about-synapse.aspx</u> maintains an excellent website with detailed fact sheets about different types of acquired brain injury as well as identification, referral pathways and how best to support these Adults in the one site. Explore this site for more <u>detailed information</u> on a range of neurological illnesses and disabilities.

A brain disorder or ABI occurs when there is damage or disruption to the brain after birth, such as:

- 1. Falls, accidents, assault, concussion and other trauma
- 2. Stroke and other vascular diseases
- 3. lack of oxygen (e.g. near drowning)
- 4. Brain tumours
- 5. Epilepsy
- 6. Infections and diseases (e.g. meningitis).
- 7. Alzheimer's disease and other dementias
- 8. Degenerative diseases (e.g. dementia, Parkinson's Dementia)
- 9. Alcohol and other drugs

A brain disorder can affect anyone.

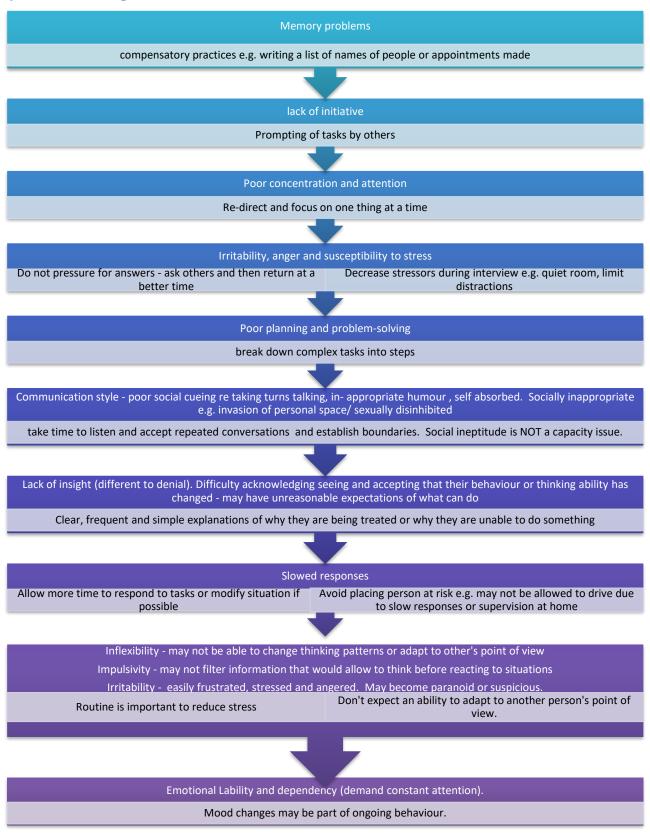
Factors that affect our perception of an Adult's ability to make decisions

Long-term effects will be different for each person, and will also vary depending on the type of brain disorder. For example, disorders such as Parkinsonian dementia and multiple sclerosis will leave our cognition (e.g. our ability to think) intact, but have dramatic impacts on the body's ability to control movement.

More common effects across all disorders:

Cognitive	Physical
Memory problems	 Movement disorders and paralysis
Lack of initiative and motivation	Loss of taste and smell
Inappropriate behaviour	Dizziness and balance problems
 Slowed responses and poor social skills 	Epilepsy and seizures
Depression and lack of emotional control	Headaches
Fatigue and poor concentration	Eyesight and hearing problems
 Irritability, anger and easily stressed 	Chronic pain.
Self-centredness, dependency and lack of insight	Movement disorders and paralysis
Poor problem-solving	Loss of taste and smell
Impulsive behaviour.	Dizziness and balance problems

Tips for enhancing communication⁹³:



93 Synapse, ibid

Unpacking different brain disorders: A brief overview of each

Traumatic Brain Injury⁹⁴

Traumatic brain injury (TBI) is caused by either a blow to the head or by the head being forced to move rapidly forward or backward. Brain tissue may be torn, stretched, penetrated, bruised or become swollen. Oxygen may not be able to get through to the brain cells and there may be bleeding.

Common causes include motor vehicle accidents, assault, falls, sport accidents, domestic violence, and young babies being shaken. The effects can be temporary or permanent, and range from mild injury, such as being momentarily stunned while playing football, to a very severe injury that may cause prolonged loss of consciousness.

Apart from the injury to the brain caused by the initial trauma, there are secondary effects that can arise from bleeding, bruising, lack of oxygen and increased pressure within the skull.

Hypoxic injury (lack of oxygen)

Common causes of hypoxia include near drowning and failed suicide attempts such as hanging or carbon monoxide poisoning. This usually leads to a diffuse brain injury, in that large areas of the brain are affected instead of very specific areas.

Brain tumours

Brain tumours can restrict blood supply to other cells or may, through exerting physical pressure upon cells, squash them. Infectious substances may cause cell death through exerting pressure if the brain swells (encephalitis) or the tissue surrounding the brain swells (meningitis), or may kill cells through direct infection. Viral infections may result in diffuse injury which can manifest as fatigue disorders such as chronic fatigue syndrome.

Epilepsy

Epilepsy involves recurring brief episodes of abnormal electrical activity in the brain leading to uncontrolled convulsions and unconsciousness, or just a momentary loss of awareness. Seizures may respond to medication. While epilepsy is a brain disorder, it can also be caused by other disorders such as a traumatic brain Injury.

Degenerative conditions

There are several mechanisms which may be at work with degenerative conditions, with the more commonly known ones including multiple sclerosis, Parkinson's disease and Alzheimer's disease.

In **multiple sclerosis**, nerve cells die when the myelin is removed - myelin is a fatty coating that acts in a similar way to the plastic insulation on electrical wiring. The exact cause is unknown, and there is no cure although treatments exist that can reduce the symptoms.

Parkinson's disease results from the loss of cells in various parts of the brain, including an area that creates dopamine. Loss of dopamine causes neurons to fire without normal control, leaving people less able to direct or control their movement. The exact cause of Parkinson's disease is unknown, and the single biggest risk factor is advancing age. The effects include slowness of movement, rigidity, tremors and balance problems.

Alzheimer's disease accounts for roughly two in three cases of dementia. The causes are poorly understood, but genes play a major role, and there is no cure. Plaques and tangles in the brain

⁹⁴ More reading and tips for practice can be found at <u>http://synapse.org.au/support-services/publications/publication-archive/acquired-brain-injury-the-facts.aspx</u>

usually develop later in life and lead to problems with short-term memory, disorientation, mood swings and behavioural issues. The average life expectancy is three to nine years after diagnosis.

Stroke & other vascular diseases

A stroke occurs when blood supply within the brain is disrupted. Arteries with the brain are either blocked, broken or begin bleeding which prevents oxygen and nutrients getting to the brain cells. When this lack of blood supply occurs to the heart it is called a heart attack - in the brain it is called a stroke. The effects vary widely as different parts of the brain are responsible for thought processes, comprehension, movement and our senses. The extent of blood shortage also determines the effect of the stroke.

Infections

Infections can injure the brain and even lead to death very quickly, so urgent medical attention is always critical.

Meningitis is an inflammation of the protective membranes that cover the brain and spinal cord, which leads to high fever, headaches, sensitivity to light, confusion, and occasionally seizures. Vaccination of young children is strongly recommended as a preventative measure. The most common causes of meningitis are viruses, bacteria, fungi, and protozoa.

Encephalitis is a swelling of the brain caused by viruses or bacteria. This can occur through insect bites, contaminated food, or other existing infections and diseases. Symptoms include an unsteady walk, sleepiness, confusion, fever, headache, light sensitivity, seizures, paralysis and impaired cognition.

Things you need to know

Brains can demonstrate neuroplasticity and people with brain injuries may be able to improve. Therefore where once rehabilitation was not considered for people with stroke, improvements and research around neuroplasticity now makes this an option in certain cases. Watch this video for more information on <u>neuroplasticity</u>

Different types of ABI and characteristics

Two examples of ABI commonly met in health contexts are stroke and alcohol-acquired brain injury.

Severe stroke

Stroke arises when brain tissue is injured due to an interruption of blood supply to part of the brain. Broken, bleeding or blocked arteries may cause blockages and deprivation of blood and oxygen to the brain causes deterioration in the brain's function. Watch this <u>video</u> by the Stroke Foundation⁹⁵ for a good overview

Characteristics of a stroke that may affect our perception of an Adult's ability to make decisions

- Tiredness, stress and pressure may affect assessments
- Difficulty concentrating.
- Speech and language may be affected.
- Adults may become frustrated and become angry when trying to communicate. Be sensitive to this and demonstrate empathy, not annoyance at this.

⁹⁵ <u>https://strokefoundation.org.au/</u>

- Loss of feeling and communication difficulties
- Visual impairment and other difficulties, depending on area of brain injured by stroke.
- Paralysis of part of body affected by stroke.

Tips for enhancing assessment and communication

- Words are only part of communication: The Adult may be able to communicate his/her decisions or thoughts in other ways. Use your observational skills.
- Visit the Adult several times to ensure that you are familiar with their communication style.
- Use a calm and slow voice that is at a normal pitch.
- Encourage the Adult to use simple gestures, such as a thumb up, to mean yes and use these gestures yourself to support your speech.
- To help the Adult decide, write down some options and help them pick a word or idea.
- Use writing or drawing is helpful even a beginning to a word may assist you.
- Use short sentences and simple language.
- Offer choices using questions.
- Ask sensitively if you need to have words repeated due to slurred speech.

Use supportive facial expressions to support your speech and indicate understanding.

Alcohol-related Brain Injury (ARBI⁹⁶)

Excessive alcohol consumption can result in a physical injury to the brain. Long term and prolonged consumption can alter metabolism, heart functioning and circulation of blood. The damage to the liver may affect nutrition absorption and hydration. All of these factors can injure the function of the brain. ARBI can affect cognition, balance and coordination of the body.

Characteristics of ARBI that may affect our perception of an Adult's ability to make decisions

- Adults with this type of trauma may be easily distracted by thoughts that seem less relevant to the conversation. Focusing upon a topic for an extended length of time can be difficult.
- Alcohol-related brain injury (ARBI) can not only occur from extremely high levels of alcohol due to binge drinking, but also from more moderate alcohol intake but over a long period of time. Alcohol has a toxic effect on the central nervous system, disrupts the intake vitamin B1, and also causes dehydration which can affect brain cells.

Effects of alcohol-related brain injury

Like other types of brain injury, ARBI can result in:

- impaired judgment and self-awareness
- social isolation
- depression and mood disorders
- lack of motivation
- distractibility and concentration issues

⁹⁶ Information for this section has been taken from <u>http://synapse.org.au/information-services/alcohol-related-brain-injury-</u>(arbi).aspx

- Impulsivity and reckless behaviour.
- Types of alcohol-related brain injury

Like other types of brain injury, it varies from mild to severe in its effects and various types of ARBI result from where the brain injury occurs:

- Cerebellar atrophy causes balance and coordination issues
- Peripheral neuropathy sensory issues with the hands, feet and legs
- Hepatic encephalopathy as an outcome of liver disease
- Frontal lobe dysfunction affects cognition, behaviour and personality
- Wernicke's encephalopathy caused by extreme thiamine deficiency
- Korsakoff's amnesic syndrome causes severe short-term memory deficits.

Is recovery from ARBI possible?

• Will vary with each individual – some will recover, some slightly and others not at all. For example, some improvement may happen when a person stops using alcohol and participates in a healthy diet. The brain has a limited ability to heal itself so improvements may actually be due to timely rehabilitation interventions.

Tips for enhancing assessment and communication

- Keep conversation focused by repeating a question, if required
- Use a visual aid such as pen and paper to focus the attention and use multi-modal engagment
- Remind the Adult of the focus of the topic, if they shift
- Use concrete statements
- Use simple and familiar words
- Deliver small chunks of information
- Talk slowly to enhance thought processing
- Focus on one subject at a time give prompts or cues when you change focus to keep track.

Adults with this disability may be unable to process conversations well but will appear at times to nod their head and may state that they understand. Always check in what they understand and remember about the conversation by asking them to repeat what is being said in his/her own words.

- Use open-ended questions to gauge understanding as Adults with this disability can often answer 'yes' or 'no' answers.
- Ask about event recall e.g. 'Did you go out today?'
- Be patient and understanding of the Adult's frustrations and needs. Ensure you appear non-threatening and non-judgemental.

Dementia

Dementia is an umbrella term for a group of symptoms that may affect any Adult. It is particularly associated with older people; however, may be found in those who are younger than 65 years of age too. One of the most common effects of dementia is memory loss; however, it is important to note that dementia and memory loss may happen at different speeds with different individuals and so a diagnosis of dementia should not automatically disqualify an Adult from having sufficient capacity to

make a decision. Dementia may also give rise to thinking, language, understanding and judgement impairments. Excellent resources for general practitioners and other health professionals are available <u>here</u>

These videos tell you a little about dementia and its potential effects on Adults and carers.

Your amazing brain explained		
What is dementia?		
What is the difference between Alzheimer's Disease and dementia?		
Living with dementia		
Carer experience of dementia		
Detecting dementia in general practice – good for all health practitioners		
Antipsychotics and dementia: managing medications		
Debunking dementia myths		

Common forms of dementia⁹⁷ are:

<u>Alzheimer's Disease</u> Is the outcome of damage and changes to nerve cells within the brain. These changes are called amyloid plaques and neurofibrillary tangles which damage nerve cells. An important fact to note is that because people with Down syndrome live, on average, 55 to 60 years, they are more likely to develop younger-onset Alzheimer's (Alzheimer's occurring before age 65) than older-onset Alzheimer's (Alzheimer's occurring at age 65 or older).

<u>Vascular dementia</u> is the second most common cause of dementia and is the result of the brain being deprived of blood. It is associated with cerebrovascular disease.

Multi-infarct dementia results from mini-strokes or decreased blood flow to the brain

Subcortical vascular dementia arises when blood vessels deep inside the brain are affected and result in decreased blood flow.

<u>Parkinson's Disease</u> is a progressive disease and affects the central nervous system. It presents as stiffness in limbs and joints, tremors, speech difficulties and physical movement initiation impairment. It is associated with dementia as the disease progresses.

<u>Diffuse Lewy Body Disease</u> is caused by the development of Lewy bodies inside the brain in areas that control memory and motor control. The Adult may present with pronounced fluctuations in mood and periods of confusion alternating with lucidity and visual disturbances. They may have trouble interpreting visual information and memory loss.

<u>Frontal lobe or Fronto-temporal dementias</u> including Pick's Disease is caused by degeneration of one or both frontal or temporal lobes. It may present in younger Adults and is more associated with disinhibition and personality or language changes initially and memory later as it progresses.

<u>Huntington's Disease</u> is a progressive brain disorder caused by a single defected gene. Symptoms develop during ages 30-50 but can appear earlier or later. A key characteristic is uncontrolled movement of the body – mainly arms, legs, head, face and upper body. Decline in thinking, reasoning, memory, concentration, ability to plan and judge are associated with this disease. Mood

⁹⁷ Websites such as <u>MyAgedCare Australia</u>; <u>Alzheimer's Australia</u> & <u>Alzheimer's Association US</u> have more detailed information.

changes such as depression, anxiety or irritability may develop. Obsessive compulsive disorder symptomology is also associated with this disease. More information: http://brainfoundation.org.au/disorders/huntingtons-disease

Infection related dementias

- Syphilis
- HIV related dementia may be a temporary or permanent side affect of Human Immunodeficiency Virus AIDS.
- Cruetzfeldt-Jacob Disease is a rare and fatal brain disorder that results in abnormal prion
 proteins. It can be inherited, sporadic or acquired. It progresses rapidly and results in rapid
 decline in thinking and reasoning, confusion, difficulty with muscle movements and mood
 changes.
- Wernicke-Korsakoff Syndrome (Alcohol-related dementia) is commonly associated with alcohol abuse; because it is caused by a severe deficiency of thiamine. However, other conditions such as HIV AIDS, poor nutrition and chronic infections may also cause the syndrome. The Syndrome may be pre-empted by an episode of encephalopathy which is an acute brain reaction to lack of thiamine. Memory loss often follows an acute episode. Apart from memory loss, an ability to learn new information or remember recent events or long-term memory gaps may arise. Other thinking and social skills may be unaffected. They may also confabulate to fill in gaps of memory.

Characteristics of dementia that may affect our perception of an Adult's ability to make decisions

- Memory loss that affect daily function
- Difficulty performing daily familiar tasks
- Confusion about time and place
- Language access difficulties & changes in personality
- Abstract thinking and reasoning problems
- Poor or decreased judgement or impulsivity

Tips for enhancing assessment and communication

<u>Alzheimer's Australia</u> summarises how to promote communication with an Adult who has a diagnosis of dementia.



AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

Delirium

Delirium is a transient, usually reversible cause of mental confusion and manifests clinically with a wide range of neuropsychiatric abnormalities. It is not found only in those who are older but is more common in this ageing population.

Characteristics of delirium that may affect our perception of an Adult's ability to make decisions

An Adult with delirium presents with decreased attention and confusion. They may exhibit disorientation, illusions, hallucinations, fluctuating levels of consciousness and other symptoms that may be confused with dementia.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnostic criteria for delirium is as follows: ^{98]:}

• Disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness.

- Change in cognition (e.g., memory deficit, disorientation, language disturbance, perceptual disturbance) that is not better accounted for by a pre-existing, established, or evolving dementia.
- The disturbance develops over a short period (usually hours to days) and tends to fluctuate during the course of the day.
- There is evidence from the history, physical examination, or laboratory findings that the disturbance is caused by a direct physiologic consequence of a general medical condition, an intoxicating substance, medication use, or more than one cause.

Interaction with dementia

Adults with dementia are at a five-fold risk of developing delirium and similarly, delirium increases the risk of development dementia. However, it is essential NOT to confuse or dismiss delirium as dementia⁹⁹. A diagnosis of dementia when an Adult only has delirium may have implications for how capacity is assessed and whether an application is necessary to QCAT. Remember that delirium may last for weeks or longer.

⁹⁸ American Psychiatric Association. (2013) *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. 5th ed. Washington, DC: American Psychiatric Association; 2013.

⁹⁹ Australian Commission on Safety and Quality in Health Care. A better way to Care: Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital – actions for health service managers. Sydney, ACSQHC, 2014

The Australian Commission on Safety and Quality in Health Care has developed resources for managers and clinicians on delirium and dementia with particular emphasis upon assessment pathways and care.

There is even an App for the phone that has been developed to help you when on the ward!

Resources

Delirium Care Pathways, developed by the Department of Health and Ageing, Australian Government 2010	D0537(1009) Delirium_combined SC
Clinician Fact Sheet: Delirium Clinical Care Standard developed by Australian Commission on Safety and Quality in Health Care, 2016 & Evidence Sources for development of Clinical Care Standard	Delirium-CCS-Clinicia Evidence-sources-De n-Fact-sheet-Web-PE lirium-Clinical-Care-Sta
Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital	A-better-way-to-car e-Actions-for-clinician

Early diagnosis and reviewing people who have risk factors for delirium and then treating the delirium quickly may decrease the number of people who are admitted to hospital with this prognosis. Consumers and family are distressed by delirium and inappropriate or lack of treatment may cause pain and even death.

Statistics suggest that consumers with dementia are five times more likely to have an episode of delirium than those without dementia. If in doubt about whether delirium could be the cause of deterioration, check all the physical signs and risk factors above as a process of elimination.

Social Workers should be cognisant of delirium, how it presents and the appropriate care and assessment pathways. By keeping this in mind, we may prevent unnecessary QCAT applications.

ractice point: Unless there is an urgent reason for a decision to be made immediately to prevent harm to the consumer or his/her property, there should be no reason to make an application for guardianship or administration whilst the consumer has delirium. Either an attorney or a Statutory Health attorney can make most health decisions until recovery.

Cognitive assessment pathways, risk factors and preventative strategies for delirium are described in the references.

Mental Illness

Mental illness is "*an observable abnormality in the functioning* of the brain"¹⁰⁰. Unlike acquired brain injury, there is not an abnormality in the structure of the brain and of course, it does not arise from a physical condition¹⁰¹.

Adults who have a lived experience of mental illness will commonly live in the community and seek assistance for management of their disease from their local general practitioner. They may never

¹⁰⁰ Synapse (2011), ibid.

¹⁰¹ Synapse (2011), ibid.

come into contact with the *Mental Health Act 2016 QLD* and its involuntary treatment provisions. Just because an Adult lives with mental illness, this does not mean that they will lack capacity for decision-making. Capacity is presumed, unless rebutted by evidence. All practitioners should familiarise themselves with the Queensland Health (QH) website on the <u>Mental Health Act (QLD)</u> 2016

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Sometimes, we engage with Adults who have been or are about to be treated under an Involuntary Treatment Order (ITO). The *Mental Health Act 2016 (Qld)* authorizes this type of Order. It is essential to note that an ITO is only to be used in specific circumstances and can only be used when the Adult's situation meets particular criteria.

Firstly, a person must fulfil the definition of having a 'mental illness' – a definition that requires a 'clinically significant disturbance of thought, mood, perception or memory'.

Additionally:

- He/she must require immediate treatment;
- The proposed treatment is available at an authorised mental health service;
- Because of the person's illness:
 - \circ There is imminent risk that the person might cause harm to themself or others, or
 - The person is likely to suffer serious mental or physical deterioration
 - AND there is no least restrictive way of ensuring that the person receives the required medical treatment.
 - The person lacks capacity to consent to the treatment or has unreasonably refused the proposed treatment for the illness.

If an Adult fits all the criteria but is willing to visit his/her own psychiatrist, then this least restrictive alternative must be acted upon, if it can be reasonably arranged in the circumstances.

It is important to note that the Mental Health Act 2016 (Qld) also delineates the conditions that are NOT indicative of a mental illness102.

- A person must not be considered to have a mental illness because of any 1 or more of the following:
 - Religious, cultural, philosophical or political belief
 - Membership of a racial group
 - Economic or social status
 - Sexual preference or orientation
 - Sexual promiscuity
 - o Immoral or indecent conduct
 - Drugs or alcohol
 - o Intellectual disability
 - o Antisocial or illegal behaviour
 - o Involved in family conflict

¹⁰² Mental Health Act QLD 2016, section 10

• Previous treatment for a mental illness or subject to involuntary assessment/treatment"

However a person may have a mental illness caused by taking drugs or alcohol or may have an intellectual disability as well as a mental illness.¹⁰³

Mental health and impaired capacity

Even Adults who are subject to Involuntary Treatment Orders do not automatically require a capacity assessment in relation to their decisions about their general health, financial and personal matters. An Adult may be unable to make decisions about whether they need mental health treatment but still be able to make decisions about their personal, health (other than mental health) and financial matters.



CASE STUDY CAPACITY FOR DECISION-MAKING AND MENTAL HEALTH

JOHN IS ASSESSED AND PLACED UNDER AN ITO. HE HAS A LONG HISTORY OF SCHIZOPHRENIA AND BECOMES AGGRESSIVE when he ceases his medication. He recently ceased his medication because he was feeling well and believed that he was now 'cured' of schizophrenia. He believes that angels visit him at night and that they are asking him to self-harm so that his illness goes away. John has significant injuries as a result of his following these commands. He does not recognize that he is unwell and refuses treatment.

ON THE OTHER HAND, JOHN RETAINS GOOD CAPACITY FOR DECISION-MAKING ABOUT OTHER MATTERS:

- HE ACKNOWLEDGES THAT HIS HEART AND ARTHRITIS MEDICATION IS STILL REQUIRED AND HE HAS BEEN TAKING THIS REGULARLY.
- He is managing his bills and rent very well and is quite diligent in paying them early and he is able to make day to day living decisions.

Types of mental illness that may impair capacity

Walker¹⁰⁴, who was a key member of the Guardianship and Administration Tribunal (as it then was) wrote a manual for Tribunal members and describes the key mental health disorders as follows:

- Neuroses (or neurotic disorders) seem to be an exaggeration or distortion of common feelings, thoughts or behaviours (like fear or sadness). Neuroses may be called names like anxiety, phobia, obsession and neurotic depression.
- With psychoses (or psychotic disorders), people are usually in some way out of touch with the real world they may have delusions (like people plotting against them), or hallucinations (like hearing voices). Consequently, they may have difficulty making sense of what is going on around them, and react inappropriately. The word psychosis is used to describe conditions which affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way it is called a psychotic episode. Psychosis is most likely to occur in young Adults and is quite common. Around 3 out of every 100 young people will experience a psychotic episode making psychosis more common than diabetes in young people. Most make a full recovery from the experience.
- **Drug-Induced Psychosis**: use of, or withdrawal from, alcohol and drugs can be associated with the appearance of psychotic symptoms. Sometimes these symptoms will rapidly resolve as

¹⁰³ Ibid, s.10.ss 3

¹⁰⁴ Richard Walker, Capacity for decision-making, (Guardianship and Administration Tribunal, 2006) 51 pages

the effects of the substances wear off. In other cases, the illness may last longer, but begin with drug-induced psychosis.

- Organic Psychosis: psychotic symptoms may appear as part of a head injury or a physical illness which disrupts brain functioning, such as encephalitis, AIDS or a tumour. There are usually other symptoms present, such as memory problems or confusion.
- **Brief Reactive Psychosis** : psychotic symptoms arise suddenly in response to a major stress in the person's life, such as a death in the family or change of living circumstance. Symptoms can be severe, but the person makes a quick recovery in only a few days
- Delusional Disorder: strong beliefs in things that are not true.
- Schizophrenia: a psychotic illness in which the changes in behaviour or symptoms have been continuing for a period of at least six months. The symptoms and length of the illness vary from person to person.
- **Bipolar Disorder:** psychosis appears as part of a more general disturbance in mood, in which mood is characterised by extreme highs (mania) or lows (depression). When psychotic symptoms are present, they tend to fit in with the person's mood. For example, people who are depressed may hear voices telling them they should commit suicide.
- Schizoaffective Disorder: the person has concurrent or consecutive symptoms of both a mood disorder (such as depression or mania) and psychosis.
- **Psychotic Depression:** Severe depression with psychotic symptoms mixed in, but without periods of mania or highs occurring at any point during the illness. This distinguishes the illness from bipolar disorder.

Factors that may affect our perceptions of an Adult's ability to make decisions

Adults with a lived experience of mental illness may exhibit a number of behaviours that, without a proper understanding of the disease or associated medications, might lead health practitioners to doubt capacity. Some examples¹⁰⁵ to be aware of:

- Adults with depression may struggle to concentrate during an assessment.
- Adults with depression may fail to see the usefulness of an assessment and may not comply with an assessment.
- Medications used to treat mental illness may mimic physical aspects of impaired capacity. For example, neuroleptics may appear to make the person tired and unable to clearly speak or think.
- Hallucinations that cause hearing or seeing disturbances can impair an Adult's capacity to pay attention to questions.
- An Adult may be deluded (fixed false beliefs). These will only cause impaired capacity if the delusion impairs his/her ability to make a specific decision. For example, an Adult who believes he should pay his entire pension (including rent money) to save the whales because he no longer needs to eat would not have the capacity to make that decision.
- Adults who are manic may have an unrealistic understanding of their ability that may put them at risk of harm.

Tips for capacity assessments

The following are some tips for conducting capacity assessments sensitively with this population of Adults:

¹⁰⁵ These are derived from The Scottish Government (2008)...Communication and Assessing Capacity: A guide for Social Work and Health Care Staff, <u>http://www.gov.scot/Publications/2008/02/01151101/6</u>

- People who have a lived experience of severe or chronic mental illness have often been exposed to capacity assessments some of which may have had negative outcomes. These Adults may feel stigmatised by the process and you should ensure that they feel as much control as they can e.g. option of choosing the time of the assessment.
- A mental illness diagnosis does not automatically mean that the Adult lacks capacity for decision-making about financial, health or personal matters.
- Adults with mental illness may have fluctuating capacity it may come and go = need constant reassessment over time.
- Decide what decision/s need to be made now. Assess the Adult only in relation to those matters and decisions. For example, delusions or poor concentration are only relevant if they impair decision-making e.g. delusions about money matters.
- Assessments may take time go slowly and if necessary, take breaks to allow the Adults to
 focus. If this is your first encounter, it is important to meet the person a few times to build
 trust and to work out when the Adult is most able to be assessed.
- Consider the possible impact of medication on the Adults' decisions and delay assessment if required until most appropriate.

ractice Point:

Trying to assess an Adult in relation to his/her decision-making capacity when the Adult is in an acute florid episode is NOT acceptable practice.

Ethical and rights-based practice demands that health practitioners seek to facilitate self-determination of the Adult as much as possible and that assessments of capacity for decision-making should be made at times that will optimize capacity; NOT when capacity is potentially diminished due to stress or other factors.

In these circumstances, an assessment of capacity for decision-making should only be undertaken if there is an urgent need to protect an Adult from suspected harm in relation to personal, financial or general health matters. Developmental disability

Developmental disability

Adults who have impairment in physical, learning, language or behaviour that began during their developmental period of life span may be included under the umbrella term of developmental disability. Developmental disability can be a nervous system disability, a sensory related disability, metabolic or degenerative in nature. There are also sub-sets within these categories. Commonly known disabilities such as autism, cerebral palsy, Down syndrome, foetal alcohol syndrome, spina bifida and general behaviour disorders are classed as being a developmental disability. It is important to note that having a developmental disability does not predict impaired capacity.

Nervous system disorders that affect the functioning of the brain and nervous system may influence intelligence and learning. Adults with Down Syndrome, Fragile X Syndrome and Autism are examples of intellectual disability of the nervous system.

Adults with an intellectual disability fall within this sub-category and often present in health contexts. Exhibiting short attention spans, limited communication or inappropriate responses to questions and poor history of adherence to treatment are just some examples of how someone with an intellectual disability may appear to a treating team. These behaviours do NOT mean that the Adult lacks capacity for decision-making.

The Intellectual Disability Rights Service publishes a resource for <u>lawyers who are acting for clients</u> with an intellectual disability. This resource provides tips on how best to engage with these Adults so that instructions can be obtained. The tips can equally apply to health contexts.

A <u>health specific resource developed</u>¹⁰⁶ by the Centre for Developmental Disability Health Victoria will guide your expectations and describes how to work optimally and with respect in this area of practice.

Useful websites for further education are:

<u>Intellectual disability mental health e-learning</u> – developed as free e-learning about intellectual disability to professionals, carers and consumers. Developed by University of New South Wales, New South Wales Health, HETI and NSW Family & Community services

The University of Hertfordshire in the United Kingdom has a useful website on <u>intellectual disability</u> and <u>health</u> that outlines practice tips including consent with Adults with impaired capacity. Apart from some legal elements being different, this site has many resources to explore.

¹⁰⁶ The Centre for Developmental Disability Health Victoria, Working with people with intellectual disability in healthcare settings (20 January 2016, Centre for Developmental Disability Health Victoria, Monash http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf

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