6. Refusal of treatment

6.1. Can a patient refuse treatment?

An adult patient with capacity has the right to refuse any medical treatment, even where that decision may lead to their death or the death of their unborn baby. This right exists even where the reasons for making the choice seem irrational, are unknown or even non-existent. The right to refuse treatment extends to all medical treatment including but not limited to ventilation, cardio-pulmonary resuscitation (CPR), dialysis, antibiotics and artificial feeding and hydration. Treating a person who has validly refused treatment could constitute an assault or battery.

Like consent to medical treatment, a refusal of treatment must be:

- freely given
- specific; and
- informed.

Where refusal of the recommended treatment is likely to have serious consequences for the health or wellbeing of the patient, consideration should be given to assessing the patient's capacity to refuse the treatment. Efforts should be made to ascertain the reasons for the refusal and whether these can be addressed by providing alternative treatment or by other means (such as by ensuring the treatment is provided by female Medical Practitioners only, if practicable). Sensitive cultural and religious issues should be accommodated where possible, for example, non-blood products for Jehovah's Witnesses.

There are some limited scenarios where a patient who would otherwise be considered to have capacity cannot lawfully refuse treatment, for example when patients are subject to certain mental health orders.

All instances of refusal of treatment must be noted in the patient's Health Record. Ideally, the patient should sign a *Procedure/Treatment Refusal Acknowledgement (Patient with Capacity)* form. Where the refusal of treatment may lead to harm and/or death, these consequences must be explained and documented. The *Procedure/Treatment Refusal Acknowledgement (Patient with Capacity)* form does not need to be used where the risks of refusing treatment are low.

There is no *Procedure/Treatment Refusal Acknowledgement* form for Minors. Where a parent or guardian is refusing treatment on behalf of a Minor, the Health Practitioner must consider the risk of significant harm arising from the refusal of treatment and the obligations under the *Children and Young Persons (Care and Protection) Act 1998.* The refusal and steps taken to try to reach agreement about treatment should be documented in the Health Record. Refer to sections 8.4 and 8.5 of this Consent Manual for further guidance.

There is also no Procedure/Treatment Refusal Acknowledgement form for adult patients without capacity. A Person Responsible can decide not to consent to a proposed treatment on behalf of an adult without capacity. Where agreement cannot be reached between the Health Service and the Person Responsible, consideration must be given to whether the Person Responsible or guardian is adequately making decisions that promote the patient's health and wellbeing and whether an application needs to be made to the Guardianship Division of NCAT seeking consent to the proposed treatment, or the appointment of an alternative substitute decision maker. The refusal and steps taken to reach agreement should be documented in the Health Record.

As with consent, if the patient's circumstances change significantly, the refusal may not remain valid and may need to be confirmed.

Refusal of treatment can be verbal, written or implied. In circumstances where the refusal of treatment may lead to death, or a serious deterioration of the patient's health, the refusal should be in writing and signed by the patient. It is also very important that, in these cases, the information communicated to the patient is documented clearly in the Health Record.

In circumstances where the patient no longer has capacity to consent to, or refuse medical treatment, and it is not an emergency, Health Practitioners are required by law to consult with and seek consent from the Person Responsible for the patient pursuant to the *Guardianship Act 1987*.

A guardian (including an Enduring Guardian) can consent to treatment being withheld or withdrawn if they have been expressly given such power in their appointment. It is important to review the terms under which guardians are appointed before making a decision and seek legal advice if you are unsure.

Where the treating team considers that life-sustaining treatment will have no clinical benefit, consent to withhold or withdraw treatment is not required from the patient or Person Responsible (including guardian or Enduring Guardian), however, Health Practitioners are encouraged to engage in discussions with the patient if possible, their Person Responsible and family to determine the patient's best interests.

Further guidance

- NSW Civil and Administrative Tribunal, Guardianship Division, Person Responsible Factsheet
- Section 10.2 Information and Consent requirements for pregnancy and birth related procedures and interventions

Example

Li is a 25-year-old who has requested that the hospital cease her life-sustaining treatment including the withdrawal of ventilation. This is expected to lead to Li's death. Li has been ventilated for over five years but has recently been experiencing frequent and severe respiratory distress and is now unable to leave a hospital environment. Li has been assessed by several specialist Medical Practitioners as having capacity and as having arrived at the decision to refuse treatment in a deliberate and seemingly rational fashion and without any coercion. She has also recorded her wish in writing and provided it to her treating medical team.

Li is an adult who has been assessed by appropriate specialists as having capacity to make the decision to refuse life-sustaining treatment and is therefore entitled to do so.

The treating medical team would be advised to obtain advice from the Ministry of Health Legal Branch if there is any doubt regarding Li's capacity, or other concerns or complexities. If there is any uncertainty, the Supreme Court can be asked to make a declaration with respect to the refusal of treatment.

6.2. Refusal of treatment using an Advance Care Directive

6.2.1. What is an Advance Care Directive?

Advance Care Directives (ACDs) are a document recording decisions or value statements that describe the person's future preferences for receiving or refusing specific types of medical treatments. ACDs are to be used when the person loses capacity. An ACD is a type of advance planning tool that may only be completed by a person with decision-making capacity. It is recommended that an ACD be signed by the person.

Where a patient has a valid ACD (discussed below) then the decisions in the ACD must be respected (unless there is a power to provide treatment without consent, for example, a patient a under mental health order).

A Person Responsible (including Enduring Guardian) cannot complete an ACD on behalf of another person. However, a Person Responsible for a patient without capacity may participate in Advance Care Planning discussions with the treating team.

There is no standard form or template for an ACD in NSW, although there are several documents in use, including a template available on the NSW Health website (see further guidance below). An ACD does not need to be in a particular format and does not need to have been witnessed. An ACD should not be confused with clinical care plans, treatment plans or resuscitation plans written by Medical Practitioners or appropriately qualified Health Practitioners.

If a patient has an ACD, it should be placed in the Health Record.

Further guidance

• NSW Health Advance Care Planning https://www.health.nsw.gov.au/patients/acp/Pages/default.aspx

6.2.2 How do I know that the Advance Care Directive is valid?

An ACD will be valid when it:

- has been made voluntarily by an adult with capacity
- is clear and unambiguous
- was intended to apply to the situation at hand.

An ACD can be valid even if the person giving it was not informed of the consequences of deciding in advance to refuse specified medical treatment. Decisions in an ACD can be based on religious, social or moral grounds. Directions do not have to be supported by rational reasons. An ACD can be valid as long as it was made voluntarily by an adult with capacity and in the absence of any overriding factor such as coercion.

If a patient has refused treatment in a valid ACD, their family or Person Responsible has no legal authority to override the ACD.

Example

Marianne is 42 and has been admitted to hospital, unconscious, following a car accident. She requires surgery to repair a shattered leg bone. Marianne's family present the treating team with an Advance Care Directive signed by Marianne refusing all treatment in relation to her dying from the motor neurone disease she was diagnosed with six months ago.

In this situation, as the ACD was not intended to apply to the situation at hand (being the car accident) and therefore cannot be relied upon to not undertake the surgery on Marianne's leg.

6.2.3. Do Advance Care Directives have to be followed in an emergency?

Where there is a known, available, and valid ACD, it cannot be overridden in an emergency. The patient must only receive treatment that is consistent with the ACD. If a patient presents with an ACD or other document that refuses treatment, a copy of the document should be made and placed on the patient's Health Record.

6.2.4. What if there is doubt about the validity of an Advance Care Directive?

Circumstances of genuine and reasonable doubt about the validity of an ACD may arise, including:

- whether the patient had capacity when it was written
- whether it was intended to apply to the current situation of the patient
- where the ACD is ambiguous or contains inherent inconsistencies.

In these circumstances, attempts should be made to obtain further information (for example, from the patient's family, General Practitioner, or a person who witnessed the ACD) about the circumstances of the ACD and whether it is still consistent with the patient's wishes. If this information does not resolve the ambiguity, legal advice can be sought from the Ministry of Health Legal Branch.

Cases where there is a suggestion of self-harm can be especially complex, and legal advice is recommended in these scenarios (see section 6.2.5 regarding mental health patients).

In cases where legal advice is being obtained, or guidance is being sought from a court, a Health Service and Health Practitioners are justified in treating the patient in the meantime, until the validity of the ACD is clarified. If there is delay in obtaining a copy of a patient's ACD, it is acceptable to treat the patient until the ACD document is available. Such treatment would be limited to emergency treatment, that is, treatment necessary to save an adult person's life, prevent serious injury to an adult person's health or alleviate significant pain or distress.

Example

Udit is a 60-year-old man who is admitted to the emergency department of a hospital with septic shock. Although appropriate medication is provided, he develops renal failure and within two weeks he is unconscious and being kept alive by mechanical ventilation and kidney dialysis in intensive care. His brother, Arjun, produces a written Advance Care Directive that he witnessed as being written and signed by Udit one year prior, which clearly indicates that Udit did not want to receive dialysis in the future. Arjun is worried Udit may not have understood the ramifications of his decision to refuse dialysis.

If an Advance Care Directive is made by an adult with capacity, is clear and unambiguous and extends to the situation at hand, it must be respected. In this situation the Medical Practitioner must be satisfied that the Advance Care Directive is genuine and valid, that is, that Udit wrote the document, he had capacity at the time the Advance Care Directive was made and it was made voluntarily. It is not necessary, in order for Udit's Advance Care Directive to be valid, that Udit should have been informed of the consequences of deciding, in advance, to refuse dialysis.

If Udit's Medical Practitioner has genuine and reasonable doubt as to the validity of the Advance Care Directive, it is appropriate to consult other family members or Udit's General Practitioner regarding his Advance Care Directive preferences. If doubt still remains, the Health Service should contact Ministry of Health Legal Branch as a matter of urgency to consider applying to the court for a determination as to the validity and operation of Udit's Advance Care Directive in the circumstances. The Medical Practitioner can continue to treat Udit while the validity of the Advance Care Directive is being determined.

6.2.5. What if the Advance Care Directive has been made by a patient experiencing mental ill-health?

In general, patients experiencing mental ill-health have the same rights with regard to making decisions about end of life care and Advance Care Planning as any other patient. However, the validity of the ACD may be called into question where:

- there is doubt regarding the capacity of the patient at the time of making the ACD; or
- there is any evidence the ACD was not made voluntarily.

However where a patient is detained under the *Mental Health Act 2007,* an ACD cannot override the power of an Authorised Medical Officer to authorise treatment.

Advice from the Ministry of Health Legal Branch is recommended in the above circumstances and a Health Practitioner would be justified in treating the patient in the meantime until the validity of the ACD is ascertained.

Further guidance (relating to Sections 6.2.1-6.2.5)

- NSW Health Advance Care Planning and End of Life Decisions for People with a Mental Illness
- Advance Care Planning policy directives and guidelines
- Section 9 Consent for patients being treated under the Mental Health Act 2007
- NSW Health Policy Directive Using Resuscitation Plans in End of Life Decisions (PD2014_030)
- NSW Health Advance Planning for Quality Care at End of Life Action Plan 2013-2018

6.3. Discharge against medical advice

A patient with capacity may decide to leave hospital against medical advice. However, as there have been cases where Health Services and Health Practitioners have been criticised and found negligent for not doing enough to convince patients to stay for treatment, it is important that attempts are made to engage the patient in a collaborative discussion indicating the reasons why the patient should stay, and the consequences of leaving so that the patient is making an informed decision. A Health Practitioner should, where circumstances reasonably allow, provide the patient with relevant information for ongoing treatment and care, which may include community care or referral to a General Practitioner. Health Practitioners should also reassure the patient that they may return to that facility or any other NSW Health facility at any time for further treatment and care.

These discussions should be well documented and where the patient or parent/guardian insists on leaving the health facility a *Discharge against Medical Advice* form should be signed, if appropriate.

A Discharge against Medical Advice form should not be used in the following circumstances:

- where the patient is aged over 16, does not have capacity and their Person Responsible or guardian is seeking to discharge them or refusing to stay for treatment. In these circumstances, consideration should be given to making an application to the Guardianship Division of NCAT or seeking legal advice
- where it is appropriate that the patient is admitted as an involuntary patient under the Mental Health Act 2007
- where a patient is a Minor and the relevant Health Practitioner reasonably suspects that the discharge of the patient against advice will put the patient at risk of significant harm (see section below regarding Minors and discharge against advice)
- where, in the professional opinion of the attending Health Practitioner, the discharge against advice does not pose actual risk to the patient in which case the patient leaving the facility can just be noted in the patient's Health Record
- where a patient 'did not wait' in the Emergency Department (see PD2018_010).

By signing a Discharge against Medical Advice form, the patient is acknowledging that they are leaving the health facility against medical advice and accepting responsibility for any consequences that flow from that decision. If a patient chooses not to sign a form, this should also be documented in the Health Record, including an outline of any discussion around the reasons for this.

If it is not practical to obtain and sign a Discharge Against Medical Advice form, the discussion about risks of leaving and follow up available can be recorded in the patient's Health Record.

Marginalised populations may have higher rates of discharge against medical advice, Health Services should regularly review whether improvements could be made to the experiences of the health service for these populations. Clinicians should adopt trauma informed care strategies and consider involving multi-disciplinary colleagues, for example, Aboriginal Health Liaison Officers, where appropriate.

Further guidance

- NSW Health Policy Directive Departure of Emergency Department Patients (PD2014_025)
- NSW Health Policy Directive Health Care Records Documentation and Management (PD2012_069)
- NSW Health Policy Directive Emergency Department Patients Awaiting Care (PD2018_010)

Example

Tom is a 24-year-old male who arrives at a busy emergency department at 9.25pm with a broken arm sustained during an assault. He is with two friends who are very concerned for his welfare. Tom is briefly seen by the triage nurse and prioritised as acute but told there would be some waiting time because of more urgent cases. He is then seen by the Medical Officer who assesses Tom and provides some analgesia for his pain.

Later on, frustrated with waiting, Tom's friends ask hospital staff about alternative care available at that time of night and they decide to seek help elsewhere.

The primary duty which the hospital owes Tom in this scenario is to assign an appropriate priority through the triage process and to observe Tom in the waiting area for any deterioration of his condition. The hospital's duty of care also extends to providing Tom with appropriate advice if it is intimated that he is going to leave the waiting area. The Health Practitioners involved should advise Tom of the risks of leaving the hospital and reassess his condition with regard to his priority. If Tom insists on leaving the emergency department the Health Practitioner should inform him of any follow-up treatment and ensure he understands he may return to that hospital for further treatment at any time. This should be documented on the *Discharge against Medical Advice* form and signed by Tom.

Additional considerations with regard to Minors and Discharge against Advice

Health Practitioners should make all reasonable attempts to engage the parents or legal guardian in discussions regarding the risks to the patient of discharging against advice.

If the parents or legal guardian insist on leaving the health facility with the patient, the Health Practitioner should initially determine whether the action will pose a risk of significant harm to the patient. Where the relevant Health Practitioner reasonably suspects that the discharge of the patient against advice will put the patient at risk of significant harm the Health Practitioner must notify the Child Protection Helpline or the Child Wellbeing Unit and, where necessary, the Police in accordance with their legal obligations under Section 27 of the *Children and Young Persons (Care and Protection) Act 1998.*

If the Health Practitioner considers that the discharge against advice does not pose a risk of significant harm to the child but may still pose some additional health risks for the child, the Health Practitioner should consider notifying the Child Wellbeing Unit and request that the parents or guardian sign a *Discharge Against Medical Advice (for parents/guardians of Minors without capacity)* form.

The purpose of the form is to document the decision of a parent/guardian to discharge a patient at their own risk notwithstanding the knowledge of risks to the patient (as specified on the form) which have been explained to the parent/guardian by the most senior available Health Practitioner. The form also serves the purpose of alerting the parent/guardian to the potential for a suspected risk of significant harm report to the Child Wellbeing Unit where there are concerns regarding risks to the safety, welfare and wellbeing of a child or young person.

Generally, Mature Minors should not sign a *Discharge against Medical Advice* form on their own behalf. If a Mature Minor wishes to leave hospital against medical advice, the strategies in Section 8.5 should be considered. Advice from the Ministry of Health Legal Branch may be necessary.

Example

Max is a seven-year-old admitted patient who has been receiving treatment for burns to 20 percent of his body. He requires regular dressing changes and medical treatment by specialised Health Practitioners at the hospital. Max's parents are insisting he is discharged one week before his scheduled discharge date because of a family wedding. Max's Admitting Medical Officer has advised against discharging Max early and has had numerous discussions with Max's parents regarding the possible risks to Max's health if they insist on discharging Max against medical advice. However, this has not changed their minds.

The Admitting Medical Officer should assess the risks to Max's health posed by the parents' actions. If the Admitting Medical Officer reasonably suspects that the early discharge against advice will put Max at risk of significant harm, they must notify the Child Protection Helpline and follow the policies and procedures within *Child Wellbeing and Child Protection Policies and Procedures for NSW Health* (PD 2013_007) and contact the Child Wellbeing Unit.

If the Admitting Medical Officer considers that the discharge against medical advice poses real risks to Max's health and wellbeing the Admitting Medical Officer should ask the parent to complete the appropriate Discharge Against Medical Advice form. The Admitting Medical Officer should document on the form the risks of discharge against advice which have been explained to Max's parents in their discussions. A follow-up treatment and care plan as explained to Max's parents should also be documented on the form.

The Admitting Medical Officer should also explain to the parents the potential for a suspected risk of significant harm report to the Child Wellbeing Unit where there are concerns regarding risks to the safety, welfare and wellbeing of a child or young person. When a report is made to the Child Protection Helpline or the Child Wellbeing Unit because the child is being discharged against medical advice, parents should generally be told before the report is made that the Health Service intends to notify the Department of Communities and Justice, unless doing so would place the child or any other person at risk.

It should be made clear to Max's parents that they may return to the hospital at any time for further care. The original signed form should be filed in Max's health record.

Further guidance

- NSW Health Policy Directive Child Wellbeing and Child Protection Policies and Procedures for NSW Health (PD2013_007)
- NSW Department of Communities and Justice NSW Mandatory Reporter Guide

6.4. When can a Medical Practitioner or other Health Practitioner refuse to treat a patient?

6.4.1. Treatment of no therapeutic value

Medical Practitioners and other Health Practitioners are under no obligation to provide treatments that in their reasonable opinion are futile, that is, treatment that is unreasonable, offering negligible prospect of benefit to the patient.

If a patient (or their Person Responsible, or family members) is requesting treatment that is unlikely to provide any benefit, the Medical Practitioner should ensure that a discussion is held with the patient to explain why the treatment is considered to be of no therapeutic value, clarify the patient's prognosis and reach consensus on an appropriate treatment plan. Where the patient disagrees with the Medical Practitioner, a second medical opinion may be offered to assess the appropriateness of the treatment plan. The discussion and any second opinion should be documented in the patient's Health Record. Continued conflict with the patient or the patient's Person Responsible or family members following a second opinion should be escalated within the Local Health District or advice sought from Ministry of Health Legal Branch.

Conversely, Medical Practitioners who provide treatment that has no therapeutic value, such as unnecessary procedures, expose themselves to legal risk.

6.4.2. Conscientious objection

General

If a Medical Practitioner or other Health Practitioner has a conscientious objection to conducting a specific procedure or providing certain treatment to a patient, they should:

- inform the patient that they object to the provision of a procedure or treatment on ethical, moral or religious grounds and that other Health Practitioners may be prepared to provide the health service they seek
- take every reasonable step to direct the patient to another Medical Practitioner or Health Practitioner in the same profession who does not have the same objection.

Termination of pregnancy

The Abortion Law Reform Act 2019 contains obligations for Health Practitioners with conscientious objections to performing, assisting or advising on a termination of pregnancy.

Further guidance

NSW Health Policy Directive Framework for Termination of Pregnancy in NSW (PD2021_018)

6.4.3. Therapeutic relationship in disrepair

In rare circumstances, the therapeutic relationship between a Medical Practitioner or other Health Practitioner, or a treating team and a patient becomes difficult to manage.

Health Services have an obligation to treat all public patients based on clinical need. However, this obligation does not prevent the Health Service from implementing strategies such as transferring the patient to a different Health Practitioner, or to a different service if it is practicable to do so. In the circumstances of a patient transfer, the Health Practitioner should ensure that the necessary information is handed over to the new Health Practitioner. Details about the circumstances of the patient transfer should be recorded in the patient's Health Record.