

# 1. PATIENT RIGHTS

## OVERVIEW OF PATIENT RIGHTS

Each patient and family member is unique, with his or her own needs, strengths, values and beliefs. Palliative care organisations work to establish trust and open communication with patient family and communities and to understand and protect each patient's cultural, psychosocial and spiritual values.

Patient care outcomes are improved when patients, and, as appropriate, their families or those who make decisions on their behalf, are involved in care decisions and processes in a way that matches cultural expectations.

To promote patient rights in a palliative care organisation, one starts by defining those rights, then educating staff and patients about those rights. Patients are informed of their rights and how to act on them. Staff are taught to understand and respect patients' beliefs and values and to provide considerate and respectful care that protects patients' dignity.

This chapter addresses processes to

- Identify, protect and promote patient rights;
- Inform patients of their rights;
- Include the patient and the patient's family, when appropriate, in decisions about the patient's care;
- Obtain informed consent;
- Educate staff about patient rights, and
- Guide the organisation's ethical framework.

How these processes are carried out in an organisation depends on the country's laws, regulations and charters and any international conventions, treaties or agreements on human rights endorsed by that country.

The implementation of patient rights is dependent on the palliative care organisation providing equitable services.

## Standards

### **1.1 Supporting processes**

#### *1.1.1 Management creates an environment that supports the implementation of patient rights and empowers the patient and family.*

##### Intent of 6.1.1

An organisation's leaders are primarily responsible for the way in which an organisation treats its patients. The leaders need to know and understand patient and family rights and their organisation's responsibilities as identified in laws, charters and regulations. The leaders then provide direction to ensure that staff, throughout the organisation, assumes responsibility for protecting these rights. To effectively protect and advance patient rights, the leaders work collaboratively, and seek to understand their responsibilities in relation to the community served by the organisation.

Patient and family rights are a fundamental element of all contacts between the staff and volunteers of an organisation and patients and families. Thus, policies and procedures are developed and implemented to ensure that all staff and volunteers are aware of and respond to patient and family rights issues, including their role in supporting patients' and families' rights to participate in the care process.

Admission to a palliative care organisation can be a frightening and confusing experience for patients, making it difficult for them to understand and act on their rights. Thus, the organisation prepares a written statement of patient and family rights, and this is given to patients when they enter the organisation for care, and is available throughout their stay. The statement is appropriate to the patient's age, understanding and language. When written communication is not effective or appropriate, the patient and family are informed of their rights in a manner they can understand.

##### **6.1.1 Criteria**

- 6.1.1.1 The leaders of the facility work collaboratively to protect and advance patient and family rights.**
- 6.1.1.2 Patient and family rights are implemented in accordance with laws and regulations.**
- 6.1.1.3 There is a multidisciplinary approach for the consideration of ethical issues.**
- 6.1.1.4 There is a written document, which is made known to patients, which describes the rights of patients.**
- 6.1.1.5 Patient rights are made known to patients in a language and form that they can understand.**
- 6.1.1.6 Where the patient cannot understand his or her rights, a mechanism is in place to ensure that his or her carers are included in the process of protecting these rights.**
- 6.1.1.7 There is a process to identify and respect patient values and beliefs.**

**6.1.1.8 Staff are trained in their role in the protection of patient and family rights.**

## **1.2 Implementation of patient rights**

*1.2.1 Patients and families are informed about the services and how to access those services.*

Intent of 6.2.1

During the entry process, patients and their families receive sufficient information to make an informed decision about seeking care. Information is provided on what care is proposed, the expected results, and any expected cost to the patient or family for the care when not paid by a public or private source. Patients and families need complete information on the care and services offered by the organisation as well on how to access those services. Providing this information is essential to the building of open and trusting communication between patients, families and organisations. This information helps match the patient's expectations with the ability of the organisation to meet those expectations. Information on alternative sources of care and services is provided when the needed care is beyond the organisation's mission and capabilities.

For patients and families to participate in care decisions they need basic information regarding the medical conditions found during assessment and on the care and treatment proposed. Patients and families understand when they will be told this information and who is responsible for telling them. Patients and families understand the type of decisions that must be made about care and how to participate in those decisions. In addition, patients and families need to understand the organisation's process to obtain consent and which care processes, tests, procedures and treatments require their consent.

While some patients may not wish to personally participate in the decisions regarding their care, they are, however, given the opportunity, and can choose to participate through a family member, friend or surrogate decision-maker.

### **6.2.1 Criteria**

**1.2.1.1 Patients are provided with information on the care and services provided.**

**1.2.1.2 Patients are provided with information on how to access services.**

**1.2.1.3 Information on alternative sources of care and services is provided when the facility cannot provide the care or services.**

**1.2.1.4 The patient (and his/her family or carers as appropriate) is informed of the estimated costs, itemised where possible, of services to be rendered, and any limitation placed on duration of service.**

*1.2.2 Patients and families are informed about the care provided, and patients and families are empowered to exercise choices relating to care.*

#### Intent of 6.2.2

The organisation supports and promotes patient and family involvement in all aspects of care through the development and implementation of related policies and procedures. The organisation uses a collaborative and inclusive process to develop the policies and procedures and, when appropriate, includes patients and families.

Compassionate care includes providing the patient with adequate information on which to make decisions, adequate relief of pain and consideration of the needs of the dying. Patients and families participate in the care process by making decisions about care, asking questions about care, and even refusing care

#### 6.2.2 Criteria

- 1.2.2.1 **The patient (and his/her family or carers as appropriate) is provided with information relating to the nature of care, and procedures and treatment to be received.**
- 1.2.2.2 **The patient (and his/her family or carers as appropriate) is informed of all risks, side-effects and benefits of any medication and treatment procedures used.**
- 1.2.2.3 **The patient (and his/her family or carers as appropriate) is informed of any other treatments or procedures available, to enable him/her to make informed choices.**
- 1.2.2.4 **The patient (and his/her family or carers as appropriate) is informed about his/her right to refuse or discontinue treatment and the consequences of such decisions.**
- 1.2.2.5 **The patient (and his/her family or carers as appropriate) is provided with information relating to the names and professional status of all staff involved in his/her care.**
- 1.2.2.6 **The patient (and his/her family or carers as appropriate) is informed of the reasons for any proposed change in the professional staff responsible for his/her care.**
- 1.2.2.7 **The patient (and his/her family or carers as appropriate) is informed that the service has the right to terminate the relationship with the patient upon reasonable notice, and in accordance with professional standards.**
- 1.2.2.8 **The patient has a right to access his/her records.**
- 1.2.2.9 **The patient (and his/her family or carers as appropriate) is informed of any proposed transfer within or outside the organisation.**
- 1.2.3 *The patient gives consent based on adequate information, through a process defined by the facility.*

#### Intent of 6.2.3

One of the main ways that patients are involved in their care decisions is by granting informed consent. The patient must be provided with all information relating to the planned care to enable him or her to make decisions. The consent process is clearly defined by the organisation in policies and procedures. Relevant laws and regulations are incorporated into the policies and procedures.

Informed consent for care sometimes requires that people other than (or in addition to) the patient be involved in decisions about the patient's care. This is especially true when the patient does not have the mental or physical capacity to make care decisions, when culture or custom designate that others make care decisions, or when the patient is a child. When the patient cannot make decisions regarding his or her care, a surrogate decision-maker is identified. When someone other than the patient gives the consent, that individual is noted in the patient's record.

### **6.2.3 Criteria**

- 1.2.3.1 The facility has a clearly defined consent process described in policies and procedures.**
- 1.2.3.2 The facility has listed those categories or types of treatments and procedures that require specific informed consent.**
- 1.2.3.3 Patients give informed consent consistent with the policies and procedures.**
- 1.2.3.4 When treatments or procedures are planned, patients know who is authorised to perform the procedure or treatment.**
- 1.2.3.5 The identity of the individual who provides the information to the patient and family is noted in the patient's record.**
- 1.2.3.6 Consent is documented in the patient's record by signature or a record of verbal consent.**
- 1.2.3.7 There is a process, which is implemented when others have to grant informed consent.**
- 1.2.3.8 Those individuals, other than the patient, granting consent are noted in the patient's record.**

### **1.2.4 *The right of patients to privacy and safety is supported.***

#### **Intent of 6.2.4**

The organisation ensures that the patient's needs for privacy are respected, especially when the patient is providing personal information and undergoing clinical examination. Patient may desire privacy from other staff, other patients and even from family members.

Medical and other health information, when documented and collected in a patient record or other form, is important for understanding the patient, his or her needs, and for providing care and services over time. The organisation respects such information as confidential, and has implemented policies and procedures that protect such information from loss or misuse. Staff respect the confidentiality of patient information by not posting information on the patient's door or at the nursing station and by not holding patient-related discussions in public places.

The misuse of patient information can result in the patient's loss of dignity, employment, and damage to personal or family relationships. Misuse can be by organisation staff, family members, or others not authorised to have access to the information.

#### **6.2.4 Criteria**

- 1.2.4.1 The patient's need for privacy is protected for all examinations, procedures and treatments.**
- 1.2.4.2 The facility respects patient health information as confidential.**
- 1.2.4.3 Patients' possessions are safeguarded.**
- 1.2.4.4 Patients are protected from assault.**
- 1.2.4.5 The process makes provision for those who are less able or unable to protect themselves.**