

Hospice Association of America

Hospice Patients' Bill of Rights

Patients have a right to be notified in writing of their rights and obligations before Hospice care begins. Consistent with state laws, the patient's family or guardian may exercise the patient's rights when the patient is unable to do so. Hospice organizations have an obligation to protect and promote the rights of their patients, including the following:

Dignity and Respect

Patients and their Hospice caregivers have a right to mutual respect and dignity. Caregivers are prohibited from accepting personal gifts and borrowing from patients/families/primary caregivers. In addition, patients have the right to:

- Have relationships with Hospice organizations that are based on honesty and ethical standards of conduct;
- Be informed of the procedures they can follow to lodge complaints with the Hospice organization about the care that is (or fails to be) furnished and regarding a lack of respect for property (to lodge complaints call the Hospice);
- Know about the disposition of such complaints; and
- Voice their grievances without fear of discrimination or reprisal for having done so.

Decisionmaking

Patients have the right to:

- Be notified in writing of the care that is to be furnished, the types (disciplines) of caregivers who will furnish the care, and the frequency of the services that are proposed to be furnished;
- Participate in the planning of the care, be advised of any changes in the care, and be advised that they have the right to do so;
- Refuse services and be advised of the consequences of refusing care; and
- Request a change in caregiver without fear of reprisal or discrimination.

Privacy

Patients have the right to:

- Confidentiality with regard to information about their health, social, and financial circumstances and about what takes place in the home; and
- Expect the Hospice organization to release information only as consistent with its internal policy, required by law, or authorized by the client.

Financial

Patients have the right to:

- Be informed of the extent to which payment may be expected from Medicare, Medicaid or any other payer known to the Hospice organization;
- Be informed of any charges that will not be covered by Medicare;
- Be informed of the charges for which the patient may be liable;
- Receive this information, orally and in writing, within 15 working days of the date the Hospice organization becomes aware of any changes in charges;
- Have access, on request, to all bills for service received, regardless of whether they are paid out of pocket or by another party; and
- Be informed of the Hospice's ownership status and its affiliation with any entities to which the patient is referred.

Quality of Care

Patients have the right to:

- Receive care of the highest quality;
- Be admitted by a Hospice organization only if it is assured that all necessary palliative and supportive services will be provided to promote the physical, psychological, social, and spiritual well-being of the dying patient. An organization with less than optimal resources may, however, admit the patient if a more appropriate Hospice organization is not available - but only after fully informing the client of its limitations and the lack of suitable alternative arrangements; and
- Be told what to do in the case of an emergency.

The Hospice organization shall assure that:

- All medically related Hospice care is provided in accordance with physician's orders and that a plan of care, which is developed by the patient's physician and the Hospice interdisciplinary group in conjunction with the patient, specifies the services to be provided and their frequency and duration; and
- All medically related personal care is provided by an appropriately trained home care aide who is supervised by a registered nurse.

Patient/Caregiver Responsibilities

The patient/caregiver have the responsibility to:

- Show respect and consideration for staff and equipment;
- Notify the Hospice in advance of any treatment, testing, or medications not provided or arranged by the Hospice;
- Notify the Hospice of changes in condition (e.g., pain, need for emergency care);
- Follow the Hospice Plan of Care and work as a Partner with the hospice team in the provision of your care;
- Notify the Hospice if the visit schedule needs to be changed;
- Inform the Hospice of the existence of any changes made to advance directives;
- Provide a safe environment for care to be provided; and
- Assume responsibility for any charges for which you have been notified of responsibility and/or incurred for services outside of the Hospice Plan of Care.