This Family Education Sheet gives you information about our commitment to you and your family.

Boston Children’s Hospital ("hospital") is committed to respecting and protecting the rights of its patients and families. Our goal is to provide care that is sensitive to your family’s culture, race, religion, gender, sex, gender identity, sexual orientation, marital status, disability, source of payment and national origin.

Equal visitation

Boston Children’s Hospital grants full and equal visitation rights to meet your family’s needs. The hospital welcomes all visitors regardless of their race, color, age, sex, gender identity or expression, sexual orientation, national origin, religion or any disability.

If we need to limit visits for health or safety reasons, we will tell you as soon as possible. We make reasonable accommodations—such as access to special services or making adjustments to our physical environment—for patients, families or visitors with disabilities whenever possible.

You and your family’s rights at Boston Children’s Hospital

General rights

- Receive medical care without regard to race, creed, color, national origin, religion, sex, gender identity, sexual orientation, marital status, age (within guidelines), or disability.
- Receive prompt, life-saving treatment in an emergency without discrimination on account of economic status or source of payment and without delay for purposes of discussing source of payment.
- Receive considerate, safe and respectful care and to have all reasonable requests responded to promptly and adequately within the capacity of the hospital.
- Receive care that is individualized to support and address your or your child’s age, personal dignity and needs.
- Get the name, staff position and licensure status, if any, of everyone who examines, observes or treats you or your child. (All such people are required to wear an identification badge.)
- Refuse to be examined, observed, or treated by students or any other hospital staff in training. This will not affect your or your child’s access to psychiatric, psychological or other medical care and attention.
- Refuse to serve as a research subject and/or to receive care when the primary purpose of that care is educational or informational rather than therapeutic.
- Upon request, get an explanation of the relationship, if any, of the hospital to any other health care facility or educational institution, in terms of how the relationship relates to your or your child’s care or treatment.
- Be given a copy of this Family Education Sheet, “Rights and Responsibilities of Patients, Families and Patient Representatives.” If you cannot read or understand this document, someone will translate or explain it to you.
- Have your spiritual, cultural and psychosocial needs respected and supported.
- Receive care in a safe setting without any kinds of abuse or harassment.
- Discuss any ethical issues you may have regarding your or your child’s treatment with the nursing and medical staff. If your questions are not answered or you have further concerns, you may contact the hospital’s Ethics Advisory Committee.
- Upon request, get a list of names, addresses and telephone numbers of relevant state client advocacy groups and protective services.
- For rape victims of childbearing age: Receive medically and factually accurate written information prepared by the Commissioner of Public Health about emergency contraception, and to get with emergency contraception upon request.
- If refused treatment because of economic status or lack or a source of payment, to have prompt and safe transfer to a facility that will receive and treat you or your child. The hospital arranges for the transfer with appropriate clinical information and staff, if necessary.
Privacy and confidentiality

- Have privacy during medical treatment or other kinds of care.
- Have confidentiality of all records and communications in accordance with Massachusetts’ law and federal law.
- Access information in your or your child’s clinical records within a reasonable timeframe, and to receive a copy of clinical records in accordance with Massachusetts’ law and hospital policy.
- Receive a copy of the hospital’s privacy practices when you register.
- Choose not to be listed in the hospital directory. This means that our staff will not forward phone calls or tell visitors where you are. Mail, flowers or gifts will not be delivered to you. Information in the hospital directory includes a patient’s name, location and phone number at Boston Children’s.
- Request that the hospital communicate your confidential health information only in accordance with applicable law and the hospital’s privacy practices.
- Not have your confidential information discussed in public areas of the hospital.
- To find out how your confidential health information may be used and what disclosures have been made as required by state and federal law.
- Request certain restrictions of the use or disclosure of your health information unless it interferes with patient care, treatment or hospital operations.
- Select who may visit you and your child, unless such visitor(s) would pose a risk to the patient, other patients or staff, or would otherwise interfere with hospital operations.
- Deny visitors to the extent permitted by law. This right does not apply to people who are directly involved in your or your child’s care.
- Request an amendment or correction to your or your child’s confidential health information if you believe the information is incomplete or incorrect, as permitted by applicable law.
- Refuse any contacts for fundraising or marketing activities.
- File a complaint about any of the hospital’s health information practices by contacting the hospital’s Privacy Officer at 617-355-5502 of HIPAA Compliance Manager at 857-218-4680. Or if you believe your or your child’s rights have been violated, you may contact:

  The Office for Civil Rights
  U.S. Department of Health and Human Services
  200 Independence Avenue, S.W.
  Room 509F HHH Building
  Washington, D.C. 20201
  www.hhs.gov/ocr/office/index.html

Decision-making, consent and being part of care

- Except when emergency services are required, a physician or other clinician will provide you and/or your family with sufficient, understandable information about your or your child’s condition, planned treatment, procedures, including potential benefits, risks or side effects, and prognosis so that you may be involved in decisions regarding the care, treatment and services.
- Based on such information, give informed consent to the care and treatment in accordance with Massachusetts’ law.
- Make advance directives if you are 18 years of age or older. This means you have the right to direct your health care or choose someone to make health care decisions for you if you are no longer able to make your own health care decisions.
- Have your decisions regarding organ donation honored within the limits of the law or hospital capacity.
- Have a family member or legal representative promptly notified of your admission to the hospital.
- Have a clear explanation of the results and outcomes of any treatment or procedure, including unanticipated outcomes.
- Be informed by your physician or other clinician of any ongoing needs following your discharge from the hospital and the availability of resources in your community that can help you.
- Get information regarding access to special services such as guardianship, advocacy services and protective services.
- Refuse consent for care, treatment and services to the extent permitted by law. You also have the right to be fully informed of the effects of refusing treatment and the potential medical consequences of your actions.
- Consult with a specialist at your request and expense.
- Transfer to another hospital, subject to Massachusetts’ law. A transfer will be made only when medically appropriate and only when appropriate information related to the care, treatment and services provided is exchanged with care providers at the receiving facility. Any transfer, except in an emergency, would be fully explained and provisions for continuity of care would be made.
- Receive care that reasonably accommodates for special needs.

Research

- Get information about any research or education projects that affect your or your child’s care or treatment. You have the right to give permission or to refuse to join in these projects. You or your child will get care regardless of whether you refuse to participate in these projects.
Pain management
• Care that incorporates pain management.
• Get regular, age-appropriate pain assessments, prompt responses to complaints of pain by staff and to be involved in the decisions about pain management.

Restraints
• Not have seclusion or restraints of any form that are not medically necessary and do not improve your/your child’s well-being. Use of restraints for medical, surgical or behavior management will comply with applicable law and hospital policy. Restraints include either a physical restraint or a drug that is being used as a restraint. Seclusion is the involuntary confinement of a person in a room or area where the person is physically prevented from leaving.

Financial services
• Upon request, get a copy of an itemized bill or other statement of charges and an explanation of the bill and/or charges, regardless of the source of payment.
• Get information about financial assistance and free health care.

Communication
The members of your or your child’s health care team will:
• Introduce themselves to you or your child
• Explain their roles in your or your child’s care
• Seek your opinion about the goals of your or your child’s care and take the time to listen to you
• Speak and write respectfully to you and/or your child
• Confirm your or your child’s identity by checking the wristband or asking the name and date of birth before administering any medication or treatment

A positive environment
To provide care that respects a person’s stage of growth and development, we:
• Consider your or your child’s interests and needs, not just those related to illness
• Ensure that our staff understands the needs and concerns of children, teenagers and young adults
• Provide opportunities for patients to grow and learn
• Try to keep your or your child’s schedule and activities as normal as possible
• Encourage you to bring your or your child’s clothes and special items from home

Responsibilities of patients, families and patient representatives
In the hospital, you have the responsibility to:
• Share information with your care providers about your or your child’s health, such as a complete health history, symptoms, treatments, medicines taken and any other information that could affect your/your child’s health. You should report perceived risks to your or your child’s care and unexpected changes in your or your child’s condition.
• Tell us how you want to take part in your or your child’s care and ask us questions if you do not understand any part of the care or what you are expected to do to participate in that care.
• Follow the treatment plan and instructions given to you by nurses and other health care providers, and express any concerns about your ability to follow the care plan, course of care, treatment or services.
• Let us know if you are not satisfied with your or your child’s care or with any other aspect of your experience at the hospital.
• Respect the rights of other patients, families and hospital personnel and be considerate of hospital and other patients’ property.
• Do not discuss or repeat information about other patients or families.
• Do not engage in intimidating or abusive behavior and/or use disrespectful language. Boston Children’s has a zero tolerance for violence. Engaging in any of these behaviors toward hospital staff could result in:
  o Transferring your or your child’s care to another hospital
  o Asking you to leave Boston Children’s
  o A permanent ban from Boston Children’s
• Contact Patient Relations with questions and concerns, to clarify hospital policies and procedures and to answer questions about this Family Education Sheet. Patient Relations can be contacted through:
  o The Hale Family Center for Families (Main Lobby) Monday–Friday, 8:30 a.m. to 4:30 p.m. 617-355-7673 (5-7673 within the hospital).
  o After 4:30 p.m. or on weekends and holidays, contact the Administrator On Duty (AOD) through the page operator: 617-355-6369 (5-6363 within the hospital).

Exercising your rights
Your concerns are taken seriously. We want to hear from you if you are not satisfied with any part of your care here. Listed below is the process to raise your concerns within the hospital. For your convenience, contacts for raising your concerns outside of the hospital are also listed.

• Bring your concerns or complaints forward to your unit’s charge nurse, unit manager or to a member of the Patient Relations staff.
• If your concern is not resolved, you may file a formal grievance by doing the following:
  1. Submit your grievance either verbally or in writing.
  2. The hospital will tell you the timeframe it will investigate and respond to your grievance.
  3. The hospital will provide a written response of its decision, which will include:
     o Name of the hospital contact person
     o Steps taken on behalf of the patient
     o Outline of the results
     o Date of completion
• Grievances regarding quality of care, safety or premature discharge will be reviewed in a timely manner.
• Patients and families have the right to file a patient safety or quality of care grievance with outside regulatory, licensure or accreditation agencies without using the process within the hospital listed above.

Regulatory, licensure and accreditation contact information

The Division of Health Care Facility Licensure and Certification
Department of Public Health
99 Chauncy Street
Boston, Massachusetts 02111
617-753-8000
www.mass.gov/dph/dhcflc

The Office of Quality ad Patient Safety
The Joint Commission
One Renaissance Boulevard
Oakbrook Terrace, Illinois 60181
1-800-994-6610
Email: patientsafetyreport@jointcommission.org
Fax: 630-792-5636
www.jointcommission.org/report_a_complaint.aspx

The Office of Health Services
Department of Mental Health
25 Staniford Street
Boston, Massachusetts 02111
617-626-8000
www.mass.gov/eohhs/gov/departments/dmh/contact-us.html

This sheet is available in the following languages:
• Arabic
• Haitian Creole
• Portuguese
• Simplified Chinese (China PRC, Singapore and Malaysia)
• Spanish
• Traditional Chinese (Hong Kong and Taiwan)