Content below extracted from: <https://pediatrics.aappublications.org/content/135/1/e255#app-2>

Patient- and family-centered care (PFCC) is an approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and health care professionals.[**1**](https://pediatrics.aappublications.org/content/135/1/e255#ref-1) PFCC applies to patients of all ages, and it may be practiced in any health care setting.[**1**](https://pediatrics.aappublications.org/content/135/1/e255#ref-1),[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2) Providing PFCC to children in the emergency department (ED) setting presents many opportunities and challenges. Unique aspects of the ED encounter include the fact that it often represents an acute visit to an unfamiliar setting without an ongoing provider-patient relationship. This technical report is intended to supplement the joint policy statement of the American Academy of Pediatrics (AAP) and American College of Emergency Physicians,[**3**](https://pediatrics.aappublications.org/content/135/1/e255#ref-3) which was reaffirmed in October 2011 (<http://pediatrics.aappublications.org/content/129/2/e561.full>) and is consistent with its recommendations. It builds on the original technical report,[**4**](https://pediatrics.aappublications.org/content/135/1/e255#ref-4) reviews current literature, and draws on previously published policy statements and reports.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2),[**5**](https://pediatrics.aappublications.org/content/135/1/e255#ref-5)–[**23**](https://pediatrics.aappublications.org/content/135/1/e255#ref-23) The current state of practice and research regarding PFCC for children in the ED setting is described, as are some of the complexities of providing such care. The 3 appendices include several resources for PFCC, including potential solutions for common challenges to providing PFCC faced in the ED, an outline for a protocol for family-member presence (FMP) during invasive procedures, and resources for promoting institutional change.

PFCC seeks to improve the health and well-being of pediatric patients and their families through a respectful patient/family-professional partnership. It honors the strengths, cultures, traditions, and expertise that all members of this partnership bring to the relationship.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2),[**3**](https://pediatrics.aappublications.org/content/135/1/e255#ref-3) PFCC embraces the following concepts: (1) care is provided for a person, not a condition; (2) the patient is best understood in the context of his or her family, culture, values, and goals; and (3) honoring this context will result in better health care, safety, and patient satisfaction.[**24**](https://pediatrics.aappublications.org/content/135/1/e255#ref-24) PFCC in the ED reminds providers that the family often has an ongoing, long-term relationship with the child, and except in extreme instances, the child returns home to be cared for by the family and the child’s medical home. ED health care professionals, the family, and the child together work to optimize the child’s care.

The development of PFCC is well described elsewhere.[**1**](https://pediatrics.aappublications.org/content/135/1/e255#ref-1)–[**3**](https://pediatrics.aappublications.org/content/135/1/e255#ref-3),[**25**](https://pediatrics.aappublications.org/content/135/1/e255#ref-25) The essence of PFCC is an understanding of the relationship between the patient/family and health care professionals as a partnership. In the past, the duties of a physician toward a patient were interpreted to give the physician an implied authority and ability to determine unilaterally what is in the patient’s best interests. As this relationship changed and became more collaborative, patients and families have become more active participants in children’s health care.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2) PFCC represents an evolution in understanding the health care provider-patient relationship, one that will undoubtedly continue to evolve. The Institute of Medicine (IOM) identified PFCC as 1 of the 6 attributes of high-quality health care in its 2001 report Crossing the Quality Chasm: A New Health System for the 21st Century.[**26**](https://pediatrics.aappublications.org/content/135/1/e255#ref-26) Furthermore, the Joint Commission provides information for hospitals to implement PFCC as well as to improve cultural competence and communication.[**27**](https://pediatrics.aappublications.org/content/135/1/e255#ref-27)In its 2006 report Emergency Care for Children: Growing Pains,[**28**](https://pediatrics.aappublications.org/content/135/1/e255#ref-28) the IOM concluded that failure to incorporate PFCC and culturally effective care into emergency care practice “can result in multiple adverse consequences, including difficulties with informed consent, miscommunication, inadequate understanding of diagnoses and treatment by families, dissatisfaction with care, preventable morbidity and mortality, unnecessary child abuse evaluations, lower quality care, clinician bias, and ethnic disparities in prescriptions, analgesia, test ordering, and diagnostic evaluation.” PFCC represents an evolution, and in the pediatric emergency setting a PFCC approach is the best practice for patient care.

PFCC relies on a model of partnership with common goals and mutual respect for the contributions of each partner. This alliance is most successful when information is shared in an unbiased and nonjudgmental manner and when the patient and family are supported in their use of that information to make their own health care decisions.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2) PFCC appreciates that adolescent development creates a changing dynamic, which ED clinicians are obligated to recognize. Effective communication is an essential component of a patient- and family-centered approach to care.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2),[**18**](https://pediatrics.aappublications.org/content/135/1/e255#ref-18),[**27**](https://pediatrics.aappublications.org/content/135/1/e255#ref-27) Traditionally, physicians have held a position of respect and authority in society, and it may be difficult for some families to enter into an open conversation with physicians. Additionally, ED health care professionals must understand that patients and families may not always know what questions to ask or may feel an inherent inequality in the partnership because of the vulnerability brought about by their medical circumstances, which may be particularly true in emergency situations. The possibility also exists that the patient and family may value potential risks or benefits differently from how the treating provider does. Thus, the provider’s ability to discuss information openly by inviting families to share their concerns is vital to good patient care.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2),[**18**](https://pediatrics.aappublications.org/content/135/1/e255#ref-18) Recognizing the role of the patient and family as team members in shared decision-making[**16**](https://pediatrics.aappublications.org/content/135/1/e255#ref-16) and validating their concerns while providing information about potential risks and benefits are critical for the entire team to feel comfortable with the plan and to ensure good patient care.[**2**](https://pediatrics.aappublications.org/content/135/1/e255#ref-2),[**18**](https://pediatrics.aappublications.org/content/135/1/e255#ref-18)

### Family Presence

A practice that requires parents to leave a child during certain procedures, such as fracture reduction, because the ED health care professional judges that it would be too disturbing for parents to watch is another opportunity for change. The ED can be made more patient- and family-centered by allowing the patient and family members to choose whether to be present after receiving complete and unbiased information from an ED health professional or team about what will happen. The ED team then should support this decision, whether or not the family chooses to be present. Guidelines for establishing a program of FMP in the ED have been published.[**20**](https://pediatrics.aappublications.org/content/135/1/e255#ref-20),[**21**](https://pediatrics.aappublications.org/content/135/1/e255#ref-21),[**35**](https://pediatrics.aappublications.org/content/135/1/e255#ref-35) A sample FMP protocol is presented in [**Appendix 2**](https://pediatrics.aappublications.org/content/135/1/e255#app-2). Development of an ED policy for PFCC that includes family presence emphasizes its importance in pediatric emergency care.

*Family-Member Presence*

In the procedure-intense acute care setting of the ED, PFCC is often most tested in the area of FMP. In the 1980s and 1990s, studies showed that parents were an asset in the setting of venipuncture and other simple procedures[**90**](https://pediatrics.aappublications.org/content/135/1/e255#ref-90)–[**92**](https://pediatrics.aappublications.org/content/135/1/e255#ref-92) if they had been prepared for what would happen and if they were given a role other than passive witness. This finding has been extended successfully to other more-invasive procedures, and parents have shown to be successful partners in providing sucrose to soothe an infant undergoing lumbar puncture or in calming the child who is receiving procedural sedation for laceration repair or fracture reduction with a familiar voice, story, poem, or song.[**92**](https://pediatrics.aappublications.org/content/135/1/e255#ref-92)

The role of FMP for resuscitations, particularly trauma resuscitations, is more controversial.[**93**](https://pediatrics.aappublications.org/content/135/1/e255#ref-93)Although some parents would not choose to be present during resuscitation, nearly all parents report that they would want the option to choose to be present or not.[**29**](https://pediatrics.aappublications.org/content/135/1/e255#ref-29),[**94**](https://pediatrics.aappublications.org/content/135/1/e255#ref-94),[**95**](https://pediatrics.aappublications.org/content/135/1/e255#ref-95) However, surveys of pediatricians, ED staff, and trauma care providers have noted a reluctance to allow family members to be present during resuscitation.[**30**](https://pediatrics.aappublications.org/content/135/1/e255#ref-30),[**95**](https://pediatrics.aappublications.org/content/135/1/e255#ref-95)–[**99**](https://pediatrics.aappublications.org/content/135/1/e255#ref-99) Providers often cite fears that it will be traumatic for family members, that families will be disruptive, or that it may result in increased litigation. Trainees seem to be particularly reluctant to endorse FMP.[**100**](https://pediatrics.aappublications.org/content/135/1/e255#ref-100)

Contrary to ED staff fears, EDs reporting their experience with FMP for resuscitation have noted rare instances of disruption by family members and increased acceptance by staff members once they had experience with FMP.[**30**](https://pediatrics.aappublications.org/content/135/1/e255#ref-30),[**95**](https://pediatrics.aappublications.org/content/135/1/e255#ref-95),[**99**](https://pediatrics.aappublications.org/content/135/1/e255#ref-99),[**101**](https://pediatrics.aappublications.org/content/135/1/e255#ref-101),[**102**](https://pediatrics.aappublications.org/content/135/1/e255#ref-102) Staff members at these institutions noted that the family members were often helpful to the staff, providing support to the patient, essential medical information, enhanced communication, and assistance with positioning of the patient.[**29**](https://pediatrics.aappublications.org/content/135/1/e255#ref-29)–[**32**](https://pediatrics.aappublications.org/content/135/1/e255#ref-32),[**100**](https://pediatrics.aappublications.org/content/135/1/e255#ref-100),[**102**](https://pediatrics.aappublications.org/content/135/1/e255#ref-102) In addition, ED staff members who experienced FMP report that present family members’ appreciation that “everything possible was done” was a benefit to staff members.[**102**](https://pediatrics.aappublications.org/content/135/1/e255#ref-102)

Family members who were present for resuscitation of their child report that they felt they served major roles: provided support to decrease their child’s anxiety, served as an advocate for their child, and provided timely information for staff. (O'Connell et al; unpublished abstract, May 2012) One study reported a positive effect of FMP on the grieving process when a resuscitation attempt resulted in death.[**103**](https://pediatrics.aappublications.org/content/135/1/e255#ref-103) Others reported no difference in anxiety and family-member well-being in family members who were present versus those who were not during a trauma resuscitation.[**104**](https://pediatrics.aappublications.org/content/135/1/e255#ref-104) Structured programs of FMP during pediatric trauma team activations showed no instances of family interference with medical care or procedures.[**72**](https://pediatrics.aappublications.org/content/135/1/e255#ref-72),[**105**](https://pediatrics.aappublications.org/content/135/1/e255#ref-105) Present family members also report that they are aware of the need to physically and emotionally regulate themselves during the resuscitation of their child. (O'Connell et al, unpublished abstract, May 2012) Three studies evaluated the time taken for completion of key components of the trauma evaluation and determined that it was not different for trauma team activations with the family present versus those without family presence, and there was no effect on the efficiency of the trauma resuscitation (O'Connell et al, Unpublished Data, May 2012).[**105**](https://pediatrics.aappublications.org/content/135/1/e255#ref-105),[**106**](https://pediatrics.aappublications.org/content/135/1/e255#ref-106)

Family presence may also improve perceptions of medical decision-making, patient care, and communication among health care providers as well as with family members (O'Connell et al, Unpublished Data, May 2012).[**105**](https://pediatrics.aappublications.org/content/135/1/e255#ref-105) Although no studies have directly addressed the effect of FMP on malpractice litigation, there is reason to believe that the presence of family may actually decrease litigation by improving patient and family satisfaction.[**107**](https://pediatrics.aappublications.org/content/135/1/e255#ref-107)

Although there have been few rigorous studies to date, and patient numbers in most of those studies have been small, there is more clinical evidence to support the benefits of FMP to patient, family, and health care professionals than there is for the competing concerns that FMP might be disruptive during procedures or traumatic to bereaved family members.[**72**](https://pediatrics.aappublications.org/content/135/1/e255#ref-72),[**108**](https://pediatrics.aappublications.org/content/135/1/e255#ref-108)The Emergency Nurses Association, the American Association of Critical-Care Nurses, the National Association of Emergency Medical Technicians, the American College of Emergency Physicians, and the AAP have all issued policy statements in support of offering FMP in emergency care.[**3**](https://pediatrics.aappublications.org/content/135/1/e255#ref-3),[**21**](https://pediatrics.aappublications.org/content/135/1/e255#ref-21),[**109**](https://pediatrics.aappublications.org/content/135/1/e255#ref-109),[**110**](https://pediatrics.aappublications.org/content/135/1/e255#ref-110) Since 2000, the American Heart Association has recommended offering the option of FMP during resuscitation attempts, and the 2010 guidelines recommend using FMP whenever possible.[**111**](https://pediatrics.aappublications.org/content/135/1/e255#ref-111) Guidelines for FMP have also been integrated into Advanced Pediatric Life Support: The Pediatric Emergency Medicine Resource[***112***](https://pediatrics.aappublications.org/content/135/1/e255#ref-112) as well as the Emergency Nurses Association’s Trauma Nursing Core Course and Emergency Nursing Pediatric Course.[**113**](https://pediatrics.aappublications.org/content/135/1/e255#ref-113)A national consensus panel that convened in 2005 conducted an in-depth literature review of  studies examining FMP and recommended that FMP be encouraged for all aspects of ED care.[**114**](https://pediatrics.aappublications.org/content/135/1/e255#ref-114) The consensus report described criteria for support staff and for possible exclusion from FMP (such as threat of violence to self, staff, or patient). Benefits to patient, family, and health care professionals were detailed and included the potential to optimize medical information gathering, improve the assessment of how the patient might function at home, and enhance the understanding of the patient as a person rather than a condition. This report also noted that although many institutions’ practices support FMP, fewer than 5% of surveyed institutions reported having a written protocol. However, some institutions have published their experiences with developing and implementing a structured FMP protocol. These examples can be used as a roadmap for institutions that would like to develop and implement their own policies and guidelines. [**Appendix 2**](https://pediatrics.aappublications.org/content/135/1/e255#app-2) presents an outline for a protocol for FMP in the ED.

#### *Unanticipated Critical Event or Death*

Caring for the child with unanticipated critical injury, illness, or death in the ED is one of the most difficult tasks for any ED health care professional, one that requires careful planning, training, and previous identification of resources within and outside the ED. Several important resources exist to guide planning and preparation for such an event,[**5**](https://pediatrics.aappublications.org/content/135/1/e255#ref-5),[**6**](https://pediatrics.aappublications.org/content/135/1/e255#ref-6),[**120**](https://pediatrics.aappublications.org/content/135/1/e255#ref-120)–[**122**](https://pediatrics.aappublications.org/content/135/1/e255#ref-122) and family input may be beneficial. Having protocols and procedures in place is critical for anticipating the needs of family members, who often arrive separately from their child, with significant emotional distress. Under such circumstances, immediate response from designated, trained staff members who are not required for the medical management of the child but whose role is to support the family is vital. Protocols should address how the ED team is to relate to media, police, private physicians,[**122**](https://pediatrics.aappublications.org/content/135/1/e255#ref-122) the medical examiner, child protective services, and organ- and tissue-procurement teams.[**6**](https://pediatrics.aappublications.org/content/135/1/e255#ref-6) Protocols should address a plan for safe and compassionate FMP and identify additional resources available to the ED, such as social services, chaplaincy, acute psychiatric services, and child life services. Space should be designated for family privacy, with adequate seating, local and long-distance telephone capability, and an accessible restroom, tissues, water, and writing materials. Written materials can reinforce and provide additional advice on how to support grieving children both immediately and over time.[**123**](https://pediatrics.aappublications.org/content/135/1/e255#ref-123)

If family members are not able to be present with the child in the ED, conveying the information of the child’s death can be a very difficult task for an ED health care professional. Recommended bereavement guidelines[**5**](https://pediatrics.aappublications.org/content/135/1/e255#ref-5),[**120**](https://pediatrics.aappublications.org/content/135/1/e255#ref-120),[**124**](https://pediatrics.aappublications.org/content/135/1/e255#ref-124) include informing the family in a private location; using the child’s name; informing the family of all medical procedures performed; noting any family efforts to help or comfort the child (such as seeking medical care, giving a good medical history, providing comfort by touching the child); offering information about autopsy and organ/tissue donation; contacting important family supports, such as members of the family’s faith community and medical home; offering private or accompanied time with the child’s body; allowing for time to make meaningful mementos consonant with religious or cultural precepts; and providing a follow-up contact. State requirements for medical examiner jurisdiction vary, which can affect an ED’s ability to allow family private or accompanied time with the body. If a medical examiner’s evaluation is not required, many EDs have found a way to keep an attendant with the child’s body until a designated funeral home can come, in that way reassuring and comforting surviving family members. The death of a child is the beginning of a lifelong process of bereavement for parents and siblings, and ED health care professionals can have a profound effect.[**5**](https://pediatrics.aappublications.org/content/135/1/e255#ref-5),[**6**](https://pediatrics.aappublications.org/content/135/1/e255#ref-6),[**121**](https://pediatrics.aappublications.org/content/135/1/e255#ref-121)