Two Worlds

Children don’t jump straight from childhood to adulthood. They spend their adolescence — roughly between the ages of 12 and 18 — living in both worlds. To further complicate providing medical care for adolescents, some mature physically, intellectually or emotionally quite early, while others take much longer. This stage can be very challenging as adolescents seek greater and greater independence in everything from how they dress to when they come home, who influences them, and how they make decisions. That need for independence also creates challenges for doctors who treat this age group. With every decision, they must balance the rights and desires of adolescents with the rights and desires of parents — demands that can often compete with each other.

In medicine, the field of bioethics asks hard questions about what is “right” and seeks to provide answers, which often come in many shades of gray. Medical ethics lives at the fascinating junction where medicine, the law and ethics converge, providing guidance as families, patients, providers and health care institutions try to determine the right course of action.

In groundbreaking or difficult cases, bioethicists often focus on what informs decision making, who has the right to decide, who is capable of decision, who has autonomy and can provide consent, and where those boundaries are. This can be sensitive, subjective work influenced by the extenuating circumstances of each case combined with legal compliance in an ethical framework.

If bioethical issues can be tough in any patient population, it makes sense that adolescence can be a difficult time of even less clarity, as children and their families are learning how and when a young patient transitions to adulthood. Simple questions can bring up complex issues.

by Brad Broberg and Teri Thomas
Public Relations
Seattle Children’s
for the adolescent patient, their parents and providers:

- What if parents want to withhold a diagnosis from an adolescent?
- What if an adolescent insists his or her physician keep sexual behavior, sexual preference or a sexually transmitted disease secret?
- What if parents and adolescents disagree on a course of treatment?
- Should an adolescent be able to consent to research study or clinical trial participation?
- Should parents be able to request drug testing? Or pregnancy testing? Can a teen refuse?
- What happens to medical decision making when the parent is an adolescent?
- What if an adolescent is ready to stop treatment during end-of-life, but a parent won’t let go?
- What are “mature minor” and “emancipated minor” doctrines, and when should the courts become involved?

When the wishes of adolescents and parents are at odds, doctors need to become diplomats, says Diekema. “The best outcomes occur when everybody comes to an agreement. You can’t treat someone effectively if they are fighting you every step of the way.”

**SOUND DECISIONS**

The teen brain isn’t yet fully mature, but what does that mean? From an evolutionary standpoint, perhaps it was vital to the survival of our species for the adolescent brain to naturally assume new risks, experiment with traveling farther afield, separate from the parent and “leave the tribe.” It may have also been important for youth to be enthusiastic sexual reproducers, to increase genetic diversity as they conquered new territories.

It’s normal for adolescents to begin to carve out independence and learn about sexuality. For all kinds of reasons adolescents may be more impulsive and live more in the moment, but that doesn’t mean they shouldn’t also be central to their own health care and decision making.

Evidence shows that health care decisions made by teens are just as good as those made by adults, Walker says. “They may need support to follow through, but they tend to make sound decisions when presented with all the information.”

In cases related to substance abuse, mental health and reproduction, most states give adolescents the legal right to make decisions about treatment. In other instances, an adolescent’s growing physical and emotional autonomy gives him or her de facto control.

“You can make a 3-year-old comply with treatment, but you can’t make a 16-year-old do something they don’t want to,” says Dr. Benjamin Wilfond, who leads the Treuman Katz Center.

In that sense, adolescents are no different than adults. Yet, because of the complexities of age and parental roles, doctors...
Bioethics Resources at Seattle Children’s

The Treuman Katz Center for Pediatric Bioethics at Seattle Children’s seeks to address the increasingly difficult task of ensuring children’s well-being and development when making tough choices about care and research. It serves as a rich resource for understanding current scholarship, research and legislation affecting ethical decision making for medical staff, patients and families.

The center’s annual pediatric bioethics conference, held each summer in July, focuses on a different topic every year and brings in experts from around the country to speak on high-profile issues. Archived webcasts and PowerPoint presentations from past sessions over the last several years are available free online. For 2011, the conference focus on “Ethical Controversies: How to Meet Society’s Obligation to Provide Healthcare to Children,” a discussion that will involve a national and global look at pediatric health and expectations for care. Previous conferences have focused on:

- 2010 — “Tiny Babies, Large Questions: Ethical Issues in Prenatal and Neonatal Care”
- 2009 — “No Longer a Child, Not Yet an Adult: Ethical Issues in Adolescent Health Care”
- 2008 — “Predicting Our Future: Genetic Testing in Children and Their Families”
- 2007 — “Current Controversies: Navigating Conflicts When Parents and Providers Disagree About Medical Care”
- 2006 — “Ethical Issues Related to Vaccination of Children”
- 2005 — “Current Controversies in Pediatric Research Ethics”

Visit the center’s Web site — www.seattlechildrens.org/bioethics/ — to access extensive resources, including past conference materials, to help you and your hospital engage patients and craft policies supported by a strong understanding of the bioethics issues underlying pediatric health care.

May be less willing to allow adolescents to decline lifesaving treatments.

“That’s a case where people are willing to push harder to persuade adolescents to obtain treatment than they might for a 30-year-old facing a similar decision,” Wilfond says.

MAINTAINING TRUST: A DELICATE BALANCE

Principles of autonomy, informed consent, confidentiality, medical decision making, refusal of care and end-of-life issues can be difficult with any patient population, but with adolescents in particular, there’s a triangulated relationship that demands extra care and attention.

As physicians seek to do no harm and provide care in the patient’s best interest, providing adolescent care requires a delicate balance. Bioethics offers a guiding framework for navigating between parent and child. In addition to decision making issues, caring for adolescents also creates confidentiality issues.

“Many of us are parents, too, and we hear things from adolescents that we’d want to know if they were our kids,” Diekema says. “But adolescents need an adult whom they can trust. If we break that trust, we run the risk they won’t get the care they need.”

Once again, state laws erase some of the gray by requiring confidentiality involving substance abuse, mental health and reproduction. But that doesn’t eliminate all tension.

“What becomes uncomfortable is when a parent says, ‘You absolutely must tell me everything my child said,’” Walker says. “That’s where the push-pull begins.”

The flip side is parents who want doctors to withhold disturbing information, such as a diagnosis, from their child. Doctors have no legal obligation to disclose the diagnosis to a minor, but they run the risk of losing the patient’s trust if and when the diagnosis is discovered.

“The key to resolving these dilemmas is communication between all of the parties involved,” Walker says. “Step by step, you work through the issues. It takes time, but that’s how you reach good decisions.”

“You can make a 3-year-old comply with treatment, but you can’t make a 16-year-old do something they don’t want to.”

— Dr. Benjamin Wilfond, director of the Treuman Katz Center for Pediatric Bioethics at Seattle Children’s