INTRODUCING HEALTHCARE INDEPENDENCE

Patients Younger Than Age 18

- Prepare patients and caregivers EARLY.
  - Ideally start at school age with small tasks (such as gathering supplies and notifying caregivers when medications are running out) and increase independence as the patient matures

- Encourage patients to increase involvement in their care; gradually increase expectations of their understanding of their healthcare and their role in health management. This will increase the patient’s ownership of her healthcare/condition, and allow her to feel proud of her ability to manage even small parts of her care.
  - Ask patients about THEIR concerns.
  - Ask patients to tell you about their medicines and allergies (with caregivers corroborating).
  - Explain the plan to the caregiver and also to the patient in language that is developmentally appropriate for the patient.
  - Ask patients to explain the plan back to you to be sure they understand it.
  - Ask patients to voice their concerns regarding the treatment plan.
  - Ask patients and families about who is responsible for all aspects of the treatment plan. For example: Do you give Johnny his medicines? Whose job is it to remember the medicine? Who calls for refills?
  - See the patient alone for part of the visit. *(See below on suggestions for how to introduce this to families.)*
  - Be aware of changes in lifestyle that may occur as patients get older that might affect treatment. Ask them: What do you do when you sleep over at a friend’s house? What do you do when you go from school to basketball practice and don’t get home until 8 p.m., but your treatment is due at 4 p.m.?
  - Include patients in decision-making as they are able, starting in early adolescence.
  - By mid-adolescence, start encouraging patients to take the lead.

- Suggest caregivers move into the role of coach. Parents or caregivers should:
  - be a sounding board for patients and advise them regarding healthcare decisions; help them discuss positives and negatives of treatment options, for example
  - role model positive health behaviors
  - be available to answer questions their child has or strategize on completing healthcare-related tasks like calling in prescriptions, etc.
  - expect mistakes
  - prioritize the treatment regimen, and give the child the responsibility for less critical items first
  - use the age appropriate Tips for Parents and Caregivers brochures (also available on the Employee Intranet).

- Discuss healthcare proxy and advanced directives at age 16.

- Confidentiality
  - Patient information becomes confidential in its entirety when a patient reaches 18 years old.
  - Patient information regarding specific areas is confidential at younger ages in Pennsylvania (and other states) and requires consent from the minor:
    - * reproductive health services (age 13)
    - * drug and alcohol treatment services (confidential at any age)
  - Minors may consent to mental health services at age 14 or older, but caregivers need to be informed if patients are admitted to an inpatient service. A parent or legal guardian may consent to outpatient mental health services for a minor without the minor’s consent. For outpatient care, there is no process for a minor to object to treatment, unlike inpatient care.
  - Minors with certain characteristics may consent for healthcare:
    - * minors who have graduated from high school
    - * minors who are or have been married
    - * female minors who have been pregnant
  - Please review the pamphlet “Minors’ Access to Confidential Reproductive Health Care in Pennsylvania,” available at this link (aclupa.org) and through the CHOP legal/compliance office.
Introducing Healthcare Independence continued

• Providers should be prepared to inform families and patients that minors are entitled to confidential care for the issues listed on the previous page. Also introduce the fact that the healthcare record becomes confidential in its entirety at age 18.
  – Explain what this means:
    * Only the patient can request records to be released.
    * Only the patient can call for results and other information.
    * Families will need the patient’s permission to access the patient’s records.
  – It is important that patients and families know this in advance so families don’t feel rejected. Frame it positively, as a step toward their child’s self-care.
• Encourage and help families and patients communicate appropriately about healthcare and healthcare decisions.
• More information on minors’ rights (foster care, juvenile justice system, reproductive rights) can be found on the Juvenile Law Center Web site, www.jlc.org

Patients Age 18 and Older

• Address the patient directly.
  – Determine the role of the family/caregiver moving forward.
• Provide information on how the patient can obtain a copy of the medical record or a medical summary.
• Offer the opportunity to complete an advance directive or name a healthcare proxy
• Ask the patient who else can be a decision maker for his or her care
• As the provider, you can determine if the patient is competent to make medical decisions. (See the Patient Care Manual policy on advance directives.)
• The patient has total control of all information unless there is a healthcare proxy. The patient can specify in what circumstances the healthcare proxy can be responsible for healthcare decisions.

Speaking with Patients Alone – How to Reassure Families

• Why speak to patients alone?
  – helps patients become comfortable talking to providers on their own
  – helps the provider get to know the patient more as an individual — his or her personality, beliefs, learning style, and developmental stage
  – allows patients to ask questions about their health they may be embarrassed or anxious to ask in front of someone else. For example, if they are not sure they are using their inhaler right, they may be too embarrassed to have their mom find out after three years of using it on their own.
  – provides more evidence to patients that you are serious about wanting them to take more ownership of their health
  – allows patients with anxieties or depression to tell someone without feeling guilty about adding to the burdens of their caregiver
  – allows time for discussion of private topics they may not feel comfortable discussing in front of their parents
• Make it the norm – speak with every patient alone after a certain age, for example, 9 or 10 years.
• Prepare patients and families for the one-on-one time before they reach this age, or at the very beginning of the first visit if they are already that age.

Have a speech prepared at the very start of the patient visit that explains the rationale. Here’s a sample script:
  – “One of our goals is to help our patients become more active in taking care of their health. As part of this, we ask most questions directly to them. Mr. or Ms. ‘Parent’s Last Name,’ you can help if they don’t know something. We want them to learn from you. We’ll ask them to listen so they know that information next time. Our goal is for your child to learn how to explain their concerns and their history completely.
  – “We also spend a few minutes alone with patients at most visits. We think it is very important for kids to be comfortable talking to a doctor or healthcare provider alone. It also gives kids a chance to ask questions they may be too nervous or embarrassed to ask in front of their parents. They may think their parents expect that they know certain things and don’t want to let you down.”

• Explain what you might ask the patient. You may ask about how they are coping with their illness, their mood, friendships, more details about school and future hopes and goals, how well they think they are doing with self-care, if they have any questions. With younger children this may be enough. As they get older (age 12 or 13) you will also want to ask about sexuality, substance use, and goals for vocation or independence. Remember to ask these questions in a developmentally appropriate way. For example, ask a 12 or 13 year old if he has kissed someone or even liked someone, before asking whether he has had sex.
• Explain limits to confidentiality to patients and families: suicidality, homicidality and abuse (or sexual activity below age 13 years, or unwanted sexual activity below 18 years)
• When you are with patients alone, start by asking if they have anything they want to talk about. Then move to neutral questions, and on to more personal issues as needed. This helps you build trust.