Chapter 2

Transition Care of Teens with Chronic Health Conditions

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Introduction

Transition is the "purposeful, planned movement of adolescents and young adults (AYA) with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems" [1]. Literature reveals that at least 30% of young adults have one or more chronic conditions, and about 5% of young adults report having a disability that affects their daily life [2]. As of 2011/2012, US National Survey of Children's Health, there are an estimated nine million young adults in the USA with a chronic condition, including 1.5 million with a disability, who are transitioning from pediatrics to adult providers [3].

In 2011, the American Association of Pediatrics (AAP), American Association of Family Practitioners (AAFP), and the American College of Physicians (ACP) released a clini-

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E. Sydney et al. (eds.), *Handbook of Outpatient Medicine*,
https://doi.org/10.1007/978-3-319-68379-9_2

Table 2.1 Six core elements of transition for adult providers

Age	**Transition step**
12–14	Transition healthcare policy statement • Create and discuss with young adult/guardian
14–17	Tracking and monitoring • Track young adult's progress to increase knowledge of health and adult healthcare system Transition readiness and goal-setting • Discuss strategies for orientation to adult practice
17–18	Written healthcare plan • Update plan to include required additional skills
18–21	Transfer of care/initial visit • Self-care assessment
3–6 months after transition	Transition completion/continuity of care with adult provider • Continue building self-care skills

cal report [4] containing guidelines to aid pediatricians, family practitioners, and internists in the transition of care of the adolescent (Table 2.1). In this report, special focus was given to caring for those with special needs, and outlined the importance of beginning transition-related conversations early, and creating a specific plan with the patient's family with focus on medical care, insurance issues, and community support. A successful transition to an adult healthcare provider occurs when adolescents and young adults gain skills and supports needed to successfully manage their health.

Barriers in Transition Care

Barriers for AYASHCN stem from factors relating back to the patient, the provider, and community at large. Patients themselves are somewhat unequipped to advocate for their own needs because there is relatively high parent involvement in the care of childhood chronic disease. This leads to lapses in the development of self-management skills, as youth tend to defer medical decision-making to their parents and rely on their parents for basics of health maintenance such as making doctor's appointments and administering medication [5]. Another barrier is lapse in insurance that many young adults experience in the transition process. In one 2008 study [6] of low-income young adults who aged out of a public program for children with special healthcare needs (CSHCN), 40% had a gap in insurance coverage after reaching age 21. Overall, 65% reported at least one adverse transition event affecting access to care. Recent healthcare policy allows for young adults to remain insured under their guardian's insurance plans until their mid-twenties. Despite this, insurance gaps and delayed care are prevalent among these low-income young adults.

Patient and Family Perspectives

Overall, many patients and their families feel unprepared for the transition process and are hesitant to develop a therapeutic relationship with a new provider [7]. Pediatric care is multi-disciplinary and family-centered in individuals with chronic health conditions, leading to strong outcomes in both the inpatient and outpatient setting [8]. Adult care tends to be more focused on autonomy and patient motivation. However, children with chronic diseases are often times unable to advocate for themselves and will usually have caretakers present for their appointments, and providers must accommodate for this change in visit dynamics.

Regarding family involvement, several studies indicated that caregivers are concerned that young adult patients cannot independently manage their own health [9, 10]. However, many young adult patients themselves report being ready to take on this responsibility [10]. Caregivers are also concerned that adult healthcare providers do not want their involvement [11]. In general, families and case managers expressed concerns about physicians' attitudes, ability to handle ordinary and extraordinary health maintenance, and ability to refer appropriately. There were additional concerns regarding the appropriateness of specialty and emergency services [5].

Provider Perspectives

Primary care providers in internal medicine face many challenges in caring for AYASHCN. As survival rates and life expectancy of these individuals increase, these disorders are becoming more common in the adult population. Several studies have shown that there is a paucity of adult subspecialty services for AYA patients with childhood-onset conditions [11, 12]. A survey of internists [13] highlighted the lack of adult subspecialists to share in the care for patients with congenital and childhood-onset disorders. This survey [13] explored internists' interpersonal concerns and stressors with caring for AYASHCN. In this survey, internists agreed with caregivers that patients may not be ready to make decisions independently and were concerned that families will not stay involved when needed. This study elicited concerns from internists, including lack of family involvement, especially for patients with intellectual disability or cerebral palsy, and the expectations of families regarding length of visits with internists. Additionally, internists felt concerns about the need to face disability and end-of-life issues at an early age and early in the doctor-patient relationship. Finally, the survey showed that internists experienced financial stress and time pressure associated with the care of this complex patient population. Provisions for billing highly complex visits are often not clearly delineated for patients who suffer from chronic disease, often resulting in poor reimbursement for additional time spent with patients.

Many internists reported that they feel uncomfortable providing primary care for young adults with childhood chronic diseases [14]. Since there are no set guidelines on transitioning children with chronic disease, internists may inherit patients merely because the patient has reached a certain age, instead of other developmental indicators, such as competence and milestones [15, 16]. Also, research has shown that poor transfer of healthcare information can lead to delays in receiving adult-oriented care [17]. Pediatricians, often left without clear guidance on creating portable medical summaries, are challenged with summarizing over two decades of health problems. Internists are often left without enough information and must generate complex histories in the limited time of an initial patient encounter.

Transition resources published by AAP, and Got Transition, can help address some of these barriers by providing resources to both healthcare professionals and patients and their families. The ACP Council on Subspecialty Societies (CSS) partnered with Got Transition [18] and formed specialty society workgroups to improve internists' ability to care for young adults with congenital or childhood-onset conditions. These new condition-specific transition tools are available for general and subspecialty practices caring for transitioning patients [4].

Initial Evaluation of Teens with Chronic Health Conditions Transitioning to Adult Providers

Portable Medical Summary

The American Association of Pediatrics recommends that each AYA preparing to transition should work with his or her pediatricians and families/guardians to generate a portable medical summary that outlines the patient's medical history [4]. This document should be shared with the patient and any future providers. Internists should review the patient's medical history before the encounter to become familiar with the patient's condition and the potential complications.

Assessment of Functional Status

The initial visit with an adult provider should include an assessment of functional status for patients with chronic diseases of childhood, as individuals with chronic childhood conditions may or may not have a developmental disability or an intellectual disability. A developmental disability (DD) is a severe, chronic disability that is attributable to a mental or physical impairment or a combination and begins prior to the age of 22. To qualify as developmentally disabled, substantial functional limitations must be documented in three or more areas of major life activity, such as self-care, receptive and expressive language, learning, mobility, capacity for independent living, and economic self-sufficiency [19]. Currently, over six million individuals in the USA have developmental disabilities [20]. A subset of patients with developmental disabilities also has an intellectual disability (ID). The prevalence of ID is estimated at approximately 1% of the population in the USA and Western European countries [21, 22]. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines ID as both an IQ score below the range of 70–75 [two standard deviations (SD) below the mean] and limitations in adaptive skill areas that originate prior to age 18 years [23]. The limitations are described as conceptual, social, and practical deficits (Table 2.2); the definition requires that individuals test at least two standard deviations below the mean in one or in combination of all three adaptive skill areas.

A practical approach to assess the patient's functional status during the initial visit is to assess the patient's activities of daily life (ADLs) and instrumental activities of daily life (IADLs). As a basic assessment, determine if the patient is **I**ndependent, requires **A**ssistance, or is **D**ependent for a particular activity: ADLs (dressing, hygiene/self-care, and feeding) and IADLs (meal preparation, telephone communication, transportation, and financial management). There are several comprehensive assessments for individuals with developmental and intellectual disabilities including the Supports Intensity Scale, or "SIS", which evaluates practical support

Table 2.2 Limitations in adaptive skill areas that originate prior to age 18 years associated with intellectual disability

Adaptive skill area	**Deficits**
Conceptual deficits	Receptive and expressive language, reading/writing/math, reasoning, and memory
Social deficits	Interpersonal communication skills, friendship, empathy, social judgment skills including gullibility and naiveté, avoiding victimization
Practical deficits	Personal care activities: eating, dressing, bathing, meal preparation, telephone communication, transportation Occupational skills: organizing school and work activities, money management, job duties

requirements of a person with an intellectual disability [24]. While it is important to be aware of such scales, it is not possible or necessary for these types of assessments to be completed during the initial primary care visit. Assessing functional status requires a baseline appraisal with a goal of anticipating the short- and long-term needs of each patient.

Education

Many young adults with chronic health conditions may benefit from physician support of their educational development, including providing emotional support as well as essential documentation for schools. Over 30% of young adults with learning disabilities drop out of high school, and physicians may play a key role in encouraging students to continue formal education [25]. Only 13% of students with learning disabilities have attended a post-secondary school within 2 years of graduating high school (compared to 54% of the typical population) [26]. The Individuals with Disabilities Education Act (IDEA), which was brought into legislation in 1990, ensures that persons with disability are provided an individualized public school education. Transition planning can occur with the family and educators in the Individual Education Plan (IEP) generated for many students with learning disabilities. Many states have databases to register disabled people to select individuals for services as funding becomes available.

Living Arrangement and Family Support

The internist should have an understanding of the patient's living arrangement to estimate the support the patient will require. Some patients may be living at home with their families, while others may be living independently with a case manager. Some may require additional support and will be living in a group home. It is important for the provider to be aware of the patient's living situation when working with patients. An understanding of the patient's living situation can help guide a discussion regarding utilization of community resources and can help the provider evaluate the patient's goals and abilities.

Employment

All individuals with disabilities are eligible for Vocational Rehabilitation (VR) services through local Department of Human Services. An individual who is eligible for Social Security Income benefits is also automatically presumed eligible for these services. VR services have benefit counselors who can guide young adults through the complicated requirements for eligibility for government benefits, such as Supplemental Security Income and Medicaid, while earning a paycheck.

Health Insurance and Benefits Relevant to Transitioning Adult

Medicaid, Medicare, SSI, and SSDI

Supplemental Security Income (SSI) is a program that provides a monthly benefit and Medicaid coverage. Eligibility for Medicaid coverage begins after SSI benefit approval in 39 states. In 11 states, Medicaid eligibility begins after a separate application for Medicaid has been approved. Even if individuals are approved in the pediatric setting, they must reapply at age 18. Most adults age 18 and older with chronic health conditions meet the medical requirements and low-income criteria to receive SSI benefits.

Social Security Disability Income (SSDI) is to be distinguished from SSI. A work history for several years before being unable to work is required to be eligible for SSDI. Some young adults fall in this category of eligibility for both types of income.

Medical Decision-Making and Guardianship

At the initial visit, adult providers will need a quick assessment of the decision-making capacity of the young adult with chronic disease of childhood that has transitioned to their practice. Equal to individuals in the general population, developmentally disabled adults should be entitled to exercise their legal capacity. Article 12 of the United Nations convention on the rights of persons with disabilities assures that they have equal rights and are provided the support they need to exercise their legal capacity [27]. If the individual is capable, a shared decision-making role may be established. Supported decision-making allows the adult-aged patient with disabilities to retain his or her decision-making capacity. Examples include decisions about managing money, healthcare, where to live and with whom, and activities to participate in during the day.

If an individual has partial decision-making capacity, there are alternatives to full guardianship that vary from state to state. These are the least intrusive measures on the patient's autonomy and should be considered. Options include a guardian of the estate, limited guardianship, joint bank accounts, representative payee, community advocate, and Trustee (Table 2.3). Additionally, as in the general population, it is important to have discussions about a living will, durable power of attorney for property and healthcare, and advanced directives and healthcare proxies (Table 2.4).

TABLE 2.3 Alternatives to full guardianship

Title	**Responsibilities**
Guardian of the estate	Responsible for the individual's finances
Limited guardianship	Limited to medical decision-making
Joint bank accounts	Guardian can monitor spending, requires both signatures
Representative payee	Person who manages funds received by government agencies, such as social security
Community advocate	Allows an agent to advocate on an individual's behalf with administrative and government agencies
Trustee	An individual who controls funds and other assets

TABLE 2.4 Advance directive/medical decision-making alternatives

Advance directive	**Definition**
Living will	Patient's wishes for end-of-life medical care when unable to communicate decisions
Durable powers of attorney for property and healthcare	Legal authority to make decisions on another's behalf when the patient is unable to do so
Advance directives in healthcare proxies	Designate a healthcare agent ahead of time; patient must be competent when appointing an individual

Full guardianship is required for adults with intellectual disabilities, and physicians make the assessment of decision-making capacity. Competence is a legal term and is determined by the courts. Guardian applicants are typically parents and family members who have determined that the patient does not have the capacity to make their own decisions.

The physician role is to complete the healthcare provider certification supporting the patient's inability to make either medical or personal decisions. A primary care provider, subspecialist, or behavioral health specialist may complete this documentation. Guardian applicants typically have 90 days from the time the physician certification is completed to petition the courts for guardianship. Consultation with a lawyer by the guardian may be necessary to coordinate the guardianship process.

Local Resources

Each state has an office for intellectual/developmental disabilities. The state agency is an important resource for short-term or long-term services, particularly around residential and vocational/day programs. Individuals with chronic health conditions should register with the state-specific office. Each state also has an Aging and Disability Resource Center (ADRC) (https://www.adrc-tae.acl.gov) which provides a database of community resources broken down into local areas. Additionally, each state has at least one University Center for Excellence in Developmental Disabilities (UCEDDs) (https://www.aucd.org). Adult providers should be familiar with these agencies as they provide information on programs, advocacy, legal resources, and consumer guidance for the developmentally disabled population.

Unique Considerations in Teens and Young Adults with Chronic Health Conditions Transitioning to Adult Providers

When working with adult patients with chronic diseases of childhood, internists have additional challenges that they might otherwise not encounter in their day-to-day practice. For example, questions of guardianship and the legal-therapeutic relationship may go unaddressed until it threatens the care of the patient. Additionally, many community resources such as schools and daycare programs that patients often utilize may cease to provide care as patients "age out" of their programs. When caring for young adults with chronic diseases of childhood, an internist will encounter two types of patients: specialist-dominated care and internist-dominated care.

Specialist-Dominated Care

Specialist-dominated care includes patients whose medical conditions are best managed with frequent visits to subspecialists, such as type 1 diabetes mellitus, cystic fibrosis, and vertically transmitted HIV. In this type of care, most health-related decision-making is completed with the subspecialist, as these patients often have few, albeit complicated, health problems. Patients who receive specialist-dominated care utilize internists to ensure that all their primary care needs are met and that they are receiving correct age-appropriate screenings. For young adults who are transitioning to adult-oriented care, patients may need additional support in finding adult subspecialists who have expertise in the management of chronic diseases of childhood. Furthermore, internists shouldn't neglect appropriate adolescent/young adult-related care, including HEADDSS interviews (**H**ome/family/community environment, **E**ducation plans, **E**mployment goals, **A**ctivities, **D**iet, **D**rugs, **S**ex education/contraception, **S**uicide/mental health) tobacco/alcohol/drug use screening, and HIV/STI testing and counseling, if appropriate.

Internist-Dominated Care

Medical conditions commonly managed by internist-dominated care include cerebral palsy, intellectual disability and autism spectrum disorders, and genetic disorders (e.g., Down syndrome, William syndrome, Fragile X). These patients tend to rely more heavily on internists because they have multiple healthcare needs, which must be coordinated between several subspecialists. Physicians must be attentive to their population's primary care needs as well as help their patients navigate the complex network of social resources in the community. With internist-dominated care, the primary care physician is responsible for coordinating care between necessary specialists, ancillary care, and community resources. The onus of understanding the medical complexities of the patient's condition, as well as the appropriate primary/preventative care, falls on the internist. Routine screenings, STI/HIV testing, and young adult primary care should be offered alongside special medical care for the patient.

Medication Reconciliation/Polypharmacy

With building independence, there is a shift in responsibility as young individuals with childhood chronic conditions are assuming more responsibility for their medications and healthcare in general. These individuals are at more risk for polypharmacy than their counterparts in the general population. A review of medications with the patient and caregiver if applicable allows providers to understand the patient's level of readiness to take an increasing role in his/her healthcare. It is important to review the adverse effects of long-term medications such as anti-epileptics which increase the risk of osteoporosis [28] and phenothiazine, which can cause weight gain and QT prolongation that increases the risk for reentrant tachycardias [29].

Secondary Medical Conditions

Adult providers routinely customize care based on their patient's medical conditions. In the case of teens with chronic childhood conditions, customized care requires an awareness of associated or secondary conditions that may occur in this population. Secondary conditions refer to those conditions that a person with a preexisting disability experiences at a higher rate than the general population and are generally regarded as preventable [30]. For example, adults with juvenile idiopathic arthritis (JIA) are more at risk for pain, anxiety, and depression than their peers [31].

In general, there are multiple secondary and coexisting conditions seen at a higher frequency in teens with chronic conditions originating in childhood including; obesity, vision and hearing problems, hypothyroidism, congenital heart disease, gastrointestinal problems including constipation and gastroesophageal reflux disease, chronic pain, and epilepsy [32–34].

Behavioral Health

Children and young adults with chronic health conditions have a higher risk of behavioral conditions. Data links chronic disease with dysthymia [35], depression [35], and anxiety [36]. Primary care providers have an opportunity to address new behavioral issues or worsening of an existing behavior disorder at follow-up visits. Underlying medical causes of behavioral changes should be considered. Pain and distress are common causes of behavioral changes and can be assessed with the caregiver's help and pain assessment tools. There are multiple primary care toolkits to assess behavior changes provided by the American Academy of pediatrics and Got Transition [18]. These assessments incorporate physical, environmental, and emotional factors. Table 2.5 outlines some commonly used screening tools for psychiatric conditions.

Anxiety

Youths with chronic disease have a higher incidence of anxiety than their peers in the general population [36]. Several risk factors have been identified including female gender, severity of chronic disease, time from diagnosis, and living in a single-parent household. Anxiety in children with chronic

Table 2.5 Screening tools for common psychiatric comorbidities

Psychiatric condition	**Screening tool**
Depression	PHQ-9
Generalized anxiety disorder	GAD-7
Obsessive-compulsive disorder	Florida Obsessive-Compulsive Inventory
Post-traumatic stress disorder	PC-PTSD
Behavioral disorders	SSBD, BASC-2

disease tends to present with more externalizing behaviors as well as somatic complaints. Young adults may express anxiety by crying, tantrums, freezing, or clinging. Other qualifiers of anxiety (including separation anxiety) may be present in young adults who have learning or other developmental disabilities.

Depression is extremely prevalent in persons with chronic disease [35]. Like other psychiatric conditions, young adults with chronic childhood diseases may present differently than older adults. For example, teens and young adults may present with irritability in lieu of depressed mood or anhedonia. A careful evaluation and mental status exam can be used to evaluate this population for depression.

Condition-Specific Medical Knowledge

When caring for adolescents and young adults with chronic health conditions, adult providers have multiple resources to increase their condition-specific medical knowledge. As these are childhood-onset conditions, the American Academy of Pediatrics (AAP) publishes guidelines on the management of most chronic diseases. Additionally, the ACP and Got Transition have online resources which include disease-specific materials for common AYA with chronic medical conditions. Finally, there is emerging adult literature on the management of chronic childhood conditions including *Care of Adults with Chronic Childhood Conditions* by Pilapil et al. [37]. Readily available resources during an initial visit can facilitate transition and improve quality of care for AYASHCN. Table 2.6 outlines some sample diseases and their long-term management.

Health Maintenance

Regarding preventive care of individuals transitioning to adulthood, the American Academy of Pediatrics (AAP), American College of Physicians (ACP), and American Academy of Family Physicians (AAFP) recommend applying the same guidelines for primary and preventive care for all adolescents and adults, including those with special health-care needs. Examples of such guidelines include the American Medical Association's *Guidelines for Adolescent Preventive Services* (GAPS) and the US Public Health Service's *Guidelines to Clinical Preventive Services*.

Sexual Health

Sexual health is often overlooked in young adults with chronic diseases of childhood. With this group, it is often assumed that they are not sexually active. Sexuality and sexual relationships are not addressed appropriately in the health-care setting [41, 42]. Although disabled adolescents may have delayed puberty and are more socially isolated, they are as sexually experienced as their nondisabled counterparts [43]. The need for comprehensive sex education in this population is great, and discussion of sexuality, contraception, and abuse must be a standard part of anticipatory guidance for all teenagers with chronic conditions.

Table 2.6 Common comorbidities in the management of AYA with chronic diseases [38–40]

Common comorbidities/long-term management of young adults with chronic diseases of childhood	
Cerebral palsy	Contractures, scoliosis—orthopedic evaluation Constipation—aggressive bowel regimen Dysphagia/Aspiration—periodic speech and swallow evaluation Gastroesophageal reflux disease—feeding by gastrostomy tube Decubitus ulcers—assess at each visit
Genetic syndromes (trisomy 21, Prader Willi, Williams)	Acquired valve dysfunction (MVP most common)—baseline echo, then periodically Behavior disorder—screen at each visit Celiac disease—consider serology Hearing loss—yearly hearing exam Iron deficiency anemia—assess yearly Sleep apnea—screen periodically Thyroid dysfunction—annual screening Visual loss (cataracts, keratoconus)—eye exam every 3 years Obesity, hypertension—annual screening
Epilepsy	Polypharmacy—evaluation of medications and side effects Sports/activity evaluation Driving evaluation—patients must be seizure free to drive
Autism spectrum disorder	Higher rates of physical conditions: allergies, asthma, gastrointestinal problems, epilepsy Higher rates of mental health conditions: ADHD, sleeping disorders, anxiety/depression

Sexual Abuse

Young men and women with invisible chronic diseases are more frequently victims of sexual abuse when compared to their typical controls [44]. The US Department of Justice reports that 68–83% of women with developmental disabilities will be sexually assaulted in their lifetimes and less than half of them will seek assistance from legal or treatment services [45]. There are many factors contributing to the increased risk of abuse including limited education and decision-making, dependence on others for care, exposure to large number of caregivers and settings, inappropriate social skills, inability to report abuse, and lack of strategies to defend themselves [46]. As much as possible, the same discussions about sexual and reproductive health should occur with the patient and/or caretaker.

Contraception

There are a variety of reasons to provide contraception. As discussed above, there is a higher rate of sexual abuse. Contraception can also be used for therapeutic amenorrhea and to treat dysmenorrhea and menorrhagia. In severely disabled individuals, therapeutic amenorrhea is useful for those who are frightened or for whom hygiene is difficult. Both contraception and the possibility of sexually transmitted diseases should be addressed, and it ideally should occur directly with patients if they are autonomous.

Cervical Cancer Screening

The current American College of Gynecology guidelines recommends that women aged 21 and older have Pap tests every 3 years [47]. There are several studies to show that women with disabilities are less likely than those without a disability to report receiving a Pap smear in the past 3 years [48]. A practical approach may be to have an initial Pap smear and then modify frequency based on the individual's sexual activity and risk for abuse. Some women with disabilities such as cerebral palsy may require accommodations including extra support staff, positioning modifications, and a lengthier visit. However, these modifications should not preclude performing the pelvic exam. Every attempt should be made to provide the same health preventive guidelines for the individuals with chronic health conditions/developmental disabilities as provided for the general population.

Health Disparities

Adults with intellectual disabilities experience inequities in health status at a disproportionately higher rate than the general population [49]. The difference in health status is multifactorial. Health disparities can be due to the underlying condition, negative determinants of health such as poverty, and the differences in healthcare access or quality of services [50]. In general, individuals with chronic health conditions have fewer resources and are less equipped to navigate the healthcare system. Some of these patients may be underinsured and may need help accessing initiatives such as food stamps/supplemental nutrition support, utilities assistance, and affordable housing. Physicians can improve healthcare access for these patients by providing referrals to a social worker and information for local resources.

Ethical Considerations

Those who care for adults with childhood illnesses contemplate bioethical principles as they deal with guardianship, shared decision-making, healthcare disparities and school modifications, sexual health needs, and end-of-life discussions. Providers sometimes consider quality of life in determining both screening and medical treatment decisions. A 2010 study showed that nondisabled people believe that the quality of life of people with disabilities is extremely low. However, when disabled people rate their own quality of life, it is only slightly lower than when non-disabled people self-report their own quality of life [51]. The literature shows that healthcare professionals' opinion of quality of life of people with disabilities is lower than both the opinion of the general public and the disabled individual's own opinion [52]. Healthcare providers must be aware of their own potential bias when discussing treatment options for medical conditions as well as for screening procedures.

Conclusion

Most adult providers have a small number of teens with chronic health conditions transitioning to their practice; there are multiple elements in the successful transition of youths with chronic illnesses from pediatric to adult providers. Pediatricians should encourage families to stay involved during the transition process while helping patients to become more autonomous and encouraging increasing self-care. There are a variety of uncommon medically complex primary diagnoses and numerous secondary health conditions. Coordination is required for the large number of subspecialists utilized. Physicians should plan increased time with these patients as well as additional time outside the office visit to coordinate services and provide care. Additional resources such as a social worker and dedicated nursing are often required. The challenges of caring for young adults with chronic disease of childhood come early, and anticipating these challenges becomes the responsibility of the primary care physician. The ultimate goal is that of *Healthy People 2020*, to attain high-quality, longer lives free of preventable disease, disability, injury, and premature death, eliminate health disparities, and create social and physical environments that promote good health for all.

Clinical Pearls

- Request and review all documentation from patient's pediatrician. Review past medical history, with attention to birth history and developmental history.
- Assess for polypharmacy, discuss long-term adverse reactions, and assess need for continued treatment.
- Assess patients' functional status and define status based on the ability to perform activities of daily living (ADLs), e.g., feeding, dressing, toileting/self-hygiene, and IADLs, e.g., grocery shopping, meal preparation, telephone communication, financial management, and medical decision-making. Describe as **I**ndependent, requires **A**ssistance, or is **D**ependent for a particular activity.
- Review specific medical considerations; common comorbidities affecting patients with chronic diseases.
- Review condition-specific medical guidelines; AAP, Got Transition, *Care of Adults with Chronic Childhood Conditions* by Pilapil et al..
- Psychiatric diseases are comorbid with chronic diseases of childhood; many screening tools are available to evaluate for common psychiatric conditions.
- In patients who do not have decision-making capacity, counsel family regarding legal guardianship or alternatives that allow for shared decision-making, advance directives, and end-of-life care.

Don't Miss This

- Provide routine young adult/adolescent care when working with transition-age patients (e.g., HEADSS screening, alcohol and tobacco counseling, STI/HIV testing and counseling).
- Discuss sexual health early and often staring at the initial transition visit.
- Anticipate lapses in insurance and ensure that your patients will remain insured while under your care.
- Recognize biases in quality of life considerations that may affect care.

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