Introduction

When was the last time you saw a 22-year-old male in your clinic? How long was the visit and what issues were addressed? It is possible that certain assumptions were made regarding that individual—about where they lived, their level of education, their personal life, and their health.

For most internists, visits with young adults are often brief and “easy visits.” After seeing multiple middle-aged or elderly patients with multiple chronic medical conditions, internists often find that there is not much to discuss in their visits with young adults, and may even view these visits as opportunities to catch up or even get ahead in their schedule. Most young adults are healthy, and these patients are sent on their way after a brief exam and a few routine labs. In fact, browsing through the United States Preventive Services Task Force (USPSTF) guidelines for a 22-year-old male, the guidelines can be summarized in a few words: check blood pressure and screen for tobacco use and sexually transmitted infections (STIs).

But why then, does this 22-year-old male become a 50-year-old obese male who develops diabetes, hypertension, and cardiovascular disease, who ends up on dialysis because of diabetic nephropathy and needs a 3-vessel coronary artery bypass graft (CABG) from severe coronary artery disease (CAD)? What was missed during those routine “easy” visits with him when he was younger and healthy? Was there anything that could have been prevented?

As it turns out, the answer is yes. During the young adult years, there are many opportunities...
for early intervention that can alter the patient’s life course. This might not be so apparent to internists, who primarily see older adult patients who have already developed fixed habits and lifestyles and already suffer from several chronic medical conditions. In fact, many adult health conditions originate in childhood and adolescence during critical periods of development [1]. Combined internal medicine and pediatric (med-peds) physicians and family physicians are more familiar with these childhood and adolescent antecedents to chronic medical conditions, as they often witness firsthand the evolution of these conditions as their patients grow older and transition into adulthood. All primary care providers have an obligation to help minimize risk factors that can cause cardiovascular disease, cancer, and other adult chronic conditions, and to help maximize health-promoting protective factors that can facilitate development along optimal health trajectories.

**Emerging Adulthood**

The period of transition to adulthood, between 18 and 25 years, now commonly referred to as “emerging adulthood” is a distinct phase in life that was first described originally by Arnett [2], and is a unique period involving a transition to independence. This phase is wrought with its challenges and changes that can impact the health of a person for years to come. As described by Arnett, emerging adulthood can be defined as an age of identity exploration, instability, self-focus, feeling in between, and possibilities [3]. It is a state of flux and transition, and one in which medical providers can take part to help navigate young adults toward their future paths.

Unlike other age groups, emerging adulthood is characterized by demographic heterogeneity. For example, most 30-year olds live independently, are in long-term relationships, and have clear career paths ahead of them. Similarly, most 16-year olds live with their parents, have just entered the dating scene, and attend high school. However, those in the 18–25 age group do not fit such generalizations—40 % of them are not enrolled in college while 60 % entered college immediately after graduating high school, 33 % are unmarried but 67 % of them live with their partner, and only 40 % have full-time jobs [4–7]. Such statistics speak to the wide demographic variety of this patient population, and affirm the importance of clarifying such issues with the patient to better understand their life circumstances, many of which may be important determinants of their adult health.

However, there are many issues that are unique to emerging adulthood. It is well known that young adulthood is the time during which people have the most weight gain and increased risk for being overweight in the future [8]. This has been accentuated in recent decades by the development of cheap, processed food high in processed sugars and saturated fats that individuals are more likely to buy due to price and convenience, as they become more responsible for food planning and preparation [9, 10]. In fact, rates of obesity at age 25 have increased by 30 % in recent cohorts [11].

Another major issue in young adulthood that can predict future behaviors is substance use. This often commences with exploratory behaviors in adolescence, but peaks during young adulthood and can predict future behavior. For example, regular alcohol consumption at a younger age is associated with increased problem drinking in adolescence and alcohol use disorder in adulthood [12, 13].

Sexual risk behavior should also be addressed during regular visits in the emerging adulthood period. Although people aged 15–24 years represent only 25 % of the overall population, they account for nearly half of all the new cases of STIs each year [14]. Moreover, it is important for providers to be aware of how new technology may be impacting sexual behaviors. People who seek partners online have reported higher risk sexual behaviors including more unprotected sex, more sexual partners, and more STIs [15–18].
How HEADDSS Impacts Prevention

Much of these behaviors can be uncovered by performing a thorough HEADDSS (home, education/employment, activities, drugs, diet, sexuality, suicide) assessment (Table 2.1) [8, 12, 13, 19–28]. Although commonly taught in medical schools to be used primarily for adolescents, this tool can be instrumental in identifying key patient demographic features, which can reveal potential risk behaviors that would benefit from intervention. For example, such an assessment can facilitate questions about drug addiction, sexual promiscuity, and symptoms of depression, all of which are important issues that if intervened on at the right time, can impact future health. As stated earlier, a routine health visit with a young adult would be incomplete if a provider simply referenced the age-specific USPSTF guidelines; completing a HEADDSS assessment is equally critical during these visits. The HEADDSS assessment delves into topics not touched upon by the USPSTF, but which have clear evidence supporting their discussion in a primary care setting.

The following cases will highlight crucial topics that, if addressed at opportune times, can redirect an at-risk emerging adult and prevent unhealthy habits and lifestyles from becoming into irreversible chronic medical conditions.

Preconception Counseling and the Emerging Adult

Lisette is a 24-year-old woman coming to see you to establish care. When you first meet her, she is a pleasant, well-groomed female. Her vital signs are notable for a body mass index (BMI) of 30, but are otherwise within normal limits. You start to flip through her chart, asking the occasional clarification question about her past medical history, which seems relatively benign, and she does not seem to have any alcohol or substance use problems. She does tell you, when you ask about sexual history, that she is monogamous with her boyfriend, and gives you a little smile, admitting she met him on Tinder. You collect the rest of the history without much standing out, and you move on to the physical exam, which is within normal limits except for her weight. You also do her Pap smear, as she is due, and collect a sample for STIs while doing her pelvic exam. You finish your exam and finalize your electronic charting, and are pleased to note that you are running 5 min ahead on your 30-min new patient exam slot time. As you stand up to leave, Lisette asks, somewhat shyly, if she can have a prescription for “birth control.” You’ve already asked her sexual history, and she tells you she uses condoms, but she and her boyfriend want to start having unprotected sex and she also heard that the pill can help her cycles, which are annoying her with their irregularity. When you ask her about her condom use, she blushes and reveals that her boyfriend only starts using protection halfway through the intercourse act. She shrugs when you ask what her thoughts are if she should become pregnant. You agree condoms might not be a good choice for her, and explain to her a little about the options of birth control. You end up writing her a prescription for some standard-dose oral contraceptives based on her answers. You remind her about using a backup method, answer her last questions, and move on to your next patient.

Lisette’s case provides an illustration of many of the routine women’s health issues faced by the internist. While obese, she is generally healthy, but is dealing with a multitude of topics that have serious implications for her future health and quality of life, specifically, her choice and pattern of contraception, her obesity and its impact on her future fertility, her attitude about pregnancy, the vague signs and symptoms that could be consistent with polycystic ovarian syndrome (PCOS), and her use of a social media application for dating. Each of these offers a thread that if followed, leading to highly relevant health topics that are frequently overlooked by the busy provider.

First and foremost, Lisette’s choice of and pattern of condom use should be explored, as it foreshadows a risk of unintended pregnancy. According to data from the 2006 to 2010 National Survey of Family Growth conducted by the Centers for Disease Control and Prevention (CDC), 37 % of pregnancies were unintended (either unwanted or mistimed) among women who had ever been married. For women like Lisette, between 15 and 24 years old and not married or cohabitating, a full 79 % of live births were unintended. Even when looking at married women ages 25–44 years, almost one in five
births were unintended during this time period [29]. When considering the factors leading up to unintended pregnancy, Lisette is not unique in her sporadic condom use. Sixty-one percent of all women using condoms do so inconsistently, a number related to a woman’s prior experience

Table 2.1 Adapting the HEADDSS for use with emerging adults [8, 12, 13, 19–28]

<table>
<thead>
<tr>
<th>H</th>
<th>Home/Family/Community environment</th>
<th>Important social determinant of health and education</th>
<th>A positive family environment during adolescence (low family conflict, high family warmth, effective child management) predicted higher levels of educational attainment in early adulthood [19]. Maltreatment in the home environment “is associated with adverse outcomes in physical health, brain development, cognitive and language skills, and social–emotional functioning [20]”</th>
</tr>
</thead>
<tbody>
<tr>
<td>E</td>
<td>Education plans, employment goals</td>
<td>Promotes financial security</td>
<td>Higher level of education directly correlates with lower unemployment rate and higher median weekly earnings</td>
</tr>
<tr>
<td>A</td>
<td>Activities, hobbies, exercise</td>
<td>Key factors that contribute to health outcomes</td>
<td>The ability to access safe environments for recreational activities may influence exercise activity [21]. Physical activity during adolescence predicted change in body mass index (BMI) during young adulthood. Sedentary behaviors during adolescence predicts type 2 diabetes mellitus (DM) during young adulthood [22]</td>
</tr>
<tr>
<td>D</td>
<td>Diet</td>
<td>Decreases obesity epidemic</td>
<td>Most weight gain occurs during young adulthood and increases risk of being overweight in the future [8]</td>
</tr>
<tr>
<td>D</td>
<td>Drugs</td>
<td>Prevents addiction behaviors</td>
<td>Initiating alcohol use earlier and heavier alcohol use during adolescence and young adulthood predict a higher likelihood of lifetime substance and alcohol abuse [12, 13, 23]</td>
</tr>
<tr>
<td>S</td>
<td>Sex, contraception, relationships, reproductive planning, and preconception care</td>
<td>Prevents unwanted pregnancies, STDs</td>
<td>Rates of unintended pregnancy are highest among women aged 18–24 [24]. “The pregnancy rate among women attending the trained clinics for pregnancy prevention was about 8 pregnancies per 100 women per year, compared to about 15 pregnancies per 100 women per year among those at the untrained clinics” [25]</td>
</tr>
<tr>
<td>S</td>
<td>Suicide, mental health</td>
<td>Identifies thoughts and/or behaviors before they have permanent consequences</td>
<td>“Up to 45 % of individuals who die by suicide have visited their primary care physician within a month of their death” [26]. Training healthcare providers in suicide prevention can decrease rates of suicide [27]. Screening for major depression using Patient Health Questionnaire-2 (PHQ-2) in a primary care setting had 86 % sensitivity and 78 % specificity with a score of 2 or higher; for the PHQ-9, they were 74 and 91 %, respectively, with a score of 10 or higher [28]</td>
</tr>
</tbody>
</table>

The original HEADSS assessment was developed by Dr. Henry Berman in 1972 for use with adolescents
with unintended pregnancy (she is 40 % more likely to use them consistently if she has been through this experience) and with feeling that avoiding pregnancy is a little or not important (these women are 2.6 times less likely to report consistent use than a woman who believes this is very important) [30]. If Lisette does want to avoid pregnancy, finding a contraceptive method that she likes and will use is important; 95 % of unintended pregnancies occur among women who use contraception incorrectly or inconsistently [31]. At minimum, discussing with Lisette her options of long-acting contraception may be in order, as both oral contraceptives and condoms have high failure rates with typical use at 9 and 18 %, respectively, over the course of 1 year [32]. If Lisette’s approach to pregnancy changes or if she continues to have sporadic use of contraception, it may be beneficial to suggest she begin taking a prenatal vitamin on a routine basis.

Another aspect of Lisette’s visit that should be addressed is her obesity. Given that you were trying to cover a broad range of her health history and focus on her contraceptive needs, her weight and its implications on her current and future fertility were not a significant topic of your discussion. While she may feel ambivalent toward pregnancy now, she may have a harder time getting pregnant when she does desire pregnancy, with 3 times higher rates of ovulatory infertility for overweight females (BMI ≥ 27 kg/m²) [33]. Once she is pregnant, obese women (BMI ≥ 30 kg/m²) are at higher risk of adverse outcomes, including gestational hypertension and diabetes, pre- and post-term birth, fetal growth and congenital anomalies, cesarean delivery, and postpartum hemorrhage. In one review, the relative risk of fetal death increased 1.21 (95 % CI 1.09–1.35) for every 5-unit increase in maternal BMI, for stillbirth 1.24 (1.18–1.30) and for perinatal death 1.16 (1.00–1.35) [34]. Weight loss prior to pregnancy reduces many of these risks, although the data are less clear on the effect on mortality. Having a chance to speak with Lisette about her weight and other aspects of prenatal care before she becomes pregnant is an opportunity that few providers utilize—only 18 % of women 18–44 years old who delivered a live infant in 2009 reported receiving preconception counseling, although 66 % of women 18–44 years overall had an annual routine check-up [35].

Reproductive planning in general is a crucial topic for women in their 20s and 30s, and Lisette’s cavalier attitude is unfortunately common. This age is a time of relentless career pursuit or higher education for some, and fertility is either purposefully delayed or something not even considered for many. Unfortunately, as is well known to many doctors, but less commonly known to patients, biology is rarely forgiving. Using data from the CDC’s 2012 report on Assisted Reproductive Technology (ART), women are less likely to become pregnant and then to carry that pregnancy to term as they age, with a drop off that occurs in the mid- to late-30s. While about 40 % of ART cycles for women at age 30 will result in a live birth, this number is closer to 30 % by age 36, and reaches 12 % by age 41. Carrying a pregnancy to term becomes a single-digit feat by the time a woman is age 42 [36]. For those who successfully deliver, the risk of birth defects increases with age. Comparing women 25–29 years to those 40 years and older, babies born to older women had a higher risk of cardiac defects (adjusted odds ratio [aOR] 2.2–2.9), esophageal atresia (aOR 2.9), hypospadias (aOR 2.0), and craniosynostosis (aOR 1.6) [37]. The risk of her 16-week-old fetus having Down syndrome, the most common genetic abnormality, is 1:733 for a 30-year-old woman, 1:265 for a 35-year-old, and 1:60 for a 40-year-old. Bringing up these statistics with a young woman can help her to plan her future.

Lisette’s fertility may be additionally impacted by your suspicion of polycystic ovarian syndrome (PCOS). Many young patients may have additional signs and symptoms of PCOS not readily apparent to the provider. Women
often depilate unsightly hair, so asking about the patient’s grooming habits can be a key part of the history. PCOS is not a trivial disorder. Patients who have PCOS are at increased risk for endometrial hyperplasia and future infertility given their chronic anovulatory cycles, and also can have hirsutism, insulin resistance, and dyslipidemia. Weight loss is a first-line intervention for the underlying hormonal and metabolic dysregulation. Those not pursuing pregnancy benefit from oral contraceptives to regulate menses, and other adjunctive medication for the hirsutism, such as spironolactone, anti-androgens, or topical hair removal agents.

Finally, Lisette’s brief mention of the social media application Tinder requires the modern internist to at least have a rudimentary grasp of the habits and knowledge of this demographic. While the technology is rapidly evolving, social media has become a primary means to meet new romantic partners discreetly and quickly, and is a mainstay of the generation. In 2013, one in five adults of 25–34 years old and one in ten of all adults of 18 and older were dating online, either through cell phone applications or online dating websites [38]. While some smartphone or Internet applications have respectable reputations, others can be a synonym for a quick way to meet a partner for a one-night stand. Knowing which means which can help tailor your line of questions to screen for high-risk sexual behaviors accordingly. A brief primer to show the diversity and range of choices is listed in Table 2.2, although the technology is rapidly evolving.

### Mental Health and Substance Use in the Emerging Adult

Joe is a 25-year-old male presenting to your urgent care clinic with a complaint of palpitations. He is wearing a T-shirt, shorts, and sandals, and sports a few days’ worth of stubble. His heart rate is 92, and he appears to be in no acute distress in your office. As you begin your questioning, he describes

<table>
<thead>
<tr>
<th>Website or application</th>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook</td>
<td>Online website with cell phone application</td>
<td>Networking with all levels of casual friends and acquaintances. Potential for connecting romantically via private messaging or “friending” someone, but generally used platonically</td>
</tr>
<tr>
<td>Coffee Meets Bagel and Hinge</td>
<td>Cell phone applications</td>
<td>Daily potential matches sent to your phone, selected from mutual Facebook connections. If both users accept, a private chat opens. Considered friendly, mostly young adult-based dating applications</td>
</tr>
<tr>
<td>Tinder</td>
<td>Cell phone application</td>
<td>“Swipe” to search through potential matches. A mutual match between users opens a message. Initially a “hook-up” app, now becoming respectfully mainstream for longer term dating</td>
</tr>
<tr>
<td>Grindr</td>
<td>Cell phone application</td>
<td>Successful application geared toward gay or bisexual men, with “hook ups” as predominant goal</td>
</tr>
<tr>
<td>Match.com</td>
<td>Online website with cell phone application</td>
<td>Longstanding subscription dating website and newer cell phone application with almost 35 million users (2015), for those looking for long-term relationships. Considered more sincere, likely due to the cost associated with signing up</td>
</tr>
<tr>
<td>Jdate</td>
<td>Online website with cell phone application</td>
<td>Specific for Jewish singles looking to meet for long-term relationships</td>
</tr>
<tr>
<td>OkCupid</td>
<td>Online website with cell phone application</td>
<td>One of the most popular free dating websites, uses extensive data to match profiles of users looking for relationships</td>
</tr>
<tr>
<td>Meetup</td>
<td>Online website with cell phone application</td>
<td>Geared toward connecting people with similar interests, not technically a dating website</td>
</tr>
</tbody>
</table>
occasional moments where he feels his heart racing and a sensation of his heartbeat against his chest. Flushing of the face and a wave of nausea overtakes him and he feels the need to remove himself from whatever social situation he is in. After a cursory and benign cardiac exam, you obtain an electrocardiogram (EKG), which demonstrates a normal sinus rhythm with no evidence of hypertrophy. Reassured, you diagnose him with panic disorder and prescribe an as-needed short-acting benzodiazepine. As you are about to leave, he asks if it is all right to continue smoking marijuana when he takes the benzodiazepine. Inquiring further, he reveals that he has been smoking marijuana nightly and occasionally using edibles to help “calm his nerves,” especially after he has arguments with his parents.

Joe clearly wants to discuss his family situation further, and you get the sense that this is the first time he has spoken to anyone about this. He says that he was laid off from his first job after college just 6 months ago, and recently had to move back in with his parents. His mother has a long history of bipolar disorder that has recently become more difficult to manage, and he often gets into heated arguments with her. He feels defeated about his work prospects and is having difficulty adjusting to his recent change in environment. You tell Joe that you will put in a referral for a therapist.

Joe’s case features many themes that pervade medical care for emerging adults. Mental health disorders, potentially related to a prior family history of such disorders, often present as mild physical complaints and may be self-treated with illicit substances. Moreover, depression and anxiety may represent difficulty adjusting to new degrees of independence or lack thereof, as many emerging adults are moving back home due to poor job prospects.

Mental health disorders frequently present in early adulthood, with 74% of all mental health disorders presenting before age 25 and 46% of all college-age adults reporting a psychiatric diagnosis within the past year [39]. These may be preceded by a family history of mental health disorders, as well as earlier childhood events that contribute to later presentations: for example, about 20% of college students report a diagnosis of a personality disorder, which typically are present prior to age 18 [39]. Joe’s family history of bipolar disorder places him at a 20–30% risk of developing a major affective disorder in his lifetime; if both parents are affected with bipolar disorder, the risk jumps to 50–75% of any affective disorder [40]. Similarly, marijuana use prior to age 18 increases the risk of schizophrenia [41].

Joe’s complaint of palpitations is not an unusual presentation for an underlying psychiatric disorder. Across all age ranges, somatic complaints of mood disorders are often the primary concern of patients presenting for medical treatment. As many as 45–95% of patients with depression report only somatic complaints, with a twofold risk of a somatic presentation in patients who do not have a definite ongoing relationship with a set primary care provider [42]. Substance use may often serve as a means of self-medication, as evidenced by frequent presentations of “dual diagnoses.” Alcohol is reported as a means of tempering the symptomatology of the extremes of mania or depression, just as marijuana is often used for anti-anxiety purposes.

The legalization of marijuana in Colorado by Amendment 64 in 2012, and its subsequent enactment in January 2014, is emblematic of a growing shift in the use of drugs once heavily controlled or considered taboo. Young adults, similar to the overall population and yet to a greater intensity, have had shifting definitions as to what constitutes “problematic use” of a particular drug. Joe’s use of marijuana is not atypical for marijuana users of his age group. A shift from purely recreational use to “instrumental use” (the goal of use being to achieve a desired effect rather than for pure recreation) has led to a greater trend of daily use, especially in young adults who seek out marijuana’s anti-anxiety properties [43]. Though overall use has decreased in the past 5 years, the proportion of teenagers who perceive great risk from daily marijuana use has dropped to 36% from 52% in 2009 [44]. Even in cases of cannabis hyperemesis syndrome, where chronic daily use is
linked to persistent cycles of vomiting, young adults have difficulty linking their usage with ill effects, as they cite marijuana’s anti-emetic properties as a reason to continue using it. As such, problematic marijuana use is increasingly difficult to categorize, yet negative effects of chronic heavy usage have been defined, as evidenced by a decrease in IQ by 8 points among daily marijuana users from prior to age 18 [45]. Exposure to marijuana in the critical neuroplasticity period of young adulthood is a risk factor for the presentation of schizophrenia, with earlier use leading to a greater risk of schizophrenia than later use [41].

Changing usage patterns for other drugs are given as examples in Table 2.3 [46]. While problematic drug use was often understood within the framework of addiction, tolerance, and withdrawal, many newer drugs (or newer usage patterns of common drugs) do not have the typical physical manifestation of tolerance or withdrawal, or are used in specific contexts, and thus many young adults do not see their usage as characterized by addiction, and therefore, not problematic. While Joe may not characterize his marijuana use as a problem, he is still certainly at risk for long-term deleterious effects of its use. In addition, although Joe reports using marijuana, he should still be screened for tobacco and alcohol, as these substances are still widely used in this age group.

Underlying many of the psychological stressors is the shifting landscape of employment opportunities for emerging adults. In the years following the economic recession of the late 2000s, the proportion of 18- to 29-year olds holding full-time jobs has dropped to the low 40s [47, 48] which according to the Bureau of Labor Statistics is the lowest proportion since the bureau first started collecting data in the 1940s. Faced with poor economic opportunities in the post-college environment, the emerging adults returning to live with their parents have earned the label of “boomerang children” (Pew Social Trends). In this critical period of identity formation and establishment of autonomy and independence from one’s parents, young adults are caught in a difficult situation, where many economic forces are pushing them to rely on their parents for support.

With the advent of the Affordable Care Act, young adults can remain on their parents’ insurance plans until age 26. Thereafter, young adults may not often consider a need for health insurance, or may opt for high-deductible catastrophic insurance. Qualitative work [49] demonstrates a perceived lack of value of health insurance for young adults, especially in those who were previously covered under their parents’ insurance. Responders frequently stated that they were at a lower risk for health problems and thus the financial burden of paying for insurance was felt to be low value for the actual cost. Lower health literacy among young adults is widespread, with less than a third aware of health insurance marketplaces and less than a quarter aware of the

Table 2.3 Changes in usage pattern of recreational drugs

<table>
<thead>
<tr>
<th>Drug</th>
<th>Change in usage pattern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marijuana</td>
<td>Daily usage for anti-anxiety properties. Increasing diversity in routes of administration, e.g., concentrated resin (“dabs”), edibles, lozenges, vaporizers</td>
</tr>
<tr>
<td>Stimulants (cocaine, methamphetamine)</td>
<td>Use in work-related contexts for increased feeling of energy and focus</td>
</tr>
<tr>
<td>Heroin</td>
<td>Transition from abused prescription opioids to heroin as a cheaper alternative</td>
</tr>
<tr>
<td>Synthetic Marijuana (K2)</td>
<td>Increasing usage in areas where marijuana is difficult to obtain. A cheaper alternative with greater potency but also greater proportion of adverse effects</td>
</tr>
<tr>
<td>Party Drugs (MDMA, ketamine)</td>
<td>Frequent use in certain social contexts is not seen as problematic, as it is only limited to that context, in spite of significant risk of harm during usage and long-term neurologic changes associated with repeated use [46]</td>
</tr>
</tbody>
</table>

*MDMA 3,4-Methylenedioxymethamphetamine*
Medicaid expansion [50]. Though coverage for preventive health visits is mandatory within the Affordable Care Act, emerging adults are less likely to request health maintenance visits. When Joe turns 26 and is faced with difficulty obtaining employer-based health insurance due to poor employment prospects, he is less likely to obtain a sufficient coverage plan and will probably opt for a high-deductible plan, which will be unlikely to include sufficient coverage for mental health services. Fewer opportunities to interact with emerging adults in a healthcare setting, as well as a predilection for urgent care presentations, ultimately translate to an increased importance of discussing underlying health and social issues with each point of contact with a young adult patient.

### A Paradigm Shift for Approaching the Emerging Adult/Young Adult Preventive Visit

Primary care providers should recognize these predominant health issues of the emerging adult (18–25 years) and young adult (26–35 years) populations and the potential to optimize the health trajectory over the entire adult life span. At a minimum, mental health issues should be screened for and addressed, given the potential morbidity and mortality from these in quality of life and suicide risk, both now and later on in adulthood. Substance use should be examined as well, and motivational interviewing skills applied with vigor, recognizing that it can be easier to work with a patient to reduce or quit substance use earlier than after decades of use. Finally, unlike in the adolescent period when pregnancy is virtually never desired, contraceptive care should be tailored to anticipate potential pregnancy within 1–3 years; and preconception care should be practiced to not only anticipate a potential pregnancy but also to optimize a woman’s health prior to conception to ensure a healthy pregnancy and decrease the risk of birth defects and/or birth complications. Table 2.4 demonstrates the shift that we propose for adult primary care providers in their care of emerging adults.

### Table 2.4 Paradigm shift for the primary care of emerging adults

<table>
<thead>
<tr>
<th>Old paradigm</th>
<th>New paradigm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescribe birth control and do Pap smear</td>
<td>Explore healthy relationships and reproductive planning</td>
</tr>
<tr>
<td>Thinking medically (i.e., ordering Holter on someone with palpitations)</td>
<td>Thinking biopsychosocially (i.e., exploring anxiety sources for palpitations)</td>
</tr>
<tr>
<td>Ask about substance use to document them</td>
<td>Actively engage in motivational interviewing and other resources to decrease substance use (recognizing it may be easier to get someone to quit if they have only been using for 4 years as opposed to 40 years)</td>
</tr>
</tbody>
</table>

**Emerging Adults with Chronic Childhood-Onset Conditions**

Emerging adults with chronic childhood-onset conditions have increased medical and psychosocial needs, and without additional support may experience worse outcomes, compared with other young adults. Emerging adults with complex medical conditions in general have lower educational achievement and incomes, and more limited work experience than their peers [51]. Emerging adults with chronic conditions are also at higher risk for developmental difficulties, unnecessary dependency, and psychosocial delay [52]. However, a successful transition to adult health care may help prevent this inequality in outcomes by increasing a sense of personal responsibility, enhancing autonomy, and facilitating self-reliance [52].
Despite the benefit of excellent transition care for these emerging adults, studies have shown that their transition to adult health care is often poor. In one study only about 20% of young adults were found to have made a successful transition to adult health care. In another, less than 25% of young adults reported that they had received appropriate transition counseling [53]. Rates of these discussions may be even lower among minorities. In general, racial/ethnic minorities and those with problems with access to care or gaps in health insurance may have poorer transition outcomes.

**Patient-Centered Medical Home**

The patient-centered medical home (PCMH) has been promoted as a promising model for care delivery for all patients, in particular adults with chronic childhood-onset conditions. The first Maternal and Child Health Bureau (MCHB) core outcome explicitly specifies that children with special health care needs (SHCN) should “receive coordinated ongoing comprehensive care within a medical home” [54]. The PCMH is a model of primary care transformation that seeks to meet the health care needs of patients and to improve patient and staff experiences, outcomes, safety, and system efficiency—in other words, to achieve the “Triple Aim” [55].

The National Committee for Quality Assurance (NCQA), which offers PCMH accreditation, requires six standards for certified PCMHs: (1) patient-centered access, (2) team-based care, (3) population health management, (4) care management and support, (5) care coordination and care transitions, and (6) performance measurement and quality improvement. According to the 2011 American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and American College of Physicians (ACP) Transitions Clinical Report Authoring Group, “planned care, as the product of a partnership among health care professionals, youth, and families, has become an essential characteristic of the primary care medical home” [56].

**Chronic Care Model and Other Models of Chronic Disease Care**

The chronic care model was developed in Seattle by the Improving Chronic Illness Care program, sponsored by the Robert Wood Johnson Foundation. It is one of the most popular models for comprehensive care of chronic illnesses. It uses a systematic approach to restructure medical care to create partnerships between health systems and communities with the goal of improving interactions between providers and patients, and in turn, health care outcomes. There are six areas of emphasis: (1) organization of health care (e.g., removing barriers to care and mobilizing sufficient care resources); (2) community linkages (e.g., creating partnerships with community-based resources and public health agencies); (3) self-management support (e.g., facilitating patient empowerment and skill-based learning); (4) delivery system design (e.g., coordinating and streamlining care processes and workflows); (5) decision support (e.g., providing guidance for providers through the electronic medical records (EMR) and other means to provide evidence- and value-based care); and (6) clinical information systems (e.g., tracking meaningful outcomes and providing feedback to both patients and providers) [57].

Other models have broadened the definition of comprehensive care for chronic conditions. These include the innovative care for chronic conditions (ICCC) model published by the World Health Organization (WHO) [58] and the expanded chronic care model proposed by Barr et al. [59]. These models also incorporate prevention efforts, social determinants of health, and enhanced community participation as core components of chronic disease care [57]. The ICCC also has a larger focus on supporting “positive policy environments” (e.g., partnerships, legislative frameworks, human
Steps for Caring for Adults with Chronic Childhood-Onset Conditions

We here present our interpretation of the ten essential steps for adult primary care physicians (PCPs) accepting care for young adults with chronic childhood-onset conditions to provide them with the excellent, comprehensive care they deserve (“Appendix”). We assume care takes place in the context of a PCMH that embraces comprehensive chronic disease management as defined by the chronic care model and other models. These steps have been adapted for adult practices from steps for children’s practices that serve children with SHCN, such as those created by the national “Got Transition?” campaign.

Step 1: Health Care Policy Statement

The first step for a practice that will be caring for adults with a chronic childhood-onset condition is developing a written health care policy statement for the transition and future care of the young adult. Attention to care transitions is an explicit part of the National Committee for Quality Assurance (NCQA) PCMH designation. This health care policy should be developed with input from young adults transitioning to adulthood. Ideally, it may also be developed jointly with children’s practices from which the adult practice often accepts transitioning patients. The policy should explicitly state the practice’s expectations of the young transitioning adults and their families, and describe the practice’s transition and future care process.

After the policy is developed, all practice staff should be educated and trained with regard to its implementation, including the specific roles of the patient, the family, and the health care team members. The policy should be prominently displayed and readily available to patients and their families.

Step 2: Tracking and Monitoring: Utilizing Clinical Information Systems

As specified in the chronic care model, practices should use clinical information systems to improve their practice [57]. Performance measurement and quality improvement is also part of NCQA PCMH accreditation. All transitioning young adults should be entered into a registry with tracking of data related to achievement of successful transition. Each adult practice should develop its own measures to define success, such as completion of each step of the transition process and improvement in relevant patient disease outcomes. It should also include measures addressing social determinants of the patient’s health (see Step 8).

For each patient, the registry should be used to track the young adults’ progress and health status. If possible this registry data should be incorporated into the electronic health records (EHR). This registry will enable “empanelment” of patients. This means linking each patient to a care team and PCP [60]. In turn this enables each physician and team to later engage in population health management (see Step 10).

Step 3: Transition Readiness Assessment and Goal-Setting

A transition readiness assessment should be conducted before the young adult transitions from the children’s practice to the adult practice. Ideally, these assessments would have been performed at least yearly beginning no later than age 14 (www.gottransition.org), but this may not be within the adult practice’s control. The assessment should include evaluation of competencies for self-care; insurance status with regard to eligibility for adult services; entitlements and guardianship; cultural and religious preferences; and young adult’s ability to perform self-care management tasks such as manage medications, keep appointments, track health issues, discuss their care with providers, manage their lifestyle choices, and perform other transition-related activities. There are several validated transition tools available, such as the Transition Readiness Assessment Questionnaire (TRAQ).
Perhaps the most important part of the transition process is the development of goals for successful health care. These goals should be developed collaboratively between the health care team, young adult, and family. These goals again will ideally be created by the young adult’s pediatric practice, but regardless will need to be (re-)addressed by the accepting adult practice. These goals should be individualized based upon factors identified during the readiness assessment, such as the young adult’s medical status, intellectual ability, independence and future functioning goals, and guardianship status [56]. Goals should be set with regard to future functional status, employment, romantic relationships, and end-of-life care [56].

This time is also an opportunity to encourage the young adult to begin to assume more responsibility for his/her health care, if he or she has not already [61]. The physician should attempt to ensure that the young adult understands his/her condition and medications, and, if parents are still closely involved, work with them to gradually release responsibility to their young adult. If the young adult is with his or her parents at the initial visit, physicians should also meet privately with the young adult, with the goal of encouraging their independence, if developmentally appropriate.

**Step 4: Written Health Care Plan**

For each young adult transitioning to adult care, a written health care plan should be developed. The basic structure and elements of this plan should be standardized by each practice. However, every plan should be customized and adapted to each patient’s unique needs [56]. Like the readiness assessment, this plan should ideally be completed by the pediatric practice no later than age 14 [62]; however, it again will need to be (re-)addressed and customized by the adult practice. Once transition goals have been created (see Step 3), the written plan should contain a list of prioritized actions to achieve these goals. Each action should have a process and time deadline for completion. Actions will need to be taken in many areas, including, but not limited to the following.

**Creation of Health Care Team**

Team-based care in an essential element of the PCMH (see Step 6). Health care team members need to be explicitly identified, including, most importantly, a point person for the young adult’s care. The ideal point person is located in the accepting adult PCP’s practice and can work closely with this physician. This person should act as an advocate and primary contact for the young adult and his/her family in navigating the transition process [52].

The point person and the physician cannot care for the patient alone. Advance PCMH practices involve many others, particularly in the care of complex patients such as young adults with chronic childhood-onset conditions. These might include nutritionist/dieticians, pharmacists, behavioral health workers or psychiatrists, social workers, care managers, even peer health coaches. Each care team will need to be customized to the needs of the patient and the environment and resources of the primary care practice.

Adult specialty physicians will also likely need to be identified and plans made to coordinate with these physicians and their practices (see Step 7). A plan should be made as well for where to receive emergency care and any inpatient tertiary care. It may also be worthwhile to review which medical situations merit emergency room visitation versus clinic phone calls or appointments.

**Insurance**

The patient’s insurance status should be scrutinized to ensure that care with all planned adult providers as well as any emergency care will be covered. If not, new providers may need to be selected or new insurance obtained. Patients and their families may need assistance in this process from a social worker or other community resources. Ideally, this insurance would also reimburse the new adult providers for transition planning and care coordination [62].
Guardianship
For families of young adults with intellectual disabilities, it is important to plan early to address guardianship issues. The legal age of majority in most states is 18 years. The Health Insurance Portability and Accountability Act (HIPAA) dictates that a physician cannot release information about a patient over 18 without the patient’s consent, regardless of the intellectual level or communication abilities of the patient \[61\]. Therefore, parents should be informed that if and when their young adult becomes 18 they will not be able to be given health information about their adult child without his or her consent or legal guardianship. There are less restrictive forms of guardianship that can provide specific decision-making support while not completely denying the young adult’s participation in that decision. Families will need assistance deciding which form of guardianship best meets their needs and then pursuing this. For more details, please see Chap. 30 of this book.

Culturally and Religiously Appropriate
Great care should be taken to ensure that the health care goals and corresponding actions are sensitive to cultural and religious practices and beliefs. For example, the emergency care plan may need to specify certain measures that are not to be taken, e.g., blood transfusions. Patient or family’s beliefs or preferences, such as preferred degree of involvement in decision-making and method and frequency of contact, and characteristics such as their health care literacy and level of understanding of the child’s chronic condition(s) should be taken into account and accommodations written into the health care plan.

Update Process
With each interaction, and no less than yearly, the young adults’ primary care provider and rest of his/her health care team should reevaluate the health care plan. In light of potential changes in the child’s medical and social status the plan should be updated as appropriate \[62\]. Any patient or family concerns may also warrant revision of the health care plan.

Step 5: Transfer of Care
Transition to adult care should occur when appropriate based upon a young adult’s developmental level, medical status, and relevant policy/licensing requirements, e.g., age of transition from pediatric practices. Whenever possible patients should only be transferred when medically stable, the adult primary care provider should confirm acceptance of care of the young adult with the childhood primary care provider’s team. A pre-transfer visit to the adult practice may also be advised in the year before the transfer of care \[56\].

The accepting adult practice should ensure they have all relevant previous medical information to assume care of the young adult. This should include the child’s complete medical records, which may require obtaining a release of medical information, as well as hopefully an updated medical summary prepared by the childhood provider’s health care team. This medical summary should include all information relevant to the patient’s present medical care and social situation. A copy should also be given to the family. There should also be a direct handoff of care between the childhood primary care provider and the accepting adult PCP, either in person or by phone \[56\]. A similar handoff between present and future point persons, if not the PCPs, should also occur.

The adult practice should ensure there is an emergency care plan, and if needed a condition fact sheet and appropriate legal documents, such as those detailing guardianship. The adult primary care provider should share this information with any adult specialists as well. Examples of a transition action plan, portable medical summary, and emergency care plan are available at www.gottransition.org.

Someone from the accepting adult primary care practice health care team should contact the childhood primary care provider within 3 months of the transition to confirm that the transition of care has been successful. Feedback should be also elicited from this children’s practice on the transfer process, so as to improve and streamline this transition process for subsequent patients.
Ideally, ongoing collaborative partnerships may be forged between childhood and adult providers. Practices should also ask patients and their families for feedback on their experience with the transfer process. The health care team should be sure all relevant data from the transition is entered in the registry so that this may be used for iterative future improvement.

**Step 6: Team-Based Care**

Once the health care team has been created and the transition of care made, great attention should be paid to provide excellent, organized team-based care going forward. Clear roles for team members should be established. Ideally, roles should be constructed such that each individual is practicing “at the top of his/her license.” All team members should be able to coordinate with each other. Optimally, this will involve frequent communication, both in person and via the EHR. Huddles—that is quick in-person meetings at the beginning/end of the day or even before/after individual patient visits—are one common excellent practice to make sure all team members are on the same page. All members should also be empowered to do their jobs individually. This may include standing orders from physicians to enable non-physician staff to complete tasks such as ordering labs or changing medications [60]. There will need to be frequent reflection to ensure workflows are optimized among team members. This is a key part of delivery system design under the chronic care model [57].

**Step 7: Care Coordination**

In particular for young adults with a chronic childhood-onset conditions, attention should be paid to the process of continued seamless coordination with specialists, who may also be transitioning from child to adult providers. Care plans or patient data registries may need to be developed to share among these providers and there may need to be planning for coordinated visits with multiple specialists and other activities of “chronic condition management” [56]. For patients with multiple adult providers, the medical summary may be shared digitally among them to aid in the coordination of care [62]. A shared document in the EHR may be the ideal mechanism for this, if all providers have access. Otherwise, more traditional means such as faxing records and phone calls will be needed to coordinate care.

The PCP and his/her health care team should put forethought into what situations necessitate consultation or referral to specialty providers. Ideally, the PCP should obtain relevant diagnostic studies before referral, preventing the need for unnecessary repeat specialty visits. E-consults, or other consultation with specialists that does not involve in-person visits, may also save time and expense. Similar thought should be put into referral to tertiary or emergency care. If such care is necessary, the adult practice should be sure to provide extra support upon discharge to prevent readmission. There may be a case manager in the practice whose sole function is managing this care coordination.

**Step 8: Address the Social Determinants of Health**

The social determinants of health are everything that affects a person’s health besides their actual disease process, i.e., where he/she lives, works, eats, and plays. These social determinants may have up to a five times greater impact on health outcomes than medical care alone.

To address the social determinants of health, practices need to assess patient’s needs with regard to income, housing, education, access to food, etc. Then, when issues are identified, patients need to be connected to resources to address these issues. Just as important as connection to resources within the health care system is connection to resources in the community. Recall, the foundation of the chronic care model is partnership between health systems and communities [57]. As more recent models for comprehensive management of chronic disease, such as the ICCC, have noted, community participation is essential to address the social determinants of health.
Each practice will need to identify relevant community resources in their community. These may include such varied resources as job training programs, food kitchens, Goodwill stores, etc. A social worker may be a good person to start with to help patients connect to these resources; however, all members of the health care team should see it as their job to address these issues. This may involve a substantial culture shift within the PCP’s practice.

**Step 9: Self-Management Support**

Young adult patients should be empowered to become managers of their own health. To do so requires support and education in self-care. Diabetes is an excellent example. Research has shown that diabetes self-management education (DSME) that teaches patients how to manage their diabetes can dramatically improve diabetes control. There are now national standards for DSME, including skill-based education on using medications safely and effectively; preventing, detecting, and treating acute and chronic complications; physical activity and nutrition; and personal strategies to address psychosocial issues. While there may not be national standards for all chronic childhood-onset conditions, the same principles should be expanded to help aging young adults to successfully manage their own health. This may take many forms, including group classes, online modules or videos, or one-on-one tutorials.

**Step 10: Population Health Management & Continuous Improvement**

The final step of successful care for adults with childhood-onset chronic conditions is population health management. This is again an essential element of the PCMH, as well as a core element of the Triple Aim. Population health was initially defined by Kindig and Stoddart [63] as “the health outcomes of a group of individuals, including the distribution of such outcomes within the group.” Now, though, it has come to mean much more, including (1) addressing not only health but social determinants of health, (2) focusing not just on treatment but on prevention, and (3) assuming shared responsibility as a health care team for patient outcomes [64]. Population health management is enabled by clinical information systems (See Step 3).

Using the patient data established in Step 3, the health care team should periodically and continually reflect on performance for all of their patients, regardless of whether or not these patients have scheduled visits upcoming. As mentioned, data should include disease measures as well as measures of social determinants of health. Data should be relevant to both providers and patients and therefore include both process and outcome measures. Practices should reflect on their performance and seek to improve it. This improvement should happen continuously using quality improvement methodology such as plan–do–study–act cycles. Quality improvement is the final necessary element of a PCMH. To improve performance, practices will need to work on improving all aspects of their practice, such as steps 6–9.

**Conclusion**

Young adults with childhood-onset chronic conditions are at increased risk for poor developmental and health outcomes, and therefore ensuring they receive excellent transition services and then excellent adult care is even more important than for other young adults. Excellent care for such patients requires (1) developing a health care policy statement; (2) utilizing clinical information systems to track and monitor patient outcomes; (3) conducting transition readiness assessments and goal-setting; (4) written, comprehensive health care planning; (5) transferring of care; (6) team-based care; (7) care coordination; (8) addressing social determinants of health; (9) self-management support; and (10) population health management and quality improvement. By implementing these steps, adult providers can achieve better, more equitable outcomes for young adults with childhood-onset chronic conditions.
### 10 Steps for caring for adults with chronic childhood-onset conditions

1. **Health Care Policy Statement**
   - written, posted and readily available
   - developed with input of young adults and their families
   - educate and train all health care staff
   - discuss with all entering young adults

2. **Tracking & Monitoring**
   - data on all patients, including detailed status of each individual
   - measures of disease status and social determinants
   - use for iterative improvement
   - ideally integrate into the EHR

3. **Readiness Assessment/Goal-Setting**
   - use a validated questionnaire
   - address: self-care, insurance, guardianship, culture/religion, self-management, etc.
   - develop goals for functional status, employment, romantic relationships, end of life care

4. **Written Health Care Plan includes:**
   - creation of health care team
   - insurance
   - guardianship
   - cultural/religious beliefs
   - update process

5. **Transfer of Care**
   - time when appropriate
   - obtain all relevant medical info
   - obtain direct handoff

6. **Team-Based Care**
   - clear roles, top of license
   - empowered
   - frequent communication and reflection

7. **Care Coordination**
   - criteria for referral and escalation or care
   - communication, especially via EHR
   - consider case manager

8. **Address Social Determinants of Health**
   - screen for income, food, housing, etc.
   - connect with internal and community-based resources

9. **Self-Management Support**
   - Educate patients for self-care

10. **Population Health Management & Quality Improvement**
    - monitor performance measures on all patients
    - use quality improvement strategies to continually improve
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Care of Adults with Chronic Childhood Conditions
A Practical Guide
Pilapil, M.; DeLaet, D.E.; Kuo, A.A.; Peacock, C.; Sharma, N. (Eds.)
2016, XXVI, 436 p. 10 illus., 9 illus. in color., Softcover
ISBN: 978-3-319-43825-2