

Young Adults Living with Primary Immunodeficiency Diseases



Chapter 31

Young adulthood is a time of independence and self-exploration when individuals separate from their parents and make life choices about education, career, lifestyle, living environment and peer relationships. Although the physical signs of primary immunodeficiency diseases often get the most attention, emotional health is just as important. The transition to adulthood is a challenging time for most people, but the potential ramifications of primary immunodeficiency diseases often require some unique life adjustments.

It is important that you, the patient, have the emotional support and skill set required to cope. Everyone experiences the disease differently, and your individual needs and strengths should be taken into consideration. With the support of family and friends, an effective healthcare team and necessary coping skills, you can lead a fulfilling and productive life.

Normalizing Your Life

Having a primary immunodeficiency disease can affect your daily life and your life choices, but you can make decisions that will help you have a normal, healthy life.

Maintain a balanced life. Those who best manage their disease are those who find a balanced approach to the disease and to life. It is understandable that you would often want a break from focusing on the disease, yet neglect of symptoms or treatment routines can lead to serious health setbacks. It is critically important to manage your disease, including your symptoms and your necessary treatments, while maintaining all the activities and relationships that promote a healthy lifestyle.

Make positive lifestyle choices. The lifestyle choices that you make affect your health. Young adults, especially those living on their own and/or

attending college, may experience living in cramped quarters, late night studying, peer pressures of drugs and alcohol, and dating. However, incorporating good care into your life is realistic. If you attend college, take a manageable course load. If you have a part-time or full-time job, make sure it suits your interests and abilities. Generally maintain good hygiene and enjoy healthy recreational activities. Know your limits.

Participate in recreational activities. Managing a chronic illness can be demanding, especially as you assume the role of healthcare manager and the responsibilities that come with adulthood. However, you should take an emotional break from the disease and form an identity outside of the disease. Make time for recreational activities that you enjoy.

(Normalizing Your Life continued)

Maintain an ongoing dialogue with your parents.

Specifically, have conversations about your changing roles and the transition of managing care. If you were diagnosed as a child, your parents probably play a large role in your healthcare. It can be a big shift for you since your parents have been managing your healthcare and school demands, and it may be difficult for your parents to let go, fearing that you may not make the best choices. It is essential that you are able to manage your healthcare on your own and at your own pace, but keeping open lines of communication and relying on your parents for support and guidance as needed can be beneficial as you navigate adulthood.

Build a support system of family and friends.

Your relationship with your family and friends will evolve as a young adult. You will need to learn to take care of yourself independently of your family and under different living conditions. This may mean depending upon friends and significant others for help while you are ill. Learning to ask for support when you need further assistance can be difficult, but you should assess which role your family members and friends are best suited to fill. Some may be helpful with logistics, like picking up medications when necessary or dropping you off at a procedure or appointment. Others may be supportive in an emotional sense, like listening to your frustrations and helping you to make sensible decisions.

Talking with Others About Your Diagnosis

Because primary immunodeficiency diseases are rare, most people are unaware of the diseases and about the ways they affect patients. You should develop strategies to respond to questions and misconceptions. Although not ill intended, people often do not understand how their comments, minimization of the illness or lack of understanding can really undermine your sense of self-worth and leave you feeling misunderstood or alone. You may encounter people in school or work settings who have never met someone with primary immunodeficiency disease before. Pressures regarding performance and attendance can be difficult. You may face resistance from fellow students and co-workers who think that you are faking it or always sick.

A very common phrase heard among patients with primary immunodeficiency diseases is, “Well, you don’t look sick.” Although not usually intended in a negative

way, non-patients do not understand how hurtful such statements can be. When you are made to feel you are making up an illness, it can leave you with the sense that you are not trusted or that you are lazy or unproductive. This experience can be incredibly devastating, especially when other well-known, recognizable chronic illnesses are not treated in the same way.

It is important that you find a comfortable way to communicate with others and deal with ignorant commentary. Such statements may become opportunities to educate others and empower yourself by owning your diagnosis and experience. You should consider sharing some information about your primary immunodeficiency disease so that people may be less judgmental and fearful.

Dating and Partner Choices for Young Adults Living with Primary Immunodeficiency Diseases

Young adulthood is a time when peer and romantic relationships are a top priority. It is important that you make positive choices in terms of maintaining your physical and emotional health. Physically, you should conduct safe sexual practices and communicate with a long-term partner about any potential health risks from infections. Emotionally, you should carefully consider revealing and discussing your disorder with your romantic partner, which can be difficult for you because of fears of rejection and lack of understanding. You must make sure that your partner is accepting and supportive of your medical condition.

Deciding when to tell a romantic partner about the disease is a personal choice, but it is best not to tell the person too early or too late. Disclosing too early without knowing a partner can lead to early rejection, and waiting too long may make the other person feel that they were not trusted. When you know that the person is someone whom you may potentially want to have a long-term relationship with, carefully consider finding the right time to have a discussion.

As you begin to develop romantic relationships, you must first be comfortable in your own acceptance of the illness. You should be prepared to answer personal questions in a sincere manner, yet be aware of what you would like to share. Questions posed by potential romantic partners may include the following:

- Can you have children?
- Is this contagious?
- Will your children inherit this disorder?

Other questions about the illness may follow. Knowing the answers to these types of questions and what you would like to share in advance can decrease anxiety and feelings of vulnerability. Consult your immunologist about how to answer such questions. Contact IDF to connect with someone who has had similar experiences through peer support: www.primaryimmune.org or 800-296-4433. Role-playing these types of discussions with family or friends can be helpful in reducing anxiety and make you feel more relaxed when these questions arise. Finding the right partner can be a very satisfying experience. Many patients with primary immunodeficiency diseases choose to marry and have children. Whatever you choose for yourself, primary immunodeficiency disease does not have to be an obstacle to leading a full life.

Post-Secondary Education for Young Adults Living with Primary Immunodeficiency Diseases

Many young adults with primary immunodeficiency diseases continue their education in post-secondary schools, including vocational and career schools, two- and four-year colleges and universities. Students should become knowledgeable about their rights and responsibilities as well as the responsibilities that post-secondary schools have toward the student.

Having this disease should not impede you from pursuing continuing education and/or living independently, but it will influence your decision in terms of obtaining healthcare, living conditions and caring for yourself. Some patients may choose to attend a local college or university and live at home. Others choose to go away to college, sometimes far

from home. Contact student support services at your colleges of choice to discuss your diagnosis and possible resources and accommodations.

Students requesting accommodations at the post-secondary level will want to work with the admissions office to identify the contact person at the school that can provide information on how to provide accommodations. Additional information regarding post-secondary education is available in this handbook. (See chapter titled “Adolescents Living with Primary Immunodeficiency Diseases.”) You can also consult the *Immune Deficiency Foundation (IDF) School Guide*, which can be ordered or downloaded at www.primaryimmune.org.

Employment Decisions for Young Adults Living with Primary Immunodeficiency Diseases

When making employment decisions, you should consider your individual strengths while making adaptable changes that will address your limitations. Although some individuals may experience anxiety around making a career choice and having a primary immunodeficiency disease, it is important to remember that everyone has limitations in terms of their abilities. You can make good choices based on your own interests, abilities and health needs, which will lead to a successful career and a positive life experience. Because of the disease, however, you must understand your rights and benefits and how to best communicate with your employer. Insurance coverage is a critical consideration in choosing a job and or career—you will likely have to make career choices based on access to good health insurance.

(See chapter titled “Health Insurance.”) To learn more about choosing health insurance, visit the IDF Patient Insurance Center: www.primaryimmune.org/patient-insurance-center.

For more information about your rights, contact these government agencies:

- U.S. Department of Justice Civil Rights Division, Office of ADA: www.usdoj.gov
- U.S. Department of Labor, Employment Standards Administration, Wage and Hour Division: www.dol.gov
- U.S. Equal Employment Opportunity Commission (EEOC): www.eeoc.gov

Managing Stress

Learning how to cope with the emotional stress of living with a primary immunodeficiency disease is extremely important, and it can vary from individual to individual. Managing pain, dealing with the unpredictability of infection, and missing out on recreational, social and family activities can predispose you to feelings of sadness, isolation and anger. You may benefit from processing your feelings with close friends and family members. It is also essential that you connect with the primary immunodeficiency community. The value of having others who “get it” and understand the complications that are unique to these diseases can be very powerful. IDF (www.primaryimmune.org) offers many programs to make those interpersonal connections. You can participate in the Young Adult Forum on IDF Friends (www.idffriends.org), an online community specifically for patients and families living with primary immunodeficiency diseases. You can contact IDF and

connect directly with another young adult through peer support. You can also attend an in-person event, like the IDF National Conference, Retreat or a local patient meeting—they are all opportunities to connect with others. You may form invaluable relationships that can be both rewarding and supportive.

You may require further assistance to cope with the challenges and stress of living with a primary immunodeficiency disease. Changes in your overall outlook, feelings of hopelessness, sadness, irritability and isolation may indicate that you may be experiencing clinical depression. Consider seeking professional assistance if symptoms persist. Talking to a therapist cannot only be a helpful experience, but it also may be necessary if such symptoms begin to disrupt your daily life.

Coordinating Your Healthcare and Being Your Own Healthcare Advocate

If you choose to move away from home or you need or want to change your primary care or other doctor, you will need to create a new healthcare team. If you were diagnosed as a child, your parents had the responsibility of making all healthcare decisions. Once you turn 18, you are legally considered an adult. At that point, your parents need your written permission to access healthcare records and to speak with your healthcare team. So, it is important that you and your parents work together with your healthcare providers

to help you take on the responsibility as your own healthcare manager.

Transitioning care from a pediatric setting to an adult setting whether home or away is a big step for parents and young adults alike. Whether transitioning to a completely new area or staying within the same care facility but assuming responsibility for your own care, you need to be your own best advocate. Therefore, it’s important for you to become familiar with all aspects of your care.

(Coordinating Your Healthcare and Being Your Own Healthcare Advocate continued)

Recommended information to record and keep readily available in a journal or in IDF ePHR

(www.idfephr.org):

- Brief history leading to the diagnosis, written by you or your physician
- Copies of laboratory evaluations confirming the diagnosis
- Current list of physicians caring for you with accurate addresses and phone numbers
- Chronology of important events such as infections and surgeries, specifically noting types of treatment and therapy, changes in therapy and subsequent responses to the treatment, therapy, infection, surgeries and/or hospitalizations
- List of your current medications
- Allergies to medications
- Infusion log if you receive Ig replacement therapy
- Immunization record or lack of immunization
- Current insurance information
- Explanation of benefits records can be kept in the journal or separately but should be periodically reviewed for accuracy

How you can advocate for yourself:

- Ask questions about your diagnosis, treatment and plan. If you do not understand, ask again.
- Understand the treatments you are receiving and why they are important to your overall, long-term health.
- Inquire about what can be done to improve your health such as diet, physical activity, sleep and social activities.
- If attending school, maintain consistent communication with the school in the event you miss days.
- Know your insurance policy and communicate if there are any changes to your provider.
- Understand the difference between a primary care physician and a specialist.
- Build positive relationships with your providers, therapists, etc. Know whom to call when.
- If you receive Ig therapy, make note of how it is going and/or any side effects.
- Ask about resources for further information at the local, state and national level.
- Connect with IDF for additional resources: www.primaryimmune.org or 800-296-4433.

Understanding the Importance of Treatment for Young Adults Living with Primary Immunodeficiency Diseases

As a young adult, you make decisions of your own. In order to make wise choices, you need to fully understand your specific diagnosis, medications and treatment. You must also know the consequences of not adhering to your current treatment. For most

patients, treatment is life-saving as well as life-long. Consult your immunologist about the vital role of your treatment in regards to your overall, long-term health.

Searching for New Healthcare Providers for Young Adults Living with Primary Immunodeficiency Diseases

When researching new providers and facilities, you should fully understand your insurance benefits and what providers and facilities are covered. Be sure to choose healthcare providers who best suit your needs. The location of the potential healthcare providers may influence where you choose to live or attend school. If you are relocating or attending college away from home, you should research immunologists in that area. Consult your current providers for recommendations, or contact IDF to locate a specialist. Many immunologists are associated with universities that can support their research, so you could consider those universities and cities. If you are moving out of state, it is also important to remember that hospitals and clinics may not be able to accept the orders from a previous physician. You should establish care, if possible, before moving day, giving the new healthcare provider time to get to know you and time to request authorization for treatment from the insurance plan.

Infusion Providers for Patients Receiving Immunoglobulin Therapy

It may not always be necessary to change infusion providers if you are relocating or if you are going away to college. If you are receiving infusions through a specialty pharmacy in a home care setting, you may be able to continue with the same provider. To find out if this could be the case, check with your current infusion provider several months before moving. Additionally, if a change in providers is required, the current provider should participate in coordinating the care and transition to the new provider.

If you are receiving infusions in a clinic or outpatient hospital setting, it will be important to coordinate the care in advance with as much notice as possible. For example, some colleges or universities may not allow infusions to be given in a dormitory and arrangements may have to be made for infusions at the student health center or a local hospital/infusion center. Additionally, the receiving clinic will likely need to get a new insurance authorization to provide care. Failure to obtain a new authorization could result in denied claims or delays in therapy which could impact your health.

Summary of Young Adults Living with Primary Immunodeficiency Diseases

As a young adult, you make choices that impact your overall health. You can take control of your healthcare by taking steps to stay healthy, making informed decisions and keeping good records. Take advantage of resources from IDF that can help you through this transition. To balance your life, build strong

relationships with family and friends, pursue a career that suits your interests and abilities, and make time for recreation. These will help you find and build the courage and strength to manage your primary immunodeficiency disease.