Immune Deficiency Foundation

Patient & Family Handbook

For Primary Immunodeficiency Diseases

Chapter 44

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Chapter 44

Young Adults Living with Primary Immunodeficiency Diseases

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Young adulthood is a time of independence and self-exploration when we separate from our parents and make choices about education, career, lifestyle, peer and romantic relationships. The transition to adulthood is a challenging time in general, but the impact of primary immunodeficiency diseases (PI) requires some unique life adjustments. The physical aspects of PI get the most attention, but the emotional ones are just as important.

It is important to have the necessary emotional support and skills to deal with chronic illness. Everyone experiences their disease differently. By using your individual strengths and coping skills along with the support of family, friends, and your healthcare team, you will succeed and lead a fulfilling and productive life.

Normalizing Your Life

Having a primary immunodeficiency disease impacts your daily life and your life choices; however, it is the decisions you make that will help you enjoy a normal, healthy life.

Maintain balance. Those who best manage their disease are those with a balanced approach to the disease and to life. It is normal to want a break from focusing on your disease, but neglecting symptoms or treatment routines can lead to serious health problems. It is critically important to manage your disease and treatments, while maintaining your relationships and the activities essential to your healthy lifestyle.

Make positive choices. The choices that you make affect your health. Young adults, living on their own and/or attending college, may be living in close quarters, keeping irregular sleep schedules with late night studying, recreation, sexual activity, and may have new access to alcohol or drugs.

Incorporating positive choices into your life in these areas is an important skill. If you attend college, take a manageable course load. If you have a job, make sure it suits both your interests and abilities. Balance your responsibilities and your recreation. Remember the importance of balance in all aspects your life. Know your limits!

Be active. Participate in healthy recreational activities. Managing a chronic illness is demanding. As a young adult you assume the role of healthcare manager as well as the other responsibilities of adulthood. It is important to take an emotional break from your disease and make time for recreational activities that you enjoy. As a young adult you are finding your place in the world beyond the shelter of your family. Rise to the challenge of fitting your diagnosis into your life, rather than fitting your life into your diagnosis.

Manage transition. Maintain an ongoing dialogue with your parents and talk about your changing roles in managing your care. If you were diagnosed as a child, your parents played a large role in your healthcare. Being responsible for your own care can be a big shift for you, and it may be difficult for your parents to let go. They may fear that you may not make the best choices. Yet, it is essential that you are able to manage your own healthcare at your own pace. Keeping the lines of communication open while utilizing your parents for support and guidance if needed will be beneficial as you manage your transition.

Build a support system. Your relationship with your family and friends will evolve as a young adult. You will learn to take care of yourself independent of your family and under different living conditions. Your friends and significant others will be important resources for help if you are ill. Asking for support when you need assistance can be difficult, so assess which of your family members and friends are best suited to help with your potential needs. Some may be helpful with logistics, like picking up medications when necessary or taking you to a procedure or appointment. Others may be sources of emotional support, who can listen to your frustrations or help you to make sensible decisions.

Talking with Others about Your Diagnosis

Primary immunodeficiency diseases (PI) are rare, so most people are unaware of the diseases and their effects. You will encounter people who have never met someone with primary immunodeficiency disease before. You may face resistance from fellow students and coworkers who think that you are faking it or always sick. Pressures regarding performance and attendance can be difficult. Develop strategies and explanations to respond to people's questions and misconceptions. People often do not understand that their comments or lack of understanding about your illness can undermine your sense of self-worth and leave you feeling misunderstood or alone.

Sometimes, while trying to explain what PI is, you may hear "You don't look sick." Although not usually intended in a negative way, this can be irritating and for some, particularly because other well-known chronic illnesses are not treated the same.

Work to develop a comfortable way to deal with comments like this. See these statements as chances to empower yourself and educate others. Sharing information about your experience with PI can help people develop an awareness and understanding of PI and other invisible illnesses.

Dating and Partner Choices

Peer and romantic relationships are a top priority for young adults. Making positive choices is important for maintaining your physical and emotional health.

Safe sex practices and clear communication with any sexual partner is vital to prevent potential health risks from infections. When you want to enter a long-term romantic relationship, you will want to make sure that your partner accepts and supports you, including your medical condition. Although it may be difficult because of fears of rejection or of being misunderstood you will need to reveal and discuss your diagnosis with your partner.

When to tell someone is a personal choice. It is best not to tell too early or too late. Although disclosing too early before you really know a partner can lead to rejection; waiting too long may make them feel that they were not trusted. Remember, healthy relationships are built on trust. Carefully consider finding the right time to have a discussion.

Before you can be comfortable sharing such personal details, you must first be comfortable in your own acceptance of your diagnosis. Prepare yourself to answer personal questions in a sincere manner and be aware of what you would like to share.

Anticipate questions like:

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

Other questions about your diagnosis will surely follow.

Preparing the answers to these types of questions and knowing what you are comfortable sharing will help decrease your anxiety and feelings of vulnerability.

If you need resources about how to answer such questions.

- Consult your immunology provider
- Role-play these discussions with family or friends
- Contact the Immune Deficiency Foundation (IDF) to connect with someone who has had similar experiences through peer support: www.primaryimmune.org or 800-296-4433.

Life is about choices. Choosing the right romantic partner can be very satisfying. Choosing to marry and/or have children or not is your choice. Choosing to enjoy and live a full life even though you have a primary immunodeficiency disease is one of the most important choices that you can make.

Pursuing Career Education

Many young adults with PI continue their education in colleges, universities, and vocational and career schools.

Having a primary immunodeficiency should not stop you from pursuing your life goals, continuing your education, finding a career, and living independently; but it will need serious consideration in your decision.

Some of you may choose to attend a local college or university and live at home. Others may choose to go away to college, sometimes far from home. In either case you will need to have access to healthcare and suitable living conditions to properly care for yourself during your education.

Become knowledgeable about your rights and responsibilities as a student as well as the responsibilities that post-secondary schools have to accommodate your diagnosis.

If you need to request special living accommodations at a school, work with the admissions office to identify the person to best help you. You should be prepared to discuss your diagnosis, accommodations, and other specific needs to be able to get the necessary resources.

Additional information regarding post-secondary education is available in this handbook. (See Adolescents Living with Primary Immunodeficiency Diseases Chapter.) You can also consult the IDF School Guide or IDF Transition Guide: Pediatric to Adult Care, which can be ordered or downloaded at www.primaryimmune.org.

Making Employment Decisions

When making employment decisions, consider your strengths and make changes that address your limitations. Although you may be anxious about having a primary immunodeficiency disease and making a career choice; remember that everyone has limitations. Make choices based on your own interests, abilities and health needs. This will lead to a successful career and a positive life.

Because of your diagnosis, understand your rights and benefits and learn how to communicate with your employer. Insurance coverage is a critical consideration in choosing a career. (See Health Insurance chapter.)

To learn more about choosing health insurance, visit the IDF Patient Insurance Center: www.primaryimmune.org/insurance.

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 vital. Managing pain, dealing with the unpredictability of illness, and missing out on recreational, social, and family activities may trigger feelings of sadness, isolation, and anger. You may benefit from sharing your feelings with close friends and family.

Negative changes in your overall outlook, feelings of hopelessness, sadness, irritability, and isolation may indicate that you may be experiencing clinical depression. If you need further help to cope, seek professional assistance. Talk to a therapist; and prevent disrupting your daily life.

You can connect with others in the primary immunodeficiency community who “get it” and understand the complications unique to these diseases can be very powerful.

IDF 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 individuals and families living with PI. Contact the IDF and connect directly with another young adult through peer support. Attend an in person event, like the IDF National Conference, IDF Regional Conference or a local education meeting and connect with others who have PI. You may form valuable relationships that can be both rewarding and supportive. Visit IDF’s Calendar of Events at www.primaryimmune.org/events to learn more.

Being Your Own Healthcare Advocate

If you choose to move away from home or change any of your providers, you will need to create a new healthcare team. If you were diagnosed as a child, your parents made all healthcare decisions for you. Once you are 18, you are legally an adult. After that, your parents need your written permission to access your healthcare records and to speak with your healthcare team or insurance company. It is important that you work with your parents and your healthcare providers to help you to become your own healthcare advocate and manager.

The transition of care from a pediatric setting to an adult setting is a major step for parents and young adults alike. To successfully assume responsibility for your own care, you need to become familiar with all aspects of your care.

The following information and resources will help you on your way to becoming your own healthcare advocate.

Information to record and keep readily available in a journal, either paper or digital:

- 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 immunoglobulin (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

Advocating 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

As a young adult, you make decisions for yourself. 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, treatment is lifesaving as well as lifelong.

Educate yourself. Become an expert; know your personal health history. Have the important details from your health records available, in a folder or in cloud storage that you can easily access.

Learn about your specific diagnosis and treatment. Utilize the IDF and its resources. If you find information on the internet, make sure that it is current and correct. Validate it with your health care team. Consult your immunologist so that you fully grasp the vital role of your treatment to your overall, long-term health.

Finding New Healthcare Providers

When searching for new providers and facilities, fully understand your insurance benefits and which providers and facilities are covered. Request a case manager from your insurance carrier. The case manager can help you navigate your particular insurer's rules and regulations, obtain authorizations, and navigate through their network. Be sure to choose healthcare providers who best suit your needs and who are in your network. Out of network providers or sources of care can carry a hefty price tag.

The location of the potential healthcare providers may influence your choices about where to attend school and live. If you relocate to attend college away from home, search for immunologists and health care systems in that area. Many immunologists are associated with universities, so consider those universities and cities. Consult your current providers for recommendations. Visit www.primaryimmune.org to access the IDF Physician Finder for help locating a specialist.

If you are moving out of state, remember that hospitals and clinics may not be able to accept the orders from an out of state physician. As a new patient in a new health care system, it may take longer than you expect to get an initial appointment. Establish care, get an appointment, and arrange to transfer your medical records before moving day. Your new healthcare provider will need time to get authorization for treatment, and review your records.

Visiting your New Provider

Be prepared and organized for your first visit. Remember, your communication is vital to your long term health.

When you first meet your new provider, treat your visit like a date.

- Introduce yourself.
- Shake hands.
- Make eye contact.
- Sit close.
- Pay attention.
- Silence your phone, and don't text or take calls during your visit.
- Let your expectations be known up front, say the reason for your visit.
- Be concise, stick to the details.
- Use words that you're comfortable with. If you don't understand the words you're hearing, ask.
- When sharing personal information tell the truth. If you smoke, drink, do drugs, take herbs, see alternative care providers, your provider is there to help not to judge.
- If you didn't comply with treatment, or follow doctor's orders. If you didn't buy your medicine or couldn't afford it; say so.
- Don't be afraid to ask a question because you might think it is a dumb question or think your doctor knows best.
- Know your medications, bring them with you or at least a list.
- Bring your records, especially if you've seen someone else or had a new problem. Keep a folder or an app with your info, immunization records, tests etc.
- Don't bring a stack of internet searches; bring a list of questions you have based on your searches. Ask them early, not at the end of the visit. Take notes. Don't leave with unanswered questions.
- Ask how the office works, who to talk to for results, emergencies, after hours.
- Review and confirm your treatment plan.
- Schedule your next follow up visit.

Locating Infusion Providers for Immunoglobulin Therapy

Many infusion companies are part of a national or regional system so it may or may not be necessary to change infusion providers when relocating. To find out, check with your current infusion provider several months before moving. If a change in providers is required, your current provider should participate in the transition of care to your new provider.

If you plan to get your infusions in a new clinic or outpatient hospital setting, arrange your care with as much advance notice as possible. Check with student health services at your new college. Some may not allow infusions 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 new clinic will likely need to get a new insurance authorization to provide care. Check with your insurance company or case manager to make sure that the new site is in network. Failure to obtain a new authorization could result in denied claims or delays in therapy which could impact your health.

Summary

As a young adult, you make choices that will impact your overall health. Maintain balance in all aspects of your life. Build strong relationships with family and friends, pursue a career that suits your interests and abilities, and make time for recreation.

It is your responsibility to be in control of your healthcare. Build a support system for yourself. Use all the resources available to you from IDF, and other local and national resources to help you. Take the necessary steps to stay healthy. Learn how to manage your stress. Make informed decisions and keep good records. Continue your healthcare with compatible providers no matter where you are.

Be courageous, recognize your strengths, manage your primary immunodeficiency disease, set your goals, and live and enjoy every moment of your life.

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