



TAKING CONTROL: OPTIMIZING YOUR POTENTIAL AS A YOUNG ADULT WITH A RARE DISEASE

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Introduction

Early adulthood (ages 18 to 26) is a time to discover what it means to be independent, explore different educational and career pursuits, travel, form relationships, and take more responsibility for one's own health.

As a young adult with a rare disease, there are many paths you can take after completing high school, including postsecondary education opportunities and vocational endeavors. While exploring these options, it is important to learn how to effectively understand and communicate your needs. There are three parts to this:

- Knowing yourself;
- Knowing your needs; and
- Knowing how to get what you need.

Learn about your rare disease and how it affects your daily activities, communications, skills, strengths, weaknesses, and social interactions. The better you understand your rare disease, needs, and rights, the better you can communicate to others and advocate for yourself. Preparing for the next steps for education and work is a time to ask many questions, reflect on goals, and start planning to better achieve them.

“Taking Control” Toolkit Series

This toolkit is a part of a “Taking Control” series, and numerous important topics are covered in the **Taking Control: Gaining Independence as a Young Adult with a Rare Disease toolkit** (<http://globalgenes.org/toolkits/transitioning/young-adult/>), including:

- Health Insurance 101;
- Managing Treatment and Receiving Medical Care;
- Independent Living; and
- Building Self Confidence.

SECTION 1:

OPTIMIZING YOUR POTENTIAL AT SCHOOL



High school students with rare conditions have many choices for continuing their education, including vocational and career schools, two- and four-year colleges, and universities.

“I truly believe that you can do anything you put your mind to, but be realistic about your goals and know your limits,” says Maija Rannikko, a young adult with a rare disease. “Maybe your degree takes you longer than four years or maybe you have to find a different way to integrate your passions into your career. But if that means you’re staying healthy, that will be more important in the long run.”

Many factors will influence decisions about education after high school:

- Areas of interest for future work/career;
- Funding and scholarships;
- Individual health needs and health status; and
- Needs for academic adjustments or reasonable accommodations.

If you haven’t been able to finish high school, there are many ways to pursue a **GED** (general education diploma) that will allow you to pursue your educational and vocational goals. Learn more about the test at the Testing Center website (<https://ged.com/>).

States offer many services through **Vocational Rehabilitation Agencies** (ED.gov). These centers, usually organized by county, coordinate and provide counseling, evaluation, and job placement services for people with disabilities. These agencies can also assist with transition and youth services for high school students and youth up to age 25 with disabilities as they move from school to adult services. Some states provide financial assistance through these programs for college and other training programs. Emily Turner, a young adult with Cornelia de Lange Syndrome, used one of these centers for many services, and would encourage others to look into them too.

“I started working with the Vocational Rehab Services in the middle of high school,” says Emily. “They helped me with resume building, searching for a job, and interviewing. I don’t know what I would have done without them. They also helped train me to drive.”

What are My Rights as a Student with a Rare Disease?

As a student with a rare condition, you need to be well informed about your rights and responsibilities as well as the responsibilities of postsecondary schools. You can learn more about the rights of students with disabilities at the **U.S. Department of Education’s Office of Civil Rights** (<http://www.ed.gov/ocr/transition.html>).

SECTION 1: OPTIMIZING YOUR POTENTIAL AT SCHOOL

There are many laws that young adults with rare diseases should be aware of when continuing to postsecondary institutions, including:

- **Family Educational Rights and Privacy Act (FERPA)** (<http://familypolicy.ed.gov/ferpa-parents-students?src=ferpa>) This Federal law protects the privacy of student education records. It gives parents certain rights with respect to their children's education records, and these rights then transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Generally, schools must have written permission from the eligible student in order to release any information from a student's education record (this includes parents of college students). If a parent contacts a college administrator or professor, the school cannot disclose any information unless the student has given permission.
- **American with Disabilities Act (ADA) of 1990** (www.ada.gov): Title II of this federal civil rights law covers state funded schools such as universities, community colleges, and vocational schools, while Title III covers private colleges and vocational schools. If a school receives federal funding, regardless of whether it is private or public, it is also covered by the regulations of Section 504 of the Rehabilitation Act, requiring it to make their programs accessible to qualified students with disabilities.

The Pacer Center's **Q&A on Section 504 and Postsecondary Education** provides a good overview of how these laws apply in college and other post-high school settings (<http://www.pacer.org/publications/adaqa/504.asp>).

- **Rehabilitation Act (and Section 504)** (<http://www2.ed.gov/policy/speced/reg/narrative.html>): This Act prohibits discrimination against children and adults with disabilities. It applies to public and private elementary and secondary schools and colleges that receive federal funding. Although Section 504 only applies to colleges that receive federal financial assistance, the reality is many do receive federal dollars.



SECTION 2: MAKING POST-SECONDARY SCHOOL MORE ACCESSIBLE

Appropriate Academic Adjustments and Accommodations

The Rehabilitation Act (Section 504) and the Americans with Disabilities Act of 1990 (Title II and III) prohibit discrimination based on disability within elementary, secondary, and postsecondary institutions. However, several of the requirements that apply through high school are different from those that apply beyond high school.

For instance, a postsecondary school is not required to provide **FAPE** (free appropriate public education) for students. Instead, it is required to provide appropriate academic adjustments as necessary to ensure that it does not discriminate on the basis of disability.

Appropriate academic adjustments include:

- Modifications to academic requirements and auxiliary aids and services;
- Reductions to course loads;
- Substitutions for certain courses;
- Provision of note takers, recording devices, sign language interpreters;
- Extended time or quiet space for testing; and
- Use of screen-reading, voice recognition, or other adaptive software and hardware for school computers.

Colleges and universities must have an Office for Students with Disabilities (actual names

will vary). Disclosure of a disability, health condition, or mental health condition is always voluntary. However, you may want to consider documenting any health conditions with the educational institution. This is important if any academic adjustments or other reasonable accommodations are needed to complete your studies, or if you think your attendance may be affected by illness. Situations can vary, and documenting your health condition may not always convince professors to be understanding. Kathryn Blake, a rare disease patient with May-Thurner Syndrome, explains her experience.

“Teachers were not always understanding of my rare disease and the time I had to miss,” says Kathryn. “When I talked to Disability Services at my university, they said that they could write a letter, but the teacher ultimately had overall jurisdiction. I would have to go through a long process to appeal the grade, if I wanted it changed.”

If you need or want an academic adjustment, inform the school that you have a disability or health condition and need an academic adjustment. The postsecondary school may require you to follow reasonable procedures to request an academic adjustment, and you are responsible for knowing and following these procedures. If you are unable to locate the procedures, ask a school official, such as an admissions officer or an advisor.

SECTION 2: MAKING POST-SECONDARY SCHOOL MORE ACCESSIBLE

Note: If you do not document your health condition ahead of time, professors and administrators will not be required to make adjustments or accommodations. You may even want to reach out to the appropriate office when you visit a campus, or when you accept an offer of admission, so you can become familiar with the school's procedures.

"I would recommend that anyone with a rare disease who is attending college visit their college's health center and meet with the director before the school year starts, ideally before you even apply to make sure they will be the right support system for you," says Maija Rannikko, a young adult with a rare disease. "When I had that meeting, I was informed of housing accommodations, academic accommodations, and the director drafted a letter to send to all of my professors to inform them of my disorder.

"I was able to live in a residence hall that would make me feel comfortable, safe, and wouldn't aggravate my symptoms. I also was referred to my college's disability services and although I had some hesitancy, I was given testing accommodations and a note taker, so I could succeed in my classes. If I could give one piece of advice to anyone with a rare disease attending college it would be this: There is no shame in taking advantage of accommodations. Under the Americans with Disabilities Act, a medical condition entitles you to these accommodations. By leveling the playing field and using the tools available to you, you can be successful in college."

Personal information is kept confidential unless your professor needs to make a specific accommodation in class (they are informed of the accommodation, not your reasons for requesting). It is not shared with classmates

or roommates. What information you choose to share with them is another decision you may want to consider, which will lead to balancing independence and privacy with an important need for social support (and perhaps opportunities to be a rare disease advocate).

Discrimination Based on Health Conditions

If you believe you are experiencing discrimination in a post-secondary setting because of a disability or health condition, your school must offer grievance procedures. These steps ensure that you may raise concerns fully and fairly, with the guarantee that you will have resolution of complaints. School publications, such as student handbooks and catalogs, usually describe the steps you must take to start the grievance process. Be prepared to present all the reasons that support your request.

Attending school while having a rare disease can be difficult, but it is even more difficult when it feels like no one understands. Connecting and communicating with others who are going through similar situations is important, and support groups can be very helpful in this way. Kathryn Blake offers this piece of advice while attending school.

"Try to find support groups," says Kathryn. "They can be so understanding. And they can tell you what has worked for them, sometimes things that people might not know. Through these support groups, I was able to find uplifting and kind women, who gave me hope and got me to where I am today."

SECTION 2: MAKING POST-SECONDARY SCHOOL MORE ACCESSIBLE

Post-Secondary Funding and Scholarships

The cost of a college education has risen significantly over the last few decades. Students and families have many options when evaluating how best to afford higher education, including:

- **Grants and Scholarships:** This type of financial aid does not have to be paid back. That's why they're called "gift aid." Most grants are awarded based on financial need. But a good portion of gift aid is awarded for academic achievement. Both grants and scholarships come from the government, colleges, and private organizations. To apply for grants and scholarships, you'll most likely have to fill out financial aid forms such as the Free Application for Federal Student Aid (**FAFSA**, <http://fafsa.gov/>) and the **CSS / Financial Aid PROFILE** (<https://student.collegeboard.org/css-financial-aid-profile>). Outside scholarships usually have their own application forms and application processes.
- **Student Loans:** If scholarships, grants, income and/or savings won't cover the cost of college, consider taking out a loan. Repaying the loan will cost more money, but in exchange, you'll get a college education. When you take out a college loan, you're borrowing money with the intention to repay it. You also have to pay interest — a charge for borrowing the money. Different types of loans have different interest rates. The lower the interest rate, the less money you pay. There are three main sources of student loans:

 - **The federal government** lends almost half of the money college students borrow each year.
 - **State agencies** offer college loans. Some of these have very specific requirements.
 - **Private organizations** like banks, other financial institutions, foundations, and colleges may offer loans to students.

Applications for this form of aid may require written essays. **Let's Feel Better** (<http://letsfeelbetter.com/the-elevator-pitch-how-to-quickly-explain-your-disease-published-in-this-months-ig-living/>), a rare disease patient blog, offers different tips for explaining a disease quickly and easily, which may help when writing these essays.

Learn more about loans at **Big Future** (<https://bigfuture.collegeboard.org/pay-for-college/loans/types-of-college-loans>).

To get additional information to make more informed financial decisions about how to pay for college, turn to this **Consumer Financial Protection Bureau** guide (<http://www.consumerfinance.gov/paying-for-college/>).

SECTION 3: OPTIMIZING YOUR POTENTIAL AT WORK



If you're a student in high school or college who's thinking about looking for a job, the best place to begin is by talking to a guidance or career counselor or Disability Student Services Coordinator. These professionals can provide good information on careers, job training, and work-based learning opportunities (such as internships and apprenticeships), and places to look for jobs online or in the community.

You can also independently research job descriptions, education or training requirements, and salary potential. A good place to start is the Bureau of Labor Statistics' **Occupational Outlook Handbook** (<http://www.bls.gov/ooh/>), which provides career information on hundreds of occupations.

Pursuing Goals and Interests

Individuals with rare conditions entering the workforce may experience a variety of unique issues and concerns. Career choices should be based on each individual's

- Intellect;
- Ability;
- Interests;
- Strengths; and
- Life goals.

Having a rare chronic illness doesn't mean lowering expectations about a career, but rather expecting a different skill set from yourself. Rare disease patients contribute to the wellbeing of the world every day. They help people, employ people, and even run businesses from their homes and hospital

beds. There is a way to achieve higher education as well as a meaningful, fulfilling career with an active, chronic illness. It just takes time, determination, and planning.

Realities and Responsibilities with Choosing a Job

Optimism and reality can sometimes be two conflicting concepts. While you'll always want to imagine yourself having the exact career that you want, your body may not always be in agreement. If you're in a wheelchair, you're not going to be an NBA basketball player. If your disease causes fatigue and flares, you're likely not going into jobs like teaching, require working long hours on your feet, or anywhere you cannot delegate responsibilities in your absence. Sami Petersen, a young adult with Ehlers-Danlos Syndrome, started a nonprofit patient advocacy organization called **SHIFT Scoliosis** (<http://www.shiftscoliosis.org/>). Many patients, like Sami, choose to start their own organization, but may feel limited due to their illness. Sami offers the following advice.

"The best advice that I would give to others looking to start an organization is to keep working toward your goal," says Sami. "If your rare disease limits your ability to do a particular task, then work on recruiting people who have that skill. There are always people who are looking to volunteer for a good cause; it is up to you to find them."

SECTION 3: OPTIMIZING YOUR POTENTIAL AT WORK

The reality is that there are some duties you will not be able to perform—at least not entirely on your own, without aid, allowances, or for a sustainable amount of time. If you refuse to acknowledge these realities, you will be responsible for any failure that might occur on your watch. For some individuals with a rare disease, it's worth the risk, but for others whose responsibilities directly affect safety, progress, or finances, they must learn to compromise.

When considering the risk your career choice might present, ask yourself the following:

- Do my symptoms ever interfere with my work projects?
- Do I sometimes need days, weeks, or even entire months off because of out-of-control flare-ups?
- Does my high pain level mean I might be at a higher risk to lose my control with a rude customer?
- Could a symptom like unbearable fatigue put others in danger if I operate heavy or delicate machinery?
- Do urgent, uncontrollable symptoms mean that leaving my physical position could put a business in jeopardy (such as being the sole cashier at a store)?
- Do I put myself in greater risk of physical harm or worsening symptoms by doing this job?
- Are my symptoms going to prevent me from being the best person for this job?
- If my symptoms could impact others' performances, paychecks, or safety, isn't it my responsibility to speak up about my abilities and inabilities?

The sooner you are open to the reality of your disease, the sooner you'll be able to work with it. There are many opportunities for rare disease patients to have a career while working within the limits of their condition. Although sometimes difficult, when one has a chronic illness, to accept the unique limits associated with having a rare disease, there are certain tactics one may take when preparing for a job. Joan Friedlander, author of *Business from Bed: The 6-Step Comeback Plan to Get Yourself Working Again After a Health Crisis* is someone who has experience firsthand living with a chronic illness. She offers this advice.

“Experience shows that as your symptoms stop presenting as an insurmountable barrier to productivity, you will feel pressured, once again, to put work before people and health, and to push beyond your limits. To prevent myself from giving in to that pressure, I adopted an 80% rule. I look at everything I feel I must do in one day, and remind myself that if only 80% gets done, life still goes on.”

Turn to *Business from Bed* for more practical advice on restoring your mental, emotional, spiritual, and physical well-being after a health crisis.

What are My Rights as a Jobseeker or Employee with Rare Disease?

As an employee, you are protected against discrimination that is connected to all aspects of employment, including hiring, firing, pay, job assignments, promotions, layoff, training, and fringe benefits. In this section, we define key laws, key terms, and how these may affect your work and employment.

SECTION 3: OPTIMIZING YOUR POTENTIAL AT WORK

There are many laws that young adults with rare diseases should be aware of when joining the work force, including:

- **American with Disabilities Act (ADA) of 1990** (www.ada.gov): This federal civil rights law protects you from discrimination in all employment practices, including: job application procedures, hiring, firing, training, pay, promotion, benefits, and leave. It restricts questions that can be asked about an applicant's disability before a job offer is made, and it requires that employers make reasonable accommodation to the known physical or mental limitations of otherwise qualified individuals with disabilities, unless it results in undue hardship. More details on reasonable accommodations are in the following sections. For more information on what the ADA covers, turn to the U.S. Equal Employment Opportunity Commission's **Frequently Asked Questions** on the American with Disabilities Act (<http://www.ada.gov/qandaeng.htm>).
- **Genetic Information Nondiscrimination Act (GINA) of 2008**: This law forbids discrimination on the basis of genetic information when it comes to any aspect of employment, including hiring, firing, pay, job assignments, promotions, layoffs, training, fringe benefits, or any other term or condition of employment. It also restricts employers, employment agencies, labor organizations, and training and apprenticeship programs from requesting, requiring, or purchasing genetic information. Read more about GINA on the **US Equal Employment Opportunity Commission** website (<http://www.eeoc.gov/laws/types/genetic.cfm>).
- **Family and Medical Leave Act (FMLA)** (www.dol.gov): This Act took effect in 1993 to help balance workplace demands with the medical needs of employees and their families. It permits employees to take up to 12 weeks of unpaid leave during a 12-month work period for a serious health condition or to care for a spouse or child with a serious health condition. Eligible employees must have worked for their employer for at least 12 months prior to requesting the leave. They must also have worked at least 1,250 hours in those 12 months. For more information on what the FMLA covers, turn to the United States Department of Labor's **Family and Medical Leave Act Employee Guide** (<http://www.dol.gov/whd/fmla/employeeguide.htm>).
- **Ticket to Work and Work Incentives Improvement Act** (www.ssa.gov): For those who receive Social Security Income or Social Security Disability Benefits, this law may allow them to work and continue some of their insurance benefits. It also has a voucher system, where users can gain rehabilitation and other services to assist them with getting a job.

SECTION 4:

MAKING WORK

MORE ACCESSIBLE



Reasonable Accommodations

As detailed earlier in the last section, the ADA requires an employer to provide reasonable accommodation to an employee or job applicant with a disability, unless doing so would cause significant difficulty or expense for the employer. A reasonable accommodation is any change or adjustment to a job, the work environment, or the way things are usually done to help a person with a disability apply for a job, perform the duties of a job, or enjoy the benefits and privileges of employment.

Common types of accommodations include:

- Physical changes, such as installing a ramp or modifying a workspace or restroom;
- Sign language interpreters or readers to help those who are deaf or blind, respectively;
- Environment changes, such as providing a quieter workspace or reducing noisy distractions;
- Time off for those who need treatment; and
- Training materials in accessible formats, like Braille or on an audio tape.

If you think you need an accommodation, request one. After making a request, the employer should discuss the options available. To read more detailed information on requesting an accommodation, turn to Job Accommodation Network's **Employee's Practical Guide to Negotiating and Requesting Reasonable Accommodations Under the Americans with Disabilities Act** (<http://askjan.org/EeGuide/IIRequest.htm>).

Discrimination on the Job

Disability discrimination occurs when an employer treats qualified individuals with a disability unfavorably because they have a disability. It also occurs when an employer treats an applicant or employee less favorably because there is a history of a disability (such as cancer that is controlled or in remission).

Not everyone with a medical condition is protected by the law. In order to be protected, a person must be qualified for the job and have a disability as defined by the law. Individuals can show that they have a disability if they:

- Have a physical or mental condition that substantially limits a major life activity (such as walking, talking, seeing, hearing, or learning);
- Have a history of a disability (such as cancer that is in remission); or
- Have a physical or mental impairment that is expected to last six months or more and is not minor.

An example of discrimination could be dismissing a candidate based on the way she walks. Eileen Grubba, an actress, writer, producer and survivor of a childhood rare disease, has experienced discrimination in this way.

SECTION 4: MAKING WORK MORE ACCESSIBLE

“The entertainment industry is tough on everyone,” says Eileen. “People often ask me where I find the courage to keep walking through those doors. Barely noticeable by now, my ‘imperfect’ sway had to be hidden because if they saw it, I was out. Sometimes they would admit that to my agents, other times they would make up excuses and keep saying no. Most actors go in worrying about performance, I go in praying they don’t notice my walk, so I can work and earn my health insurance.”

It is illegal to harass an applicant or employee because that individual has a disability, had a disability in the past, or is believed to have a physical or mental impairment that is expected to last six months or more. **Harassment** can include offensive remarks about a person’s disability. Although the law doesn’t prohibit simple teasing, harassment is illegal when it becomes frequent and/or severe. The law also protects people from discrimination based on their relationship with a person with a disability (even if they do not themselves have a disability).

If you think your ADA rights are being violated, contact the nearest **Equal Employment Opportunity Commission** (www.eeoc.gov). There is no charge to file a violation, and you can file in person, by mail, or by phone. In my most states, there is a 300 day limit to file from the day of the alleged discrimination. In some states, the time limit is 180 days.

Health Insurance at a New Job

Once a job offer is made, there may be important health insurance issues to consider. First and foremost, an individual with a rare condition will need to know if there is employer-provided insurance, and make decisions if more than one plan is available. Some questions to consider include:

- Does the plan cover my prescriptions?
- Are my medications on the “formulary” or must they be ordered through a specialty pharmacy? Will I have to pay out-of-pocket for specialty pharmacy orders?
- Is there a mail-order option?
- Does the plan permit me to see the providers I want or allow me to be hospitalized at the medical centers of my choice?
- Will I need to change some or all of my current providers?
- Does the plan require referrals for each specialist visit, or do I simply need to choose “in-network” specialists?
- What does it cost to go “out-of-network?”

Additional questions and important points to consider in regards to health insurance can be found in the **Taking Control: Gaining Independence as a Young Adult with a Rare Disease** toolkit that is part of this series. (<http://globalgenes.org/toolkits/transitioning/young-adult/>).

RESOURCE GUIDE



More Information on the Americans with Disability Act:

- **Americans with Disabilities Act Questions and Answers** (<http://www.ada.gov/qandaeng.htm>): This online booklet is designed to provide answers to some of the most often asked questions about the ADA.
- **Disability.gov** (<https://www.disability.gov/>): Disability.gov is the U.S. federal government website for information on disability programs and services nationwide.
- **Employment Rights Under the Americans with Disabilities Act** (<http://www.disabilityrightsca.org/pubs/506801.htm>): This resource provides an overview of the Americans with Disabilities Act and answers many of the frequently asked questions.
- **JAN Job Accommodation Network** (<http://askjan.org/>): This helpful resource provides information on workplace accommodations and the Americans with Disabilities Act or legislation. It also has a newsletter and legal resources.
- **JAN Job Accommodation Network’s “Employees’ Practical Guide to Negotiating and Requesting Reasonable Accommodations Under the Americans with Disabilities Act (ADA)”** (<http://askjan.org/EeGuide/IIRequest.htm>): This guide provides information on requesting an accommodation.
- **United States Department of Justice’s A Guide to Disability Rights Laws** (<http://www.ada.gov/cguide.htm>): This guide provides an overview of Federal civil rights laws that ensure equal opportunity for people with disabilities. To find out more about how these laws may apply to you, contact the agencies and organizations listed within the guide.
- **United States Department of Labor’s “Wage and Hour Division Family and Medical Leave Act Employee Guide”** (<http://www.dol.gov/whd/fmla/employeeguide.htm>): This 16-page, plain language booklet is designed to answer common FMLA questions and clarify who can take FMLA leave and what protections the FMLA provides.

Pursuing Goals and Dreams:

- **Business from Bed** (<http://www.joanfriedlander.com/books/business-from-bed/>): This book, written by Joan Friedlander, presents 6 steps readers can take after recovering from a medical emergency.

Searching for Employment:

- **Ability Links** (<https://www.abilitylinks.org/home.aspx?pageid=1024>): AbilityLinks is a web-based community in the United States where qualified job seekers with disabilities and inclusive employers meet and gain access to valuable networking opportunities. Job seekers who want to connect to employers by voluntarily self-identifying having a disability use AbilityLinks to post resumes and apply for jobs. No information about disability type is asked.

RESOURCE GUIDE



Preparing for Postsecondary Education:

- **Office for Civil Rights’ “Students with Disabilities Preparing for Postsecondary Education: Know your Rights and Responsibilities”** (<http://www.wrightslaw.com/info/sec504.transition.ocr.pdf>): This pamphlet explains the rights and responsibilities of students with disabilities who are preparing to attend postsecondary schools, and the obligations of postsecondary schools to provide academic adjustments and services.
- **PACER Center’s ADA Q & A: Section 504 & Postsecondary Education** (<http://www.pacer.org/publications/adaqa/504.asp>): This webpage covers the questions most commonly asked of PACER staff regarding the ADA and postsecondary institutions.
- **Wright’s Law “Key Differences Between Section 504, the ADA, and the IDEA”** (<http://www.wrightslaw.com/info/sec504.summ.rights.htm>): This article compares Section 504 of the Rehabilitation Act and the Americans with Disabilities Act with the Individuals with Disabilities Education Act (IDEA).
- **LD Online’s “The Law After High School”** (<http://www.ldonline.org/article/6098>): This article answers questions like, “Do the legal rights of students with learning disabilities continue after high school?” and “What accommodations would I be entitled to in college?”

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