



TRAVEL GUIDE

for traveling with a medically-complex child



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Traveling with Pediatric Medical Complexities

Vacationing improves your mood, reduces stress, even temporarily boosts productivity. People who travel are more satisfied with their physical health and well-being. Vacationing even increases creativity. Do these benefits apply to those who live with serious pediatric illness? Of course! Traveling also has the ability to take you out of your daily routine and into new surroundings and experiences which can reset your body and mind. Especially for children, traveling inspires curiosity and adventure, and offers opportunities to be brave. It cultivates growth as a family, makes families more adaptable, and creates opportunities to lean on each other. Is traveling quite a lot of work for you and your child? Absolutely! Want to tackle it in bite size pieces and start local? Awesome, try a staycation! Ready for the trip dreams are made of? Start now. Enjoy these tips, leave plenty of time to prepare, and have an amazing time!

Explore expectations

As with most things, deciding what is most important to you with traveling is the place to start. Why are you taking this trip? What do you hope for with this trip? What is most important about this trip? What might this trip improve, reduce, or provide? What are the most important things you want to happen on this trip? What would be the worst thing that could happen on this trip? Exploring these questions as individuals and as a whole family creates a solid foundation for the travel decisions yet to come. Understanding each other's hopes and expectations can help us make better decisions when planning the trip and increase each person's capacity to enjoy the trip through flexibility and helping accomplish each other's hopes. Happiness increases up to 8 weeks prior to a well-planned trip; grab all 8 weeks by planning ahead!

Choose your mode of travel and trip details

As you make decisions about your travel, take a look at every option. Tools like a 'pro & con' list and letting go of previous decisions or judgments will really help you sort through important questions like where do you want to go, how do you want to get there, and who should go on this trip. Do you want to go to the beach? Is your child's equipment airplane friendly? Does a 'trip of a lifetime' get you excited or do you want to get away and just relax? Deciding the style of vacation (beach, national parks, amusement park, cruise) and mode of travel (plane, car) is worth the time to really sort it through. Maybe you have 'deal breakers' like never changing briefs of a larger child on an airplane, or your child can't tolerate being positioned upright for more than 30 minutes. Sort out decisions you are unsure of. Keep decisions realistic and lean on others to help make your travel happen. New to travel with your medically-complex child? Try local travel for the first time! Choose a fun hotel and activities within a few minutes or hours of your home to vacation for a few days. Another important decision requiring careful thought is who comes on the trip. Sometimes at-home respite for your medically-complex child allows for rejuvenation and focus on other family members, and sometimes having the whole gang together is perfect.

Preparation

70% of stress related to a well planned trip occurs in the preparation phase, so let us help guide you along. Medically, check with your doctors, prepare for if symptoms to worsen, and arrange for extra medications and equipment that is portable. Pack by either person or task, and use lists to be sure you have everything you need! Contact your health insurance to learn what out of area benefits look like in case something happens. Call ahead to your airline, hotels, and attractions to discuss your specific needs. Search online to learn from other family's experiences with your activities and destination.

Medical needs

Medical problems may arise while on vacation, just like they do at home, and with solid preparation you can manage them just like you do at home. Input from all medical team members is critical, each specialist could voice unique concerns about how the travel might affect your child and, as well as add solutions. Have practitioners formalize orders, prescribe extra medications, help you anticipate medical challenges and how to react, discuss planned activities and potential challenges (rollercoasters with hypotonia), and even connect you to colleagues where you're headed if you need care while there. Organize all your child's medical information and keep it with you digitally and on paper. Plan for extra medications and extra supplies, batteries for powered devices, portable equipment, tube feeding food to be shipped ahead, etc. Start early, keep notes, etc.

Packing

Having the right items and knowing where to find them keeps the focus on the fun, the people, and the wonderful memories you're making on this trip. If the thought of packing brings stressful feelings, start early and do it piece by piece. Make a detailed list of supplies and items, triple check it, and consider shipping items ahead to your lodging if you are short on space. Use packing cubes and see through ziplock bags (2.5 gallon+) to start and stay organized through the whole trip. Don't forget your equipment cords, battery banks, baby and cleaning wipes, extension cords, power strips, and extra copies of your medical papers. Pack all items for the first night together so you can get some rest quickly after a very full day.

Lodging

Where you stay will become your home and away from home; choose somewhere that is as accessible and accommodating as possible. Call locations before selecting and ask lots of questions about the facilities to ensure that you will be able to have access and what you need. Bring extension cords, power strips, device power cords, and portable equipment for sleeping needs, such as bed rails, wedge pillows, or even sleeping tents. If you're staying with family set some time aside to discuss plans and each other's concerns. This will encourage open communication, critical to being great house guests! When you get to your lodging take some time to settle in. This helps kids feel at home, lets you know where medical equipment is, and identifies early any supplies you might be missing.

Flexibility

While traveling, being flexible is critical. Remembering your personal goals for the trip can help keep even frustrating times full of new memories, stronger relationships, laughter, growth, and stronger connections to people, places, and your child.

Find more about traveling with a medically complex child in each of these topics and more at bradesplace.org.





Medical Needs When Traveling

Travel can be safe and fun for most children with serious illness. Preparation, realistic expectations, and input from medical team members can help your trip be successful!



Medical Information

Preparation is key to successful travel for children with medically complex diagnoses, and something that can be done well in advance.

Input and orders from providers

Gathering input about your travel plans from each active member of your child's medical team is important. Tell them your plans (timing, location, activity details), ask any questions, and ask for their input. Have them formalize and sign any needed orders, routine and PRN prescriptions, letters of medical necessity, and equipment needs.

Anticipate medical challenges

Anticipate what symptoms and problems might worsen during the trip, such as dystonia worsening with a road trip because of increased time without position changes. Next, with your medical team's input, create a plan to respond to the worsening of symptoms. This might include increasing medication PRN to help with the worsening dystonia or adding an extra dose of your seizure rescue medication for added safety while far from your pharmacy (see link to anticipatory symptom management forms). Having a proactive plan in place is the best preparation for handling worsening symptoms or 'what if' situations.

"Traveling, whether over to the next city or the next country, is a great way to share new experiences, create wonderful memories and expand your horizons with those you love. " Nina Van Harn, parent

Organize medical information

Whether as a hard copy or digital, compile detailed medical information including in case of emergency information (see link), diagnoses, medications, allergies, insurance, current orders, nutrition, communication, medical team contacts, past surgeries, hospitalizations, and POLST/MOLST forms. The Lightning Bug App (see link) is a great tool for compiling this information and you can download a copy as a PDF.

Keeping papers and information handy

Keep your child's medical information easily available by putting it on your phone, emailing it to yourself, or storing it in a google drive folder. Print out a hard copy and keep it in your 'go bag' or first aid kit.

Other Tips

Extra supplies

Be sure to have several days extra of medications, supplies, and treatments.

Identify needed medical resources on arrival

Upon arrival, identify the location of medical facilities if you have scheduled treatments or medical care planned. Also ask your host or hotel staff about the closest children's hospital, urgent care, etc. in case it is needed.

Activities with your child

Carefully consider how your child's unique body will tolerate various activities. For example, long times in the sun can be especially tiring for some, and even mild amusement rides can be a danger for those with abnormal muscle tone. When in doubt, discuss your plans with your medical team and ask for their insights.

Where to attend to care in public

Most attractions and amusement parks have a first aid or security room with a bed that could be used for feeding, medication delivery, changing briefs, or attending to other needs that are best done in a comfortable and private setting.

Links

Anticipatory Symptom Management Form:

www.bradesplace.org/wp-content/uploads/2022/05/Anticipatory-Symptom-Plan.pdf

Lightning Bug App:

www.ppcc-pa.org/app-resources-2/lightning-bug-app

CPN In Case of Emergency Form:

www.api.courageousparentsnetwork.org/app/uploads/2020/04/EmergencyPlan-.pdf

AAP In Case of Emergency Form:

www.bradesplace.org/wp-content/uploads/2022/05/AAPICE.docx

Luggage/Car seat In Case Of Emergency Tag:

www.bradesplace.org/wp-content/uploads/2022/05/ShortEmergencyForm.pdf





Airplane Travel

Air travel can get you to your destination with just a few hours in-flight! With planning, extra time, and assistance from TSA and airline staff your family can fly right through the air travel experience with your medically complex child.



Managing a successful flight begins before you even buy the tickets! There are a few things to consider when booking the flight:



Each airline has specific policies for equipment and accommodations, presented in their 'accessible travel' policies (links on following pages). These policies answer questions about in-flight oxygen use, administering certain medications during flight (infusions, enteral feedings), battery requirements for powered devices, and the use of safety/mobility equipment like wheelchairs and car seats. Choose the airline that works with your child's needs.

Book the flight by phone

Let the airline experts help you by calling them directly to book your tickets. They can answer all of your specific questions about flying with your child such as if your safety seat will fit that plane, arranging for an airport escort, etc. They will also ensure that you complete the airlines requirements, such as alerting them 48 hours in advance when flying with oxygen or medical devices.

Planes are unique

Older planes may have narrow aisles that prohibit manual wheelchair use, or small bathrooms that make it very difficult to change an older child. Identify the amenities that the plane offers, such as in-flight power for equipment or seat dimensions for seating requirements.

Timing is everything

Prioritize flight times that will work with your child's schedule and needs. Consider what time of day will they best handle the airport chaos, tolerate postural flight demands, need a complex drug infusion, etc. Would your child benefit from a layover break or do better with nonstop flight?

Consider changeable flights or add-on flight insurance

Give yourself the peace of mind by paying for flight insurance so that unforeseen changes are handled without additional expenses.



Packing: Carry-on or Check?

While checking all of your luggage can make it easier in the airport, it is essential that you carry-on everything you might need in the next 24 hours in case of unplanned travel emergencies. All mobility aids, medical devices, and medications (in their original bottles) should be carried-on and do not count towards your carry-on limits. If space on the plane is limited, you may be asked to gate-check some of these items. That's alright, they'll be returned once the plane lands. As a general rule, remember that if you won't survive 24 hours without it, it doesn't belong in your checked baggage. Keep essential supplies for feeding, toileting, hygiene, and extra clothing in your carry on.

Pack your carry on with the TSA security screening in mind! Pack medications in a large ziplock bag so they can be easily examined without becoming disorganized. If you have liquid medications or a tube fed child, simply make the agent aware, and they will exclude it from the liquid quantity rule.

TSA Checkpoint/Security

TSA agents are trained to accommodate your medically-complex child and make the security screening as easy as possible. They can personally escort your family through the security screening process from start to finish if you provide them with a 72-hour notice. You can also call the 'TSA Cares Line' (see link on following page) with specific questions and to arrange for your escort through security. If you have medical equipment or medications that should not be X-rayed, simply alert the TSA agent and they will use an alternate screening method.

For children with autism familiarization with the security checkpoint ahead of time can be really helpful on the day of travel. Learn more about this through the 'Wings for All' program at https://thearc.org/our-initiatives/travel.

TSA Notification Card

Print and complete the TSA notification card (link on following page). Showing this to the check-in agent will help ensure that your security screening goes smoothly.

In-Flight Tips

Oxygen

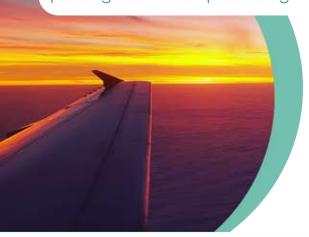
Airlines don't allow oxygen tanks, but FAA approved portable oxygen concentrators are permitted and can be a nice option for the entire trip. Contact your oxygen supplier and see how to navigate this, they may loan you one to use for the trip. If they will not, there are rental companies that you can contact.

Other Devices

Verify that your devices are FAA approved (particularly their batteries). Even though the plane may have outlets for use during flights, most airlines require you have enough battery life for 150% of your in-flight time. Your DME provider can help you get more batteries just for the trip and answer any FAA questions you have about the devices.

Bathroom

We all hope not to have to change a larger child's brief while on the plane, but if you do, ask the flight attendant how to best navigate this. The back of the plane might offer the most privacy, chux or a travel blanket can protect your child from the floor and placing trash in a ziplock bag will minimize residual odors.



Links

Airline Accessibility Policy Example

https://www.delta.com/us/en/accessible-travel-services/overview

Travel Options

https://complexchild.org/articles/2016-articles/march/options-for-air-travel/

TSA Resources

TSA Cares: (855) 787-2227

www.tsa.gov/travel/special-procedures

"Traveling with your children may open all your eyes to things you didn't know about the world and even your own family... a trip can change your family. I hope you have many happy travels!" -Nina Van Harn





Car Travel

Road trips offer an adaptable family travel experience which is appealing when traveling with a child with medical complexities. Flexible schedule, plentiful packing space, comfortable seating, and the ability to accommodate necessary adjustments as they arise are just a few of the perks that car travel can bring to your family's trip.



Planning Ahead

Centering your planning on your child's needs, tolerances, and limits is key to successful travel.

How much time can they spend in the car before they need a break?

Changing positions, delivering scheduled medications, and bathroom needs are all examples of reasons to schedule planned breaks. Map out your route ahead of time, and keep rest stops and other care needs in mind.

What is likely to go wrong while driving, and what will I do if it does?

Hope for the best but plan for the worst. Thinking through what might go wrong is an important step in planning ahead. Knowing that you have a plan will put your mind at ease. Consider your child's symptoms, and what you will do if they need an intervention while on the road; for example, if your child is prone to pulling on their G-tube, plan for what you will do if they pull it out while you are driving. Contingency planning can give you confidence that you are ready to handle what comes your way.



Vehicle Tips

Organizing the vehicle

Keep the items you will need to access frequently (medications, feeding, hygiene, suction) in a specific, easy to reach location and commit to return them there when not in use. Small bins under van seats and door organizers on the back of bucket seats are great storage places. Consider arranging bins or bags by task, one for respiratory care, feeding/G-tube care, hygiene, distracting activities, etc. Use rear or trunk storage for items you won't need while driving.

Keeping an eye on things

Rear-view mirror extensions give you a safe view to the back seats, helping you keep one eye on the road and the other on what's happening in the car.

Having the necessities

Add your own essential items to packages of wipes, small trash bags, various size ziplock bags, plastic cups, scissors, and charging cords. When you need them you will be happy that you have them!

Comfort

Positioning in the car

With mobility or muscle tone concerns, add a second car seat safety system to your everyday car seat system. Alternating between them increases comfort and car time tolerance. If safe for your child, using an approved EZ-on vest system with a body pillow for positioning support can significantly improve comfort in the car.

Seat belt security

Seat belt buckle covers are a great tool to be sure seat belts don't come off when they should be on.

Activities

Old phones or tablets are great on the road devices when pre-loaded with games and videos (Disney+, Netflix). Download content ahead of time via wifi so your child will have full access even without an active phone or data plan. Don't forget the headphones.

Links

National Park Pass Access Pass is free (\$10 processing) to US citizens with disabilities, and admits 1 vehicle including up to 4 adults and children under 16 to all national parks. www.nps.gov/subjects/accessibility/access-pass.htm

Play with me or inclusive parks & playgrounds nationwide directory. www.accessibleplayground.net/playground-directory/

Museums for all -discounts or free passes to many nationwide museums. www.museums4all.org/





Packing

Packing well is essential to a great trip. Having the right items (and knowing where to find them) helps keep the focus on the fun, the people, and the amazing memories you're making!



Packing 101

How to make your list

No doubt your medically-complex child has more stuff than all family members put together! Pre-made packing lists can help make your own unique list. To make your list think through your child's routines during a typical day and write down each and all of the supplies you use. Then do the same not chronologically but by body system (GI, respiratory), and once again by tasks (feeding, suctioning, bathing), adding new items to your list each time. This triple check will help to catch things that may otherwise be forgotten. Lastly, check your list against your monthly supply order receipt and a visual inspection of your supplies at home.

Organization

How you organize is very individual. Is it better to have each family member manage their own items and suitcase, or do you have everyone's hygiene items in one packed bag, all the PJs in another, or a bit of both? Packing cubes or large, clear ziplock bags (2.5 gall or even bigger) help keep things together and easily found. Consider bags that expand for extra space as you buy things on your trip. If you are taking a flight, keep an eye on the weight of each bag and redistribute as necessary.

Go Bag

If you need a go-bag, you probably have one already. If you don't have a go-bag, you will want one while traveling. Put essential items for your child's care for 12 hours in an easily carried bag that stays handy through your whole trip. Expand it for this trip to include a spare or two of each tube (G-tube, trach, ostomy wafers), your ICE form, a comfort item, and a higher quantity of the other essential materials. Keep this bag handy at all times; it can be a lifesayer.

Stress management

Thoughts can race about if you've remembered everything, have enough, how you'll fit it all, how you'll find anything, etc. Have confidence in the comprehensive list you made and leave plenty of time to pack. You'll do a great job! If packing is stressful put on some music, start early, minimize distractions, maybe even pack supplies way ahead of time to break it up. You've got this; fun in the journey can start with packing!

Tips

Items to keep handy

Handicap placard, battery pack for phone & tablet charging, scissors, sharpie, chux pads (they give you a clean surface and clean up messes), wipes; add your favorite items too!

Items with purpose

Bring an item that comforts your child during distressing or tired times; bring a favorite item that will help when having to wait; and bring items for outside (sunscreen, misting bottle, cooling towel).

Misc. things not to forget

Cords for phones and equipment (feeding pump), power strips, extension cords, laundry bags, lots of ziplock bags for organization and wet or soiled trash, laundry pods, and insurance cards.

Personal items

Headphones can provide entertainment, solitude, and control over environmental noise; consider a pair for each family member. Consider giving each family member their own backpack to carry water, snacks, and entertainment devices.

Boredom busters

Old phones or tablets can be preloaded with movies, games, and pictures for fun and don't need a phone plan or data to access downloaded items (Netflix, Disney+). Other portable activities, snacks, reading books, etc. can make the trip more enjoyable.

First night tips

Chances are your first day of travel will be very full. Make the first night easier by packing everything you all need for that first night (PJ's, hygiene, next day's clothes...) in one suitcase or packing cube to prioritize getting a good night's sleep!

Documents and papers

Update your in case of emergency (ICE), your medical information (allergies, Rx, Dx, PCP, etc.), and digitize this information so you always have access via your phone. Email it to yourself, make a google drive, or use an app like Lightning Bug, but be sure you also print it out and keep a copy in your go-bag/first aid kit, your glove box, etc.

Consider shipping items ahead

Would shipping items ahead to lodging locations be helpful, such as briefs, wipes, enteral feeding supplies, etc.? On the box include a supervisor's name as well as 'guest supplies' for arrival on (date) for the (name) family. Add a tracking code to the package and when it arrives call the hotel to confirm and find out exactly where it will be stored for you so that upon arrival it can be found easily.

"Gone are my days of throwing a couple things in a backpack and heading off for the weekend or a week with friends. Our packing list for overnight travel now includes a 14-page checklist, an almost Herculean organizational effort, a sense of humor, a sense of adventure, and a great love of life." -Lana Jones





Lodging

Your lodging is your home away from home. A hotel, cruise ship, vacation rental, or staying with family or friends can each work well. Knowing how the location meets your unique needs helps prepare you for potential challenges.



Location

Pros and Cons

Consider your child's unique needs when planning what lodging works best for you. For children with a lot of equipment, where packing and unpacking often would be challenging, consider central lodging. For children with difficulty traveling in the car, consider lodging closer to your activities. Also, think through your home routine and consider how your routines will change based on accommodation changes. Choose lodging that will meet your child's needs and work best for your family and travels.

Accessibility

Being able to utilize the whole lodging facility is important and a direct call is the easiest way to get the most accurate information on accessibility. Explain your situation and ask for specific details about room accessibility, if there are elevators nearby, if there is a fridge in the room (medication, food), if the bathrooms and showers are wheelchair friendly, if there are ramps to access the pool and dining areas, etc.

Staying with family

Staying with family can strengthen lifelong relationships and make meaningful memories with people you love. Open communication is key to being a good house guest; take the lead in a conversation about your child's needs, listen to your host's questions and concerns, and express your gratitude and excitement to be staying with them.

Shipping ahead

Sometimes shipping supplies ahead saves precious space and simplifies the day of travel. Call ahead to discuss this with your hotel, identify a manager's name to put on the package, and confirm the address. Ship with a tracking code and once it arrives call the hotel and confirm where the package will be stored so that you can easily find it when you arrive.

Tips

What to bring

Pack extension cords, power strips, personal and medical device power cords, and your child's favorite items for comfort and fun. Bring anything that helps your child feel at home!

Before you arrive

Call ahead on the day of your arrival to share your excitement to stay at their facility and let them know of your unique needs (accessibility, fridge, pre-shipped supplies, etc.) so that they have time to resolve any challenges before you arrive. Explain your medical needs and ask them to change all the bedding, including the mattress cover and bedspread. Asking for extra towels, pillows, and blankets might be helpful for positioning, changing station, etc.

Setting Up/Moving In

Taking time to unpack and set things up will help you know where to find supplies, identify any missing items, and help family members feel at home.

Bed accommodations

Portable safety bed rails can be temporarily added to a bed to provide for safety. Safety sleep tents are perfect to replace your pediatric safety sleeper at home. Use wedge pillows to help with positional needs for reflux, aspiration, or respiration.

Hotel Script

When calling the hotel ahead of time introduce yourself, your child, and their needs; and explain that you are looking for information about an upcoming stay.

Ask about facility accommodations based on your needs, such as wheelchair accessibility to rooms, showers, and the pool. Ask if there is an in-room fridge for medications, an onsite restaurant, if any parts of the hotel are not accessible, etc.

Ask about local medical services, such as pharmacies, children's hospitals, and emergency medical services. This is especially important if the location is rural, or at a resort that is removed from city infrastructure (such as a mountain or beach resort).

If you would like to ship some supplies ahead, let them know and explain why it would be helpful. Confirm the shipping address, and obtain a specific manager's name to include on the outside of your package.

"Have grace with yourself. There are going to be times you forget something or you arrive someplace to find it to be less accessible then you thought, but don't let that stop you ...

The more you get out and explore the world the better at it you will get!"

Amand Upton, parent





Staycation

Local vacationing may fit your family's needs best. Staycations can provide many of the benefits of distance travel and might be exactly what your family or child needs!

Staying local doesn't have to mean staying at home.

Checking in to a local hotel or renting an AirBnB can help create that vacation ambiance without the hassle and expense of traveling far from home. For parents who feel uncertain about vacationing far from home with their medically complex child, staycations offer a less

stressful experience that lets you push your boundaries without overextending yourself.

Planning a staycation

Properly planning and arranging your staycation is essential to getting the most out of it.

Reflect, identify needs, set expectations

Identifying your hopes and expectations for the staycation is the first step. Ask yourself what will make this experience a success for you and your family? Are you hoping to rest and relax, to create exciting new memories, or to feel closer as a family? Knowing what is most important to you will help you plan for success, and help you recover when things seem to be going poorly. Take a moment to reflect on these topics:

Vacationing is meaningful to me because
Vacationing worries me because
For me/my child/my family traveling would help us
This staycation will be a success if it makes me feel
I feel comfortable traveling (miles/hours/minutes) from (home/my medica
team/a hospital).

Activities

Now that you understand what's important to you, choose staycation activities that align with your goals. Here are a few ways to start planning your itinerary

What do tourists do when they visit your area? Look online for top family activities in your area. You may find that some of the attractions you take for granted are more interesting than you thought!

Search for family-friendly attractions that will be accessible for your medically complex child.

If you grew up in the same area you live in now, think back on your favorite places and activities. Take a trip down memory lane, and show your children what it was like when you were their age!

Staycation Tips

Bring the exotic home by having ethnically themed activities and meals each day (themes like Hawaii day, Italy day, Mexico day, etc.). Enjoy travel videos and documentaries from other lands; even exploring on Google Earth together can be fun!

Make new routines at the house. Sleep in, stay up late, switch up mealtime, and make it feel like you're on vacation!

Set ground rules. Explore your priorities (spend time together, make new memories, relax, etc.) and set rules to help those happen.

Put yourself in "Vacation Mode". Take vacation days from work, answer your phone selectively, try and minimize housekeeping, and generally act as if you were out of town.

It's OK to do activities with only some family members. Be upfront about it and take a lot of pictures and videos to share when you get home. You can even "bring along" those still at home with a video call.

Links

National Park Pass Access Pass is free (\$10 processing) to US citizens with disabilities, and admits 1 vehicle including up to 4 adults and children under 16 to all national parks. www.nps.gov/subjects/accessibility/access-pass.htm

Play with me or inclusive parks & playgrounds nationwide directory, find a great place to take a break at:

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Museums for All -discounts or free passes to many nationwide museums. www.museums4all.org

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