

Empower

Understand

Thrive



EMPOWER
MY CONGENITAL HEART



**A Peer-Powered
Guide to
Confidently
Navigating Your
Cardiologist
Appointments**

Let's start with some basics...

Before Any Doctor Visit

1 Set a calendar reminder!



A great way to remember routine visits is to schedule them during your birthday month or on a recurring break from school or work.

2 Know how to get there!

If in-person, note the address.



If a video visit, note the link or number to call.

3 Arrange transportation!



If you don't have a ride, consider calling your insurance or your hospital/clinic's patient financial services to get help.

4 Pre-visit test check!

Check if any tests need to be done before or during the visit by contacting the doctor's office.

Activate your patient portal (see next page).



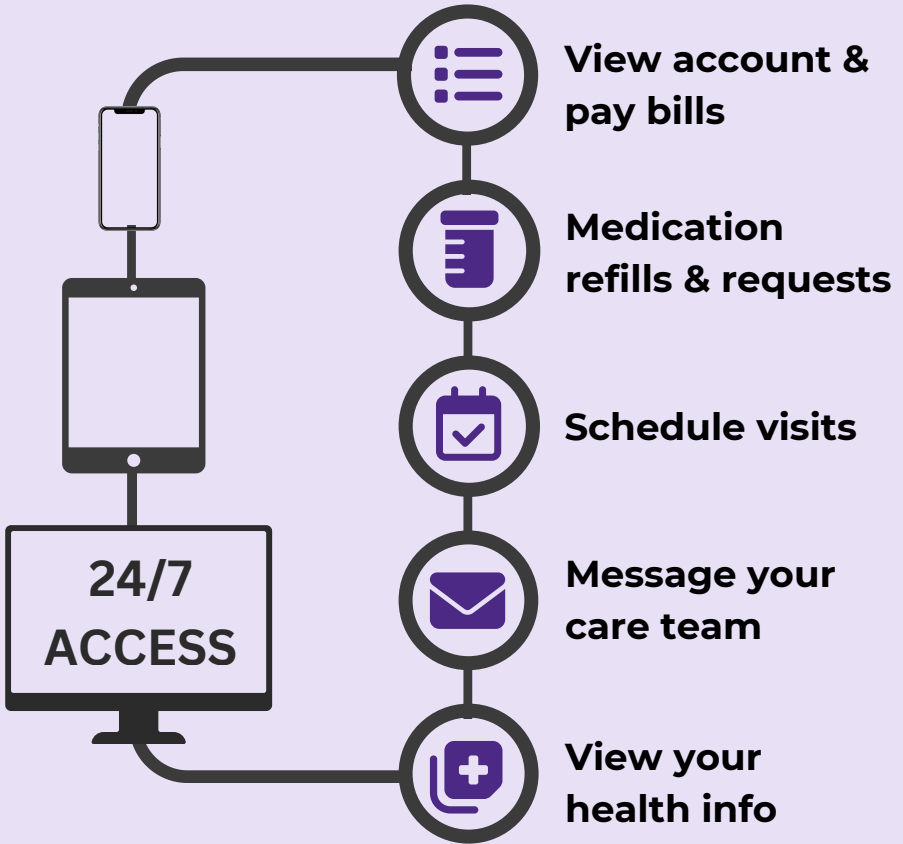
Basics of a Patient Portal

Why?

A convenient way to help manage your healthcare.

What?

Free, secure access to health data from anywhere with an internet connection.



How?

Your doctor's office can provide information to help you access the portal.

You can then set up an account with a username and password.

Your Medical Records

When to Get Your Records

Obtaining all your records can take time, so request their release as soon as possible. The health system is complex—**be proactive!**

Where & How to Get Your Records

Electronic & paper records, including radiologist reports, can be obtained from the hospital's Medical Records department after signing release forms.

Images, such as CT, MRI, X-rays, ultrasounds, or echocardiograms, may be **held by other departments**, such as Radiology or the Echo Lab. Some hospitals may require separate requests for each part of the record, such as one for "paper" records and others for radiology and echo images.

You can request records directly for yourself or another doctor's office, or sign a release allowing your doctor's office to request them.

The Medical Records Department may also be called:

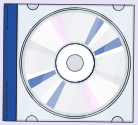
- ◆ Health Information Management (HIM) Department
- ◆ Patient/Health/Medical Records Department
- ◆ Patient Information Services
- ◆ Clinical/Medical Documentation Office
- ◆ Records and Information Management
- ◆ Medical Archives

Your Medical Records



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Always **carry copies of your imaging CDs**. They let you share images—not just reports—with your doctors and can be transferred between health systems. Even if you request that images be sent, issues may arise. Bringing your copies ensures your doctor can review them directly and without delay.



Getting Imaging CDs

If you have a test that includes images (like a CT, MRI, ultrasound, or Echo), ask for the images before the test begins. **Typically, the facility can provide CDs with your images right after the test.**



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Joe Valente, Patient with Tetralogy of Fallot

“Request a copy of your PDF records and digital images, then save them onto a USB / thumb drive keychain to keep your information accessible at all times.”

Who to Bring to My Visit?

A **trusted friend, family member**, or someone familiar with your medical condition, whom we like to call your **healthcare leader**.

How do I know who my healthcare leader is?



PEER EMPOWERMENT

Alison Gill, Patient with Tetralogy of Fallot

“ I recommend anyone in your circle that will TRULY listen. ”

Ask yourself several questions before deciding who your healthcare leader is:

- ◆ Whom do you call to discuss your latest doctor appointment or medical concerns?
- ◆ Who has a medical background or credentials?
- ◆ Who has the best clinical skills on your team?
- ◆ Who knows your medical history and condition best?



Resource: Team Uncle Joe ACP handbook on how to pick your healthcare leader & proxy
bit.ly/TUJCarePlanning

What to Bring to My Visit?



Identity card

(e.g., driver's license, passport, etc.)



Health insurance information

At a minimum, know your insurance company name and the name and date of birth of the primary beneficiary (the main person on the insurance).



Medical history and imaging

CDs or reports of any tests done outside of your doctor's office.



Current medication list.

Preferably, bring all your medication bottles and dosages.



Notes and questions (see next!)



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Bring a book, a podcast, or a game to pass the time during long wait times. Don't forget a phone charger and a snack.

Why and What Notes Should I Take?

Why?

Take Notes

Having notes helps maximize your time with the doctor.

What?

Notes to Take



Any **symptoms** you are experiencing, or **testing** completed.



Date of your last **dental** visit.



Lifestyle topics to discuss – these can be about family planning, job, disability, diet, exercise, travel, etc.



Record of your blood pressure, heart rate, oxygen levels, etc., as suggested by your doctor.



Any **questions** for the doctor (read further for some tips).

During My Visit

Your health is a shared decision between you and your doctor.

Test results and follow-up plans can be confusing.

Consider taking the time to fully understand test results and formulate a plan **that's best for you.**



Review your list of questions with your doctor!



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Joe Valente, *Patient with Tetralogy of Fallot*

“ I like to pull out my list of questions with a pencil, including test results I am concerned about, and engage the provider over the list. This gets them out from behind the computer, allows them to see my concerns, and allows us to have an in-depth conversation about these topics. I often find providers writing notes on my notes. ”

Before I Leave My Visit

Follow-up on the plans

- ◆ Establish follow-up timing for visits, testing, and other procedures.
- ◆ Schedule the planned appointments or tests.
- ◆ Get access to the patient portal if it has not already been established.



PEER EMPOWERMENT

Joe Valente, *Patient with Tetralogy of Fallot*

“ Always leave your appointments with a follow-up scheduled and all referrals and labs in hand, even if they’re in another office in the same facility. We assume electronic medical records have made these things seamless, but they often make them more complicated. There is no substitution for a hard copy — paper is still king. ”

Some Questions to Ask My Doctor

General Questions

- ◆ When should I have my next appointment?
- ◆ What should I expect in the long term regarding my heart condition?
- ◆ Are there things I can be doing every day to help me?
- ◆ Do I have any exercise limitations?

Test Related Questions

- ◆ What do these tests show me?
- ◆ Why do I need these tests?
- ◆ What do the test results mean?

Medication Related Questions

- ◆ How does this medication help my heart?
- ◆ Are there any side effects?
- ◆ Should I avoid certain over-the-counter medications or any specific ingredients?

These are examples are meant to be a guide, and not a full list.

After My Visit



Visit The Patient Portal

Review

- ◆ After Visit Summary.
- ◆ Test results.
- ◆ Patient education materials (diet, lifestyle, exercise, etc.).

Access

- ◆ Current medications/allergies.
- ◆ Vital signs (height, weight, heart rate) from the visit.
- ◆ Plans for next steps.
- ◆ Appointment scheduling link.

Message

- ◆ Your doctor's team, as needed.

Abilities within different patient portals may vary based on the health system.

After My Visit:

Communicating with Providers



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David Novich, *Patient with Aortic Disease*

“ If you forget to ask something, don't beat yourself up, I'm always thinking of questions hours or days after an appointment. These are ongoing relationships with your medical professionals and you can continue to ask questions whenever they pop up. ”



PEER EMPOWERMENT

Leigh Kamping-Carder,
*Patient with Single Ventricle,
Tricuspid Atresia, Fontan*

“ If you leave a message or send an email and don't hear back, don't take it personally. Cardiology teams are busy. Don't be afraid to follow up again with a message or phone call. ”



Resource: A guide to more effective, less stressful cardiology visits.

TheHeartDialogues.SubStack.com

After My Visit:

Understanding my Medical Bill

*Medical bills will start coming in after your visit.
Let's break down some key ideas so you can
navigate them with confidence.*

EOB (Explanation of Benefits): A statement you receive **from your insurance company** detailing what they pay for your medical services and what you owe.

Bill: A statement **from your provider's office** that reflects the services rendered and the amount due.

- ◆ Your initial bill may not reflect your actual amount owed.
- ◆ **Do not pay any medical bills until you receive your EOB.**
- ◆ Ensure your EOB and your bill match.



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Call your doctor's office if there is any part of your bill that you do not understand.

Here's a 4-minute video on medical bills:

English:

bit.ly/AAPMedicalBills

Spanish:

bit.ly/AAPFacturasMedicas



Videos by the Congenital Heart Public Health Consortium, made available by the American Academy of Pediatrics: bit.ly/AAPCHD