

# Empowered Patient Tool Kit & Resources



# Where Do I Start?

**1. Schedule an appointment with your healthcare provider.**

**2. Prepare yourself with the right questions for getting diagnosed.**

-Everyone wants help with medical information. You are not alone; it is very common to find things to be confusing and overwhelming at times. Asking the right questions will help you to understand your diagnosis and how to manage it.

-You should feel comfortable asking questions when:

- You see a doctor, nurse, pharmacist, or other health care provider.
  - You prepare for a medical test or procedure.
  - You are prescribed medication.
  - You go to the emergency room or are admitted to the hospital.
- If you are not sure what questions to ask, start with the “My Care Questions” form found on page 5 of this resource packet.

# I've Been Diagnosed, Now What?

- **Know my diagnosis**
  - Use our information pages “Knowing my diagnosis” and “Patient Tips” to get a head start on being educated on your diagnosis.
- **Understand my doctors’ orders and discharge instructions**
  - It’s important to understand your follow-up care plan after your diagnosis in order to obtain the best treatment. Use our “Follow-up Care” questionnaire form to make sure you and your doctor are on the same page.
- **Protect my health**
  - Using the “Patient Tips” information page, learn what steps you can take to protect your health.
- **Take charge of my health**
  - Small changes in your lifestyle can have a huge impact on your overall health.
- **Manage my health and medications using the printable patient information pages found in this packet**
  - Manage your appointments, medications, health history, contact info and more using our customizable and printable pages
- **Know all the resources available for me, and use them**
  - Along with speaking to your doctor, we have provided you with other resources to utilize.
- **Know my rights as a patient**

# Patient Tips

## **Become Informed**

- Research information about illnesses or conditions that affect you.
- Research options and possible treatment plans.
- Find a center of excellence for your condition.
- Ask questions.
- Always get a second opinion.

## **Keep Records**

Use the forms in this packet to:

- Keep track of and document your medical history including any medical conditions you have, illnesses, immunizations, allergies, hospitalizations, all medications and dietary supplements you're taking, and any reactions or sensitivities you've experienced.
- List names and phone numbers of your doctors, clinics, and pharmacies for quick and easy reference.

## **Work With Your Doctor**

- Share your health history with your care team.
- Share up-to-date information about your care with everyone who's treating you.
- Make sure you understand the care and treatment you'll be receiving. Ask questions if you're not clear on your care.
- Discuss any concerns about your safety with your health care team.

## **Find A Trusted Advocate**

- If you're not able to observe or participate fully in your care, ask a family member or friend to assist. They can accompany you on appointments or stay with you, help you ask questions, understand care instructions and suggest your preferences.

## **Protect Your Health**

- Avoid people who are ill.
- Wash your hands often.

## **Follow Your Treatment Plan**

- Be sure you receive all instructions verbally and in writing that you can read and understand. Ask questions about any instructions that are confusing or unclear.
- Take medications exactly as prescribed.
- Use home medical equipment and supplies only as instructed.
- Report anything unusual to your doctor.
- Schedule and go to all follow-up appointments.

# Know My Diagnosis

When you speak with your health care provider, ask these 3 questions to help get the right diagnosis:

## My Care Questions

### 1. What could be causing my problem?

Answer:

### 2. What else could it be?

Answer:

### 3. When will I get my test results and what should I do to follow up?

Answer:

## When to ask questions

- You see a doctor, nurse, pharmacist, or other health care provider.
- You prepare for a medical test or procedure.
- You are prescribed medication.
- You go to the emergency room or are admitted to the hospital

## What if I ask and still don't understand?

Let your health care provider know if you are still unsure of your diagnosis, or do not feel like you know what you need to know.

# Know My Diagnosis

In addition to asking questions to help get the right diagnosis, it is just as important that you communicate what you do know with your health care provider. Arriving to your appointment prepared to answer any questions is key.

- **Keep a detailed record of all symptoms and report them to your doctor**
- **Have both yours and your family's medical history with you**
- **Bring your list of all medications and supplements you take.**
- **Don't leave out any piece of information, and always give all information to both doctors and nurses.**
- **Do your own research ahead of time. Be informed about your illness, upcoming procedures and medications.**

# Take Charge Of My Health

Part of managing your health and diagnosis is taking control of your health and wellness at home. By making a few small changes in your everyday lifestyle and diet, you can see big changes in your overall health. Along with the help of your doctor, it is important to incorporate a healthy diet and exercise into your life. Your doctor will be able to help you create an exercise plan appropriate to your abilities, along with nutrition that is geared toward and beneficial to your diagnosis

## Take Charge Of Your Health:

- Drinking more water
- Eating a well-balanced diet, modified to fit your needs.
- Exercise. Just 15 minutes of walking per day is all it takes!
- Set goals and work toward them.
- Think positive.



# My Health Goals

Take Care Of Your Body, It's The Only  
Place You Have To Live. –Jim Rohn

Date:	
Goal:	
Plan Of Action:	
Expected Date:	Completed Date:

Date:	
Goal:	
Plan Of Action:	
Expected Date:	Completed Date:

Date:	
Goal:	
Plan Of Action:	
Expected Date:	Completed Date:



# My Diet Plan

Date/Day Of The Week:		
Dietician/Nutritionist/Doctor Name:		
Phone Number:		
Diet Plan (i.e. – Low sodium):		
<u>Breakfast</u>	<u>Lunch</u>	<u>Dinner</u>
Snack Ideas:		
Restrictions:		
Calories Per Day:		
Resources/Cookbooks:		

# My Exercise Guide

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

# ICE Card {In Case Of Emergency}

ICE, or “in case of emergency,” is a program that allows first responders such as paramedics, firefighters, and police officers, as well as hospital personnel, to contact and notify your next of kin in an emergency situation. This also enables them to obtain necessary medical information in a timely matter.

It’s important to provide your basic information, and an emergency contact listed on the ICE card, and additional health information that is essential to help medical responders provide the best care for you.

Below is an ICE card that you can fill out and print on sturdy paper, or you can order durable card stock from [www.pituitarybooks.com](http://www.pituitarybooks.com). This card should be kept with you at all times, in your wallet for example. A larger card on the next page can be kept in your home, somewhere visible, like your refrigerator.

## In Case Of Emergency

Full Name:

Date of Birth:

Blood Type:

Allergies:

Current Medications:

Conditions:

ICE Name:

Phone:

Doctor:

Phone:

# ICE Card {In Case Of Emergency}

## In Case Of Emergency

Full Name:

Date of Birth:

Blood Type:

Allergies:

Current Medications:

Conditions:

ICE Name:

Phone:

Doctor:

Phone:

# Medical History

Name:	Birth Date:
Allergies:	Blood Type:
Primary Doctor:	Chronic Conditions:
Medications:	Known Allergies:

Date	Immunizations, Illnesses, Surgeries, etc.	Notes

# Medical Professionals

**Name:**

**Specialty:**

**Name:**

**Specialty:**

Address:

Phone:

Fax:

Email:

Notes:

Address:

Phone:

Fax:

Email:

Notes:

**Name:**

**Specialty:**

**Name:**

**Specialty:**

Address:

Phone:

Fax:

Email:

Notes:

Address:

Phone:

Fax:

Email:

Notes:

# Symptom Tracker

Symptom	Date	Time	Duration/Frequency	Notes

# Medical Appointment Log

Date/Time:	Doctor:	Phone Number:
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Reason For The Visit:

Symptoms:

Questions For The Doctor:

Lab Tests/Procedures:

Diagnosis Results/Prescription Given:



# Medical Appointment Follow-Up Care

Follow-Up/Post-Discharge Care Information	
Diagnosis:	
Symptoms/Signs I need to call my doctor for:	
Who to call with questions/concerns:	
Name:	Phone Number:
Do I need to make arrangements for care at home? If Yes, list arrangements below:	
Do I need to order equipment and supplies that I will need at home? If Yes, list below:	
Do I have a follow up care plan? What is it?	
Communicate test results/records with my primary doctor, as soon as possible.	
Understand my post-discharge medications, and know if they are different than before admission	
Make a list of all medications and take it with me to all my appointments	

# Medical Appointment Follow-Up Care

Follow-Up Appointment #1
Where:
Date/Time:
Reason for Visit:
Things to bring (e.g. my current medication list):
Questions to Remember:

Follow-Up Appointment #2
Where:
Date/Time:
Reason for Visit:
Things to bring (e.g. my current medication list):
Questions to Remember:

**EVERY DAY  
MAY NOT BE  
GOOD...  
BUT THERE IS  
SOMETHING  
GOOD IN  
EVERY DAY.**

# The Medications You Are Taking

## **Know About Your Medication:**

- What is it for?
- What are BOTH names of your medication? (“brand” and generic)
- What will the medicine do?
- How should you take the medication?
  - How many times per day?
  - How much to take at once?
  - How long to take the medication?
  - How to take the medication? (Food, empty stomach, etc)
- What should you expect from the medication?
  - Results to look for?
  - Possible side effects?
  - Signs to stop taking the medication and call my doctor?
- How should you store the medication?
- Refills?
- It is important to always take your medication exactly as prescribed by your doctor.

## **Talk To Your Physician:**

- Make sure they know all of your prescription and over the counter medications that you take, including vitamins and supplements.
- If you aren't happy with how you are responding to the medication, call your doctor right away.

## **Get To Know Your Pharmacy/Pharmacist:**

- Have the name and telephone number of your pharmacy available.
- Call the pharmacy to check on availability of the medicine you are prescribed.
- Make sure your pharmacist is up-to-date on all of the prescription and over the counter medications that you take, including vitamins and supplements.
- Confirm they are up-to-date on your prescription benefit information, allergies and/or drug intolerances, and phone number.
- Plan how to pay for your prescription.
- Always confirm that your prescription is correct when picking up. Check and compare:
  - Instructions
  - Imprint on medication
  - Dosage
  - Refills
- Call ahead for refills. You should expect to have your refill ready in 24 hours.

# Weekly Medication Checklist

## SUNDAY

- Morning
- Afternoon
- Evening

## MONDAY

- Morning
- Afternoon
- Evening

## TUESDAY

- Morning
- Afternoon
- Evening

## WEDNESDAY

- Morning
- Afternoon
- Evening

## THURSDAY

- Morning
- Afternoon
- Evening

## FRIDAY

- Morning
- Afternoon
- Evening

## SATURDAY

- Morning
- Afternoon
- Evening

# Medications And Supplements

Medication/ Supplement	Dosage	Frequency	Take With Food/ Empty Stomach?	Purpose Of This Medication	Side Effects/ Restrictions

# Do I Need A Patient Advocate?

A time of illness is a stressful time for both patients as well as for their families. Even the best organized plans can go wrong, judgment is impaired, and realistically, you are not at your best when you are sick. Most patients need and are encouraged to have someone who can look out for their best interest, and help make sense of the confusing healthcare system – in other words, an advocate.

## **What Is A Patient Advocate?**

An advocate is a “supporter, believer, sponsor, promoter, campaigner, backer, or spokesperson.” It is important to consider all of these aspects when choosing an advocate for yourself or someone in your family. An effective advocate is someone you trust who is willing to act on your behalf as well as someone who can work well with other members of your healthcare team such as your doctors and nurses.

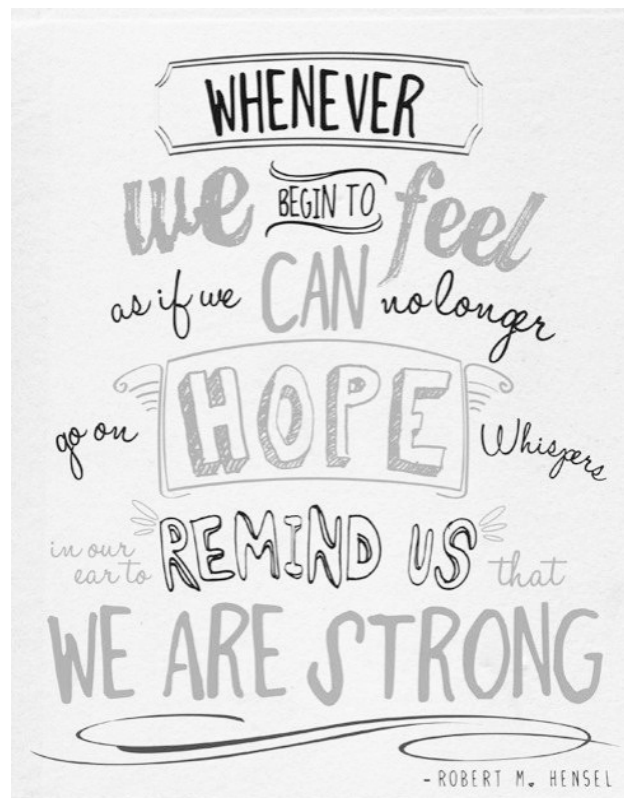
An advocate may be a member of your family, such as a spouse, a child, another family member, or a close friend. Another type of advocate is a professional advocate. Hospitals usually have professionals who play this role called Patient Representatives or Patient Advocates. Social workers, nurses and chaplains may also fill this role. These advocates can often be very helpful in cutting through red tape. It is helpful to find out if your hospital has professional advocates available, and how they may be able to help you.

## **Using An Advocate**

- Select a person you can communicate with and that you trust. It’s important to pick someone who is assertive and who has good communication skills. Make sure that the person you select is willing and able to be the type of advocate that you need.
- Decide what you want help with and what you want to handle on your own. For example, you may want help with:
  - Clarifying your options for hospitals, doctors, diagnostic tests and procedures or treatment choices
  - Getting information or asking specific questions
  - Writing down information that you receive from your caregivers, as well as any questions that you may have
  - Assuring that your wishes are carried out when you may not be able to do that by yourself.

# Do I Need A Patient Advocate?

- Decide if you would like your advocate to accompany you to tests, appointments, treatments and procedures. If so, insist that your doctor and other caregivers allow this.
- Be very clear with your advocate about what you would like them to know and be involved in Treatment decisions? Any change in your condition? Test results? Keeping track of medications?
- Let your physician and those caring for you know who your advocate is and how you want them involved in your care
- Arrange for your designated advocate to be the spokesperson for the rest of your family and make sure your other family members know this. This will provide a consistent communication link for your caregivers and can help to minimize confusion and misunderstandings within your family.
- Make sure your doctor and nurses have your advocate's phone number and make sure your advocate has the numbers for your providers, hospital and pharmacy, as well as anyone else you may want to contact in the case of an emergency.



# The Universal Doctor-Patient Agreement

## As your healthcare partner

### We pledge to:

- Explain each diagnosis, treatment, follow-up care thoroughly, in a way you can understand.
- Listen to all of your concerns and answer any questions you may have.
- Always tell you the truth.
- Treat you with respect and compassion at all times.
- Respect your privacy and follow confidentiality laws with your medical information.
- Include your family or advocate when you would like us to.
- Hold ourselves to the highest quality and safety standards.
- Be responsive and timely with our care and information to you.
- Provide instructions on how to meet your health care needs when I am not available.
- Provide you with all the necessary information to make informed decisions about your care and treatment options.
- Work with you, and other trusted partners who treat you, in the coordination of your care.
- End every visit with clear instructions about expectations, treatment goals, and future plans.
- Communicate openly about benefits and risks associated with any treatments.

## As a patient I pledge to:

- Ask any questions I may have, share my feelings and concerns, and be an active member of my healthcare team.
- Treat you with respect and consideration.
- Always tell you the truth.
- Give you all necessary information needed to correctly diagnose and treat me, including health history and all the medications I am taking.
- Research and learn about my condition.
- Respect your commitment to my healthcare.
- Participate in decisions about my care, and communicate any problems I have with it.
- Communicate all health changes to my doctor.
- Make necessary changes in life to lead a healthier lifestyle.
- Let you know ahead of time if I have family, friends or an advocate to help me with my healthcare.
- Call you first with any problems or questions, unless it is a medical emergency, then call 911.



# Patient's Bill Of Rights

## **Preamble**

The Pituitary Network Association (PNA) is an international non-profit organization for patients with pituitary tumors and disorders, their families, loved ones, and the physicians and health care providers who treat them. PNA was founded in 1992 by a group of acromegalic patients in order to communicate and share their experiences and concerns. PNA has rapidly grown to become the world's largest and fastest growing patient advocacy organization devoted to the treatment and cure of pituitary disorders.

PNA is supported by an international network of the world's finest physicians and surgeons. Our goal is to reach every patient who may be forgotten, abandoned, or worse yet, undiagnosed after many years of suffering. We are doing this in three ways: (1) By providing public awareness programs and educational seminars, (2) By assisting the medical community in developing uniform standards for early diagnosis, surgery, radiation, pharmacological treatment and follow-up, and (3) by having interactive Web sites and referral programs on these Web sites.

## **Patients' Rights**

- Pituitary diseases, tumors and the resultant hormonal imbalances shall be recognized as a serious, major public health problem afflicting a large segment of the world's population.
- The financial and intellectual resources of my government and our public and private health services shall be as fairly allocated to me and my disorder as they are to any other life-threatening and life-altering disease.
- I have a right to an early and appropriate diagnosis, treatment, care and medical intervention by the experts in these fields of medicine. I have an inalienable right to be told of - and allowed to use, whenever possible, any and all medications and treatment methods past, present or future -which will complete or assist in my healing.

# Patient's Bill Of Rights

- Upon completion of any medical evaluation, treatment and care, I am entitled to the emotional and psychological care afforded anyone else with psycho-social affective disorders.
- I reaffirm my right to be treated completely so I may reclaim my place in society and my family as a fully functioning and contributing member.
- I shall not be discriminated against in my workplace or any other part of society because of my physical, mental or emotional state.
- There shall not be any financial, insurance, job, or promotional stigma attached to my diseases discovery, medical care or emotional recovery. My future life shall only be limited by conditions not under man's ability to rectify.
- My family and coworkers have a right to be informed and counseled about my illness and its many manifestations. In order for them to understand and accept the temporary limitation to my job performance and my family obligations, they must if possible, become part of my healing environment.
- I reaffirm to the world: I am a valuable member of the society and family of man. My life is too valuable to waste. It is too costly to society and too detrimental to my family to allow me to merely exist at their sufferance and largesse.
- I have the right to be believed! Just because a physician has not yet heard of, or seen, my symptoms before, does not mean they are not real and deserving of medical care and further investigation.

# "Pituitary" Related Word Search

K F H Z R L P Q N Y E G K U N J X J Z N C S X C K  
 X D G Q X I A I A E T N T P L Y A N O E C Y R X F  
 A D D I S O N S M U U P I R K C D I A C I A S B P  
 I J F O T X H R M I J R J R R L T N D A N E Q T R  
 Q Z I T S A Y R A G E T O O C A N P L I N N N A O  
 I L A W B V P M G C V N M S I O R G O G K O O W L  
 K F V G V J O H I J U E I D U A D P U F D M K N A  
 O P T P I O P K E C G S A R T R H N L A Y R Y X C  
 R X R I R I I I U A P R H H C A G B E A X O B V T  
 O D G X S W T T L L G D K I R O Q E B O N H W E I  
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 R O O B S V R R F O N S T P Y G O L O H C Y S P O  
 A N W Q G T I H M E Y N E V T H E T H Y R O I D S  
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 I S H R O G M A D I K Y L H P Z O P P S M W A A E  
 U M A B I E O R T S E W C A Y L R R H L W L N Z P  
 T M A J E R O A T F E L C H N T B K A D A H O J K  
 I N Y F C M P E B X D P R H M D P O D G W X G Z C  
 P E I A E J N D O I V C J C E E S M W L T A O A D  
 J N M B J B W A L I G X C R L X N H E E X Z P T V  
 K K D N S N O C R Y W V A M O N E D A C B L Y N O  
 M I C R O A D E N O M A F T N G K K B L Y D H J K

ACROMEGALY  
 ADDISONS  
 ADENOMA  
 ADRENAL  
 CLEFT  
 CRANIOPHARYNGIOMA  
 CUSHINGS  
 CYST  
 EMPTY  
 ENDOCRINE  
 GAMMA

GLANDS  
 GROWTH  
 HORMONE  
 HORMONES  
 HYPOGONADISM  
 KNIFE  
 MACROADENOMA  
 MICROADENOMA  
 NEUROENDOCRINE  
 NEUROSURGEON  
 PANHYPOPITUITARISM

PATIENT  
 PITUITARY  
 PROLACTINOMA  
 PSYCHOLOGY  
 RADIATION  
 RATHKE  
 SYNDROME  
 THYROID  
 TRANSSPHENOIDAL  
 TUMOR

# "Pituitary" Related Word Search

## Solution

+ + + + + P + N + E + + + + + + + N C + + C +  
+ + + + + A + A E + N + + + + A + O + + Y R + +  
A D D I S O N S M + U + I + + C + I + + + A S + P  
+ + + + + H + M + + R + R R + T + + + N E + T R  
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+ + + + + O + + + U E I D U A D P + + + M + + A  
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T E T + + + S A D N E G + + + + + + + + + D + +  
I S H + + + M A D I + + L + + + + + + + + + A + +  
U + + + + + O R T + + + + A Y + + + + + + + N + +  
T + + + E R O A T F E L C + N T + + + + + + O + +  
I + + F C M P + + + + + + + + + D P + + + + + G + +  
P + I A E + + + + + + + + + + + S M + + + + O + +  
+ N M + + + + + + + + + + + + + + + E + + + P + +  
K + + + + + + + + + + + A M O N E D A + + + Y + +  
M I C R O A D E N O M A + + + + + + + + + + H + +