

# **#CIAAGADVOCACYCHAT**

HOSPITAL

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1 PM EST



## ***SELF-ADVOCACY IN TODAY'S MEDICAL ENVIRONMENT***



**CIAAG**

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# SELF-ADVOCACY

## *What is Self-Advocacy?*

- The action of representing oneself or one's view or interests

## *Why Do We Need to Advocate?*

- To ensure we have access to the necessary treatments and therapies to manage our illnesses/conditions
- To convey your personal beliefs and values to another
- Helps to set clear expectations





# THE MEDICAL SYSTEM IS CHANGING



In 2010, the United States embarked upon restructuring the healthcare system.



The Affordable Care Act created the National Health Promotion & Prevention Council.



The National Health Promotion and Prevention Council was tasked with numerous objectives

# THE NATIONAL HEALTH PROMOTION AND PREVENTION COUNCIL OBJECTIVES

1

Focus on  
Preventative  
Health Model

2

Changed the  
medical model  
from a biomedical  
approach to a  
biopsychosocial  
approach

3

Established an  
initiative for  
nation-wide  
population-based  
studies to take  
place.\*

4

Have patients self-  
manage their  
illnesses/conditions  
via alternative and/or  
complementary  
therapies

The ultimate goal is to move patients off pharmacological treatments and have patients self-manage their illnesses/conditions via alternative and/or complementary therapies. This need arose from the rising healthcare costs resulting from the baby boomers reaching retirement age and experiencing more health related issues which resulted in higher overall healthcare costs for the nation. This strategy is to help reduce healthcare costs and justify the expansion of a universal healthcare system.

\*CIAAG will be providing a full presentation on the national population-wide research projects being conducted in a future Advocacy Chat.





# IMPACT ON DOCTORS & PATIENTS

- Doctors are being required to provide patient care based on algorithms and medical guidelines rather than their clinical judgement.
- Patients are finding their stable medical regimens abruptly cut off or dramatically changed without their consent.
- Patient's need to become their own best-advocate to ensure they continue to receive access to the appropriate bio-medical care they need.







# DOCUMENT, DOCUMENT, DOCUMENT!

- Often times when people find themselves in this situation they panic and become overwhelmed with emotion. It's important to slow down, and take things one step at a time.
- *The most important thing you can do* in this scenario is to keep a detailed record of everything that takes place. In addition, keep a file to store all written correspondences, including emails and other electronic correspondences.



# KNOW YOUR RIGHTS!

If your provider is formally discharging you as a patient:  
**Know Your Rights!**



- ✓ They must provide you advanced written notice (number of days varies by state with average notice between 15 - 30 days)
- ✓ They must provide you a reason for your discharge as a patient.
- ✓ Your provider must continue to provide emergency services and necessary prescription medications during this time-frame.





# COMMON SCENARIO'S



- *Your provider is refusing to continue to provide medications and/or is changing your care in a manner inconsistent with your needs.*
  - Step 1: Send a written request for a full copy of your medical records.
    - You will need these to establish care with a new provider.
    - It's recommended you review your records for any inconsistencies or missing information.
  - Step 2: Contact your insurance carrier and request the assistance of a healthcare advocate to help you re-establish care with a local provider.
    - **Example Script:**
      - *"My name is (Insert Name). I am a patient of (Insert your doctors name). (Then provide a brief description of the problem you're having)." I would like your assistance in locating a new provider that can assume my care as soon as possible."*
      - You can then request the healthcare advocate's assistance with either working with your current doctor to re-establish the care you are seeking or you can work with the healthcare advocate to find a new medical provider to take over your care.
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# MAKE A LIST

When seeking a new provider it's important provide the healthcare advocate with a full list of your healthcare needs, including but not limited to:

- Full medication list (including scheduled medications)
- Special Accommodations
- Specialists
- Home-Health







# LEARN THE LINGO

Certain terminology can be more effective when working with insurance representatives and other medical professionals.



## REMINDE THEM OF THE IMPORTANCE OF CONTINUITY OF CARE

Continuity of care is preventing a gap in care and/or abrupt disruption in its delivery, to ensure patient quality of care over time.



## IF YOU ARE IN NEED OF SCHEDULED MEDICATIONS

Educate the healthcare advocate on the most recent guidance from federal agencies to ensure the continued access to scheduled medications in order to prevent life-threatening withdrawal syndrome.





# USE FORMAL DOCUMENTATION

- In pursuing assistance with accessing controlled medications it may be valuable to share the most recent federal announcements with your healthcare advocate. we recommend sharing the following federal announcements with your healthcare advocate, including, but not limited to:

*Centers of Disease Control issued a statement:  
No Shortcuts to Safer Opioid Prescribing*

*FDA identifies harm from sudden  
discontinuation of opioid medications & requires  
label changes to guide prescribers on  
individualized tapering*

## IMPORTANT ARTICLES

- [FDA Waiver of Informed Consent for Clinical Trials for Human Subjects](#)
- [FDA identifies harm from sudden discontinuation of opioid medications & requires label changes to guide prescribers on individualized tapering](#)
- [Centers of Disease Control issued a statement: No Shortcuts to Safer Opioid Prescribing](#)
- CIAAG Founder, Lauren Deluca, was featured in [USA Today](#) for heralding the safety announcements issued by the CDC
- Suboxone Manufacturer Indivior [Indicted](#) in Fraudulent Marketing Scheme
- [Opioid Manufacturer Indivior's Chief Executive Officer Pleads Guilty in Connection with Drug Safety Claims](#)
- [Indivior Loses Bid to Toss Charges Over Popular Opioid Treatment](#)

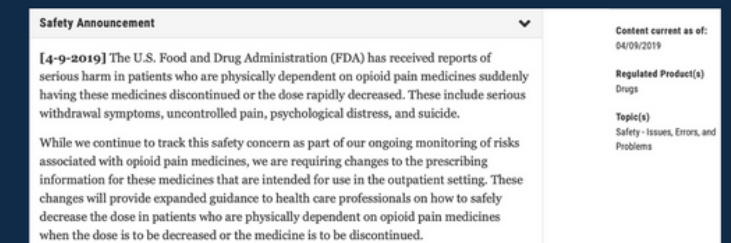
## FDA ANNOUNCEMENT AGAINST FORCED TAPERS

CIAAG met with members of Congress and Senate, April 7th-9th 2019 and successfully advocated for the FDA announcement against forced tapering.



Link to Announcement

[Click Here  
to Read](#)



**\*Both documents can be found at [www.ciaag.net](http://www.ciaag.net)**



# USE FORMAL DOCUMENTATION

- Make sure to remind them know it is their responsibility to ensure the safe delivery of your medical care. Failure to do so is a violation of your patient rights.
- Feel free to share with them your knowledge of the changes within the healthcare system, especially in regard to the management of people with painful illnesses/conditions.
- Provide a copy of CIAAG's "*Know Your Rights*" flyer.\*

\*CIAAG's flyer can be found by visiting our website, [www.ciaag.net](http://www.ciaag.net), under the Important Articles Section of our home page.



# UNDERSTAND YOUR ENVIRONMENT

- Once you established care with a new provider you may need to advocate for them to continue your current treatment regimen.
- Providers are being taught to implement medication sparing approaches and to utilize alternative and/or complementary therapies to manage complex illnesses/conditions.
- This new approach to care leaves providers and patients at odds with one another. Providers want to move patients into new treatment models and patients want their treatments to remain undisturbed.
- As a patient you have a right to receive individualized medical care based on your unique circumstances.
- The increased use of disease/illness specific guidelines and medical care via algorithm is impeding the doctor's ability to provide the individualized care that a patient needs.





# KNOW YOUR ENVIRONMENT

- It's important for you to recognize that our medical providers are under a tremendous amount of pressure to reduce the prescribing of scheduled medications, especially opioid pain relievers.
- Numerous federal guidelines have been issued recommending various forms of step-therapy before patients are afforded access to controlled medications for their illnesses/conditions.
- Patients who have successfully been maintained on scheduled medications need to learn how to best advocate for themselves to ensure their medical regimen is not unduly disrupted due to the political influences over our private medical care.



# WHAT TO DISCUSS?

- Important things to discuss with your new provider (or even your current provider):
  - Medical history/experience with providers
    - Postive? Negative?
  - Tell them if you have any form of PTSD or any medical related stress response.
    - Telling providers this ahead of times helps let them know what type of behaviors may be triggering to the patient and allow them to work collaboratively with you to ensure a comfortable and trusting experience over time.
  - Expectations with your new provider:
    - Service expectations from their office (returning calls, helping facilitate appointments, assist with special accommodations, providing prescriptions, etc.)
  - Current Medical Regimen:
    - Pros and Cons.
      - What are your current needs and future needs?
      - What are the positive/beneficial parts of your health regimen?
      - Are there areas you would like to see improved/incorporated into your care plan?

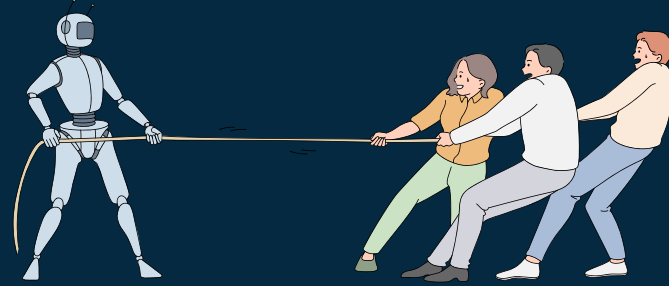


# TIPS FOR SELF-ADVOCACY

- The expanded use of medical guidelines requires our providers to document a patient's history of treatment approaches and their outcomes before they are able consider the use of medications (including scheduled medications).
- This gives your provider the opportunity to review what treatments and/or medications you have already tried to determine if there are alternative treatments that have not yet been pursued that may be of benefit to the patient.
- Advancements in medicine are rapidly growing. It is important to be open to your providers suggestions to help manage your illness/condition.
  - Note: If a provider is recommending the use of an alternative and/or complementary therapy to manage your illness/condition, it should never be contingent upon the patient needing to give up their effective treatments (including medications).
  - Any alternative and/or complementary care mechanisms should be offered in addition to the patients pharmacological therapies unless mutually agreed upon otherwise by the patient and provider. Proper delivery of medical care requires the informed consent and collaboration of all parties.



# DESPITE YOUR BEST EFFORTS...



- Despite the best self-advocacy and documentation to support your case, you may still find your provider unwilling to continue your previous medical regimen.
- Unfortunately, in today's environment, providers are becoming less willing to write prescriptions for scheduled medications for a variety of reasons; including but not limited to:

## MEDICAL GUIDELINES INFLUENCING PATIENT CARE CARE BY:



Advising against the use of scheduled medications to manage pain/illness.



Recommending the use of alternative/complementary approaches to the management of illnesses/diseases despite a lack of evidence to support their efficacy.



Creating a Step-Therapy Approach toward treatment.



# DESPITE YOUR BEST EFFORTS...

## PROVIDER CONCERNS:

- Reprimand from law-enforcement and/or medical boards
- Loss of medical license
- Loss of license to prescribe controlled substances
- Threat of DEA asset forfeiture
- Concerns over medical malpractice lawsuit
- Stigmatization by their peers
- Increased workload demands (often uncompensated)
- Patient developing addiction (whether founded by patient profile or not)
- Diversion of scheduled medications
- Potential wrongful death allegations

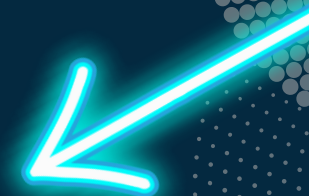






# LET YOUR LAWMAKERS KNOW!

**IF YOU FIND YOURSELF IN THIS POSITION IT'S IMPORTANT TO NOT GIVE UP!**



While the state lacks any formal resources to assist you, we recommend you reach out to your state offices to make them aware of your situation.



Our lawmakers need to be made aware of the impact these new healthcare changes are having on the delivery of safe patient care.



Recommended offices to contact, include:

- Your state House of Representatives Member
- Your state Senator
- Governors Office
- Health & Human Services
- Centers of Medicare/Medicaid: Civil Rights Office
- State Medical Board
- State Insurance Commissioner



*Note: Your specific circumstances will dictate which offices are the most appropriate to contact.*

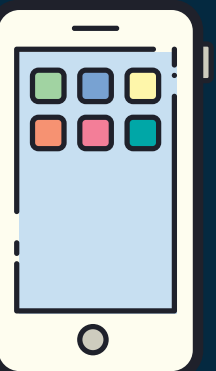


# LET YOUR LAWMAKERS KNOW!

## SAMPLE SCRIPT:



*"Dear Representative (Insert Name),*  
*My name is (insert name). I am reaching out to let you know about the difficulty*  
*I am having while trying to access proper medical care in our state. (Provide a*  
*short summary of what's taking place). Are there any resources or services your*  
*office provides or can direct me to that would be of assistance in this matter? If*  
*not, I would ask your office to consider taking steps to allocate resources to help*  
*patients like myself that find themselves unable to access necessary medical*  
*services and/or medications. As the healthcare system continues to change*  
*over the next decade, we need to ensure there are mechanisms in place to*  
*handle patients that are falling through the cracks."*





# FILE A FORMAL COMPLAINT




- If you feel your medical care was not handled properly or if you were discriminated against, stigmatized or treated inappropriately we recommend filing a formal complaint with the appropriate agency/authority.
- There are a number of agencies and other processes established to accept consumer complaints.
- When a complaint is filed with an agency they are required to start an investigation into the allegation. This investigation often entails speaking with the parties involved in the incident and working toward a collaborative solution and may even offer mediation between parties.
- Every persons situation is unique. Your circumstances will dictate which agencies are appropriate for you to file a formal complaint with.





# FILE A FORMAL COMPLAINT



- We recommend you file your complaint with all relevant agencies overseeing the area your complaint concerns. This will provide maximum impact in getting your issue taken seriously.
  - Filing formal complaints may not change what happened to you but it can help change processes for the future!
  - Agencies often rely on analyzing the type of complaints they are receiving to determine if there are any systematic issues taking place that may necessitate a more proactive response. By filing complaints with all of the appropriate agencies, we are sending a larger message to our leaders, alerting them to the systematic problems that need to be addressed within our healthcare systems.
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# WHERE TO FILE COMPLAINTS

Agencies and/or entities that you may want to file complaints with include, but are not limited to:



- Hospital/ or Medical Group Administration
- State Medical Board
- State Insurance Commissioner
- Centers of Medicare/Medicaid: Office of Civil Rights
- Health & Human Services: Office of Civil Rights
- Professional Licensure Board
- State Attorney General's Office: Division of Civil Rights

If you need assistance determining how to proceed with filing a medical complaint please contact us for assistance by sending an email to us at [info@ciaag.net](mailto:info@ciaag.net)



THANK  
YOU



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