

HEADACHE TOOLKIT!



Welcome to the HEADACHE TOOLKIT!

We are happy you are here!

This kit is designed to help make it easier for kids and families to find the path for more comfort and control when headaches become a problem. When headaches start happening more than once in a while and make it hard to do things like go to school, hang out with friends, or participate in favorite activities, it's time to take action.

Tackling something like headaches is a team effort! It takes kids, parents, and medical providers working together to get things under control and set everyone up for success. Everything in this kit is designed to help make it easier to collaborate, communicate, set goals, and most importantly, take **ACTION**.

Let's break down what you'll find in the tool kit, why it's here, and what you should do with it:

INTRO COMIC

Ever curious about why you get headaches and why your medical team might want to talk about things like sleep and stress? Wonder no more! Check out this comic that breaks down the basics.



HEADACHE DIARY

Getting a correct diagnosis and the best treatment plan depends on getting a really good understanding of the nitty gritty of your headache experience. When we truly understand symptoms and patterns, it makes it easier to find the ways to help you feel better. This worksheet helps you track your experience so you can:



- 1) Better understand yourself
- 2) Have a more productive conversation when you see a medical provider.

HEADACHE HISTORY FORM

Since headaches tend to run in families, it's helpful to know who else in the family gets headaches, what those headaches are like, and any treatments that have or haven't helped. This makes it easier to figure out what's going on with you, and gives some good clues about creating the best treatment plan. You fill this out this form to track anything you might



know that could help you and your doctor figure out your plan.

HEADACHE SYMPTOM CHECKLIST

Describing your headache experience accurately is really important to your healthcare provider because it helps to figure out what kind of headaches you have (tension, migraine, etc), and what treatments could be most helpful to you. This checklist helps you break your headache pain down into the information you and your doc need to know to figure things out.



WHAT KIND OF HEADACHE DO I HAVE?

Let's get technical! This handout breaks down the actual clinical criteria for migraines and tension headaches from the International Headache Society's International Classification of Headache Disorders and translates it from doctor speak into normal human language.



PREVENTION AND RESCUE STRATEGY OVERVIEW

With headaches, it's all about playing prevention. The research is clear that there are many things that you can do that can improve headaches and keep them from taking hold. We all do better and increase our chances of success when we have a good plan of action. But before we can make that plan, we need to understand what should go into it. This overview breaks down the options.



ACTION PLAN CHEAT SHEET

Now that you know the many things you can do to help yourself feel better, it's time to think about putting together your own plan. What does that actually look like? Great question! We put together this "cheat sheet" of example goals so you can see what it looks like and create your own (or just take them straight from the list)!



PREVENTION ACTION PLAN

Now it's time for you to create some headache prevention goals for yourself! We can't tackle everything at once, so this worksheet helps you and your medical team to work together to choose a few things that can have the biggest impact on helping you feel more comfortable and in control. You bring this to each appointment so you can track progress and create new goals as things improve.

RESCUE ACTION PLAN

When a headache starts, quick action is important to minimizing how bad it gets and how long it lasts. This worksheet helps you develop the plan that is best for you, including the medications your doctor recommends, and the other strategies that help you feel better as quickly as possible. Fill it out with your doctor so everyone is on the same page.

Appendix:

SAMPLE SCHOOL NOTE

A good game plan also means having a plan for how to handle headaches at school. Schools need documentation from a medical provider to make this happen. This is an example of a common accommodations letter that your doctor could provide.









Soooo... You're having a

HEADACHE?



DID YOU KNOW?

There are over 200 types of headaches, with MANY different causes, but the most common headaches are caused by sensitivities of something called the *Trigeminal Nerve*.

When it gets annoyed, the trigeminal nerve releases signals to your brain, which responds by sounding an alarm in the form of a headache.



The *Trigeminal Nerve* originates in the brain stem and runs down both sides of a person's face. It sends and receives nerve signals from the eyes and face, and is also responsible for motor functions such biting and chewing.



LIKES

Taking meds quickly

Adequate sleep

weird!



Just Remember:



Headaches are not your fault.

The longer these pain cycles repeat, the harder it is to turn them off down the road. If you start managing your pain properly now, the easier it will be in the long run!



Healthy diet

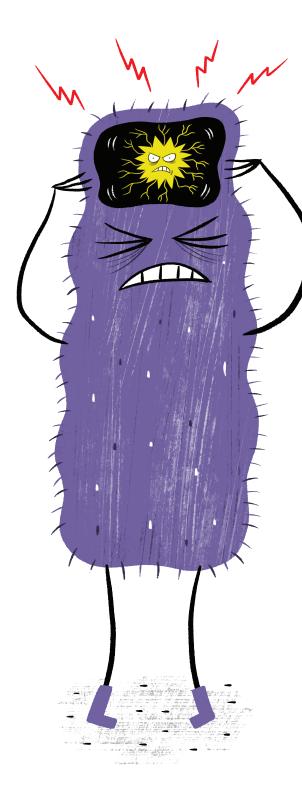


Improper sleep

For more info, check out our FREE Headache Resources!







HEADACHE DIARY

Understanding Your Headaches

Getting a correct diagnosis and the best treatment plan depends on getting a really good understanding of the nitty gritty of your headache experience. When we truly understand symptoms and patterns, it makes it easier to find the ways to help you feel better.

Date:		
Time of day	pain started:	
What were you doing right before it started?		
Time of day	pain went away:	
What did you	u do to help yourself feel better?	
(medications (incl eating, drinking, r	ude dosage), cold pack, rest or sleep, meditation, etc)	
Did it help?	☐ Yes ☐ No	
How much?		

Did the headache interfere with anything you wanted or needed to do?

(e.g. left school early, missed an entire day of school, couldn't do homework, missed soccer practice, missed a birthday party, etc) Other symptoms (if any) besides head pain: (e.g. nausea, vomiting, sensitivity to light, sensitivity to sound, sensitivity to moving around-like walking or running) What did you eat and drink today? How many ounces of water? _____ How many hours did you sleep last night? Any stressful stuff going on? It is common for women to have headaches around their period. Is it close, before, during, or right after your period? ☐ Yes ☐ No ☐ N/A Anything else that you think may have contributed to getting the headache? (e.g. weather changes, allergies, changes in medications, time staring at a screen, etc) More headaches?





HEADACHE HISTORY FORM



Instructions:

Since headaches tend to run in families, it's helpful to know who else in the family gets headaches, what those headaches are like, and any treatments that have or haven't helped those headaches. This helps to figure out what's going on with you, and gives some good clues about creating the best treatment plan.

You may not know that much about a relative's headaches, and that's okay!

Just fill in what you can and leave the other boxes blank.

Family member's first name:
Relationship to your child: (e.g. mom, maternal grandma, etc)
Type of headache: (migraine, tension headache, etc.)
Frequency:
Age of person when headaches first started:
8 I
Treatments that have helped:



Anything else that you know about this person's headaches:

(like other pain experiences they have, any allergies, and any other symptoms that happen with their headaches)

Additional family members?







HEADACHE SYMPTOM CHECKLIST

Describing your pain experience can be helpful to your healthcare provider. This can help to determine what kind of headaches you have (tension, migraine, etc), and what treatments will be most helpful for you! We know that not all of your headaches will be the same. Just choose what applies to MOST of your headaches.

Also, it is fairly common for kids to have **BOTH** migraine headaches **AND** tension-type headaches! If you have 2 distinct types of headaches, you can fill this out twice, once for each of your types of headaches.

* It's important to know that this worksheet is **NOT** meant to give you a definite diagnosis. It is designed to help you understand your own symptoms better, and be able to communicate that information to a qualified medical provider.

Where in your head do you feel the pain? Check all that apply: \square Whole head \square Front / Forehead \square Side(s) of head \square Back of head Is the pain on one side of your head or both sides? ☐ My left ☐ My right ☐ Both sides What does the pain feel like? Check all that apply: Aching Sharp Dull Pulsing or throbbing (like a heartbeat in your head) ☐ Pressure / tightening ☐ Something else: ____ Some people (but definitely not everybody) get a "warning sign" before their head pain actually starts. This is called an aura. Check any symptoms that you sometimes get either before your head pain starts or when your head pain first begins: ☐ Blurry vision and / or trouble seeing ☐ Numbness or tingling in your face, hands, or feet □ "Floaters", squiggly lines, bright lights, or other new things in your vision □ Weakness of an arm or a leg ☐ Dizziness (feeling like the room is spinning or you are spinning) ☐ Trouble talking Something else:



Some people have additional symptoms with their headaches besides head pain.

Check all of the symptoms that you have with at least some of your headaches:
Pain in your neck Nausea (Feeling like you might vomit)
☐ Vomiting ☐ Belly pain
☐ More tired than normal
☐ Bright lights bothering you more than they usually do
☐ Loud sounds bothering you more than they usually do
\square Motion / moving around (such as bending over to pick something up, or going up or down stairs) bother you more than it usually does
☐ Trouble concentrating (such as on school work)
☐ More irritable / grumpy than normal
☐ Something else:
How long do your headaches normally last for if you don't treat them with medication, rest, or something else?
Less than 2 hours 2 - 4 hours More than 4 hours

Do you sometimes miss things you need to do or want to do because of headaches?

This can be school, work, social events like time with friends, after school activities like sports, etc.)

☐ Yes ☐ No





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WHAT KIND OF HEADACHE DO I HAVE?

According to the International Headache Society's International Classification of Headache Disorders (3rd edition), here's the criteria for migraine headaches:

A headache is likely a migraine if:

• It lasts at least 2 hours untreated (or 4 hours for adults)

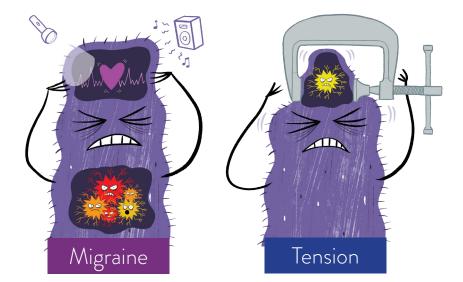
AND at least TWO of these four statements are true:

- The pain could be described as moderate or severe (which usually means it makes it hard to do your daily activities).
- It is on one side of your head (although it is common for kids and teens to have pain on both sides of the head).
- The pain feels like it is pulsing or throbbing or like you can feel your heartbeat in your head.
- Motion/moving around makes it worse.

You also have at least ONE of the following:

- Nausea
- Vomiting
- Sensitivity to light
- Sensitivity to sound





Kids likely have a tension-type headache if:

They don't meet the migraine criteria and if:

· Headache lasts at least 30 minutes

AND at least TWO of these four statements are true:

- The pain is on both sides of the head.
- The pain feels like it is pressing or tightening (not throbbing).
- The pain could be described as mild or moderate (which usually means it is not affecting your daily activities too much, if at all).
- Motion/moving around does NOT make it worse.

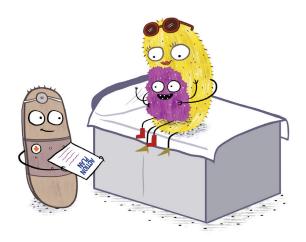
BOTH of the following are true:

- No nausea or vomiting
- There isn't sensitivity to both light and sound (but you can have one or the other).





HEADACHE PREVENTION & RESCUE STRATEGY OVERVIEW



What you and your provider need to know to put together a plan to prevent headaches AND create a solid rescue plan for when the pain starts.

The research is clear that there are many things that you can do that can improve headaches once they start and prevent them from taking hold. We all do better and increase our chances of success when we have a good plan of action. But before we can make that plan, we need to understand what should go into it. This overview breaks down the options.

After you check them out, you and your provider can decide which strategies are most important for you right now. Everyone is different, so it's important to think about what is best for you. This is often a question of motivation ("what do I feel I want to and can do?") and impact ("what is going to make the biggest difference?").

To create the best plan possible, it's very helpful to understand the details of your own headache experience. We encourage you to use the **Headache Symptom Checklist**, and the **Headache Diary** to track your symptoms. When you truly understand symptoms and patterns, it makes it easier to find the ways to help yourself feel better.

Because headaches often run in families, getting information about what has worked for family members can often give some clues about what can work for you too. The Headache History worksheet can give you some good insight.

Use all this info to help you and doc work together to fill out both your **Headache Prevention Action Plan** and your **Headache Rescue Action Plan**.

PREVENT:

Things you can incorporate into your daily life that can help stop the headache before it starts

Drink

Aim for 64 ounces of water each day.
 If you can't get that much, see how close you can get!

PROTEIN





SWATER §



Eat

- Don't go too long without eating. Keeping your body fueled and regulated is important. This means 3 meals a day and some snacks.
- It's especially important to eat breakfast each day. Include some protein so your blood sugar is more steady (ups and downs can be a headache trigger).

Some ideas: a hard-boiled egg, a protein bar or shake, nuts, and Greek yogurt.



• Get 30 minutes of exercise each day. Find something you think is fun, and that gets your heart rate up/makes you a little short of breath. It's great if you can exercise outside!

Examples: walking the dog, playing basketball, dancing to music, and walking with a friend.





Have Fun

• Find a way to do something fun each day. It lowers stress and creates all kinds of good neurochemicals in your body that prevent and reduce pain.

Relax

• Figure out what makes you feel less stressed, and make it part of your daily routine. This can be things like listening to music, drawing, talking with a friend, doing a meditation, taking some slow deep breaths, or spending time outside. ImaginAction is a great website to practice self regulation strategies and is free to use. It can be helpful to build these activities into your daily routine so you remember to do it each day. ImaginAction:

Sleep

- Aim for 8-10 hours of sleep each night. When does that mean that you need to go to bed each night?
- Create a relaxing bedtime routine. Try to do this for the hour before bed each night. Examples can be taking a shower or bath, listening to music, drawing, doing a meditation on an app, doing some yoga or stretching, or reading for pleasure. Write it down.
- · Go to bed within an hour of the same time each night and wake up within an hour of the same time each morning, even on weekends (we know you don't want to hear it but it is actually really important)! What can I do
- Limit naps. No napping is ideal, but if you do nap, keep it to 30 minutes or so.

Check out this handout on sleep that has even more great information:

Meds and supplements

- · Some medications are designed to prevent headaches. Check with your doctor about if this may be a good choice for you.
- Remember that some of these types of medications and supplements can take a long time to work (we are talking many weeks). Find out from your doctor how long it should take you to see a difference before you stop taking it.

Other important stuff

- · Acupuncture is a proven way to prevent and manage headaches. It can take a while to be effective, so you need to stick with it for a while.
- · Cognitive behavioral therapy with a mental health provider can be a key part of managing chronic pain.

Learn more in this handout:

 Neuromodulation devices can also help to manage and prevent headaches by calming or retraining the nerves. These devices can be used each day to help your nerves be less sensitive and cause less headaches. Some of the devices can also be used for "rescue" or stopping the headache after it has started.

Check out this article from the American Migraine Foundation to explore options:















to improve sleep?







• You may have heard about other interventions for migraines like Botox injections or a new class of medications call CGRP inhibitors. We don't want to skip over them as a strategy because they are out there in the world, but they are typically only used after other treatments haven't worked. This is typically done when a kid or teen has tried multiple other headache medicines for prevention (usually at least 2 preventive medicines for at least 3 months each) and they aren't working. **These handouts can make those injections easier:**

There are a also few things that you should know:

- These interventions always involve a medical provider that specializes in headaches and is likely part of a headache or pain clinic.
- Both Botox injections and CGRP inhibitors are technically "off-label" for kids. This means that they aren't FDA-approved for people under age 18 and that there is more limited research information on kids than adults. Are they still used for kids and teens under 18? Sometimes! That's why it is so important to have a specialist involved. (To be fair, there are a lot of medications out there that are commonly used "off label" for kids.)
- The CGRP medications are typically only prescribed for pediatric patients who have "chronic migraine", meaning they have at least 15 headache days per month, with at least 8 of those headache days meeting criteria for migraine.

RESCUE:

What to do after the headache starts:

- ACT FAST: when it comes to managing migraine attacks, earlier is better.
 Do not wait to treat...it makes it harder. It's important to have your rescue stuff with you wherever you are. Remember, the faster that you do your rescue plan, the better it will work!
- Medication: it's usually best to take medications as soon as you feel a headache coming on. Work with your doctor to create a specific game plan for that below.
- **Neuromodulation:** Consider calming the nerves with one of these devices.
- Take a time out: If possible, take a good but limited break: it's often helpful to lie down in a dark quiet room for 30 minutes if you're able to. If you're at home you might be able to rest for a little longer. Just try to not to throw off your schedule too much or cause yourself extra stress. We want you to still be able to sleep at night!
- Self regulation: calm your body and your mind with self-regulation strategies like breathing exercises, listening to audio books, meditation apps, or exploring ImaginAction.



TRACK!

Use the headache diary to collect data about how things are changing.

Figuring out what is best for you is a lot easier when we can track.



Preparing for your headache procedure:





How to Apply Numbing Cream Before Common Headache Procedures:







HEADACHE ACTION PLAN CHEAT SHEET



Now that you know the many things you can do to help yourself feel better, it's time to think about putting together your own plan. You don't have to tackle everything at once. Trying to make too many changes at one time can actually work against you. Let's stick with 2, maybe 3 goals to start!

It's a three step process: set the goal, write down the actions you'll take to achieve that goal, and then figure out what support you need from your family, friends, and/or medical team. We put together this "cheat sheet" to give you examples about how this works. You don't need to use these examples but feel free to do that if they work for you! There are separate Headache Prevention Action Plan and Headache Rescue Action Plan worksheets where you can fill in your own goals.

Examples:

Drink:

Goal: Drink 64 ounces of water each day.

Action(s) I will take: I will label 4 water bottles each day and make sure I drink all of them before the day is over.





Goal: Eat breakfast each day.

Action(s) I will take: Give mom a shopping list of breakfast foods with protein in them that I like, and decide each night what I will eat the next morning.

(Great examples of easy breakfasts include protein shakes, protein bars, a hardboiled egg, toast with peanut butter, and Greek yogurt.)

Support I need from (mom, dad, doctor, school, etc.): Buy the foods on the list from the store each week and remind me if I'm forgetting to eat breakfast.

Move:

Goal: I will exercise for at least 30 minutes 4 days a week.

Action(s) I will take: I will walk the dog when the weather is nice. On other days I will do a dance video online.

Support I need from (mom, dad, doctor, school, etc.): Pay \$10 for a fitness app each month and walk the dog with me when I'm having a hard time staying motivated.















Have Fun:

Goal: I will invite a friend over twice a week.

Action(s) I will take:

Text friends on Sunday each week to make plans.

Support I need from (mom, dad, doctor, school, etc.): Help pick up/take home my friends.



Relax:

Goal: Listen to ImaginAction each night before bed.

Action(s) I will take: Find the website and bookmark it on my phone.

Support I need from (mom, dad, doctor, school, etc.): Remind me if I haven't started to listen to it by 8:30 each night.



Sleep:

Goal: Get 8 hours of sleep each night.

Action(s) I will take: Put my phone in the kitchen to charge each night and be in bed with the lights out by 10pm.

Support I need from (mom, dad, doctor, school, etc.):

Mom will let me have 2 hours of extra screen time on the weekend if I meet my bedtime goal each night Sunday through Thursday.

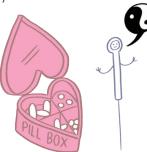


Meds and Supplements:

Goal: Be more consistent with meds.

Action(s) I will take: Put meds in my pill box.

Support I need from (mom, dad, doctor, school, etc.): Mom will buy me a new pill box. Also, mom will remind me to take my meds at 8pm if I haven't remembered on my own.



Other Stuff:

Goal: Try acupuncture once and if I like it, keep doing it.

Action(s) I will take: Remind mom to make an acupuncture appointment for me.

Support I need from (mom, dad, doctor, school, etc.): Make the appointment and take me to it.









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HEADACHE PREVENTION ACTION PLAN

Let's bring this back to the next appointment so we can track your goals!

Pro tip: This isn't a chance for judgment and shame, but a way for the adults to support you and find ways to decrease barriers and figure out the best next goals for you.

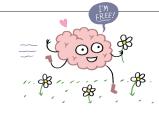


Now it's time for you to create some headache prevention goals for yourself! We can't tackle everything at once, so choose a few things that can have the biggest impact on helping you feel more comfortable and in control. Bring this to each appointment so you can work with your medical team to help you figure out the next steps to take as you discover what works best for you.

In case you missed it, the **Headache Prevention and Rescue Strategy Overview** goes over all the strategies that can work for you. Feeling stuck or not sure what could be a good goal for you? Check out the **Headache Action Plan Cheat Sheet** to get some ideas about what goes into a solid headache action plan.

Name:	Date:
Here's the things I want to work on in the next few (pick up to three)	weeks:
□ Drink □ Eat □ Move □ Have Fun □ Relax □ Sleep □ Meds	& Supplements Other:
Goal 1:	
Action(s) I will take:	
Support I need from (mom, dad, doctor, school, etc.):	
Goal 2:	
••	
Action(s) I will take:	
Support I need from (mom, dad, doctor, school, etc.):	







HEADACHE RESCUE ACTION PLAN

When a headache starts, quick action is important to minimize how bad it gets and how long it lasts. Fill this out with your medical team so you know exactly what to do to help yourself feel better.

	When I feel a headache coming on, the first things I will do: Meds:
-	Other things that help:
2.	If no better in minutes, do this:
	Other things that help:
3.	When to contact your medical provider:
	• If I'm having side effects from the medicine and I want to stop it. (Be sure to talk to your doctor first!)
	• If my headaches are no better in weeks.
	• If I miss more than days of school.
	Needing rescue meds more than times per week on average
	\bullet Rescue medications not effective and/or a migraine that is lasting for more than 1 day
	Having side effects from rescue or prevention medications
	 When daily tasks like going to school, seeing friends, exercise etc stop happening because of the pain for more than a few days and/or start to have an impact on daily life. For more info on pain and daily functioning, check out this.
	Other questions or concerns, including:

4. How to contact your medical provider:

□ phone: ____ □ email: ____

☐ patient portal: _____

 \square other: \square



Are there meds I should take together?

It might seem weird to take different medications at the same time, but sometimes taking 2 or 3 meds at the same time is the best way to knock out a migraine attack.

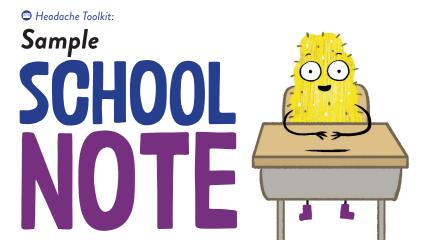
Additionally, your medical provider might have you take a second dose of a medication. For instance, triptan medicines, which are frequently prescribed for migraine, are often re-dosed at 2 hours if the migraine isn't gone.

Other important stuff to know:

- Any specific side effects or info I should have about these medications:
- Have your meds and/or neuromodulation device with you! This means that you will need your rescue meds and/or neuromodulation device at
- You'll also need to have a plan for how you can use your other strategies like self regulation skills and hydration during your school day. This can be worked out with the school ahead of time so you'll know you have what you need.
- Schools often require a doctor's note for any accommodations and medications. Ask your medical provider for a note that allows you to take your medicines and/or use your devices and strategies at school.

Here is an example of what that can look like to get you started:





To Whom It May Concern:

[Patient name, DOB] is under my care for headaches. Please allow him/her to go to the nurse's office at onset of a headache and take [medications and/or neuromodulation device]. This medication can be repeated in [number of hours] if needed. Please allow him/her to rest in a dark quiet room for 30 minutes if desired.

Additionally, please allow [name] to carry a water bottle with him/her throughout the day, and please allow restroom breaks as needed.

Optional:

- Please allow [name] to have a snack if desired, as this is helpful in managing headaches.
- Please allow [name] to take brief breaks (20-30 minutes) in a quiet place (such as the library) as needed, for headache management.
- While [name] is making every effort to attend school every day, there may be rare days when he/she needs to miss school because of a migraine. Please allow flexibility if he/she is needing to miss an occasional day of school due to migraine. This could include (excused absences / excused tardies / extended time on assignment / anything else relevant to the patient).
- Please allow [name] to take a break from screens when needed.
- Please allow [name] some flexibility with make-up work if he/she has needed to miss a day of school due to migraine. This can included modified assignments, shortened assignments that allow for demonstrating mastery, and extended time to complete assignments. [Name] may also require support from the school on the planning and execution of make up work if there is an extended absence.
- Please reach out with questions and concerns. These accommodations are medically necessary to maintain health and well being, and allow them to function at school.

I appreciate your help!



