Patient Self-Advocacy Guide

This conversation guide is designed to be a tool to help patients navigate conversations with their care team about a hypertensive emergency. It gives examples of how to tell your care team about your needs or concerns, and questions that you might ask your care team to learn about your options for a birth that is safe for you and your baby.
Think of it as a tool – use whatever words or ideas you find helpful and leave the rest.

It is our hope that you will be listened to and treated with respect; we acknowledge that how your care team responds is beyond your control.

Setting Expectations

When you're preparing for an emergency during your long-term care.

It can be useful to **clarify how much time you have with your provider** during an appointment:

- "How much time do we have together?"
  - "I would like to discuss what is important to me during my prenatal care."
  - "I know our appointment time is limited, and I want to prioritize the questions that I have for you today. goal/priorities

Throughout your prenatal care, tell your provider about **your goals, priorities, and birth plan** (or send them a message in your patient portal, though, there may be a fee!). Ask your care team to document your birth plan and preferences in your chart. You can always revisit, add to, or change your preferences later in your pregnancy! This will help your care team honor your preferences if there is an emergency later in your pregnancy.

Examples:

In these examples, the bold parts are ways you can signal what matters to you. The italics are examples of preferences (your preferences might be totally different from these!)

"I would like" **"It would make me feel cared for / respect if…"** **"It's really important to me that…"** **"My hope is to be able to…"**	*That I receive care in my first language; if there is an emergency, I [do/do not] want to wait for a professional interpreter to be available before taking the next steps.* *my partner/support person to be included [or not] in my emergency care decisions."* *If part of my birth plan ends up not being possible, please explain WHY my original birth plan is not possible, and explain all my other options to me in detail. That way, we can come up with a new birth plan together.* *I can manage my anxiety during an emergency. Please just tell me the bare minimum of what I need to know. Knowing all my options will overwhelm me."* *carry my child to term, but in an emergency, I would like to prioritize [my own / my child's] health"*

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Recognition & Expressing Your Concerns

When you're worried that you may be experiencing an emergency and are seeking help.

At the end of this guide (pg. 5), there is an infographic with warning signs for an emergency. **If you are in the "Red Zone" while at home, or after clinic hours, you should go straight to the emergency room**. The following section is applicable if you are in the "Yellow Zone" during office hours.

Calling before coming to the clinic

When you first notice that you are in the "Yellow Zone," call the clinic straight away. Share the information below to alert staff that you could be experiencing an emergency. Depending on the clinic, you could be speaking to the front desk staff, the triage nurse, or your provider when you call. First, introduce yourself and give context:

- "My name is _____ and I am [weeks] pregnant" or "I gave birth [days/weeks] ago."
- "My name is _____ and I am the partner/support person for _____ who is [weeks] pregnant" or "gave birth [days/weeks] ago."
- "My provider told me to call and be seen right away if I experience these symptoms."

Next, describe your concerns:

- Signal there is a problem:
  - "I am concerned/worried about my safety."
  - "I am concerned about my health and my baby's health."

- Describe the problem:
  - "I am experiencing [describe all of your symptoms; refer to the infographic on page ##]"
  - "These symptoms started [describe when]."
  - "I have heard these can be symptoms of pre-eclampsia."

Then, underscore your expertise:

- This did not happen during my last pregnancy. This does not feel normal for me.
- This is my first pregnancy, but I know my body, and this is not normal.

Finally, request to be seen:

- "I need to speak to a provider" / "I would like to speak to the provider I have been seeing who is familiar with my situation."
- "I would like to request an urgent appointment."

Communicating a concern to your provider

Ideally, the front desk and/or triage staff will share information with your provider. In practice, you may have to repeat what you shared with them to other members of your care team. Use the same language as above ["describe your concerns"] for reference

You can also ask your provider to document what you're sharing:

- "Would it be possible to write my concerns in my medical record?"

Responding to Dismissal, Disrespect, and Mistreatment

You are in charge of your pregnancy. You are also in charge of your body, and what other people can do to it. Consider speaking up if you feel that you're being **mistreated, disrespected, ignored, and/or dismissed** repeatedly. Here is some language you could have in your back pocket to self-advocate.

If you feel your concerns are being **ignored or dismissed**:

- Reiterate: "Would it be possible to write my concerns in my medical record?"
- "What information has been shared with you about my case and my concerns?"
- "What information have you used to decide that I am safe/ that this is not an emergency?"
- You can ask the provider if they will do tests (e.g., blood pressure reading, urine analysis) to rule out emergencies.
- "I would like to speak with a supervisor/another provider for a second opinion about my concerns." / "I value what you're saying, and I would feel better if I got a second opinion."
- "I do not feel like my concerns or my safety are being taken seriously."

If you experience **mistreatment or disrespect:**

- "I do not understand what is happening and things are moving too fast. Please pause and talk to me directly about what is happening in my body."
- "Your words/actions have crossed a boundary for me, I need time alone"
- "Is there a patient relations coordinator or mediator at this clinic who I can speak with about this?"
- "I need to step away" or "I need you to step away for a moment"
- "I am not happy with the way I have been treated [give examples]. I would like to request a new provider." / "Could I have a follow-up appointment with another provider?"

Understanding Your Diagnosis & Next Steps

When your provider tells you about your high blood pressure emergency and you need to make a plan.

Creating a shared understanding of the condition

If you are told you are having a hypertensive emergency, it is important to quickly get on the same page as your provider. You can use the following phrases to unlock a shared understanding of your condition. This will help you make the best decision for you.

- "What is the problem and how serious is it?"
- "What is the current risk to my health and my baby's health?"
- "If things don't improve, what should I be concerned about?"

Understanding the Next Steps

As providers explain the hypertensive emergency, they may provide suggestions for what to do next, and explain the courses of action they are suggesting. Some people feel empowered by knowing all the information, and why these suggestions are being made; others might only want to know what is necessary (see examples under "Setting Expectations"). Do what feels right for you! If you do want more information, the following questions can help you make an informed decision.

Understanding the Next Steps Cont.

"What are the next steps?"
- "What would my treatment look like while I'm here in the clinic?"
- "Why are you choosing this treatment in particular? Are there any alternatives?"
- "I would like to know the possible side effects."
- "What I'm hearing you say is that you are recommending this because...[state in your own words]. Is that correct?"

Clarifying timing
- "How urgent is the need to begin treatment and is there any flexibility to the timeline?"
- "How much time do I have to think about my options with my birth partner?"
- "How much time do I have before I need to go to the hospital?"

If the provider recommends you go to the hospital

You are in charge of your pregnancy. You are also in charge of your body, and what other people can do to it. Sometimes treatment for high blood pressure can take a long time. If this is the case, it is important to understand what you might need to get in order at home, and what things to expect if you must go to the hospital. Note: your provider can only offer their most educated guess about what will happen at the hospital. As with any emergency, things may change quickly and often. We encourage you to feel empowered to ask why.

At the hospital
- "What happens if I don't go? What are the risks?"
- "What is going to happen when I get to the hospital?"
- "Where should I go once I get to the hospital? To the emergency room or to labor and delivery?"
- "What will they already know about my case?"
- "How should I prepare to make treatment as successful as possible?"
- "If I need to give birth today, what could that look like?"

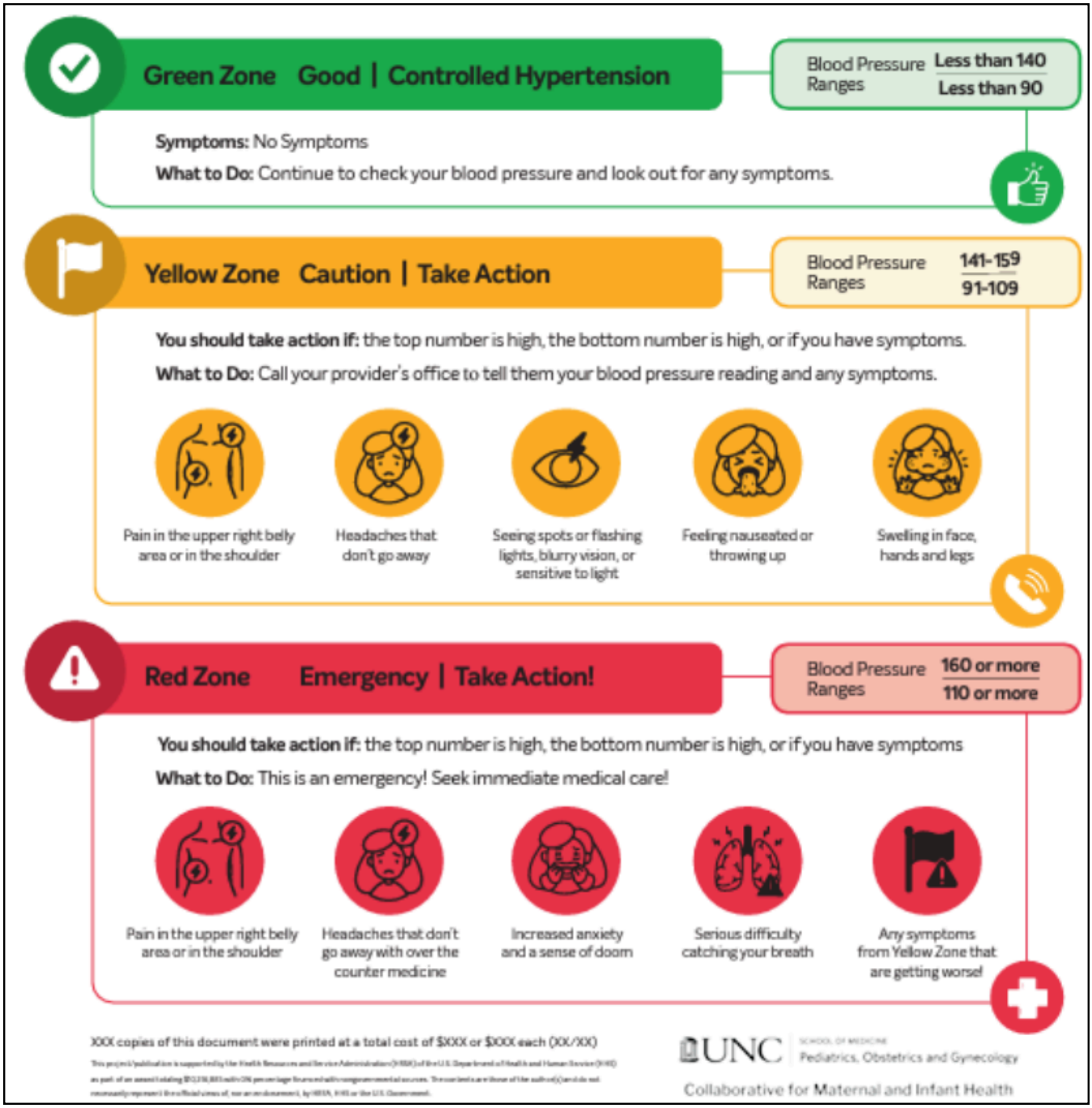
Logistics
- "How much time do you think [the treatment] is going to take?"
- "Will I need to call out of work/school?"
- "Do I need to be prepared to stay overnight?"
- "Can I eat/drink?"
- "Do I need to alert my support people/find childcare/pet care/grab my go bag?"
- "Can I leave my car here?"

To learn more about ACHIEVE, please visit this QR Code:

For additional education resources, please visit this QR code:

Warning Signs for a Hypertensive Emergency

Worksheet from UNC Collaborative of Maternal and Infant Health



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