

# Interoception Advocacy Card for Doctor, Nurse, or Other Medical Provider

## SECTION 1 – WHAT INTEROCEPTION IS:

**Interoception is the sense that allows us to notice internal signals coming from the body.**

Interoceptive signals inform our emotional experience and allow us to notice when we are feeling hungry, thirsty, in pain, sick, anxious, etc. (Craig, 2002). Research indicates that some people have unhelpful interoception levels (Khalsa, et. al., 2018). This can affect our ability to accurately sense and/or communicate important medical symptoms. For more information, see <https://www.kelly-mahler.com/what-is-interoception>.

## SECTION 2 – WHAT I WANT YOU TO KNOW ABOUT MY PERSONAL INTEROCEPTION LEVELS:

**Sometimes my body signals are:**

- ☐ **Too small**, which causes me to miss certain signals (e.g., pain from an ear infection or the discomfort of a fever). Or sometimes I might not notice signals until they are very intense (e.g., I don't realize that I'm sick until I am really, really sick).
- ☐ **TOO BIG**. My body signals can be very overwhelming and intense (e.g., my heart pounding so loudly that I can't think of anything else; a hangnail causing me weeks of pain). This is a real experience for me; I'm not exaggerating. Also, sometimes the body signals are so big that I can't make sense of everything that I notice (e.g., feeling twenty different internal sensations at once makes it hard to know what is important).
- ☐ **DiStOrTeD**. This can make it very hard for me to pinpoint exactly what I feel. Sometimes I have a vague feeling, like feeling "icky," but the specific signals are hard to identify. Or sometimes I notice that something is off in a certain body part, such as my stomach, but I can't clearly notice or explain the exact feeling (e.g., whether it is hunger or anxiety).

## SECTION 3 – HOW YOU CAN HELP ME:

- ☐ **When asking me to report my symptoms, please give me extra time to process your questions and respond.** Noticing and describing how my body feels can range from very difficult to downright impossible. But with extra time, I may be able to give you an answer.
- ☐ **Schedule more time to see me.** Since I need more time to process and respond to your questions, this can be very helpful for me to get proper medical care.
- ☐ **Avoid the use of vague, open-ended questions like, "How do you feel today?"** These questions are really hard for me to answer. If I am struggling to answer a question, provide me with choices for answers, including the option "none of these."
- ☐ **Adapt traditional pain scales.** Because I experience pain differently, it is hard for me to rate or describe my pain in detail. Try to give me concrete ideas of what each pain level means. Also, consider that my pain experience is very different, so a 1/10 on a pain scale for me might be an 8/10 for someone else—or vice versa.

- ☐ **Take me seriously.** Even if I can't notice or describe details of my pain, illness, or discomfort, that does not mean nothing is wrong. It just means that I have a difficult time noticing or indicating exactly how my body feels. Sometimes I have a vague feeling of pain or discomfort, but I can't pinpoint where it is coming from. Or sometimes I notice a certain feeling, but putting it into words is really challenging. On the other hand, some days, I may feel every little ache, pain, or twinge, which might seem unusual to you; but it is my real experience. I am not exaggerating. This is not attention-seeking behavior. It is real.
- ☐ **Teach me.** Being sensitive to or confused by my body's cues might make it hard for me to know when I actually need to see a doctor. If I come in often or with a minor problem, it is not to get attention. Please help me by teaching me what I should do if my body ever feels this way in the future.
- ☐ **Give me support in determining the effectiveness of a medication.** It can be very hard for me to determine if a medication is making me feel better, worse, etc. due to my interoception challenges. When possible, provide me with concrete ways to measure changes or a method for getting input from a trusted person.
- ☐ **When giving me recommendations, please don't ask me to do things contingent on how my body feels** (e.g., "Come back in a few days if your cough feels worse"; "Take it easy if you notice your head starting to hurt"). Please give me concrete steps to follow.
- ☐ **Please make things visual.** Write out your questions. Provide a body outline for me to point to where I feel the symptoms. Write down the steps you want me to follow after the visit. It is often hard work for me to communicate during my visit, and I can become overwhelmed. Visuals can be very helpful.
- ☐ **Use alternate forms of communication.** During the visit, giving me time to write or type responses can be helpful if I have a hard time communicating symptoms verbally. Between visits, options such as emails or portal messages can be very helpful.
- ☐ **Understand that I may need to schedule frequent checkups.** Since my body signals can sometimes be unreliable, and might not warn me of a possible health issue, frequent checkups can provide me reassurance and ensure that I am healthy.
- ☐ **Include this card in my chart/electronic file.** That way, other medical staff will have this important information.
- ☐ **This is something else that can help me:** \_\_\_\_\_

Craig, A. D. (2002). How do you feel? Interoception: the sense of the physiological condition of the body. *Nature Reviews Neuroscience*, 3(8), 655-666.

Khalsa, S. S., Adolphs, R., Cameron, O. G., Critchley, H. D., Davenport, P. W., Feinstein, J. S., ... & Meuret, A. E. (2018). Interoception and mental health: a roadmap. *Biological Psychiatry: Cognitive Neuroscience and Neuroimaging*, 3(6), 501-513.