



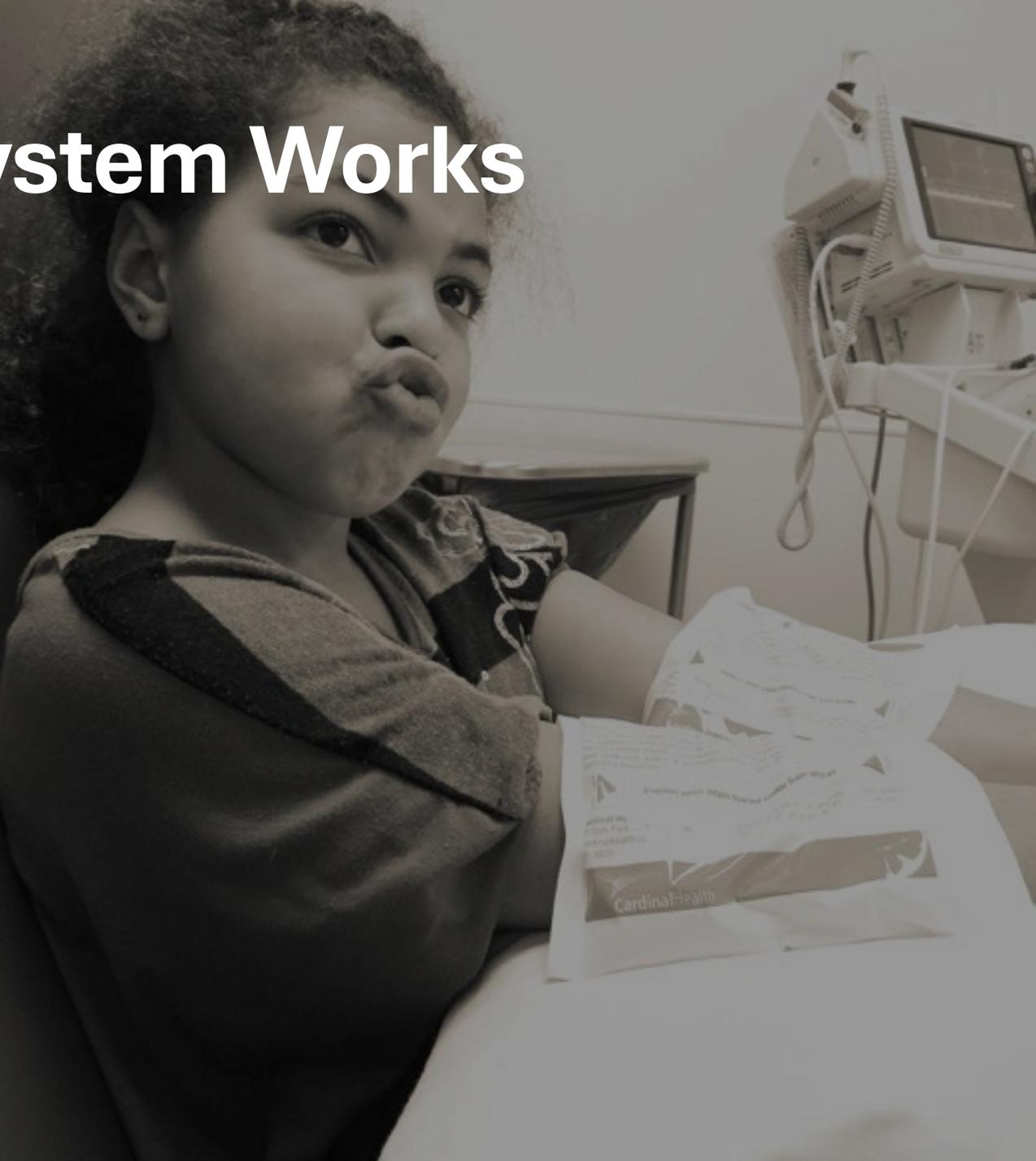
Designing Health systems to Empower Patients in the Diagnostic Process

Nancy Netherland – Family Voices of California



Two Kids, Two Diagnostic Stories

When the System Works



When the System Fails

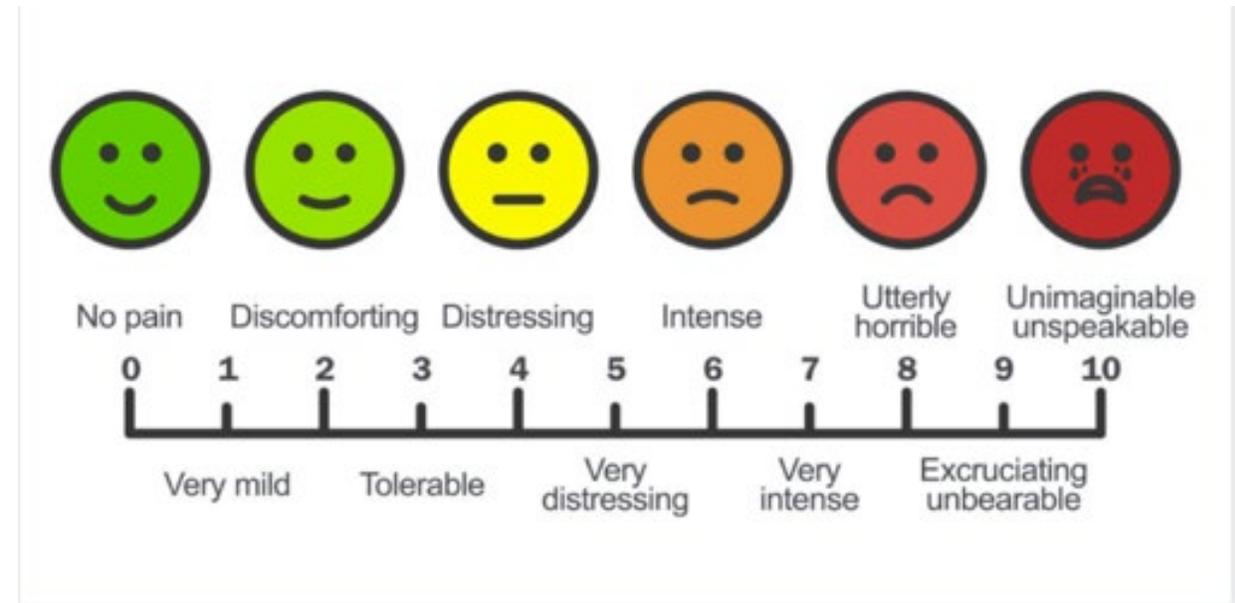


What Changed — And Why



Tools We Built — Because the Existing Ones Didn't Work

| Pain Journal | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|----------------|---------|------|---------|-------|---------|------|---------|-------|-----------|------|---------|-------|----------|------|---------|-------|---------|------|---------|-------|----------|------|---------|-------|---------|------|---------|-------|
| Day | Monday | | | | Tuesday | | | | Wednesday | | | | Thursday | | | | Friday | | | | Saturday | | | | Sunday | | | |
| Date | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Daytime | morning | noon | evening | night | morning | noon | evening | night | morning | noon | evening | night | morning | noon | evening | night | morning | noon | evening | night | morning | noon | evening | night | morning | noon | evening | night |
| Exact Time | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Severe | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 |
| | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 | 9 |
| | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 |
| Pain | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 |
| | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 |
| | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 |
| | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 |
| | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 |
| | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| No | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Medication | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pain Location | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pain Duration | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Remarks | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Relief through | | | | | | | | | | | | | | | | | | | | | | | | | | | | |



So we made
our own.

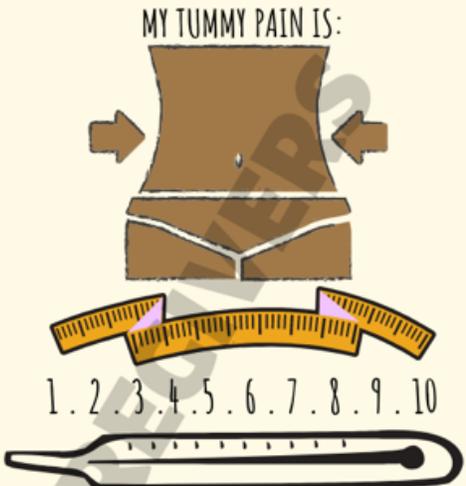
DATE: _____

WHERE MY PAIN IS:



1. 2. 3. 4. 5. 6. 7. 8. 9. 10

MY TUMMY PAIN IS:



1. 2. 3. 4. 5. 6. 7. 8. 9. 10

HIGH TEMP = _____

OTHER SYMPTOMS = _____

NOTES ON PAIN & OTHER THINGS = _____

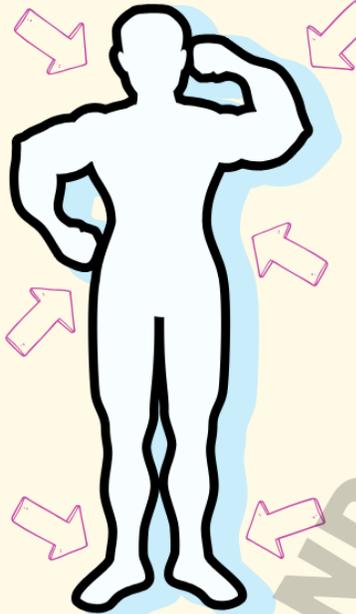
LIKE WATER  LIKE A ROCK

1. 2. 3. 4. 5. 6. 7. 8. 9. 10

Nausea icons that
matched what
nausea actually
looks like when
you are eight
years old

DATE: _____

WHERE MY PAIN IS:



1 . 2 . 3 . 4 . 5 . 6 . 7 . 8 . 9 . 10

MY HEAD PAIN IS:



1 . 2 . 3 . 4 . 5 . 6 . 7 . 8 . 9 . 10

NOTES ON PAIN & OTHER THINGS=

NAUSEA LEVEL =



PUKING ALL DAY NADA

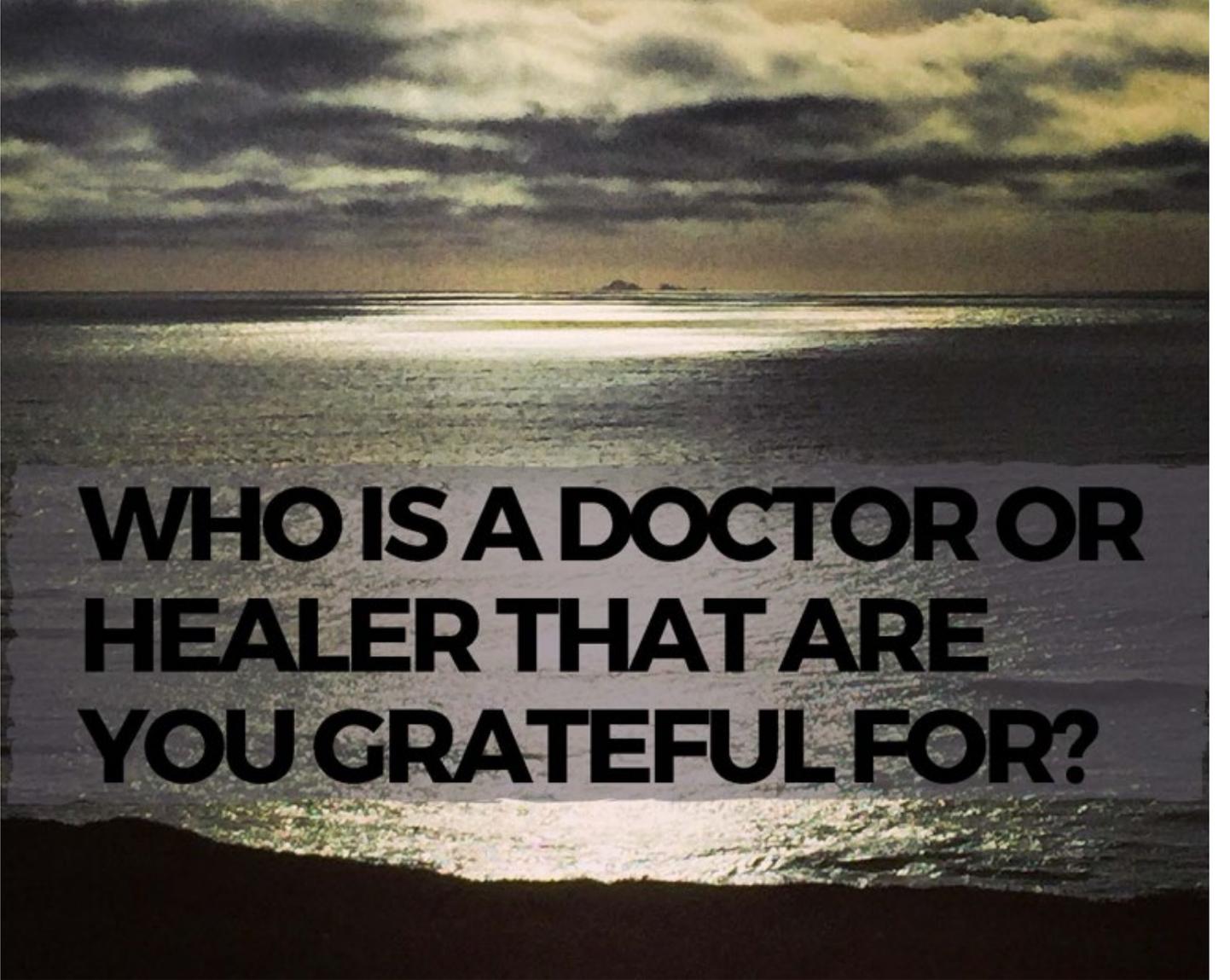
1 . 2 . 3 . 4 . 5 . 6 . 7 . 8 . 9 . 10

NOTES ON PAIN & OTHER THINGS=

Flipping the Dynamic



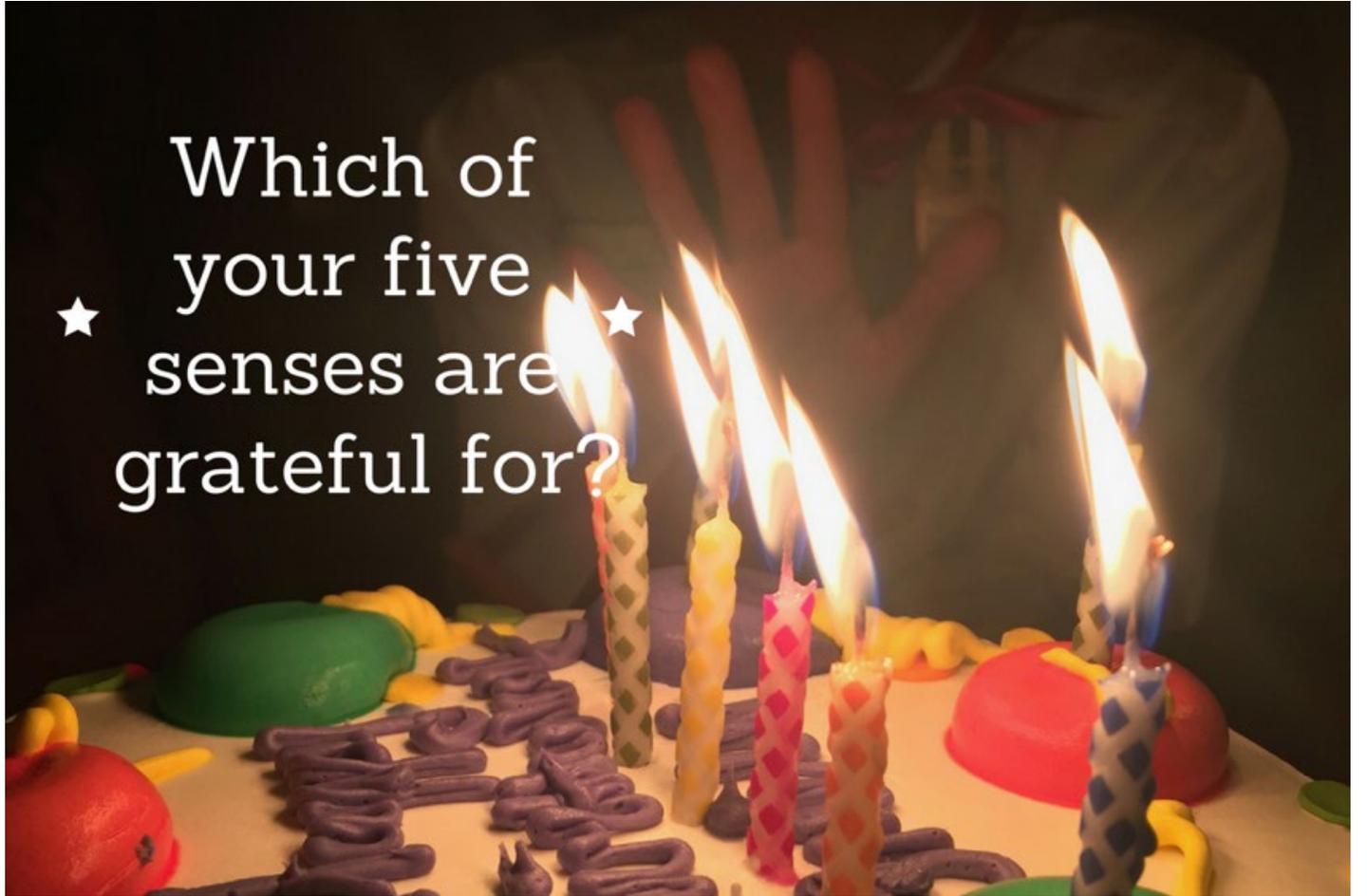
Here is why
it matters



**WHO IS A DOCTOR OR
HEALER THAT ARE
YOU GRATEFUL FOR?**

**Not Just
Extracting
Information**

Which of
★ your five ★
senses are
grateful for?



**Participants
not Subjects**



★ What season are you grateful for? ★

TIARA — Trauma Informed and Resiliency Awareness



Participating in the Diagnostic Process

HOLD UP!!



I NEED A BREATH BREAK !!

kidsandcaregivers.com

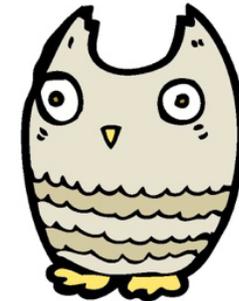
I AM TIRED



I NEED MORE
HELP THAN USUAL

kidsandcaregivers.com

PLEASE EXPLAIN AGAIN



I NEED TO REALLY UNDERSTAND
THIS

kidsandcaregivers.com

Lala CareMap 2025

Self identifies as Black, Teen, and as a digital artist and lover of dogs, horseback riding, ramen & Anime.



The system identifies her as a Medically Complex Former Foster Youth insured by CCS/Medi-Cal who is Bi-racial living with complex medical needs, multiple behavioral health Dx, neuro-divergencies, and learning disabilities w/ an Elevated ACES score

What We're Actually Asking For



**Listening
and Co-
Creation**



**Families
need tools**



Thank-You

