

Speaking RA: Rheumatoid Arthritis Patient Lexicon Guide

Listening
Powered by inVibe



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A Little About Who We Are

An Entirely New Way To Listen

inVibe helps healthcare organizations better understand their customers by capturing authentic stories and translating sound science into actionable insights.

Changing How We Listen



Frictionless Research

Our proprietary technology enables low-friction, high-speed data collection.



Authentic Stories

Our platform allows participants to speak freely, anywhere, anytime and without judgment.



Human + Machine Intelligence

Our structured methodology combined with sociolinguistic analysis and AI-powered acoustic metrics provides unique emotion and customer insights.



Interactive Dashboard

Our interactive dashboard allows researchers to explore, filter, and search the acoustic metrics and lexical data.



Why We Were Listening

As part of an internal research effort, our team was interested in learning more about the Rheumatoid Arthritis (RA) patient experience and lexicon. Our key objectives were to:

- (1) Explore the way in which patients speak about their symptoms and disease experience
- (2) Capture language and perspective differences/similarities throughout the patient journey



How We Decided to Listen

To capture stories and descriptions of patients' disease experience, inVibe designed a study in which patients were asked 8 questions focused on describing their experiences living with RA.

Methodology at a Glance

- **Total Sample:** 44 patients (19 recently diagnosed patients, 25 long-term diagnosed patients).
- **Questions Asked:** 8 voice-response questions, including reactions to visual stimuli
- **Data Collected:** Over 2.5 hours of voice data was collected in 72 hours

For this research, virtual voice-response interviews were conducted using inVibe's proprietary research platform.



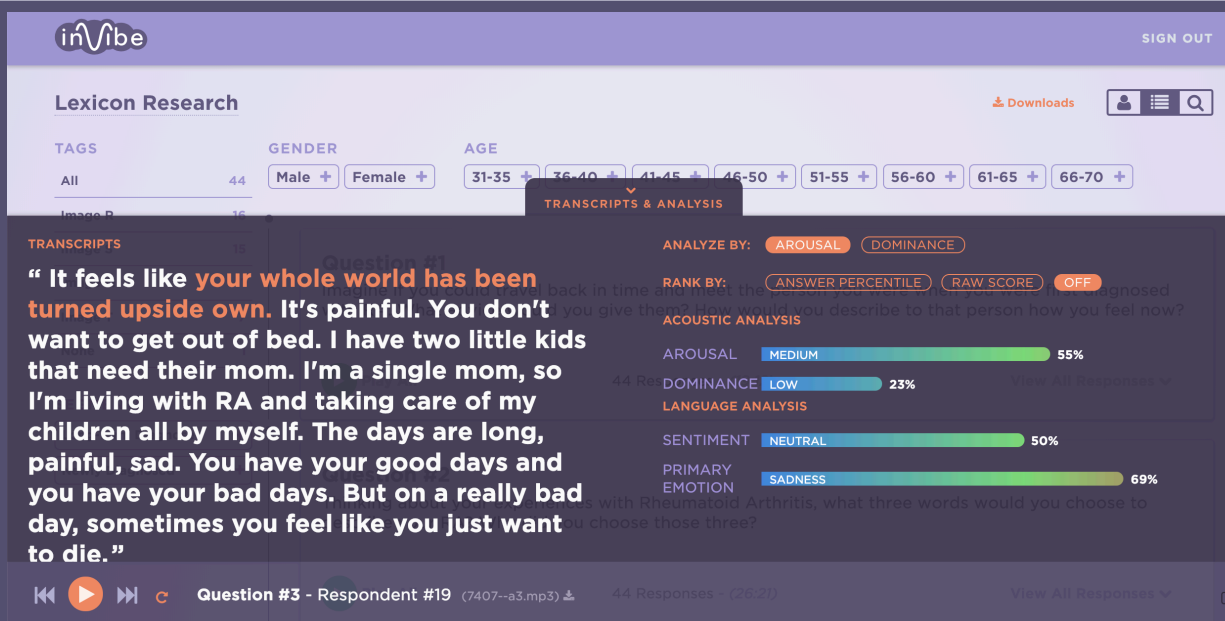
Participants
screened-in...



...Reviewed
stimuli...



...And responded with
their perspective



After responses were transcribed, our team used our interactive dashboard to identify the patterns that mattered, taking into account both the AI-powered acoustic measures and a sociolinguistic driven analysis.

A black and white photograph of an open book with a dark bookmark. The book is open to two pages, and the pages are slightly curved. The background is dark and out of focus.

Understanding the RHEUMATOID ARTHRITIS Patient Story

The emotional impact of RA is as important as its symptoms, and while bad days are truly painful, they also leave patients feeling completely incompetent. On a bad day, patients may want to be alone, but they also feel lonely.

RA symptoms are complex and not always easily explained. Although patients may share their symptoms with their physicians, the emotional impact of RA can take a backseat in those conversations.

For recently diagnosed patients, immediate symptoms are top of mind, but for more experienced patients, they frame their symptoms within the context of long-term consequences. And while they still feel the emotional impact of RA, patients who are more experienced are also more positive and hopeful, which is a stark contrast to recently diagnosed patients who may be struggling and feeling helpless.

Patients feel misunderstood and want others to know they're not lazy, and while their outward appearance may not always show signs of RA, inside they can still feel its effects. Even though there are treatments, they don't always take away their pain. In fact, RA is a battle they face on a daily basis.

When it comes to defining RA and its impact, the emotional consequences are as important as the physical symptoms.

Patients chose three words to describe their condition, and along with the overall pain and symptoms, they also shared words that revealed their emotional state, most commonly frustration, hopelessness, and depression.

Patients with more disease experience also used language about their physical state, describing themselves as trapped or constrained by their condition.

Long-term Diagnosed Patients

Recently Diagnosed Patients



Emotional State

adjusting, aggravating, altering, anxiety, challenging, changing, despondent, discouraged, draining, enlightened, **frustrating**, hopeful, life relieved, sad, surprised, terrible

defeat, **depression**, discouragement, distress, hopeful, **hopelessness**, **inconvenient**, overwhelmed, sad/sadness, scary, trouble, upsetting



Symptoms

achiness, achy, exhausting, fatigue, **pain**, **painful**, sharp soreness, **stiff**, **stiffness**, swollen, uncomfortable, unpredictability, weight

achy, bothersome burning, energy, fatigue, heat, lack of **pain**, **painful**, sore, stiff, swelling



Physical State

adaptive, brick wall controlled, **debilitating**, disforming, immobile, long-lasting, remission, restricting strapped, trapped, ugly, unhealthy

Debilitating, handicapped, helplessness, hinderance, restricting

**Bolded, larger font indicates most frequent lexical items*

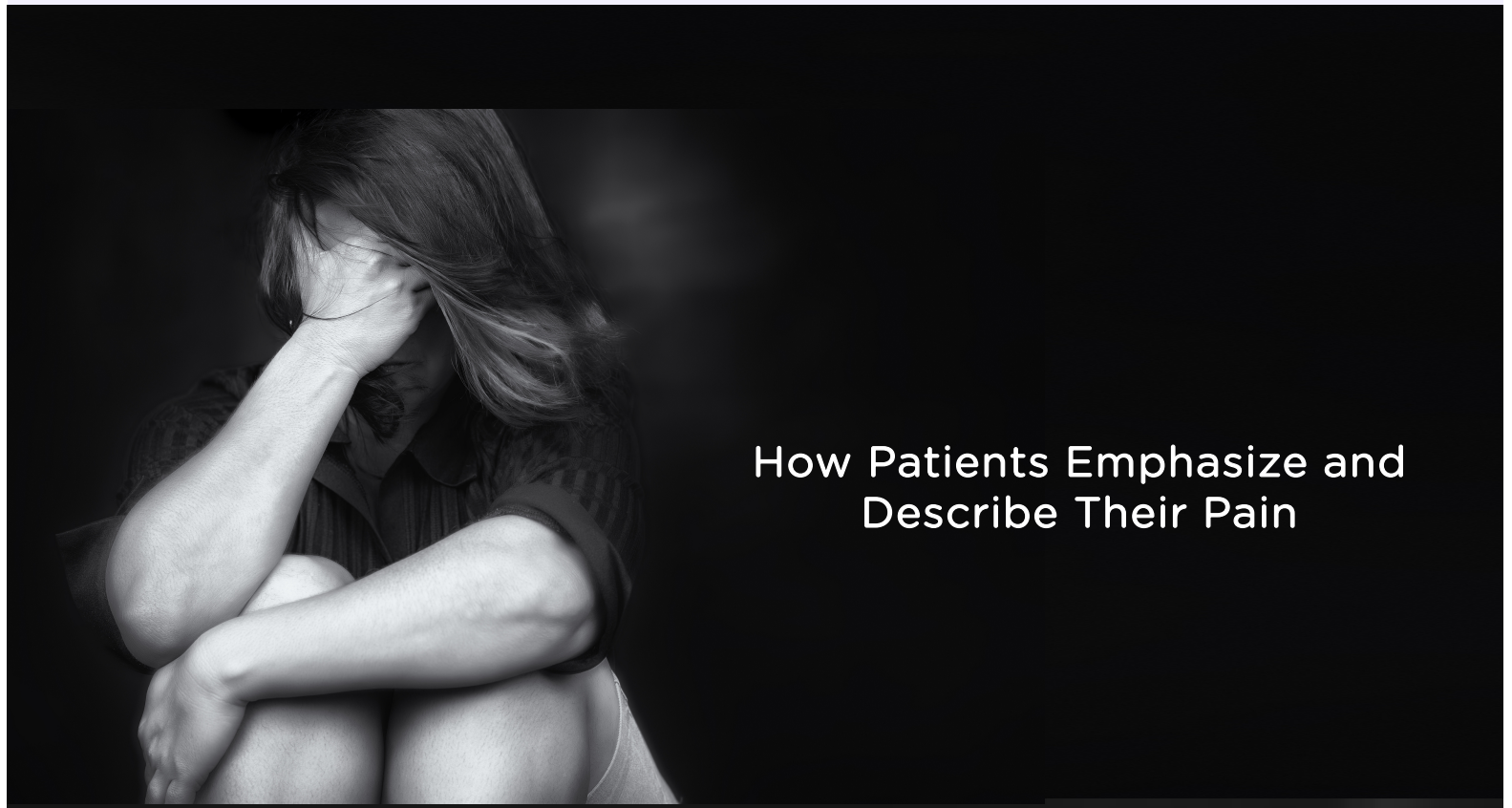


“

It feels like your whole world has been TURNED UPSIDE DOWN. It's painful. You don't want to get out of bed. I have two little kids that need their mom. I'm a single mom, so I'm living with RA and taking care of my children all by myself. THE DAYS ARE LONG, PAINFUL, SAD. You have your good days and you have your bad days. But on a really bad day, SOMETIMES YOU FEEL LIKE YOU JUST WANT TO DIE.

(Recently Diagnosed Patient)

”



How Patients Emphasize and Describe Their Pain

Some days you feel a dull pain, but it just feels just **terrible**

When you do move, your **whole body** just hurts

Excruciating pain and you can't move

Unimaginable until you live through it

You feel like **even breathing hurts**

You feel a **sharp** pain

Feels like **childbirth**

Getting **hit by a bus**

Your body **aches**

It's **super painful**

*Long-term
Diagnosed Patients*

It's **painful**

Pain **constantly**

Excruciating pain

I feel a **lot of pain** and it can be **sharp**

Moving hurts, **just thinking about moving hurts**

A **sledgehammer** in every joint in your body, **agony**

Being **hit with a hammer** in every joint in your body **numerous times**

*Recently Diagnosed
Patients*

Bad days are truly painful...

RA patients explained their “bad days” using heightened expressions of pain.



Patients emphasized their pain through description of its **pervasiveness** (“whole body”), **unrelenting nature** (“constantly”), and the **extreme** nature of that pain (“excruciating,” “terrible”).



A few patients used visual language to describe their pain, including comparing their pain to being hit by a bus, childbirth, and being hit by a hammer.



Recently diagnosed patients used lower rates of intensification (i.e. words of emphasis) than more experienced patients, as well as have less variation in their language when describing their pain.

...And bad days also leave patients feeling completely incompetent.

When explaining a flare or bad day with RA, patients talked about how they feel **unable to move or function normally**.

Objects & Tasks vs. The Morning & Broad Impact



Long-term diagnosed patients focused more on **specific objects and daily tasks** (i.e. holding a glass of water, washing dishes) than recently diagnosed patients who focused on the morning (e.g. get out of bed) and spoke more generally about its impact (e.g. go on with your day).

How They Explain What They Can't Do



Patients who had been diagnosed longer **emphasized their inability** structuring their responses as “can’t” statements (rather than statements like “holding a glass of water *is difficult*”), which focuses attention on the inability rather than the task.

Recently diagnosed patients talked about **having “trouble”** with certain tasks rather than complete inability and also used less “I can’t” structures, instead removing themselves from the subject position with “you can’t” phrasing.

Inability & Limited Movement

I am unable to move
I am unable to function
I **cannot** get out of bed
I **cannot** interact with people
I **can't** get things done, things like **vacuuming**
I **can't** hold a **glass of water**. I **can't** dress myself. I **can't** wash **dishes**
I **can't** seem to get comfortable
You **can't** function like a normal person
You **can't** be productive
There's days I **can't** hold a pen
Imagine yourself being in a straight jacket

Limited movement in my hand
RA feels like I ran a marathon yesterday, I can barely walk

Long-term Diagnosed Patients

Recently Diagnosed Patients

I **have trouble** opening jars
I **have trouble** keeping up with my kids
I'm unable to do the little things
You **just can't** go on with your day
You **just can't** get your day **started**
Difficult for me do my daily routine
RA makes me unable to get **out of bed**

You can hardly move
All your actions seem to be in slow motion

On a bad day, patients may want to be alone, but they also feel lonely.

Patients shared that on a bad day they not only feel unable to move, but also don't want to. Wanting to "stay in bed" or "go to bed" was a common theme across both recently diagnosed and more experienced patients.



They also talked about their body position ("curl up in a ball") and hiding ("crawl under the covers").



On bad days, patients also described themselves as "lonely," "sad," and "frustrated." They also shared that interactions are increasingly difficult, leading them to avoid people all together.



Long-term Diagnosed Patients

I want to go **bed**

A bad day just feels like you want to **curl up in a ball and not have to interact**

I just want to **crawl under the covers** and just stay in **bed** all day

Recently Diagnosed Patients

Just basically want to **lay in bed** and even that doesn't help

You don't want to get out of **bed**, and all you want to do is to sit somewhere very still and not worry about it. But you can't. So you **hide yourself** in your room with the lights off and the TV on and just **wallow** in your own misery on your worst days



“You want to curl up in a ball and not move from the pain”

It feels very humbling

I just feel **alone and sad**

Kind of feel like an egg, very **fragile**

Makes me feel really **ashamed** of myself

It's **embarrassing** and it makes me feel like **less of a person**

Very **depressing** because your mind wants to be able to do all these things that you should be able to do and your body can't

I feel **helpless**

The days are **long, painful, sad**

Sometimes you feel like you **just want to die**

People around you start and then it gets to be **frustrating**

Joints are so stiff, your movements are so limited that it gets to be so mentally **frustrating**

**Isolated &
Emotional**



Joints, Fatigue, & Illness Metaphors

Aside from pain, patients also explained bad days as impacting their joints specifically, being accompanied by exhaustion, and compared their experience as being sick (e.g. having a virus, flu, cold).



Less Variation, More Signs of Difficulty

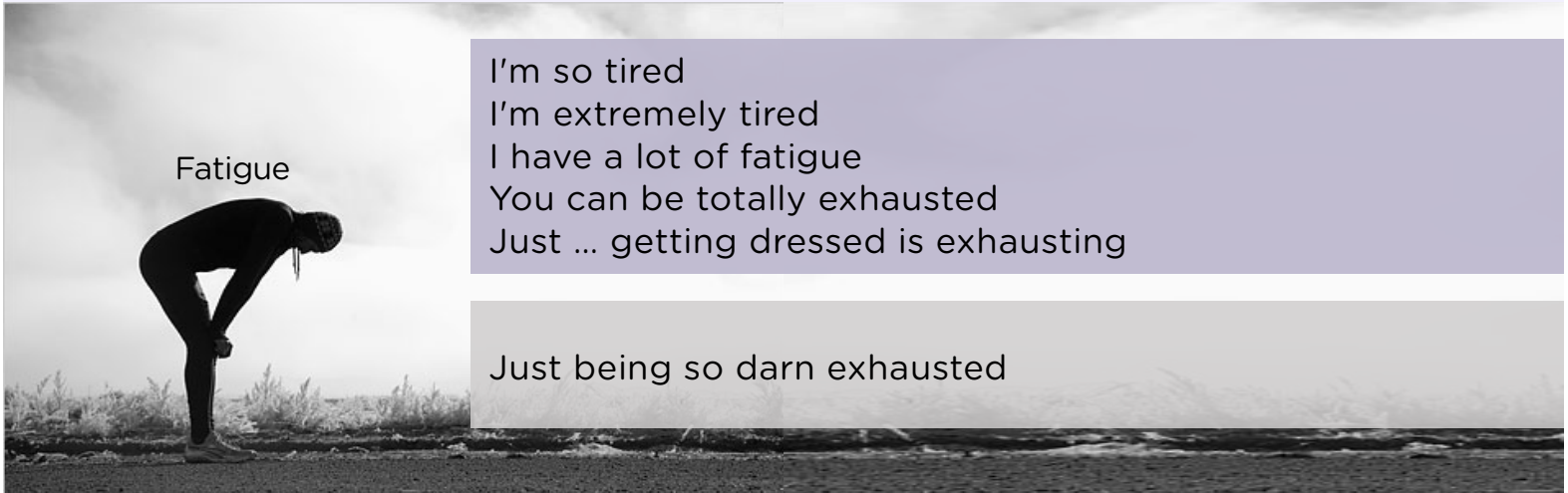
Recently diagnosed patients spoke less about fatigue and did not use the illness metaphor frequently. They also had more markers of hesitation in their descriptions, indicating they may struggle to explain how a bad day feels.



Joints

Very stiff, swelling and pain
Swelling and a lot of pain, and stiffness
Joint pain
Discomfort-ness
Most times it's achy joints, achy muscles
Your joints will be aching and you just will feel listless
Joints are on fire

Pins and needles just going through joints
Achiness and soreness, my bones are made of broken glass
It starts out it's a stiffness, like ... you need to be oiled,
really, like greased at the joints



Fatigue

I'm so tired
I'm extremely tired
I have a lot of fatigue
You can be totally exhausted
Just ... getting dressed is exhausting

Just being so darn exhausted



Illness

It almost feels like the flu or a really bad virus
It just feels like your body has a cold
A migraine headache in all the joints of your body
It just feels like your body has a cold
Having a very bad flu. Your body aches
Sometimes you have fever

It's almost like having a flu 24/7

Long-term Diagnosed Patients | Recently Diagnosed Patients

“...EVERY DAY IS A BATTLE OF PAIN, and getting some semblance of relief is almost impossible right now. I’m still working on getting the right medication dosage, and maybe someday we’ll have it under control, but as it stands right now, I’M NOT UNDER CONTROL AND I AM MISERABLE.”

(Recently Diagnosed Patient)



Although patients describe physical symptoms to their physicians, the emotional impact of RA can go unreported.

SYMPTOMS FIRST, IMPACT ON LIFE SECOND

When sharing how they would discuss their RA with their physician, patients said they **start off discussing the location of the pain**, then explain their symptoms (some mention simply using a rating scale and others say they offered their physician a visual, e.g. swollen knuckles, how they can't bend their hands).

Impact on life tended to be deprioritized in their descriptions, with patients mentioning this last in their answers and only focusing on things they struggle to do (e.g. walk up the stairs). Their answers tended to lack the the emotional content that their other responses had and they rarely discussed the emotional impact of the disease (e.g. frustration or isolation).

“Well, I usually start out with telling him that it’s really **a bad day today** or ... I’ve been doing pretty good. And then I explain **where my issues have been**, whether it’s the inability to use my hands or lower section maybe is a little bit more inflamed where I have **more trouble** sitting or walking, getting in and out of cars, things like that ... Explain the pain, **and try to explain** the intensity of pain or how much better it might be.”

(Long-term Diagnosed Patient)

“I would describe my symptoms as **pain in the elbows, the fingers, the toes, the knees and shoulders and hips**. On a pain scale of 1-10, I’m usually at least at a five. The pain is sharp and **sometimes I just have trouble getting up and functioning** because of my fatigue.”

(Recently Diagnosed Patient)



“ So it's REALLY HARD IN THE RHEUMATOLOGIST'S OFFICE TO FILL OUT THE FORMS AND TO TALK ABOUT HOW YOU'RE DOING. Because the forms talk about the past week, when a lot of times you're not seeing your RA doctor for like two or three months at a time. And so I think they need a better system to see how you're doing, the ups and downs. It would be really nice if they could connect to some of the apps that are out there SO THAT WE CAN SHOW THEM HOW THE WHOLE MONTH or the whole two months or three months went and get better feedback for them and for us. ”

(Long-term Diagnosed Patient)

There are barriers in-office that prevent patients from accurately and honestly sharing their symptoms with physicians.

IN-OFFICE CHALLENGES



Forms & Ratings: Patients often mentioned filling out forms before visits that rated or recorded their symptoms, which the doctor then used during their evaluation. This tactic can limit patient responses and prevent the physician hearing directly from the patient how they feel.



Only One Moment: Patients also said that they're often asked to report on how they CURRENTLY feel, rather than how they've felt over the course of a few months, which was challenging as they didn't always believe one point in time was a true representation of their experience.



Simply Not Asking: A few patients said they don't share the impact their RA has on their life with their physician because they were simply not being asked. Since patients often follow the communicative lead of their physician during office visits, they can feel unable or uncomfortable bringing up topics not initiated by their physician.

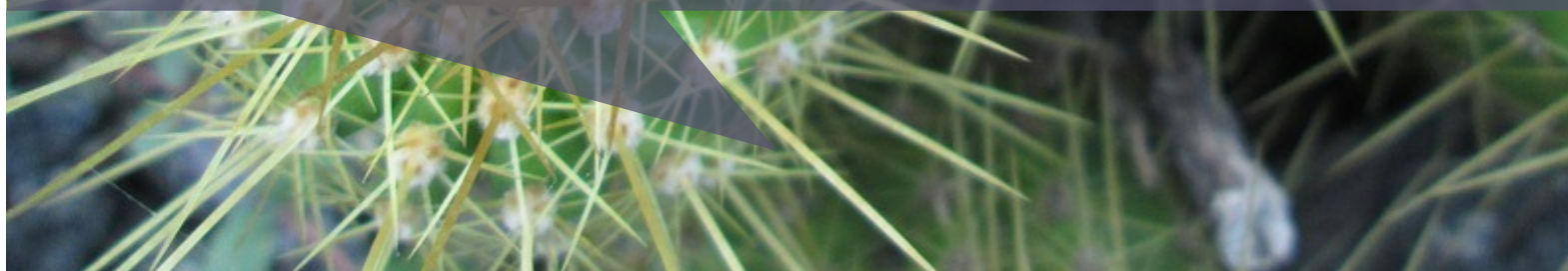
"They never ask me to share my thoughts, I don't know if it would do any good. I'm sure everyone pretty much feels the same."

(Recently Diagnosed Patient)



“ I would say the cactus, because it's like ... in one way, physically, it's for me, **IT'S PAINFUL. IT'S PAINFUL TO TOUCH. IT'S PAINFUL TO DO EVERYTHING**, and **IT IS LIKE WALKING ON PINS AND NEEDLES AROUND HERE SOMETIMES**. Sometimes **MY PARENTS DON'T KNOW WHAT TO SAY TO ME, AND I DON'T KNOW WHAT TO SAY TO THEM**. So, I would definitely say the cactus. ”

(Recently Diagnosed Patient)



Recently diagnosed patients chose imagery (like a cactus or coals) that represented their current symptoms, such as stinging pain and burning joints, rather than those that represented long-term consequences.

THEME: Pins & Needles



- *I get that sensation of **pins and needles** a lot*
- *It is like walking on **pins and needles***
- *It's just a **constant pokey, achy, sharp** pain*
- *Touching it feels like **needles poking** you*
- *The **pins and needles** that I feel, it's just painful*

THEME: Joints on Fire



- *My joints burn like hot fire and it's very painful*
- *My joints are on fire*
- *It can feel like **lava burning**, the pain, the throbbing... **in your joints***
- *Every day it feels like someone has cut me open and put hot burning coals in my joints*

...But for those patients with more disease experience, the long-term effects, even though they might not feel them, are not forgotten.


Patients who have been **diagnosed longer** see their condition as an ongoing decay or process and explained that imagery of a crumbling brick wall resonated with them the most (rather than those illustrative of their symptoms experience).

THEME: Widespread Decay



- *I feel like I'm older than I am and I'm falling apart*
- *I feel like my body's falling apart, it's in pieces, really destroyed and some pieces are just hanging on*
- *I feel at times like I'm falling apart just like that brick wall is falling apart*
- *My whole body is breaking down. It's old and going away ... It's slipping away, piece by piece*
- *Rheumatoid arthritis is ... rapidly destroying my joints and destroying everything about my body*

“ The one that I think most closely resembles how I feel about my rheumatoid arthritis is the crumbling wall. Where it's in pieces, really destroyed and **some pieces are just hanging on**. It's that, to me, **represents my body** and what's happened to it. And all these years with rheumatoid arthritis is just like that crumbling wall. **Rheumatoid arthritis is just slowly, well not even slowly it's pretty rapidly destroying my joints and destroying everything about my body.** ”



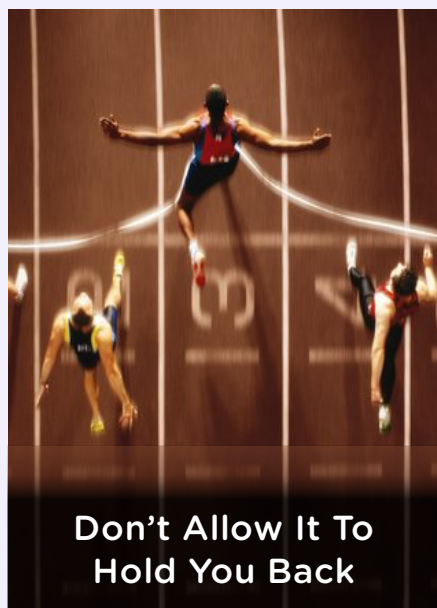
“ The image depicting the broken wall, is the one that I resonate with most. It was the second image. I felt that I identified with that one, BECAUSE THE WALL IS STILL STANDING, AND THAT'S HOW I AM. I'm still standing, BUT JUST AS PIECES OF PLASTER OR CEMENT HAVE BROKEN AWAY, AND IT'S NOT AS STRONG, OR AS PRETTY AS IT USED TO BE, THAT'S LIKE ME, TOO. My joints are there, but they're not functioning as they should. I'm having inflammation that other people don't. But OVERALL, I AM STILL MYSELF, AND I STILL HAVE THAT INTEGRITY. ”

(Long-term Diagnosed Patient)



RA patients who are more experienced tend to be most positive...

Patients who have been **diagnosed longer** described their RA experience in more positive overall phrases and imagery. When creating their own tagline and posters, they highlighted themes of progress, victory, and overcoming challenges.



THEME: Progression

Move forward. Don't stop. Continue going. The Future's in Front

Keep On Moving

Let's Move

Don't Allow It to Hold You Back



THEME: Perseverance

Don't Give Up, She Ain't Done For Yet

Capable Beyond Belief

Freedom from RA

Survivor

Overcoming Obstacles

Warriors

...While recently diagnosed patients may be struggling and feel helpless.

When asked to create tagline for their RA experience, **recently diagnosed patients** described darker, more negative imagery and titled their experience with themes detailing struggle and constant pain.



THEME: Symptoms and Suffering

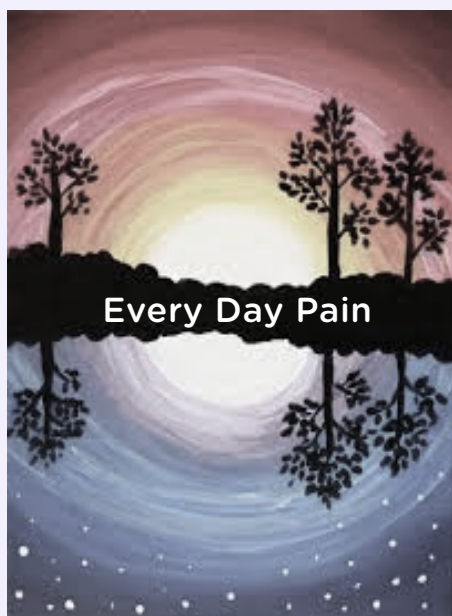
Help Me

Pain and Fatigue? Please Help, Someone

Unbearable Suffering and Pain

On Pins and Needles

Hopeless



THEME: Constant, Extensive Pain

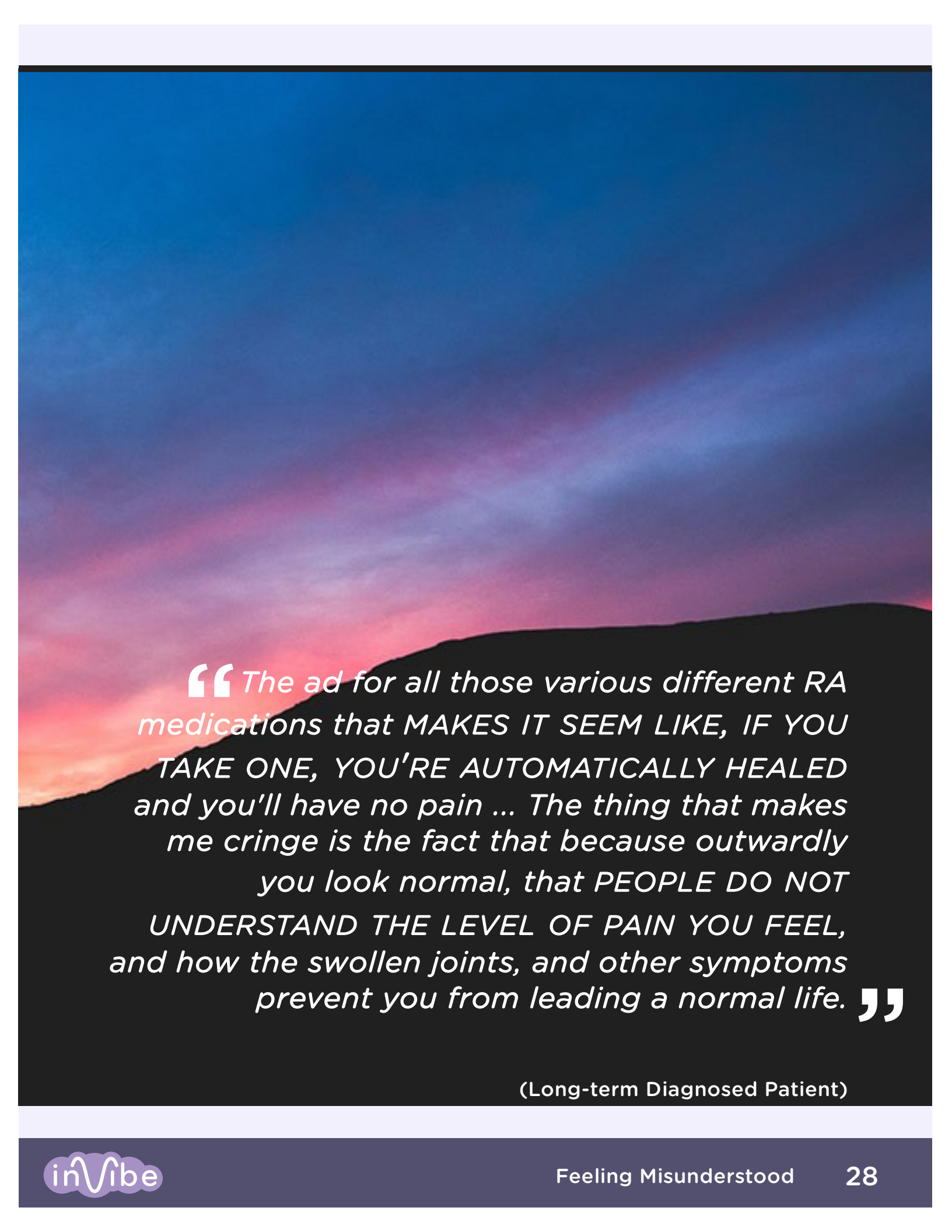
Every Day Pain

Every Day is Full of Pain, but Not Every Day is the Same

Learning to Live Life the Second Time Around

How Much Further Can this Disease Go?





“ The ad for all those various different RA medications that MAKES IT SEEM LIKE, IF YOU TAKE ONE, YOU’RE AUTOMATICALLY HEALED and you’ll have no pain ... The thing that makes me cringe is the fact that because outwardly you look normal, that PEOPLE DO NOT UNDERSTAND THE LEVEL OF PAIN YOU FEEL, and how the swollen joints, and other symptoms prevent you from leading a normal life. ”

(Long-term Diagnosed Patient)

Patients feel misunderstood. They want others to know they're not lazy and their appearance may not reflect what they're feeling.

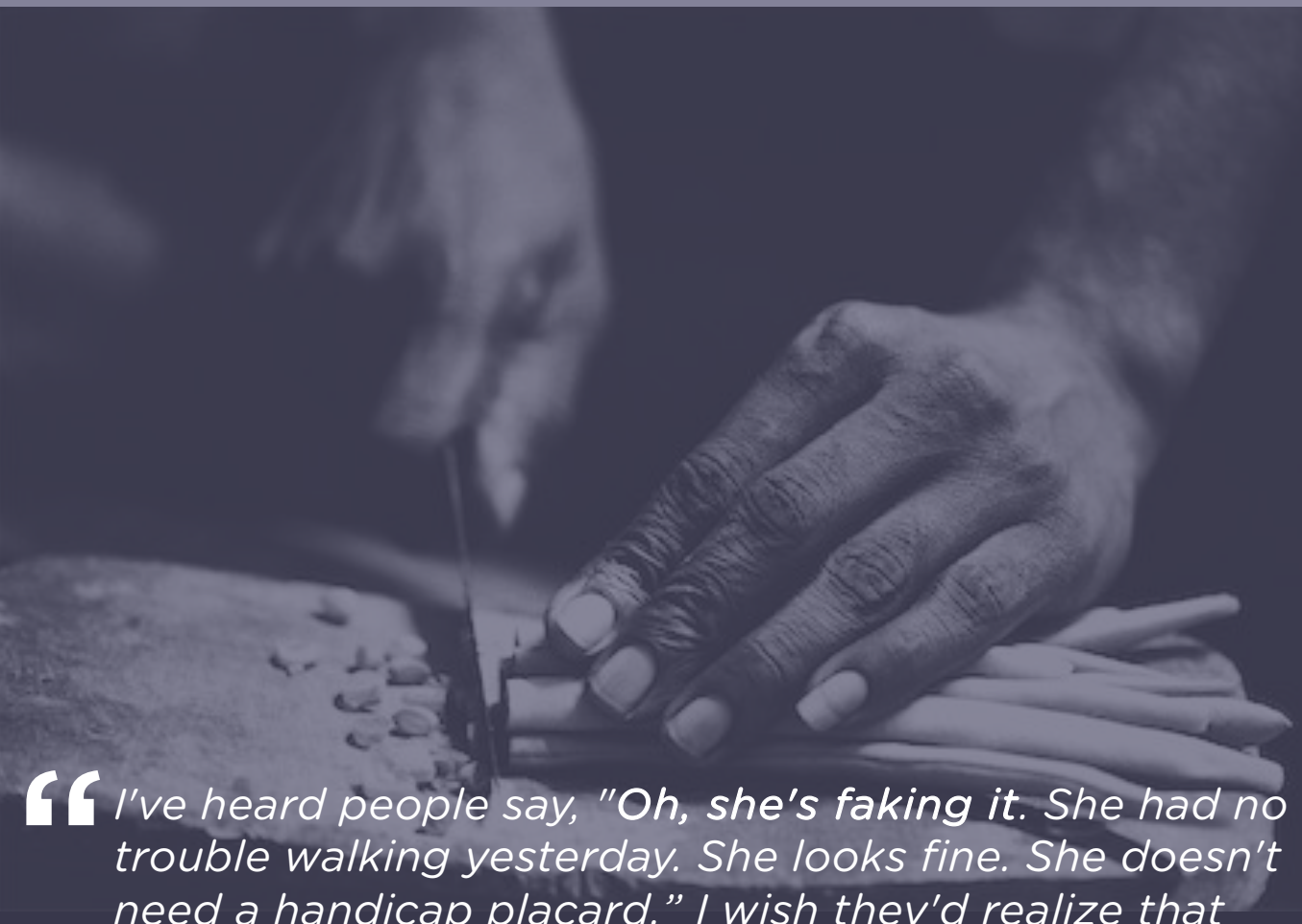
Misperception #1

Outward Appearance Reflects What They're Feeling

Because their symptoms may not have outward signs, patients often feel as though they're seen as lazy or as making excuses, rather than as having a condition that can limit their ability to perform certain tasks.

- *And they'll say, "Oh, you just have to ... You're lazy," or, "You just don't want to do that," or, "It needs to be done, but why don't you do it?"*
- *I feel like sometimes I'm judged -- thinking I'm trying not to do things or I'm making an excuse.*
- *Oh, she's faking it. She had no trouble walking.*
- *They don't understand why I can't do the things that I used to do because I don't look sick.*
- *They don't understand what it's like, because it's not something you can see. It's something that I feel but they don't.*

Patients paint the picture of RA as a **hidden condition** that creates a sense of isolation, not only because patients want to be alone when they're in pain, but also because they feel like they can't be understood.



“ *I've heard people say, "Oh, she's faking it. She had no trouble walking yesterday. She looks fine. She doesn't need a handicap placard." I wish they'd realize that arthritis doesn't necessarily change the way you look. You can look fine. You might not be able to walk fine or open a door. You might not be able to cut your food to feed yourself.*

It changes daily, and I wish they'd say things like, "It must be awful living with something that changes daily so you don't know how you're going to feel or what you can and can't do that day." **”**

(Long-term Diagnosed Patient)

And while there are treatments, they don't always take away their pain.

Misperception #2

RA is the Same as Osteoarthritis and is Easy to Manage

RA patients say that because of the word “arthritis,” other people mistake RA to be osteoarthritis and as a result aging. This misunderstanding leads outsiders to position it as easily manageable and a common problem.

- *“It's all in your head” or “**Take** an aspirin, it'll go away.” This is not something that goes away.*
- *I'm tired of hearing people say, “**Take** some Tylenol or take some Motrin, that you're just being dramatic.”*
- *People say, “**Oh**, I have arthritis. **Oh**, I know, sometimes I can't do that or when it rains my arthritis hurts.”*
- *They say things like, “**Oh**, I have that in my hip. I have that in my pinkie. My grandma has that. You're too young for that.”*
- *I wish people would not say, “**Oh**, I know how you feel.” You don't know how I feel.*



Patients use **constructed dialogue** to explain what words or phrases bother them the most and often start these with the **discourse marker “Oh.”** While “Oh” can have many uses and meanings, in this case patients are indicating a change in the reported **speakers’ evaluation of their condition and decrease in perceived severity.**



Patients also use **directives** in their constructed dialogues (e.g. “Take some Tylenol”) which indicates that they see others are positioning their disease as **having a solution that is simple** enough for a non-medical professional to address it adequately.

What We Heard When We Listened: High Level Insights



The Emotions of Their Symptom Experience

Patients see emotional consequences of RA to be as impactful as physical symptoms.

Inability and isolation often define bad days, but patients don't always share this with their physician.

Patients position office visits as more about showing their symptoms than explaining their impact.



Misperceptions & Needed Support

More experienced patients share imagery of hope, whereas recently diagnosed patients use language of hopelessness.

Recently diagnosed patients see their condition as defined by symptoms rather than long-term consequences.

Misperceptions create an us/them positioning and can leave patients feeling isolated.

What We Heard When We Listened: Implications



Resolving a Communication Gap

The emotional impact of RA is pervasive and often defines bad days, however **patients do not prioritize this in discussions with physicians**, wherein the focus of the conversation is often showing/explaining symptoms rather than the impact on their life.

Patients **need support to reprioritize their discussions with physicians** to begin their in-office evaluations with the quality of life and emotional impact of their RA.

Consider messaging that conveys the importance of patients not only **sharing the impact**, but also **opening with this** to ensure physicians hear and focus on this, rather than simply location of symptoms.



Creating Self-Advocates

Patients feel isolated by their condition and also have an us/them mentality, which makes them likely to form strong bonds with other patients. Overall, recently diagnosed patients have less hope in their language and are less focused on long-term consequences, which means **they are not as likely to advocate for themselves in office**.

To increase patient self-advocacy, consider efforts to **improve recently diagnosed patients' expectations** for improvement, including connecting them to other patients who may have a better sense of hope, potential outcomes, and understanding of disease progression.

Contact Us

Interested in Learning More?



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