



Spoonie Struggles

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Abb: Pixabay

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Abstract

chronic illness
chronic pain
comorbidities
invisible illness
daily struggles

the CAPACITY pyramid [invisible illness edition] CHRONICALLY BY MEH

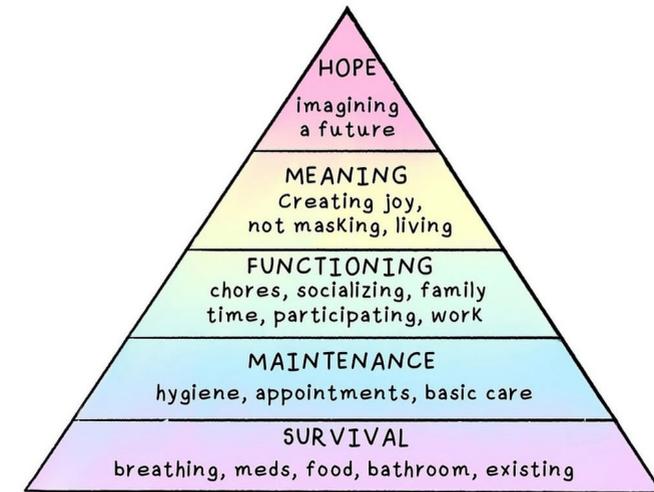


Abb: @chronicallymeh

People with chronic pain or illnesses are often left to cope alone after receiving a diagnosis. While they are aware of their condition, they lack the necessary strategies and contacts to help them cope. Various content can be found online expressing how those affected feel. This ranges from hopeful and pleading posts to sarcastic and angry ones. Some find solace in their faith, some portray themselves as fighters and some show that disabled people can be fashionable too. A more recent development is completely unvarnished insights into the everyday life of a person with health problems. Hospital stays, photos in bed and selfies with dark circles under their eyes show 'painfluencers' in moments that would otherwise remain hidden.

What other coping methods can be found? I plan to find them in my research, using netnography, cultural probes and co-design workshops. Using these findings, I intend to create a toolkit to help people with chronic illnesses adapt to their new reality.

qualities and descriptors of pain



acute
chronic
persistent
intermittent
episodic
dull
stabbing
throbbing
burning
searing
shooting
sharp
gnawing
excruciating
debilitating
intolerable
manageable
refractory
cramping
aching
radiating
localized
diffuse
tender
sensitive
intractable
breakthrough
neuropathic
nociceptive
nociplastic
inflammatory
visceral
somatic
mechanical

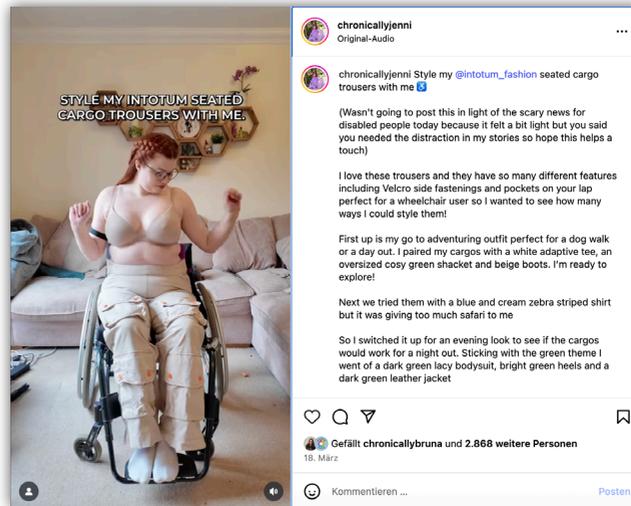
Abb: Andrii Iemelianenko

Medical-aid Fashionistas

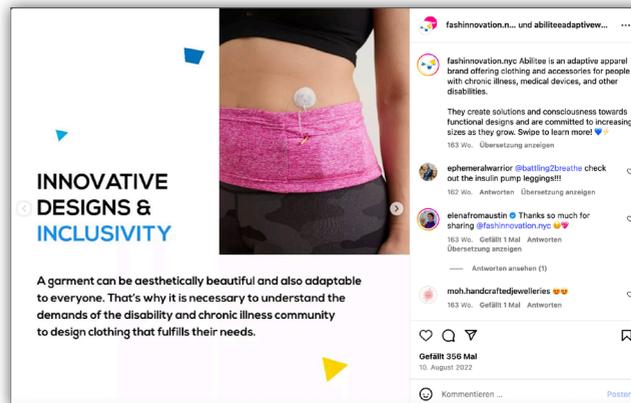
Some creators show you how to style especially for disabled people designed clothes, others give spoonie fashion advice, and some tell you, how you can adapt your wardrobe, so it's more comfortable to wear if you are in chronic pain.

From glam canes and decorated crutches to wheelchair/cane OOTDs; “disabled and cute” identity hashtags persist, reframing aids as fashion.

#01

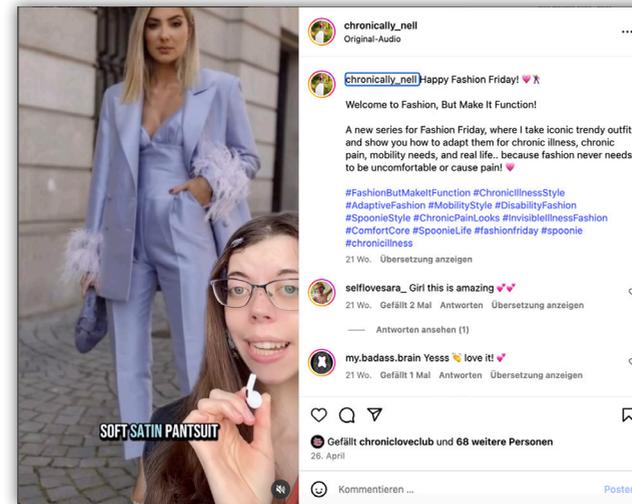


#02



- Instagram posts from:
 #01: @chronicallyjenni
 #02: @fashinnovation.nyc
 #03: @chronically_nell
 #04: @chronically_nell
 #05: @chronically_nell

#03



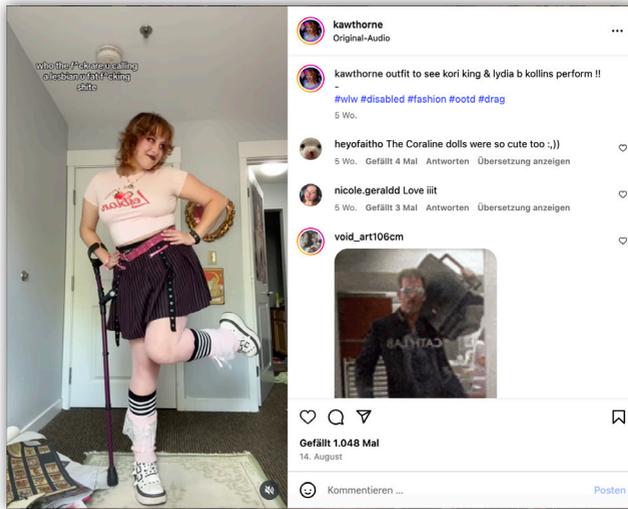
#04



#05



#01



#02



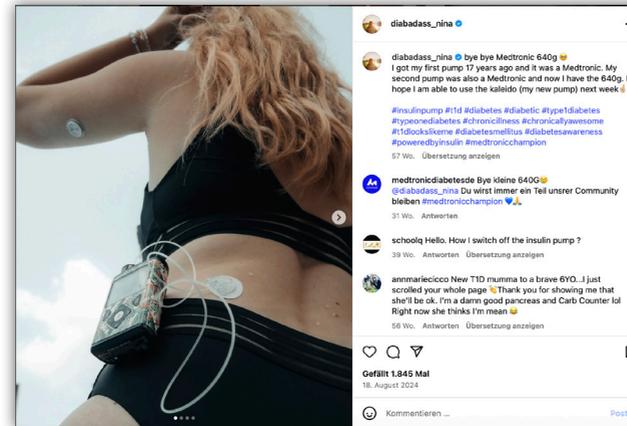
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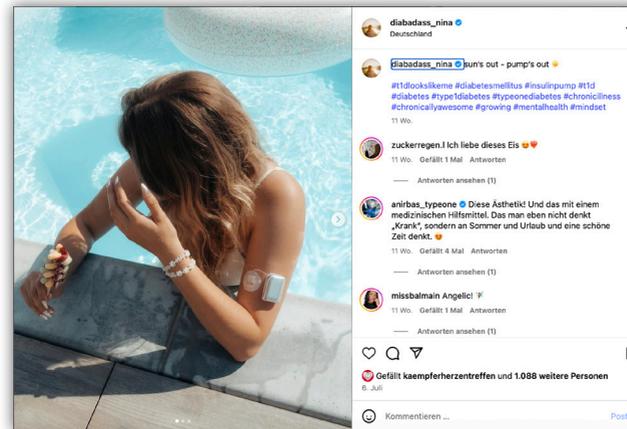
#04



#05



#06



- Instagram posts from:
#01: @kawthorne
#02: @charlotteamylouise
#03: @charlotteamylouise
#04: @alexadvocates
#05: @diabadass_nina
#06: @diabadass_nina

Info posts

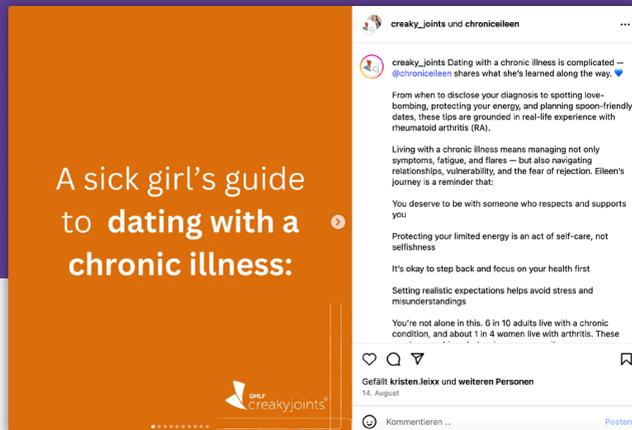
Work/relationship scripting

Short scripts for dating disclosures (“code words” for flares) and workplace accommodation language get shared and iterated.

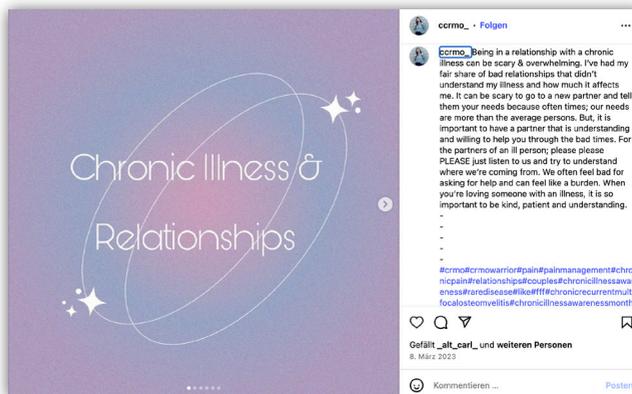
A lot of the content shared is tips-based, offering guidance on how to interact with people living with chronic pain or illness.

explain
educate
help
inform
warn

#01



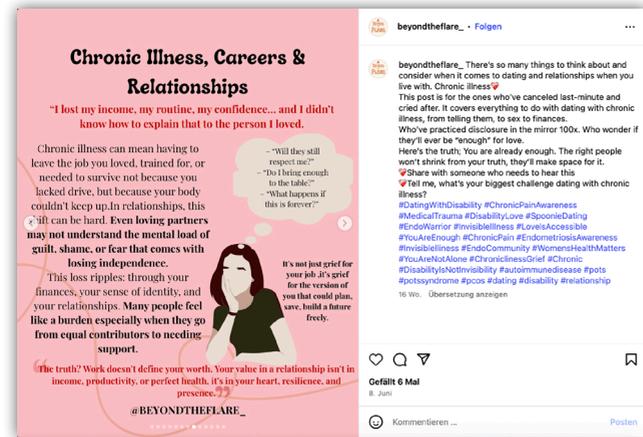
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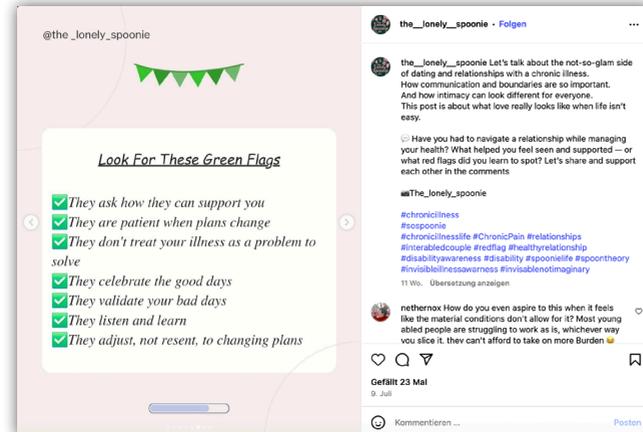
- Instagram posts from:
- #01: @thepotsiepanda
- #02: @msukireland
- #03: @rootedfamilychiro
- #04: @endometriosisoutrun
- #05: @lindsaybraman



#03



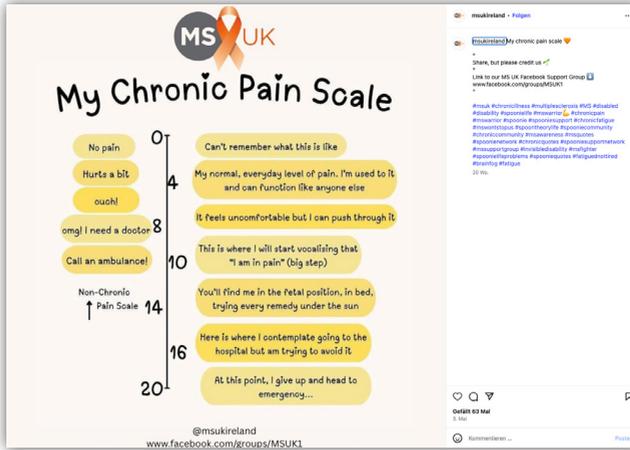
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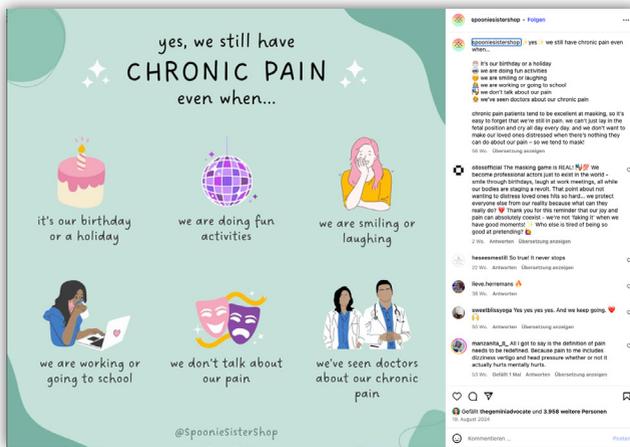
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explain
educate
help
inform
warn

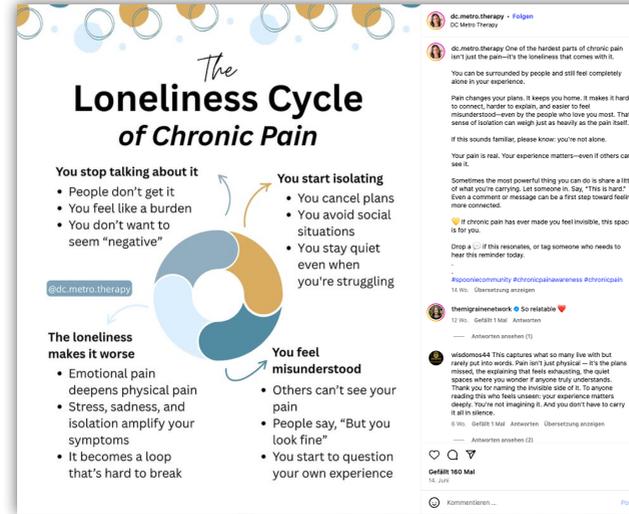
#01



#02



#03



#04



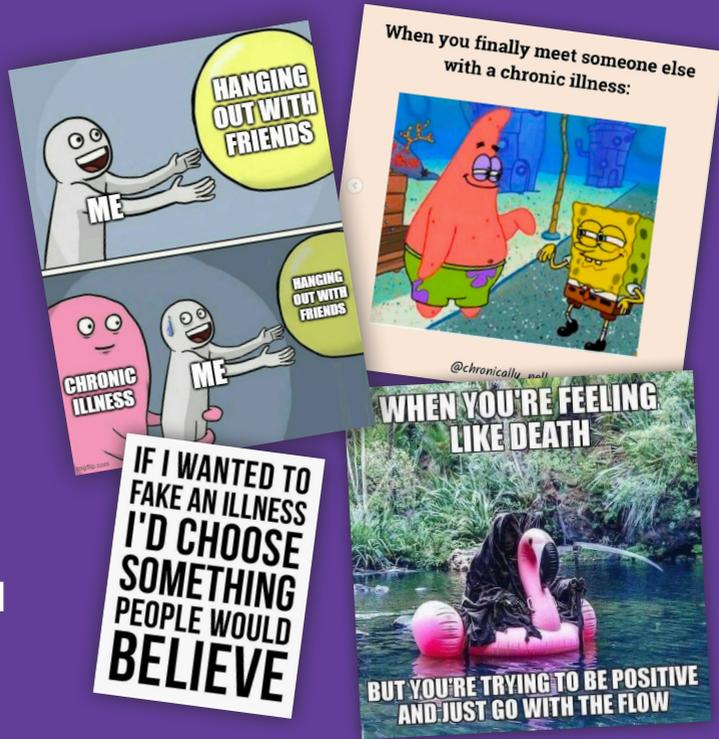
#05



Instagram posts from:
#01: @msukireland
#02: @spooniesistershop
#03: @dc.metro.therapy
#04: @thepotsiepanda
#05: @chronically_brave

Mememes

dark humor
real
relatable
explanatory
angry
sarcastic
annoyed
metaphorical



Meme culture surrounding chronic illness and chronic pain is often quite sarcastic. It can feel like a slap in the face. There is anger towards people who give health advice without being asked and annoyed reactions against doctors and the healthcare system. These reactions are about daily situations that people with chronic illnesses

have to deal with, such as explaining a dynamic disability to colleagues or friends. A recurring topic is not being believed when living with an invisible condition, being gaslit or accused of faking it. The memes help with coping, make people feel less alone and facilitate connection in a world that can feel really isolating for chronically ill people.



Me trying to manage doctors appointments, medications, insurance, symptoms, side effects, house cleaning, cooking, laundry, employment, and relationships.





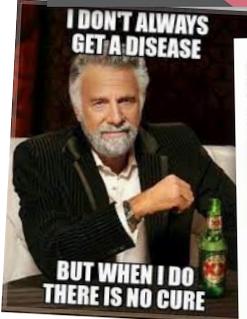
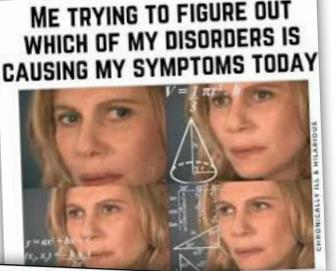
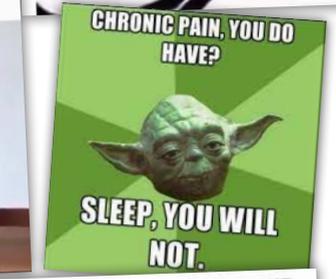
Late-night "painsomnia" posts

Night-owl solidarity threads, coping tips, and dark-humor memes about not sleeping from pain and other relatable chronic illness topics.



laylamesner DisabilityThr... 03/26/25
A big part of ableism is the inability to understand that disabled people don't pretend to be more disabled than we are—we pretend to be LESS disabled than we are.

It's hard to rest when chronically ill/ have chronic pain because you're never really "resting", it's more like "lying down so I don't get worse" vs rejuvenating rest like healthy people get. I'm not resting because I want to, I'm resting because I NEED to.

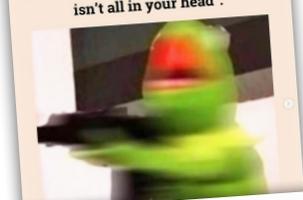


When a healthy person tries to relate to your pain or fatigue



"Internal screaming"

When someone says "are you sure it isn't all in your head?":



When someone says "are you sure it isn't all in your head?":

HAVE YOU TRIED I HAVE TRIED EVERYTHING



When someone says "are you sure it isn't all in your head?":

THINKING ABOUT HOW SOME HEALTHY PEOPLE EXPERIENCE DAYS WITH NO PAIN



When someone says "are you sure it isn't all in your head?":

LIKE NOTHING HURTS?... ANYWHERE?? WHAT IS THAT EVEN LIKE???



How people expect me to react to "you're so pretty for a disabled person"



When the people in your life still don't understand the 'chronic' part of chronic illness

I Can't Believe It's Not Better!



When someone says "but you don't look disabled"



ME: EXPLAINS WHAT A CHRONIC ILLNESS IS HEALTHY PERSON:

FOREVER EVER?



When someone says "are you sure it isn't all in your head?":

me: ha ha sucks living with chronic pain sometimes random strangers: but have you tried- me, suddenly holding like 6 knives: i have fucking tried the underwater horse yoga yes

waluigi simulator @doodlemancy

me: ha ha sucks living with chronic pain sometimes random strangers: but have you tried- me, suddenly holding like 6 knives: i have fucking tried the underwater horse yoga yes

Are you sure it's not just anxiety?

Me:



Educating someone about your illness like



When the yoga & healthy eating still doesn't cure you



When someone says they can cure your chronic illness with yoga:



When you don't look sick



well you don't look stupid yet here we are.

Me reading the side effects on my new medication like:



machine yearning engineer @confusionm8trix turning 27 next month

NOT SURE IF THE PAIN MEDS AREN'T WORKING OR IF THEY ARE AND THE PAIN I WOULD BE IN WOULD HAVE KILLED ME ALREADY



The ibuprofen in my body trying to figure out what to work on first



If I had a dollar for every ibuprofen I've ever taken



When you're having a chronic illness flare up with symptoms bad enough to send anyone to the ER but it's not your first rodeo so you gotta just wait it out...

"Side effects may include bleeding from the ears, seizures and cannibalism"

People in the ad:



When I realize I forgot to take my pills:



Your symptoms and side effects teaming up to beat you up



ME



WE'RE ALREADY DISABLED. MY BODY

WHAT ABOUT A CO-MORBIDITY?

Them: "What did you do over the weekend?"

Me:



logan @brainwrxrms my symptoms: "get progressively worse" me: oh thank god i thought i was faking this whole time

FINDS BAND-AID FOR CHRONIC SYMPTOMS



NEW DOCTOR DOESN'T BELIEVE IN YOUR ILLNESS BECAUSE YOU DON'T HAVE THE SYMPTOMS

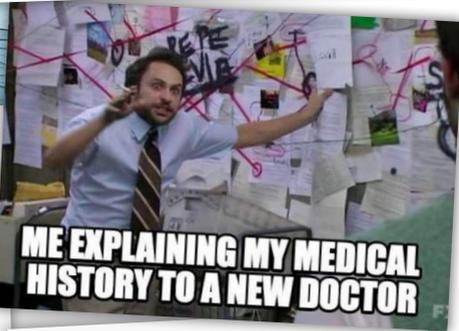


myibslife
@myibslife

me: i don't feel good

doctor: ok well idk whats wrong. probably nothing. actually. have you considered you might be faking it? this appointment will be \$3,948

me: perfect thank u



doc: there's nothing more we can do
me: what have you done so far?
doc: nothing



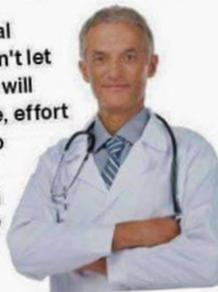
Doctor:

Ma'am, I'm afraid I have some bad news. Your test results came back positive and...



SICK ON TV

You are a medical mystery but I won't let you suffer so we will invest more time, effort and resources to figure this out. I won't give up on you. Don't worry about how to pay for all this.

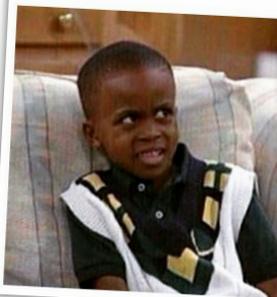


SICK IN REALITY

I don't know what's wrong with you and there's nothing more I can do. You must be a drug-seeker. Here, take these anti-depressants. Oh, and lose some weight.



When a doctor reads your medication list



Doctor: You can't possibly have that many diagnoses.



When you have to see one doctor just so you can see your other doctor



«So far you have survived 100% of your worst days.»

– *Russell Sabella*



Abb: megfoundationforpain.org

Quotes

fight
explain
hope
bargain
pray
accept

Quotes about chronic illness that circulate on Facebook or older websites often frame illness through the language of individual responsibility, faith, and moral character. They portray being ill as a test, something to be endured with strength, optimism, or spiritual trust. Common phrases describe people as “fighters” or “survivors,” suggesting that coping with chronic illness is less about medical reality and more about personal

resilience. At the same time, these quotes sometimes carry a subtle sense of blame or bargaining: that if one believes hard enough, behaves correctly, or remains positive, then illness can be managed or even overcome. While such messages may offer comfort to some, they can also reinforce pressure on chronically ill people to present themselves as strong, faithful, or inspirational rather than simply allowed to be unwell.



And ye shall serve the Lord your God and He shall bless thy bread, and thy water; and I will take sickness away from the midst of thee.
EXODUS 23:25 (KJV)

Heal me, O Lord,
- and -
I shall be healed;
save me, and
I shall be saved,
for you are my praise.
[Jeremiah 17:14]

Heavenly Father,
heal the sick,
comfort the sorrow,
encourage the discouraged,
and give us strength.
BibleGodQuotes.com

HAVE DEFIANT HOPE
Because reasonable hope isn't really hope
lga copen
RestMinistries.com

I hope when people in pain see how I am dealing with chronic pain they aren't wishing they could be so lucky to cope as well. My hope is that they realize God is my strength -- and He is available to them as well. I am weak. But He is strong. He will be strong for all who ask Him. I couldn't "do" illness without Him.
- lisa copen

JESUS HEALS
ISAIAH 53:5 ...AND WITH HIS STRIPES WE ARE HEALED
FIG 1.  →  FIG 2.

Prayer for the Sick
Father of goodness and love,
Hear our prayers for the sick members of our community and for all who are in need.
Amid mental and physical suffering may they find consolation in your healing presence.
Show your mercy as you close wounds, cure illness, make broken bodies whole and free downcast spirits.
May these special people find lasting health and deliverance, and so join us in thanking you for all your gifts.
We ask this through the Lord Jesus who healed those who believed.
Amen.
jesusplus.org

"In the midst of pain, you can still find peace. In the depths of fatigue, you can still find strength."
@thespooniescommunity

It's a **PRIVILEGE** to CARE for the sick.
It is an **HONOR** to be present when humans are **BROUGHT** into this **LIFE** and when they **LEAVE**.
nursesgettogether.com

The Worst part of having a chronic illness **Surprisingly ISN'T** my debilitating symptoms
It's not even the horrible side effects from the prescriptions it's the **looming judgment** from those who do not understand, or don't care enough about me to research and try better understand what I'm going through

Please
Don't Judge
You don't know what it took for someone to get out of bed, look as presentable as possible, face the day & face the world.
You know nothing of their daily struggle
CHRONIC ILLNESS AWARENESS
What is it Like to Live w/ Fibromyalgia & Chronic Pain/Fatigue? On FB

When 'i' is replaced By 'we'
Even 'illness' Becomes 'Wellness'

"PEOPLE WILL SOONER AID A SICK DOG LYING ON THE SIDEWALK THAN TO TRY TO FIND SHELTER FOR A SICK PERSON. IT'S TOO MUCH TO DEAL WITH."
MICHAEL ZASLOW
© Lifshark Quotes

Have you realized that people will tell you they care, but they don't seem to show it unless you get sick, die, or become famous.

"Sometimes life doesn't turn out the way you may have wanted it and chronic illness can alter even the best laid plans, but that shouldn't hold you back from your future."
Peter Waite, HealingWell.com
7 Jan. 2013 12:15 pm

"We either make ourselves miserable or we make ourselves strong. The amount of work is the same."
- Carlos Castaneda
alliance health

The challenges I have faced - among them material poverty, chronic illness, and being raised by a single mother - are not uncommon, but neither have they kept me from uncommon achievements.
Sonia Sotomayor
PICTURE QUOTES .COM

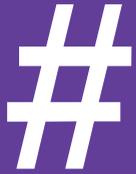
Even people who have had a chronic illness for a long time are getting sad. It still hurts when they have to give up on things they used to be able to do. They are trying to be happy to be a part of the community, but inside they are crying because they cannot keep pace with their healthy friends. Sometimes a chronically ill person also need to do what they find difficult, for that simple reason to feel alive.
ME words

Someday
I'll be able to look back on today and be grateful for being strong but today I'm just trying to keep my strength up and make it to tomorrow
@lisa

Your job won't take care of you when you are sick.
Your friends will.
Stay in touch.

I have a chronic illness and I'm dealing with it in my own way. I do not want lectures, meaningless advice (like get some fresh air) or to be told that I'm not doing things the 'right' way. I'm doing what's right for me
70X72

It feels good to hear someone say, "take care" but it feels so much better to hear someone say, "I'll take care of you!"
THEY'RS AWESOME, TUMBLR



A

Accessibility
Acceptance
Aches And Pain

B

Bed
Bad Day

C

Chronic
Chronic Fatigue/ Ill/ Pain
Cocooning
Comorbidity
Comfort
Cozy
Crash
Crip

D

Disabled
Disabled Life
Disability
Dynamic Illness
Dynamic Dysability

E

Equity
Equality

F

Fatigue
Faith
Flareup

G

-

H

Help
health
hope

I

Insomnia
Invisible
Invisible Disability
Invisible Illness

J

Journey

K

Keepgoing

L

-

M

My Faulty Gene
Masking

Mental Load

N

Never give up
Not just lazy
Not a victim

O

-

P

Pain
Pain Journey
Pain Day
Pijama
Positive Mindset
Pushing Through

Q

Quality of life

R

Restless
Resilient
Resilience

S

Struggling
Sick
Soft But Strong
Spoonie

Spoonie Community

Spoonie Memes
Spoonie Life
Spoonies
Spoonie Theory
Spoonie Warrior
Survivor

T

Tired

U

-

V

-

W

-

X

-

Y

-

Z

-

Comorbidities

Comorbidities are two or more concurrent or sequential illnesses or disorders in one person that may affect health and treatment, without one condition necessarily causing the other.

Dynamic Illness / disability

A dynamic illness is a disorder characterized by abnormal, fluctuating, or changing physiological processes or symptoms over time, unlike a static or constant condition. This term can refer to dynamical diseases that involve sudden shifts in physiological dynamics, such as epilepsy or tremors, or it can be used in the context of a dynamic disability, where the severity or ability to perform certain functions changes significantly.

Equity

Equity is fairness that considers individuals' different circumstances, providing them with the exact resources and support they need to achieve an equal outcome.

Spoonie

A spoonie is a person living with a chronic illness or long-term health condition who uses Christine Miserandino's Spoon Theory to explain their limited daily energy reserves. In essence, "spoons" represent units of energy, and spoonies must carefully "budget" them for tasks, as they can't simply replenish them by resting as much as a healthy person might.

CHRONIC ILLNESS MASKING

*The invisible ways we pretend to be “okay,”
even when we’re not.*

Forcing yourself
to keep plans
even when you
feel awful.

**Saying “I’m
fine”** when
you're anything
but.

Laughing to hide
brain fog or
confusion.

**Over-explaining
or justifying** why
you can't do
something.

Hiding mobility
aids or
medications out
of
embarrassment.

**Silently
struggling**
because asking
for support feels
too vulnerable.

**Powering
through** when
you need rest.

Minimizing your
symptoms so you
don't seem
“dramatic.”

Pretending noise
or light isn't
bothering you.

Acting “normal”
so no one
worries.

Apologizing for
needing help.

Smiling when
you're in pain.

imprint

Publisher
Trends & Identity

Author
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Lecturers
Prof. Dr. Bitten Stetter
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Print
Zürcher Hochschule der Künste (ZHdK), Inhouse

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#chronicillness
#chronicpain

