Patient talk: Navigating concurrent conditions while deferring treatment

Jodi Ettenberg, BCL, LLB

Bridging the Gap

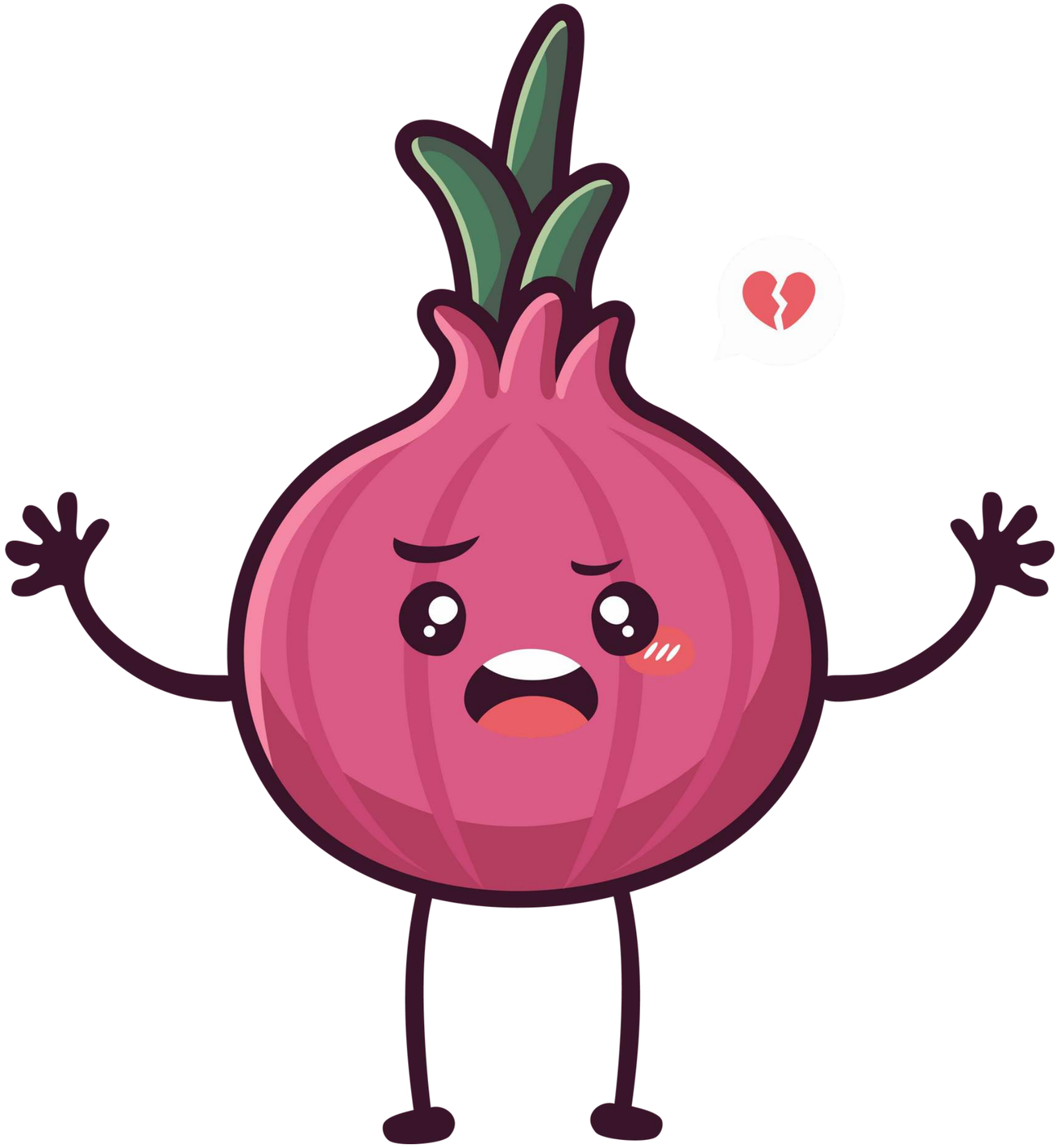
Đặc Sản
22 PHAN BỘI CHÂU, P. BẾN THÀNH, Q.1
ĐT : 38245196
BÚN MẮN
BÁNH CANH CUA - GỎI CUỐN

my “lucky llama shirt” for patching

Bridging the Gap

flat life again after my leak reopened

Bridging the Gap



My “onion of catch-22s”

1) Multiple punctures with large needles;
leak site is unknown

Bridging the Gap

My “onion of catch-22s”

1) Multiple punctures with large needles; leak site is unknown

2) Heritable connective tissue disorder

Bridging the Gap

My “onion of catch-22s”

1) Multiple punctures with large needles; leak site is unknown

2) Heritable connective tissue disorder

3) Mast Cell Activation Syndrome

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My “onion of catch-22s”

1) Multiple punctures with large needles; leak site is unknown
2) Heritable connective tissue disorder
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4) Imaging shows adhesive arachnoiditis

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Bridging the Gap

My “onion of catch-22s”

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5) Shared outcomes not reassuring

6) I had RIH after only 3 months leaking

7) Other factors: cost, travel time, support on the ground, lack of local care team, access to RIH meds.

Bridging the Gap

Finding my way through

1

CURIOSITY

Bridging the Gap

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SYMPTOMS & VARIABLES TEMPLATE, BY JODI ETTENBERG

INFO: I made this spreadsheet in order to track data related to my conditions. Over the years, I've found that things I did not realize were correlated — like full moon times, or weather changes — impacted my symptoms in consistent ways. I have been keeping data in notebooks since my spinal CSF leak began in 2017, but wanted a digital chart where I could keep track of everything in one place, and colour-code the chart based on what was occurring over time. A big thank you to dataviz wiz Giorgia Lupi, who shared her own chart as inspiration. From there, I built one of my own.

TO USE: To use this chart as your own, you'd need to go to **File ➡️ Make a copy**, which will copy this into your Google Sheets homepage. You can then modify any of the symptoms on the column header to insert the symptoms you expereince, and/or remove any columns you think are not helpful to track for your conditions. You can then change the Conditions / Variables column below for your own conditions and variables, and — if you'd like — select the colours you prefer.

HOW I TRACK USING COLOURS: Instead of using a 1-5 or 1-10 severity scale, I use the colours below to show stable vs. severe, and with deeper colours signifying that the symptoms are at a severe level that day. For variables that are not on a scale (e.g. whether I tasted CSF that day), I just use an (x) in the spreadsheet to denote that I expereinced it that day. A **full moon** is among the variables I track because I have found my nerve pain to be worse on the day before and day of a full moon. It took tracking that over time for me to realize it was the case.

Sx = symptoms

Conditions and/or Variables	Colour for 'stable'	Severe symptoms colour	
Leak sx	Stable	Severe	
CSF taste			
MCAS sx	Stable	Bad	Severe
Sleep	Norrmal	No sleep	
HRV	Normal	Abnormal	Super abnormal
RHR	Normal	Abnormal	Super abnormal
Full moon	Full moon		
Period	Period begins		

For the **WEATHER column,** I use https://www.extremeweatherwatch.com/ or weather checks of highs/lows over time for my city. If you live in a city this site covers, they make this data availalbe at month end.

QUESTIONS/SUGGESTIONS: If you have any comments or questions about this template, you can write me at jodi-at-legalnomads-dot-com, or find me at @legalnomads on Instagram. For my writing about chronic illness please see my personal site or my Patreon site. For writing about travel, celiac disease, and digital nomad life, please see Legal Nomads.

I hope this template is helpful!

-Jodi

my symptom & variable tracker

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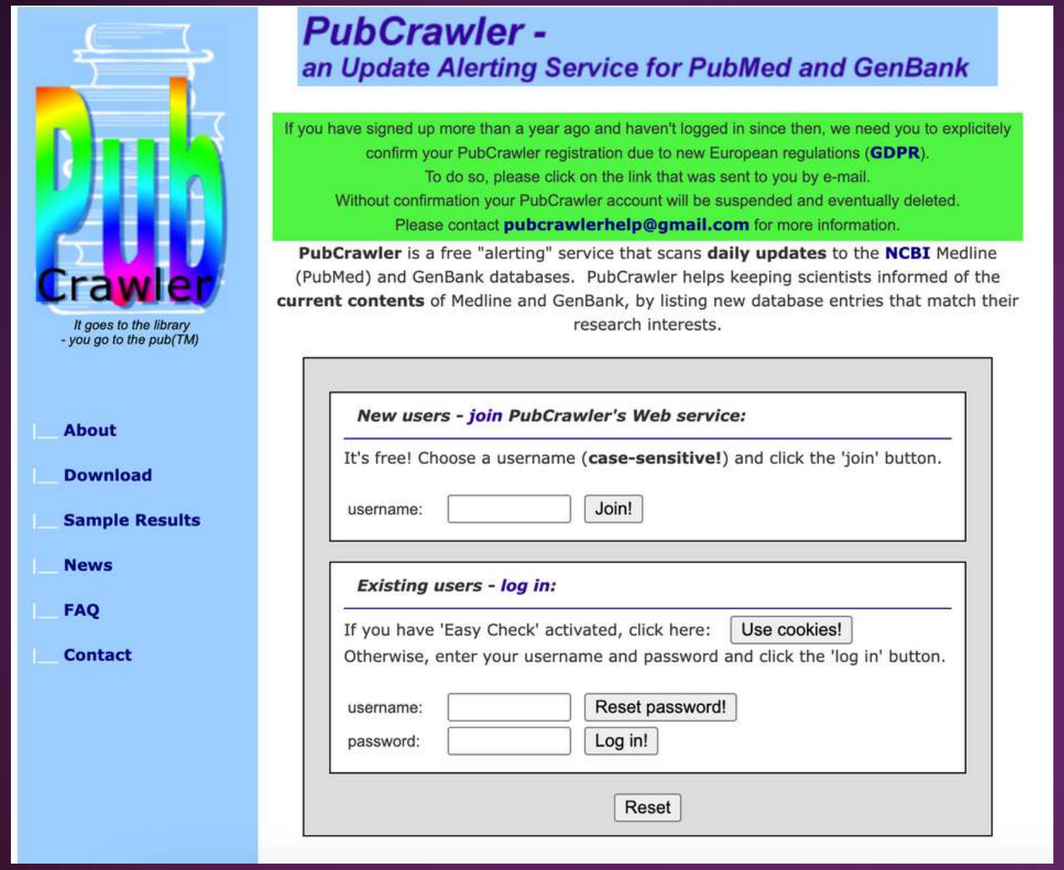
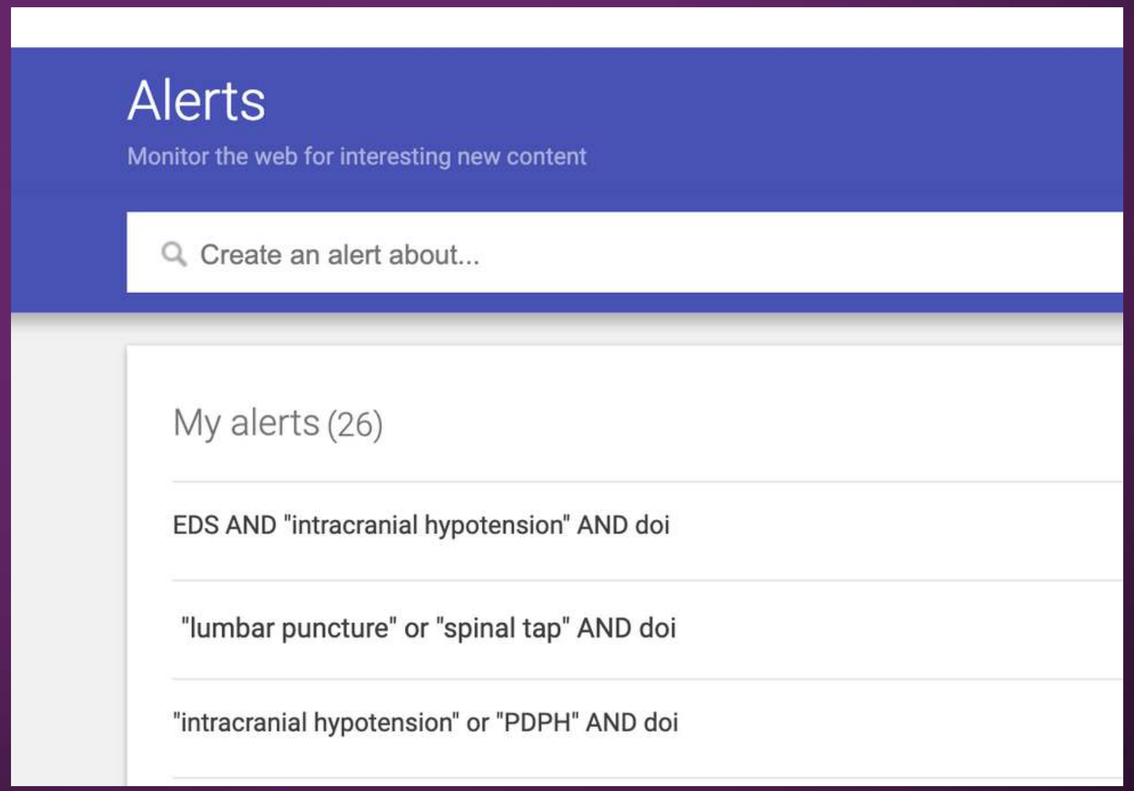
PubCrawler & Google Alerts





Bridging the Gap

Finding my way through

1

CURIOSITY

2

BECOMING MY OWN LAB RAT

Bridging the Gap

Finding my way through

1. CURIOSITY
2. BECOMING MY OWN LAB RAT
3. TURNING INWARDS

Bridging the Gap

Thank you