

Patient talk: Navigating concurrent conditions while deferring treatment

Jodi Ettenberg, BCL, LLB







**my “lucky
llama
shirt” for
patching**



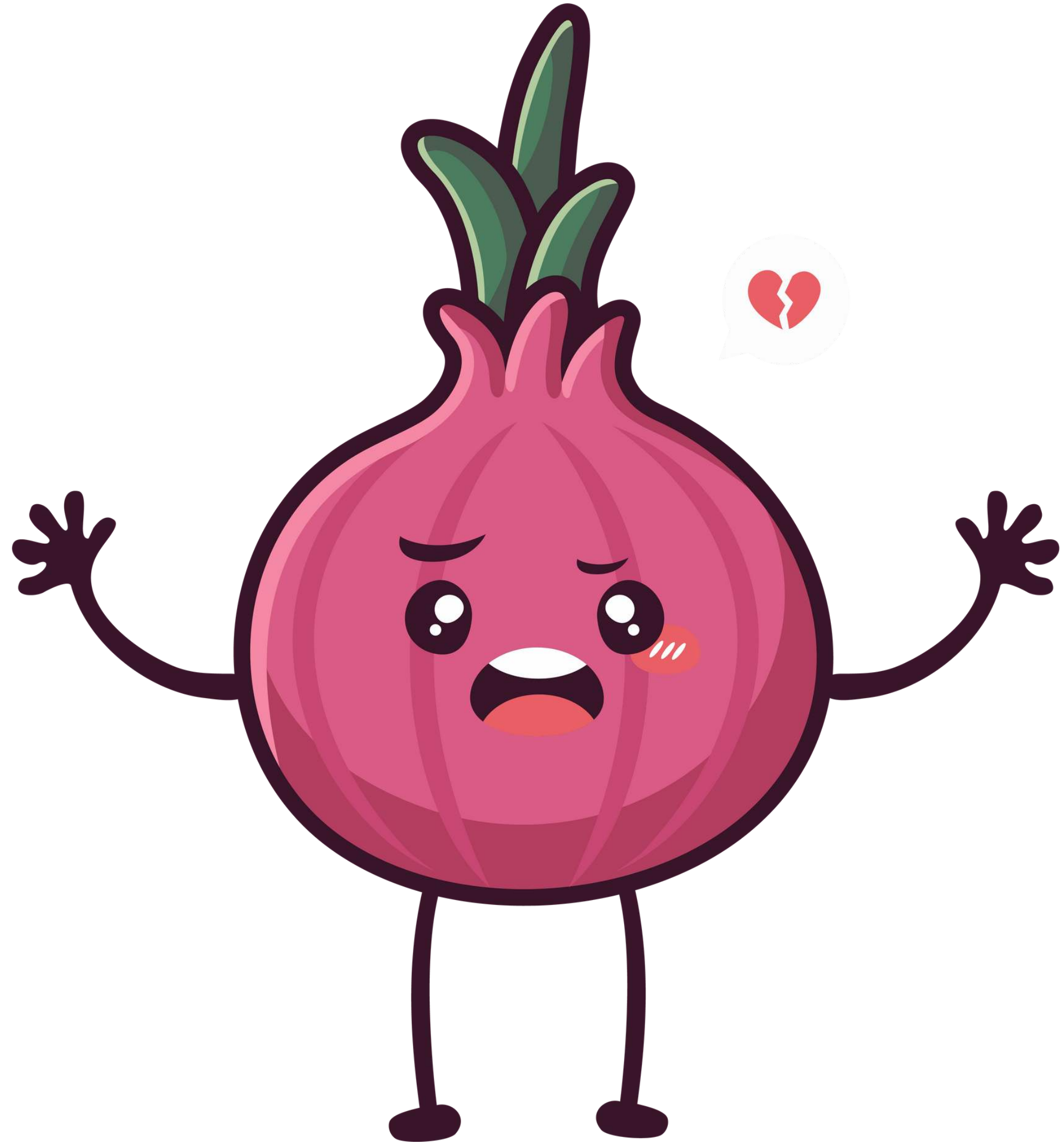
Bridging the Gap



**flat life
again after
my leak
reopened**

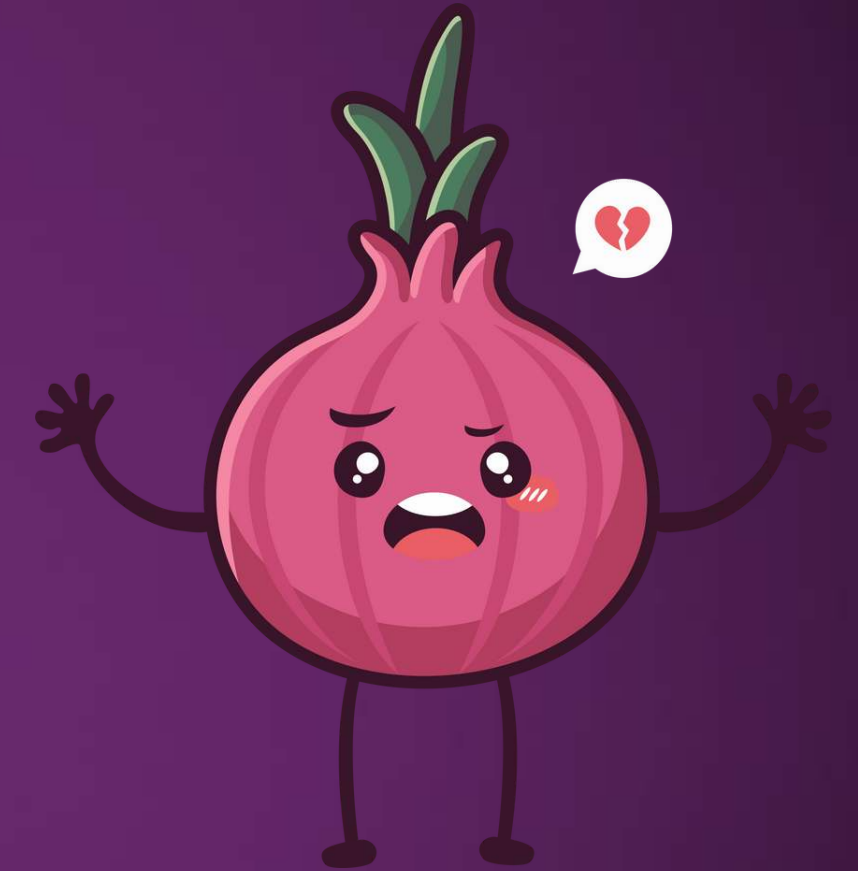


Bridging the Gap



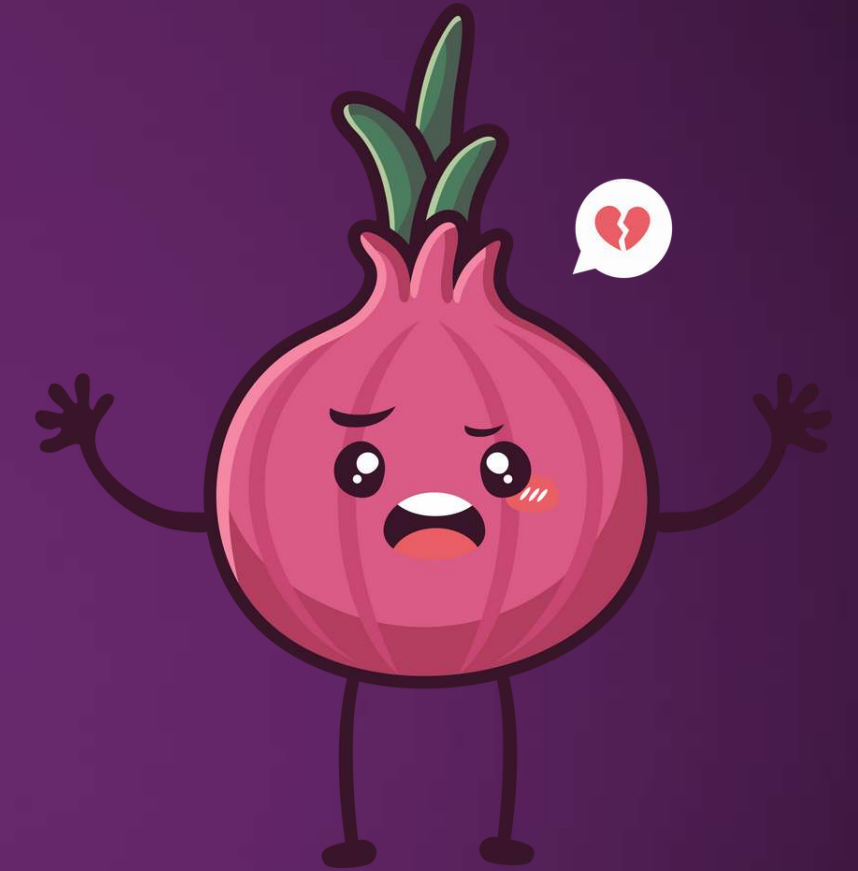
My “onion of catch-22s”

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



My “onion of catch-22s”

- 1) Multiple punctures with large needles; leak site is unknown
- 2) Heritable connective tissue disorder



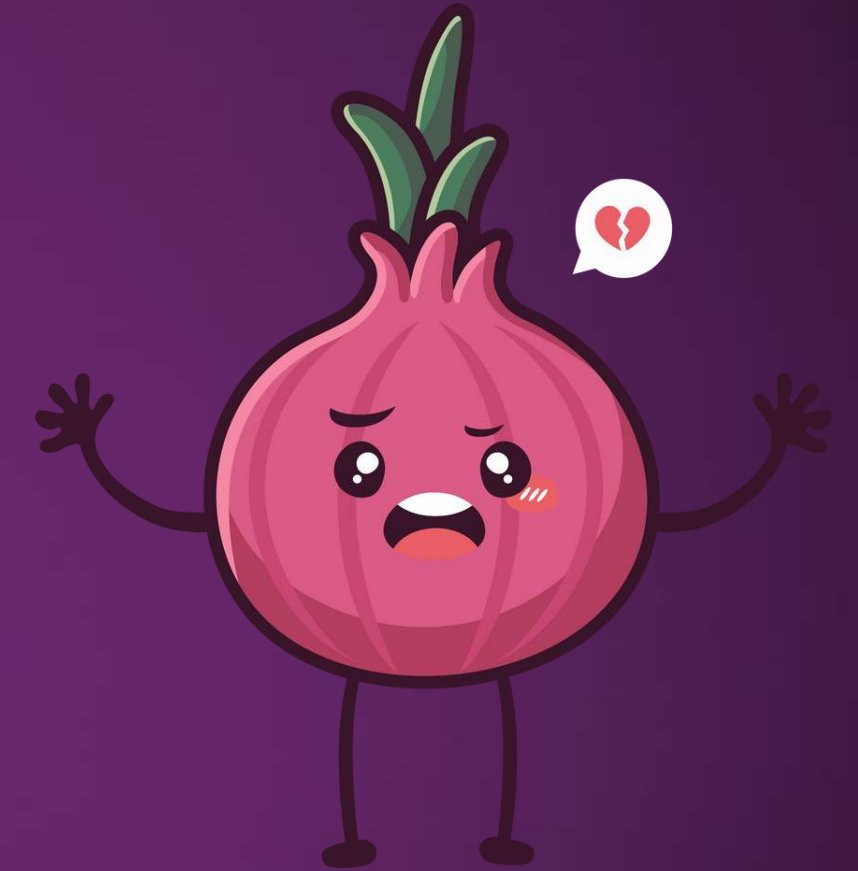
My “onion of catch-22s”

- 1) Multiple punctures with large needles; leak site is unknown
- 2) Heritable connective tissue disorder
- 3) Mast Cell Activation Syndrome



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- 3) Mast Cell Activation Syndrome
- 4) Imaging shows adhesive arachnoiditis



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- 4) Imaging shows adhesive arachnoiditis
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- 6) I had RIH after only 3 months leaking



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
- 4) Imaging shows adhesive arachnoiditis
- 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.



Finding my way through

1

CURIOSITY





SYMPTOMS & VARIABLES TEMPLATE, BY JODI ETTEBERG

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 experience, 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 experienced 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	Normal	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 available 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



Bridging the Gap



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username:
password:

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My alerts (26)

EDS AND "intracranial hypotension" AND doi

"lumbar puncture" or "spinal tap" AND doi

"intracranial hypotension" or "PDPH" AND doi



Bridging the Gap

Finding my way through

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CURIOSITY

2

**BECOMING MY
OWN LAB RAT**



Finding my way through

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3

**TURNING
INWARDS**



Thank you