

Resilience Journal

modes of embodiment

This journal belongs to:

Welcome to the
Resilience Journal.

The Resilience
Journal is a soft
data record and
visual map of you,
living with your
illness/ disability.

This journal may also be:

A space in your life to
honor the nuances and
depth of pain.

A time to recognize
unseen ways of being,
care, and survival.

A tool for visibility,
organizing, and
building community
with others.

However you use it—
as a ritual,

an advocacy tool,

or data artwork—

this journal is designed
in hopes to invoke
more care and clarity
within your life

through the process
of reflecting, tracking,
visualizing, and sharing
typically overlooked
aspects of being.

Over time, you may
see key patterns and
qualities that make up
your lived experience
as a whole.

Your relationship
to your illness is
entirely uniquely
your own

and it is an honor to
bear witness to your
remarkable acts of
resilience.

Gathering Soft Data

Soft Data is
intimate and fuzzy.
It is data that is
full of opinions,
suggestions,
interpretations,
contradictions and
uncertainties.

This journal is dedicated to tracking 'soft data' as opposed to 'hard data.' Soft data is data as human experience— full of opinions, suggestions, interpretations, contradictions, and uncertainties; a.k.a. qualitative data.

Living with illness/ disability, we often keep track of our experiences as medicalized, hard data. Quantitative data in the form of medicine dosages, vital tests, and other hard datasets give some understanding to our state of being.

This perspective often becomes limiting, and does little to reflect back to ourselves the nuances or depth of living with illness.

We are often denied from acknowledging certain aspects of living with illness/ disability. Can we identify and honor the overlooked soft data in our everyday lives to paint a fuller, more representative picture of our lived experience?

Gathering Soft Data with the Mind

Begin with a question:
*How does my illness/
disability present itself in my
daily life?*

Use this next page to brainstorm, recall, and record various examples of your living experience. Think about illness/ disability from a variety of perspectives- it can be concrete things you do or experience, abstract forces, cultural, where you seek care, how you give yourself care. Take 5 minutes to reflect and write down your experiences. You may want to add to this over several days as you go about your life, thinking about this question.

Gathering Soft Data with the Body

Ask the same question:
*How does my illness/
disability present itself in my
daily life?*

Take a moment to answer this question with your body. This can involve mindful embodiment, feeling the sensations in your body as you stay still, as you move around, as you breathe. Take 5 minutes to focus on 'listening' to your body in the present moment while asking this question. After exploring this question, use this space to record what you experienced. This can be stream-of-consciousness writing or drawing shapes and scribbles. You may want to repeat this exercise on different days.

Bodymind: an intricate and often times inseparable relationship between the body and the mind, and how these two units might act as one.

Source: Wikipedia

The bodymind concept is an approach to understand the human body and mind as a single integrated unit. It attempts to address the mind-body problem and resists the Western traditions of mind-body dualism, and the term is often used in disability studies.

While gathering data, it is helpful to spend time trying out different approaches to accessing these parts of yourself, both with the mind and the body. Some methods might work, while some not so much.

Through this process of gathering, you may uncover immense depth and multi-dimensionality in your bodymind. You may also evoke hidden memories and emotions. Take your time in re-discovering your bodymind.

Gathering Soft Data with the Bodymind

Easy, Medium, Difficult Days Exercise

This embodiment exercise is adapted from a movement workshop by Yo-Yo Lin and Lara Marcin entitled "Modes of Embodiment: An Expressive Toolkit for Chronically Ill and Disabled Bodies" in 2019.

How does my illness present itself on easy days?

Take 5 minutes away from the page. Focus on how your bodymind feels on days when you experience more ease with your illness/ disability. (This may be difficult if you are not having an easy day.) How do you feel on an easy day? How do you move? What do you do to celebrate? Answer these questions for yourself while being present with your bodymind—this can involve movement or staying still. After 5 minutes, you may record your answer to this question by writing, drawing, and/ or choosing a short movement from your exploration that you can repeat to yourself in later reflections.

How does my illness present itself on difficult days?

Take 5 minutes away from the page. Focus on how your bodymind feels on days when you experience more difficulty with your illness/ disability. (This may be hard if you are not having a difficult day.) How do you feel on a difficult day? How do you move? What do you do to care for yourself? How might you honor this pain? Answer these questions for yourself while being present with your bodymind—this can involve movement or staying still. After 5 minutes, you may record your answer to this question by writing, drawing, and/ or choosing a short movement from your exploration that you can repeat to yourself in later reflections.

How does my illness present itself on medium days?

Take 5 minutes away from the page. Focus on how your bodymind feels on days when you experience not much difficulty or ease with your illness/ disability. (This may be difficult if you are not having a medium day.) How do you feel on a medium day? How do you move? What do you do to check-in with yourself? Answer these questions for yourself while being present with your bodymind—this can involve movement or staying still. After 5 minutes, you may record your answer to this question by writing, drawing, and/ or choosing a short movement from your exploration that you can repeat to yourself in later reflections.

Take your time to sit with your soft data.

It takes a lot of emotional,
physical, and mental energy
to reflect upon the details of
your lived experience. It can be
overwhelming at times.

Remember, there is no right way
or wrong way to do this journal.
Take many breaks. Use this tool
in a way that works for you.

Some good questions to keep in mind:

What are some aspects of
living with my condition
that are present but often
overlooked that I want to
acknowledge?

Could this be something
I can use to share with
others my experience?

How much is this data
gathering process a tool to
learn about myself? How
much is it a method for
honoring my experience?

How can I design this
to be an enjoyable daily
ritual for myself?

Organizing Soft Data

Examining Data Visualization

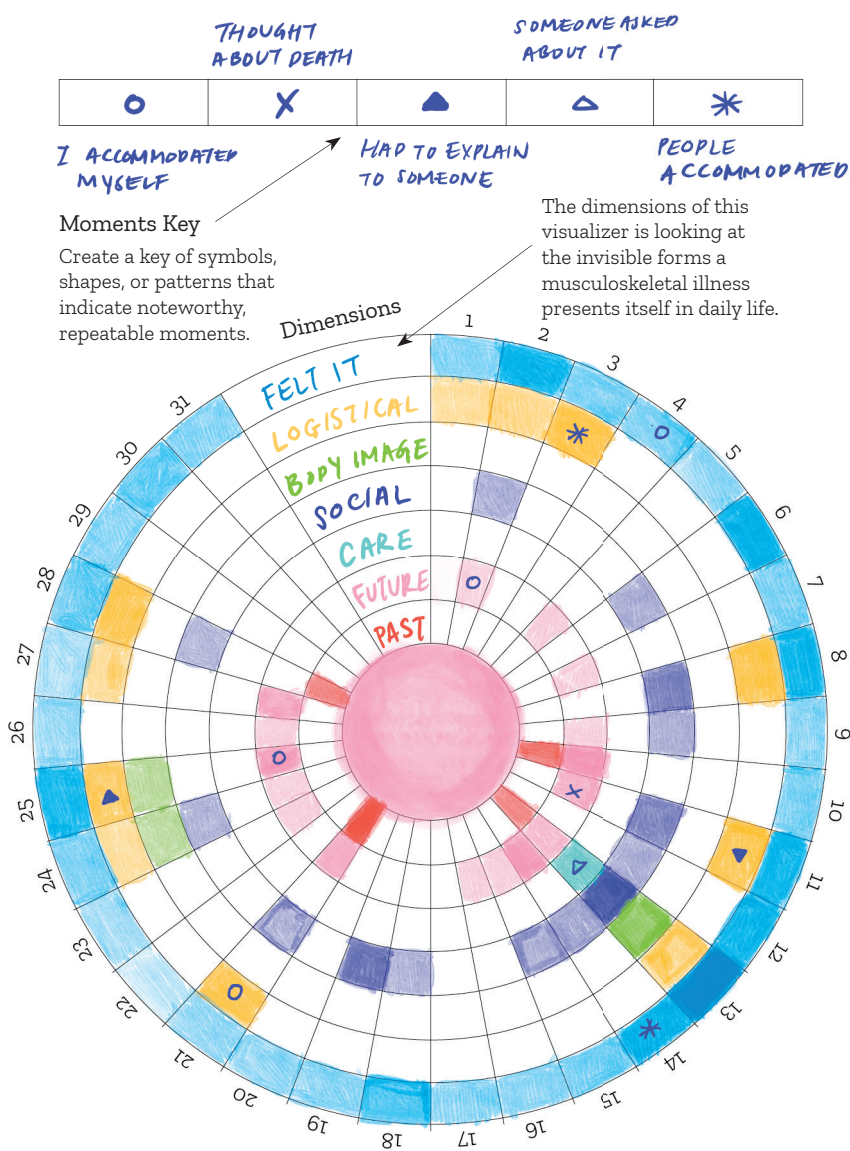
There are many different ways of visualizing data. For this journal, we have a month-long circle visualization comprised of 31 sections and 7 layers. Each section is a day of the month (numbered) and each layer is a different 'dimension' you track.

These dimensions can vary depending on your unique experience. To the right, there is an example of a completed visualizer by the author answering the question: *How does my illness present itself in my daily life?*

The dimensions read from outer ring to inner ring: Felt It, Logistical, Body Image, Social Pressures, Getting Care, Future Visions, and Past Trauma. Each day, a rectangle is filled in with its assigned color.

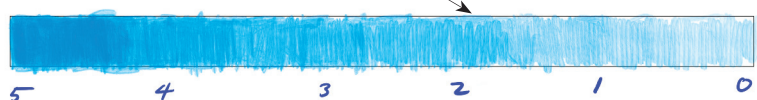
Above the circle is a 'moments' key where symbols represent an event or action. Some of these actions include: "I accommodated for myself" and "Had to explain it to someone." These are marked in a rectangle they relate to when they occur.

Below the circle is a gradient (light to dark) key where the darkness of shading represents the intensity of the tracked experience.



Intensity Key

The darkness of the shading represents the intensity of the experience in this visualizer. Feel free to customize this gradient to your liking.



Organizing Soft Data

Take the data you have gathered and add the experiences into this chart. Through organizing, you will begin to see how certain experiences have similar themes and belong to certain categories of being.

Experience	Dimension (category of being)
o) Example: I had to ask for help from a stranger to carry my bags up the subway stairs.	Logistical
1)	
2)	
3)	
4)	

These categories will become your dimensions and certain events will become notable moments you keep track of. This process will allow you to identify what you want to keep track of in your journal for the next few months. Use this space to draw connections, make distinctions, and outline your complex experiences.

Moment (repeatable event)	Intensity (0-5)	Notes
I explained my illness to them.	2	Could also be seen as an example of access or interdependence.

Experience	Dimension (category of being)
5)	
6)	
7)	
8)	
9)	
10)	
11)	

Moment (repeatable event)	Intensity (0-5)	Notes

Setting Up For Data Tracking

Dimensions: List up to 7 different dimensions. These will make up the layers of your circle.

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.

You are welcome to use the provided dimensions:

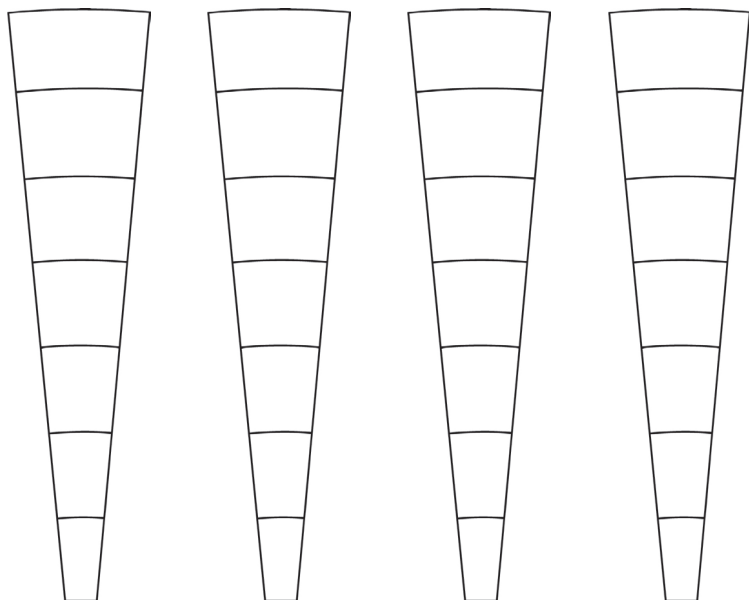
- 1. Felt It
- 2. Logistical
- 3. Body Image
- 4. Social Pressures
- 5. Getting Care
- 6. Future Visions
- 7. Past Trauma

Moments: List up to 5 different repeatable events—these can be feelings or actions.

- Symbol
- 1. =
 - 2. =
 - 3. =
 - 4. =
 - 5. =

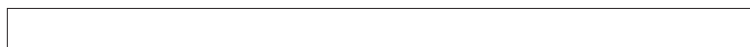
Color / Fill Tests:

What colors or fills would you want to use? You may use up to 7 colors or use a single color. Experiment with how you fill in boxes. Note the boxes get smaller as you go down the layers.



Intensity:

You may fill this in as a gradient scale as a way to represent the intensity of the experience on a scale of 0-5.



5 4 3 2 1 0

Tracking Soft Data

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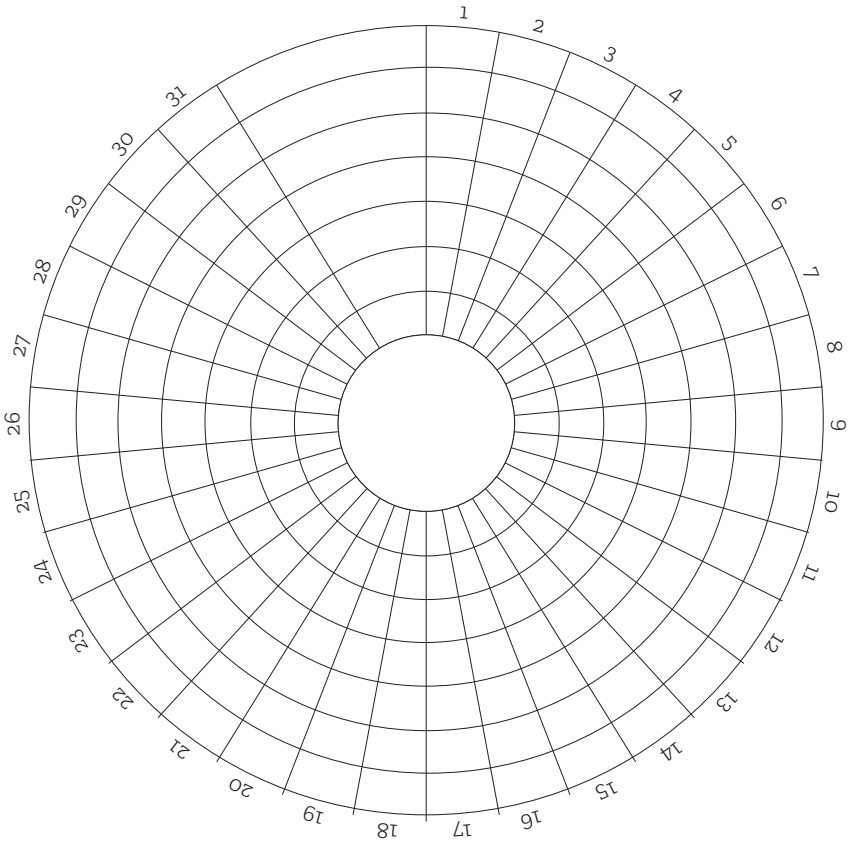
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What did you learn about
yourself this month?

In what ways did you self-
advocate this month?

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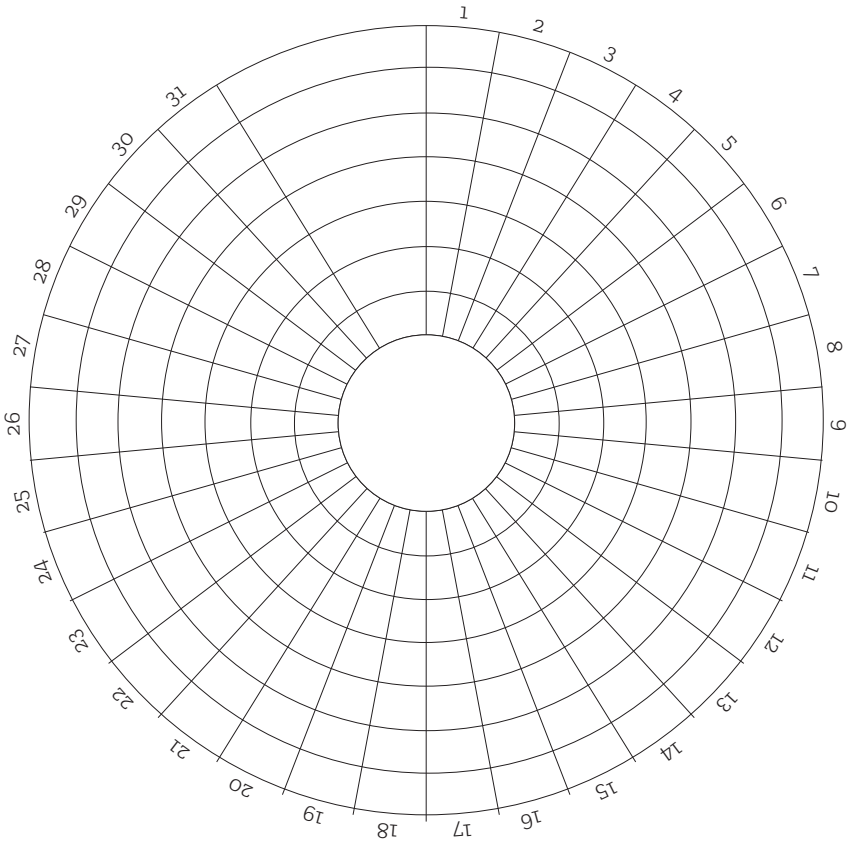
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Do you notice any patterns
from the previous month?

How has your experience with
your illness/ disability changed
or stayed the same?

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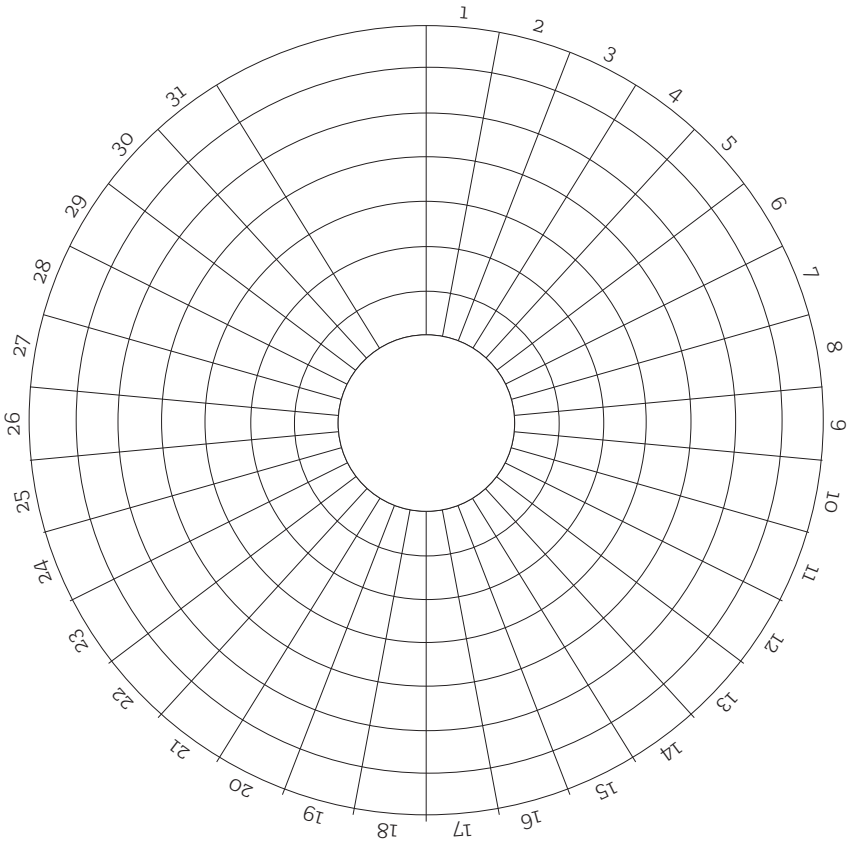
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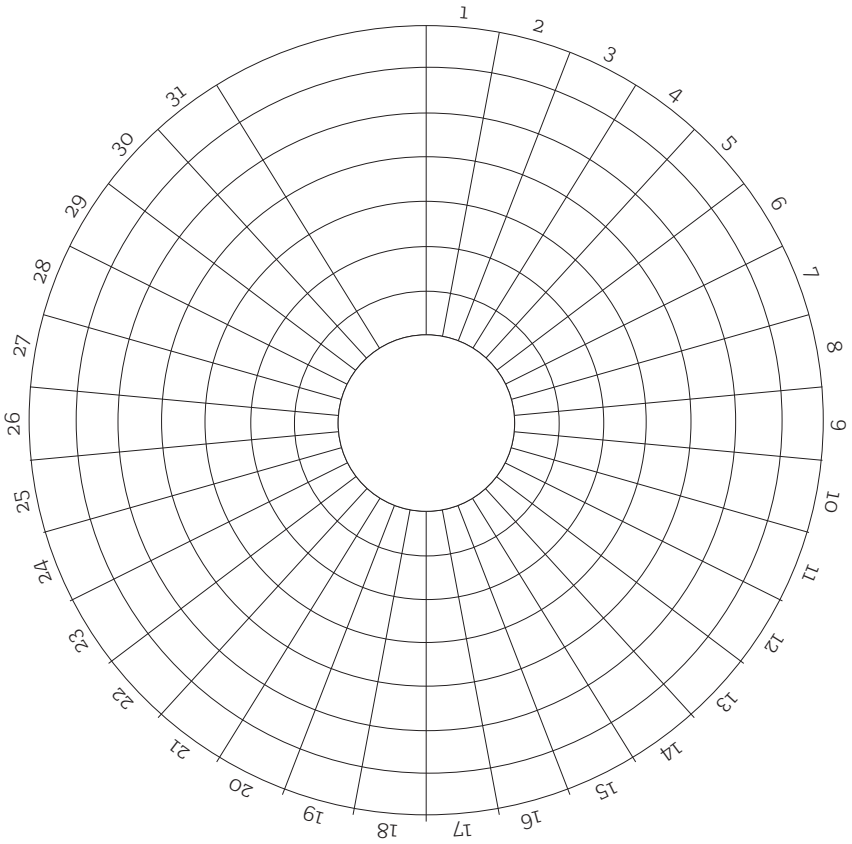
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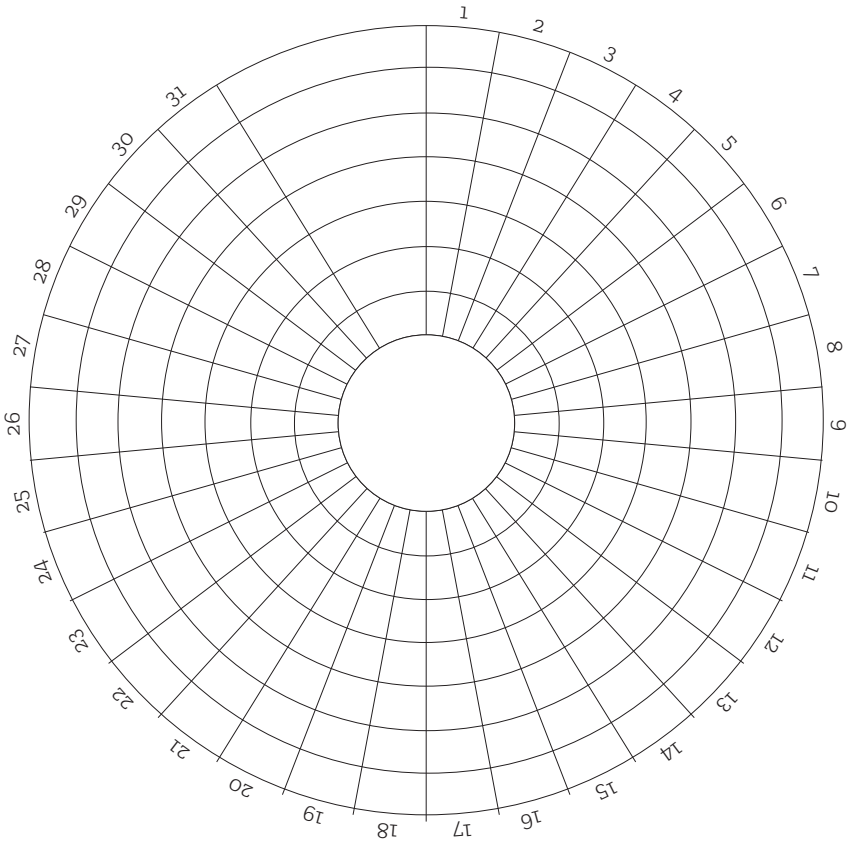
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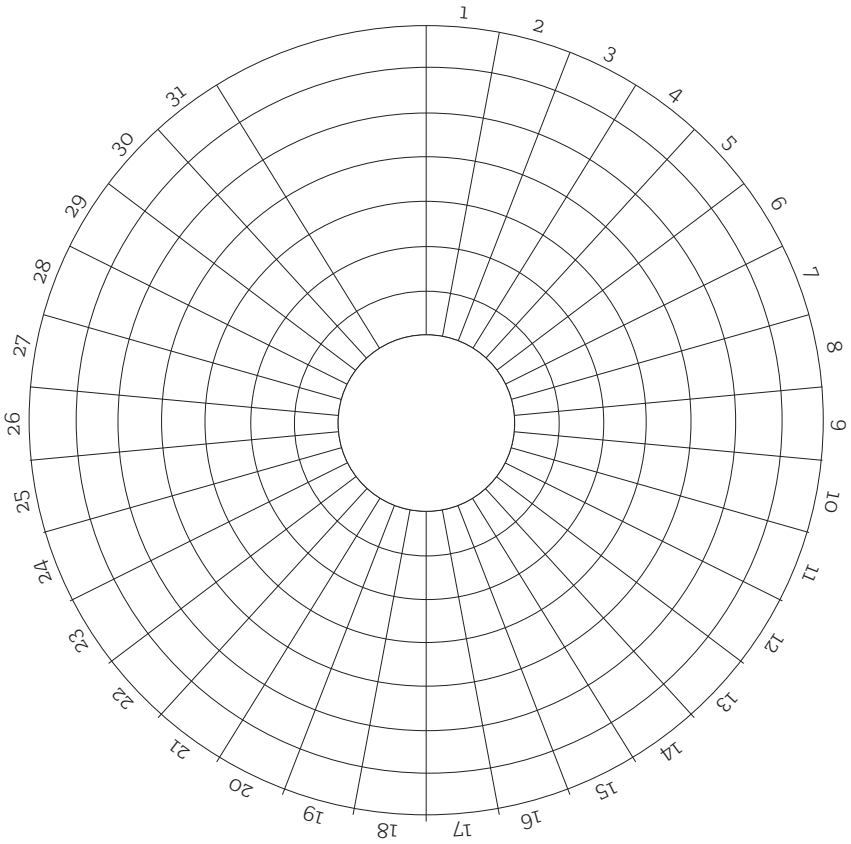
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NOTES

This journal is developed by artist Yo-Yo Lin. She currently identifies as chronically ill and lives and works in NYC deepening her knowledge in health trauma, tool-making, and community-building.

The 'Resilience Journal' is one component of 'Modes of Embodiment'— a digital and physical toolkit that seeks to be an expressive resource and living archive by and for the chronically ill and disabled.

'Modes of Embodiment' was made possible with support from Eyebeam. This journal was produced with support from Eyebeam, The Laundromat Project, and Denniston Hill.

If you would like to share your journal pages and be a part of a growing database of acts of resilience, get in touch:

embodiment.archive@gmail.com

EYEBEAM