

How to Develop Communication Books for PPA/PPAOS

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National Aphasia Association's PPA/PPAOS Educational Series

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Personal website (with resources): www.zezzes.com

Outline



What are communication books, and why use them?



What topics and items should go in the book? What should it look like?



How do we use the book?



Other tips + sample communication book walk-through

People can communicate in many different ways



Oral Speech



AAC
(augmentative and alternative communication)



Sign Language



Written Language

People can communicate in many different ways



Oral Speech



AAC
(augmentative and alternative communication)



Sign Language



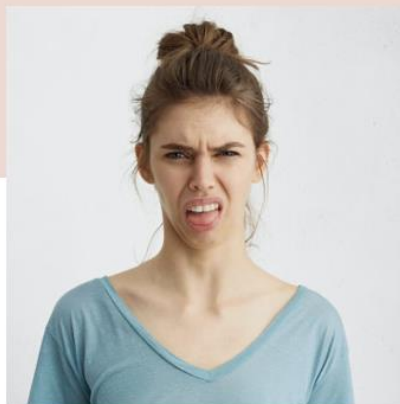
Written Language

What is AAC?

Augmentative and Alternative Communication (AAC)

Body-based systems

- Using the body alone to convey message
- Gesture
- Body language
- Facial expressions



Tool-based systems

- Using equipment + the body via an access point (for example, pointing)
- **High tech:** speech generating device (SGD), iPad/phone applications
- **Low/no tech:** usually paper-based; communication book, communication boards, pen and paper, whiteboard

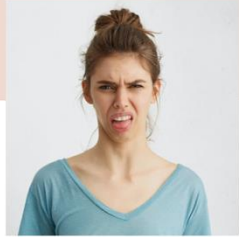


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Communication books
are a **low/no-tech** type
of AAC!

What are communication books?

- They are made up of **multiple printed pages** (3x5in, 5x7in, 8.5x11in) that you flip through



What are communication books?

- They are usually **organized by topic** (e.g., grooming, food, clothing)

GROOMING



Lipstick



Deodorant



Brush



Floss



Hair Pick



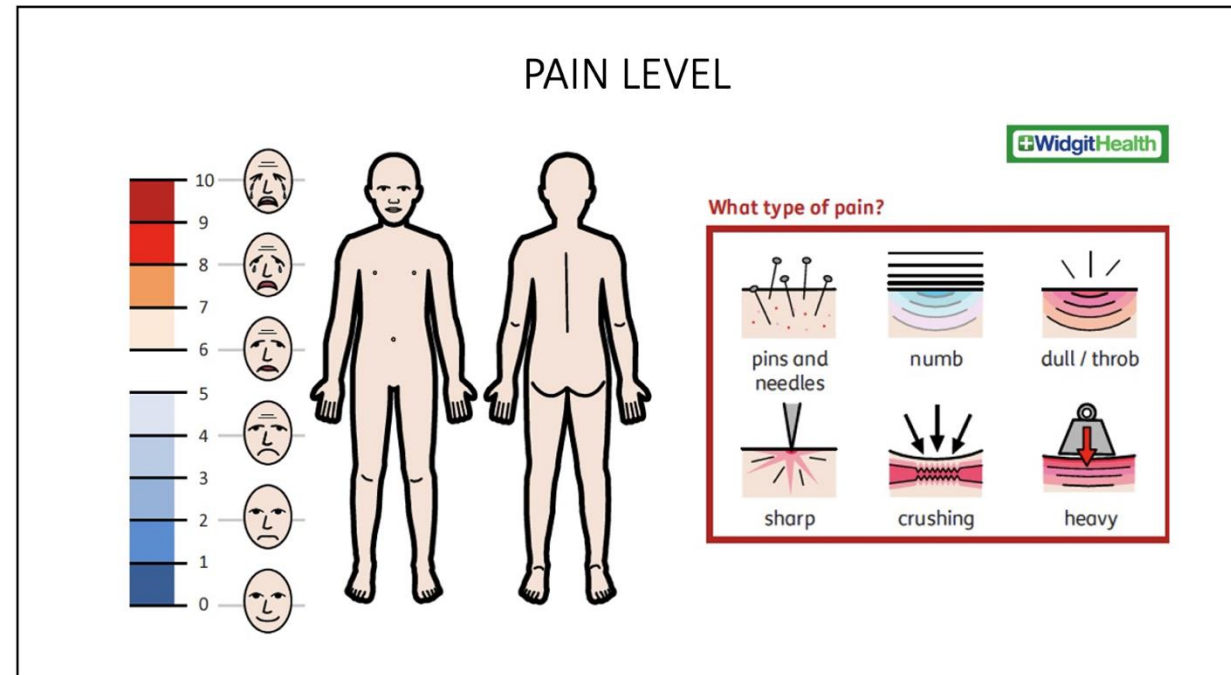
Tweezers

What are communication books?

- Some pages can be dedicated **visual supports** (e.g., pain level, alphabet and numbers, maps)



A B C D E F G H I
J K L M N O P Q R
S T U V W X Y Z ?
1 2 3 4 5 6 7 8 9 0



What are communication books?

- Some pages can be **scripts** (longer personal stories)
- Developed in speech therapy or with support from a loved one

Woodworking



I have loved woodworking for many years. I started out when I was in high school shop class, where I realized I had a passion for it. I mostly make tables and benches for my family and friends. I have all of the tools I need in my garage. I love sanding down the wood and seeing the final product.

What are communication books?

- For topics like “grooming” or “food”, they often contain **several items per page**
- Usually, some combination of words and pictures (depending on the individual’s strengths and needs)

GROCERIES



Milk



Yogurt



Bread



Apples



Bananas



Lettuce



Carrots



Pasta



Deli Meat



Toilet Paper



Cereal



Peanut Butter



Potatoes



Soda



Cookies

What are communication books?

- They can contain **anything you want!**



Why choose communication books?



Pros:

- Highly customizable
- Allow for different levels of picture- and word-based support
- Provide another method of communication other than speaking orally
- Can be used for comprehension as well as expression
- Can be easier for some to navigate than high-tech systems



Cons:

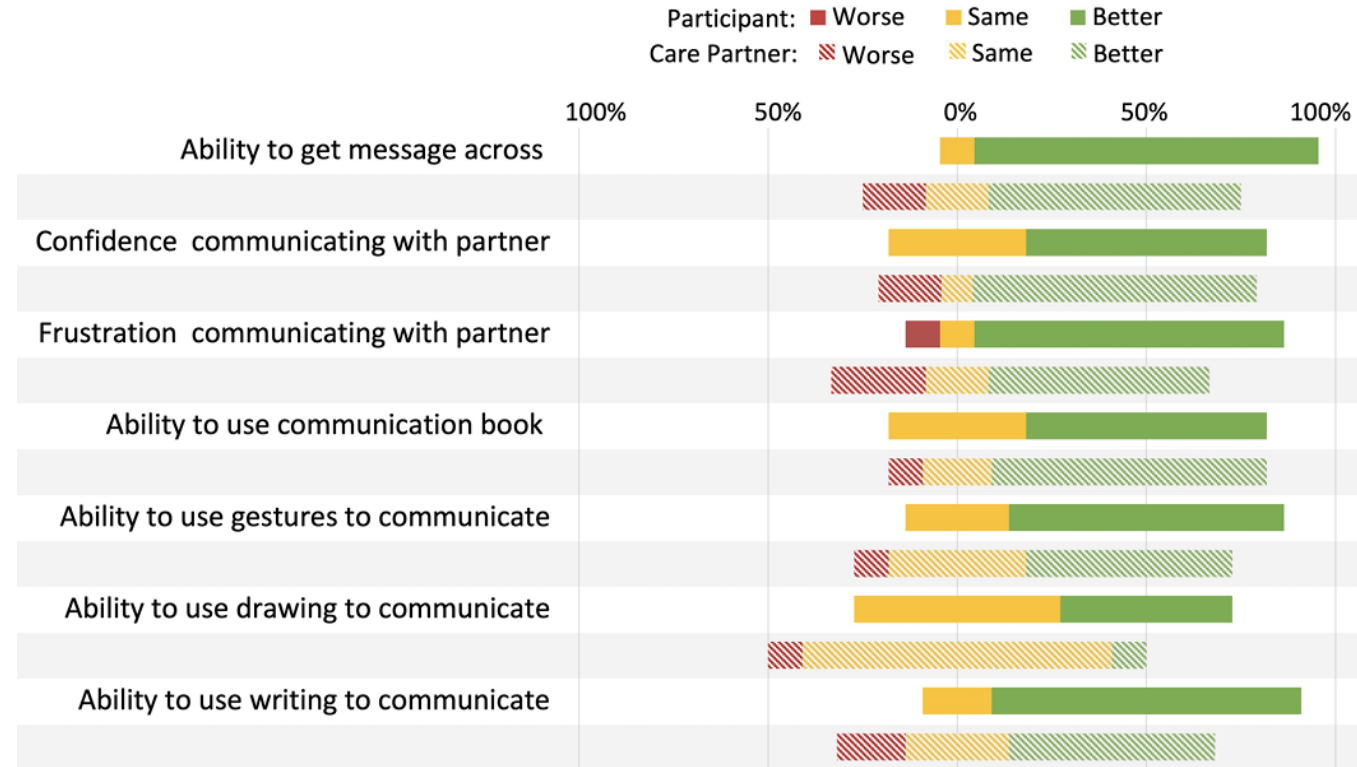
- Can take a lot of initial work to create
- Needs can change over time, requiring modifications or losing usefulness
- Can be bulky/cumbersome in paper form (***but there are solutions for this!*)
- Too many pages can be overwhelming



Why choose communication books?

A combined restitutive, compensatory, and partner-focused treatment approach for PPA (Robinaugh et al., 2024)

- Used communication book training, multimodal training (gesturing, writing, drawing), and communication partner training in combination with word retrieval and script training
- Most people reported **improved multimodal communication, better ability to get their message across, increased confidence, and decreased frustration**



Why choose communication books?

AAC Strategies and Tools for Persons With Dementia

(Bourgeois, Fried-Oken, & Rowland, 2010)

- Key findings include that people with PPA:
 - Are more successful in communication when they use AAC
 - Can use AAC with both family members and with clinical researchers
 - Can make use not only of low-tech communication boards, but also natural AAC supports (photo albums, newspapers, maps) available in their daily environments

AAC-RERC Webcast Series

Children's Hospital at Boston, Duke University, InvoTek, Inc., Oregon Health and Science University, Pennsylvania State University, State University of New York at Buffalo, University of Nebraska at Lincoln

AAC for Persons with Primary Progressive Aphasia

Melanie Fried-Oken, Ph.D., Oregon Health and Science University

Outline	Notes
Slide Title	Duration
1. AAC-RERC Webcas...	00:10
2. AAC for Persons wi...	00:14
3. Learning Outcomes	00:41
4. Primary Progressiv...	00:31
5. Video	00:30
6. Characteristics of P...	00:32
7. Types of primary p...	00:55
8. Diagnostic Criteria ...	01:08
9. Diagnostic Criteria ...	00:32

AAC for Persons with Primary Progressive Aphasia - Dr Melanie Fried-Oken

Research Briefs

AACRERC - 3 / 14

AACRERC 618 subscribers

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[Link to AAC in PPA Talk \(above on YouTube; click here\)](#)

Link also here:

<https://www.youtube.com/watch?v=XUAOqKuPlyU&list=PL9C7CF7E0B2F19902>

AAC and PPA: Other articles (including from Wauters et al., 2023 systematic review)

Bier, N., Brambati, S., Macoir, J., Paquette, G., Schmitz, X., Belleville, S., Faucher, C., & Joubert, S. (2015). **Relying on procedural memory to enhance independence in daily living activities: Smartphone use in a case of semantic dementia.** *Neuropsychological Rehabilitation*, 25(6), 913–935. <https://doi.org/10.1080/09602011.2014.997745>

Cress, C. J., & King, J. M. (1999). **AAC strategies for people with primary progressive aphasia without dementia: Two case studies.** *AAC: Augmentative and Alternative Communication*, 15(4), 248.

Fried-Oken, M., Daniels, D., Ettinger, O., Mooney, A., Noethe, G., & Rowland, C. (2015). **What's on Your Mind? Conversation Topics Chosen by People With Degenerative Cognitive-Linguistic Disorders for Communication Boards.** In *American Journal Of Speech-Language Pathology* (Vol. 24, pp. 272–280). https://doi.org/10.1044/2015_AJSLP-14-0057

Góral-Półrola, J., Półrola, P., Mirska, N., Mirski, A., Herman-Sucharska, I., & Pachalska, M. (2016). **Augmentative and Alternative Communication (AAC) for a patient with a nonfluent/agrammatic variant of PPA in the mutism stage.** In *Annals of agricultural and environmental medicine: AAEM* (Vol. 23, pp. 182–192). <https://doi.org/10.5604/12321966.1196877>

Mooney, A., Beale, N., & Fried-Oken, M. (2018). **Group Communication Treatment for Individuals with PPA and Their Partners** (Vol. 39, pp. 257–269). <https://doi.org/10.1055/s-0038-1660784>

Murray, L. L. (1998). **Longitudinal treatment of primary progressive aphasia: A case study.** *Aphasiology*, 12(7–8), 651–672. <https://doi.org/10.1080/02687039808249564>

Pattee, C., Von Berg, S., & Ghezzi, P. (2006). **Effects of alternative communication on the communicative effectiveness of an individual with a progressive language disorder.** *International Journal of Rehabilitation Research*, 29(2), 151–153. <https://doi.org/10.1097/01.mrr.0000210046.02044.4d>

Rebstock, A. M., & Wallace, S. E. (2020). **Effects of a combined semantic feature analysis and multimodal treatment for primary progressive aphasia: Pilot study.** *Communication Disorders Quarterly*, 41(2), 71–85. <https://doi.org/10.1177/1525740118794399>

Routhier, S., Macoir, J., Imbeault, H., Jacques, S., Pigot, H., Giroux, S., Cau, A., & Bier, N. (2014). **From smartphone to external semantic memory device: The use of new technologies to compensate for semantic deficits.** *Non-Pharmacological Therapies in Different Types of Dementia and Mild Cognitive Impairment: A Wide Perspective from Theory to Practice*, January, 93–111.

What topics should go in the book?

- People with PPA/PPAOS tend to prioritize **connection, personal interests, and stories**
- Care partners tend to prioritize **basic day-to-day needs**
- It is great to include both!
- For **common topics**, see resources like Lingraphica's "Interest Inventory" (first page pictured here →)
- For **engaging personal topics**, see StoryCorps' "Great Questions" list!
(link: <https://storycorps.org/participate/great-questions/>)

Interest Checklist

Rate each of the personal interest areas below:

		 VERY	 SOMEWHAT	 NOT AT ALL
Eating out		☐	☐	☐
Family		☐	☐	☐
Food/meals		☐	☐	☐
Friends		☐	☐	☐

What topics should go in the book?

- In general, **anything that increases independence and/or life participation** (be it social connection or personal care)
- Make sure the decisions on what to include are a **collaboration** between the person with PPA/PPAOS and the care partner!
- Dedicated pages can be made for specific occasions and/or settings →

Example 1: The Piano Player

If someone with PPA/PPAOS regularly plays the piano, you can create a page specifically for that topic. It can be in their main book, but you can also keep a copy on the music rack so it is always accessible while they play!



Example 2: The Park-Goer

If someone with PPA/PPAOS regularly goes to the park, you can create a page specifically for communicating about things they like and see there. You can also include needs that may arise there (e.g., bathroom, hot/cold, tired, thirsty).





What kinds
of items
should I put
in the book?

Try to prioritize things that are:

- 1) **important to you**, and
- 2) **come up often**

For example, “glacier” might not come up very often for most people, but if the person with PPA/PPAOS studied glaciers for 20 years, it might be a good item to include!



What kinds of items should I put in the book?

In general, it's good to include:

- **Personal information** (e.g., name, address, birthday, phone number, etc.; can have an “about PPA” page)
- Information about, names, and faces of **family and friends**
- Education, career, past/future trips
- **Favorite** foods, places, movies, TV shows, hobbies, stories
- Commonly used items
- Daily activities

What kinds of items should I put in the book?

Time-invariant information is best!

- *For example, your daughter Sarah is 20 years old right now, but that will change – her birthday won't change*

If the person with PPA/PPAOS is consistently naming something, that might be less of a priority for now, whereas something harder to name might be a higher priority

- *For example, you might use their toothbrush often, but if you can name it independently, it doesn't need to take up limited book space presently!*

What kinds of pictures/text should I use?



It's best to include pictures of your actual home and your own personal items where possible.

This also includes pictures from trips you take or experiences you share together!

These will tend to be recognized the best and for the longest in the disease course (as opposed to stock images from online, or objects that don't look "typical" for their category, like an unusual-looking kettle).



What kinds of pictures/text should I use?



When you take pictures, try to make sure the item is relatively isolated in the picture.

In other words, try not to have too busy of a background, or other items also present in the picture.

For example, if you want to take a picture of a banana, it's okay if you can tell it's in the kitchen, but try not to take a picture of it in a bowl with lots of other fruit present.



What kinds of pictures/text should I use?



Same topic, different levels of support

For some people with PPA/PPAOS, reading ability stays quite strong (especially for single words), while for others, it is not feasible.

Consider this when selecting text alongside the pictures.

If the person with PPA/PPAOS has created scripts with their SLP, if there are key sentences, phrases, or personally relevant texts (e.g., poems they wrote), or stories with greater detail they would like to include, these can be great options!



I like **woodworking**.



I make **tables** and **benches**.



I enjoy woodworking. I make tables and benches. I work in my garage. I make things for my family and friends.



I have loved woodworking for many years. I started out when I was in high school shop class, where I realized I had a passion for it. I mostly make tables and benches for my family and friends. I have all of the tools I need in my garage. I love sanding down the wood and seeing the final product.

What kinds of pictures/text should I use?

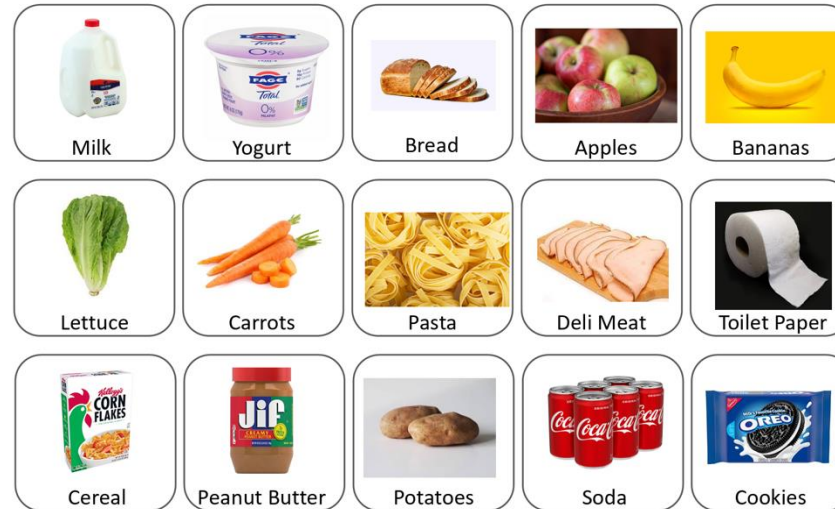


Notice how many images tend to be on a single page in the example pages provided and use that as a reference.

Pictures should be large enough to see and recognize clearly, and without too much clutter per page. Text should also be in legible fonts, large enough, and with spacing between lines.



GROCERIES



How do we use this book?

- It takes time to learn how to navigate the book
- **Practice finding specific items/pages** (e.g., “show me your map!”), and build up to more **open questions** (e.g., “what did you do for work?”)
- **Be patient with each other and with yourselves!**
- The book can be used both “*expressively*” and “*receptively*”: the person with PPA/PPAOS can point to directly communicate *their thoughts*, AND a care partner /loved one can point to help the person with PPA/PPAOS *understand them*
- Make sure to give plenty of time for a response before asking again or rephrasing



Other tips

Keep it consistent!

Try not to reorganize everything a bunch over and over; you'll lose your muscle memory for where to find things. It's better to make a new page or add a new row.

Book use is a team effort 😊

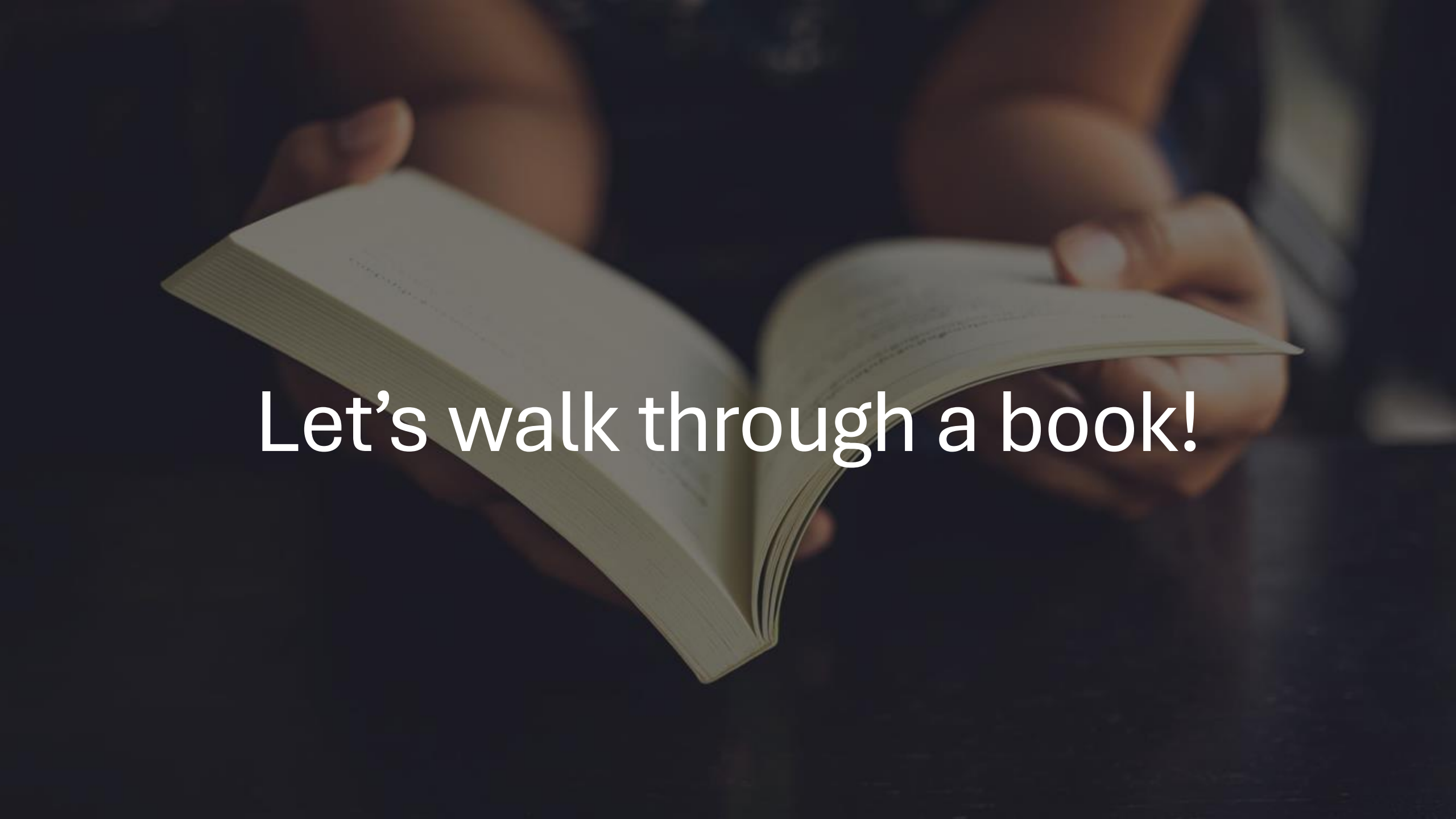
The person with PPA/PPAOS may be more independent with navigating the book, or a communication partner may need to take the lead. You can scan page to page and confirm if what they're looking for is on the page.

Go virtual!

You can take pictures of the pages to keep on your phone/iPad for more accessibility and options. Some people prefer this.

Get organized

You can create, organize, and label photo albums on your phone to make the pictures easier to find. (I can provide a step-by-step how-to for this for folks interested!)

A close-up photograph of a person's hands holding an open book. The book is open to two pages, and the text on the pages is visible but slightly blurred. The person's hands are positioned on the left and right sides of the book, holding it open. The background is dark and out of focus. Overlaid on the center of the image is the text "Let's walk through a book!" in a white, sans-serif font.

Let's walk through a book!

I have primary progressive aphasia (PPA). Talking and writing are difficult for me. This book helps me to communicate. You can help by being patient and asking questions.

This book was created by Dr. Gary Robinaugh and Dr. Maya Henry at UT Austin's ARTLab in support of individuals with PPA/PPAOS. Pages are examples of the different topics, formats, and content that can be included in a personalized communication book. Please feel free to use any of these pages directly or as a reference for creating your own books!

Fred Johnson

123 Example Rd.
Texas City, TX 12345
(123) 123-1234

Emergency Contacts:

James Johnson	(111) 222-3333
Naomi Johnson	(444) 555-6666

FAMILY

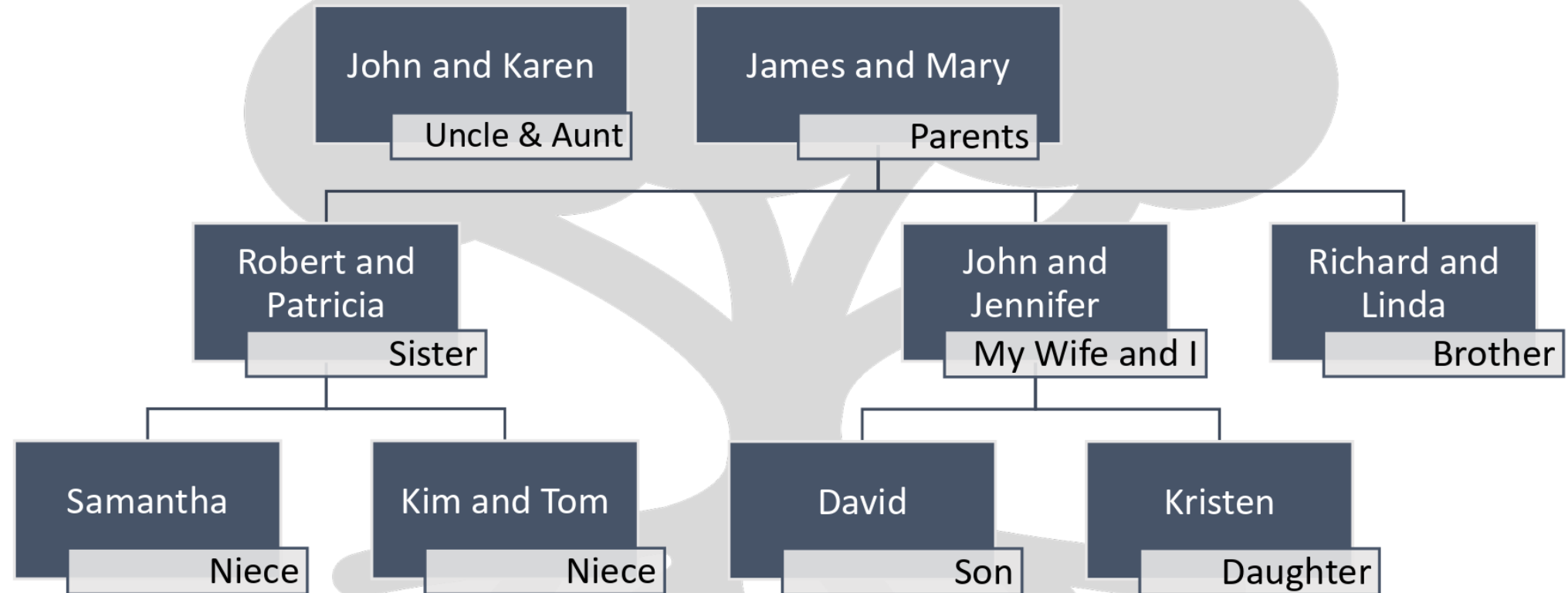


Angel is a **radiologist**.
He and **Nicole** live in
Omaha with their children
Yvette and **Liam**.



Lucas is an **English teacher**.
He and **Paula** live in
Kansas City.

FAMILY TREE



GROCERIES



Milk



Yogurt



Bread



Apples



Bananas



Lettuce



Carrots



Pasta



Deli Meat



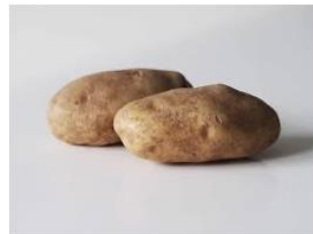
Toilet Paper



Cereal



Peanut Butter



Potatoes



Soda



Cookies



CHIPOTLE

MEXICAN GRILL



BURRITO



BURRITO BOWL



LIFESTYLE BOWL **NEW**

ORDER →



QUESADILLA **NEW**



SALAD



TACOS

PLACES TO GO



Costco



H-E-B



The Park



Home



Gold's Gym



Downtown

The Park



The Park



Walk



Tree



I need the bathroom



Roses



Bench



Dog



I need water

Painting Class



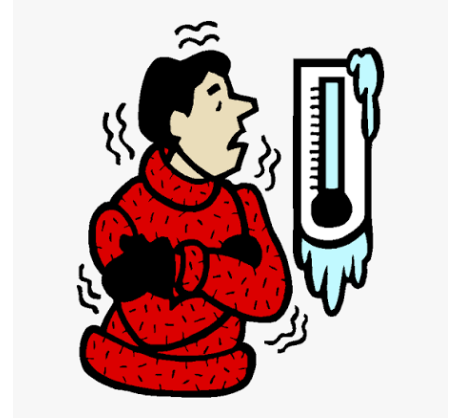
Paint



Paintbrush



Canvas



I'm cold



Pencil



Water cup



What?



I'm done!

CLOTHING

Coat



Hat

Skirt



Dress



Sweater



Shirt



Shorts



Glasses



Sunglasses



Jeans



Shoes



Sandals



Heels

Socks



I AM FEELING...

sad



happy



angry



tired



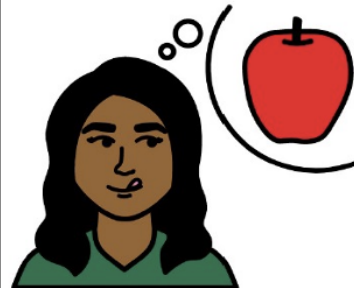
frustrated



anxious



hungry



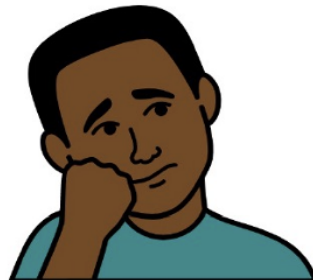
sick



relaxed



bored



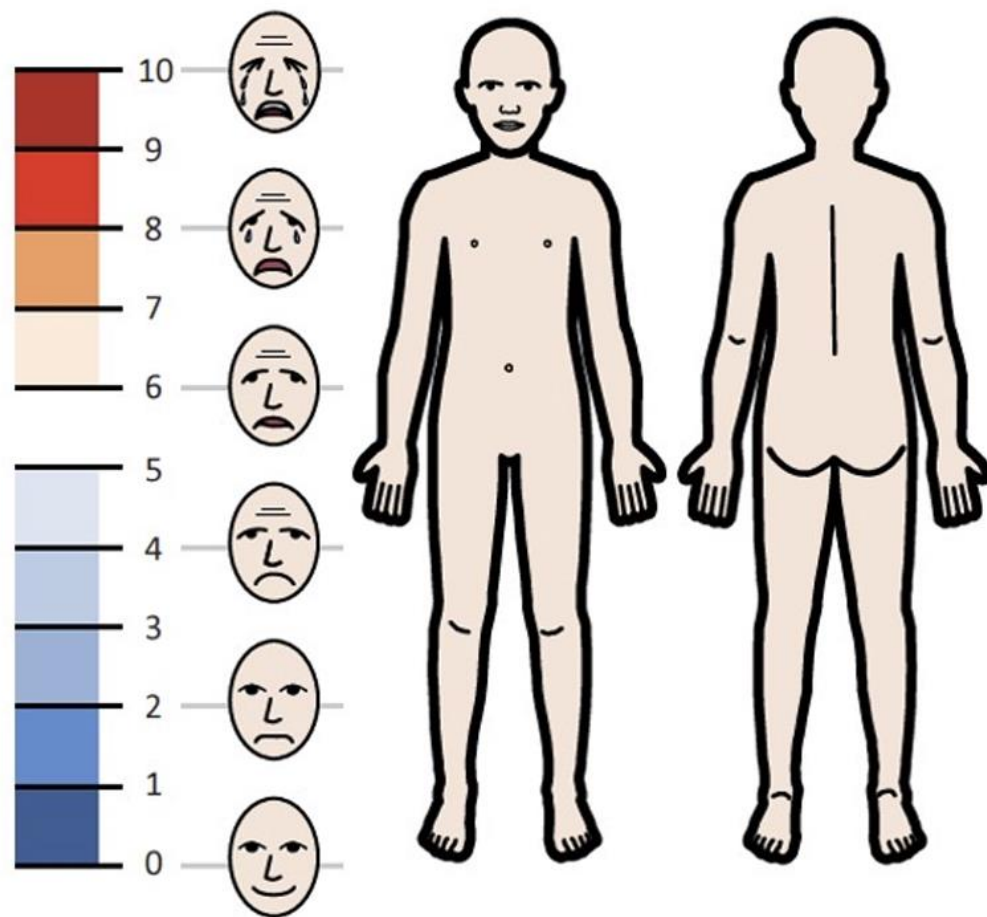
excited



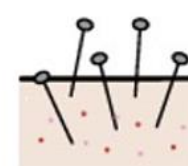
pain



PAIN LEVEL



What type of pain?



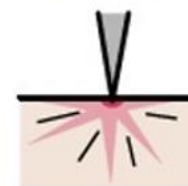
pins and
needles



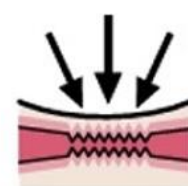
numb



dull / throb



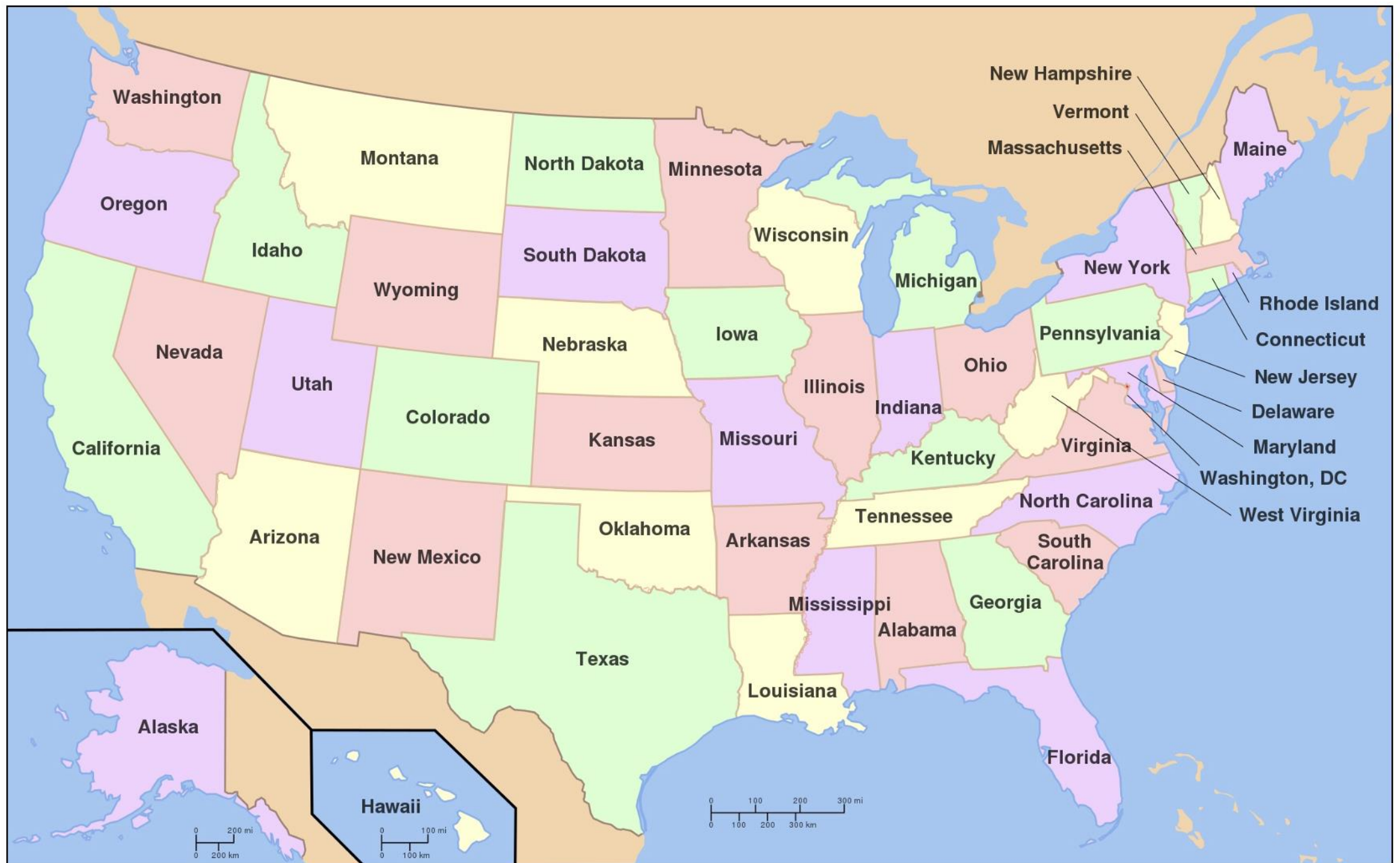
sharp

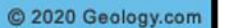


crushing



heavy





Months

January
1 2 3 4 5 6 7 8 9 10 11 12

February
1 2 3 4 5 6 7 8 9 10 11 12

March
1 2 3 4 5 6 7 8 9 10 11 12

April
1 2 3 4 5 6 7 8 9 10 11 12

May
1 2 3 4 5 6 7 8 9 10 11 12

June
1 2 3 4 5 6 7 8 9 10 11 12

July
1 2 3 4 5 6 7 8 9 10 11 12

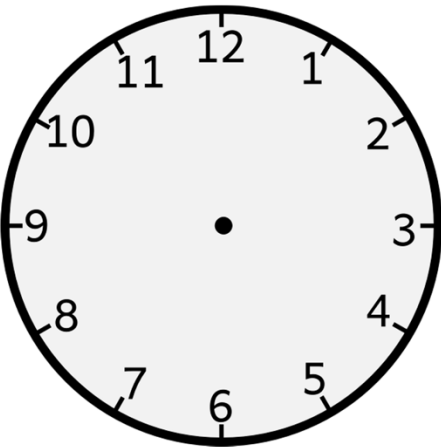
August
1 2 3 4 5 6 7 8 9 10 11 12

September
1 2 3 4 5 6 7 8 9 10 11 12

October
1 2 3 4 5 6 7 8 9 10 11 12

November
1 2 3 4 5 6 7 8 9 10 11 12

December
1 2 3 4 5 6 7 8 9 10 11 12



:05

:10

:15

:20

:25

:30

:35

:40

:45

:50

:55

:00

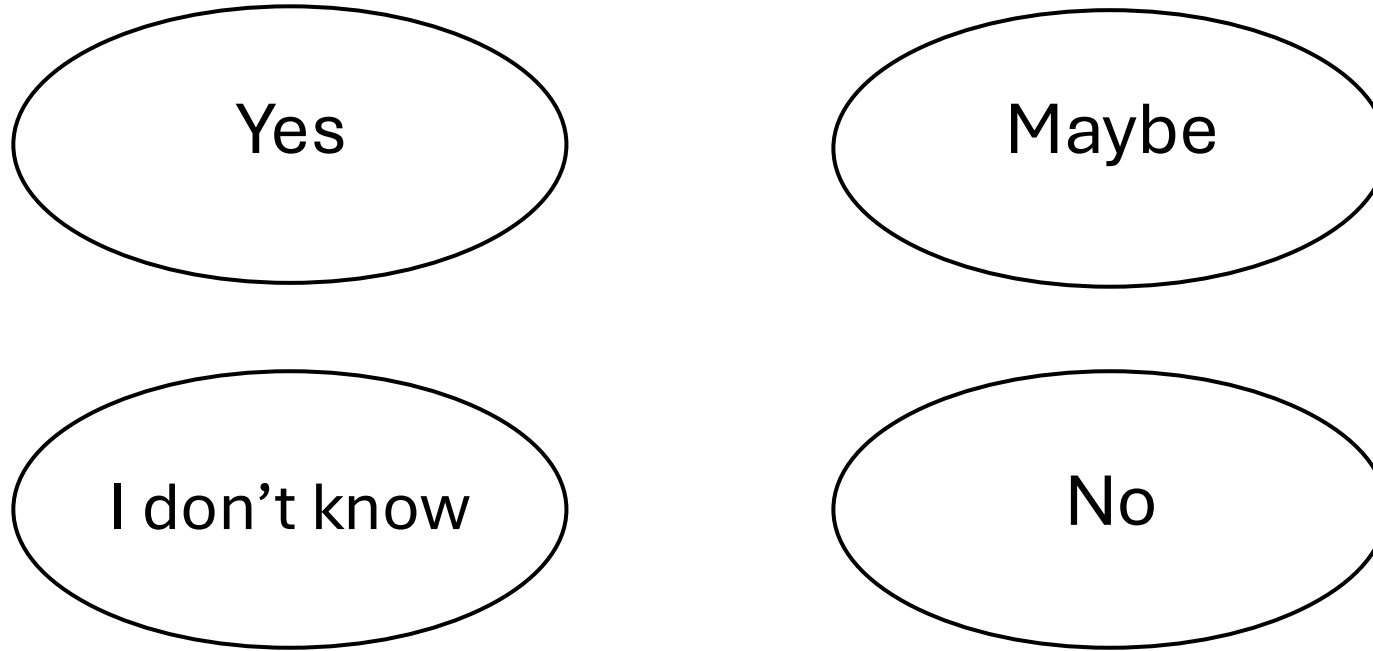
AM/PM

Days of the Week

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
1	2	3	4	5	6	7

Yes/No Visual Support

(adapted for yes/no confusion)



NOTE:* I have had some success with folks with yes/no confusion using this type of visual (AKA, when there is enough physical space between “yes” and “no” and when there are multiple other options present). For folks who benefited from this type of visual, it did not always produce 100% accuracy, but accuracy did increase substantially. If you want to test this at home, **ask yes/no questions you already know the answers to, and see how they do. If still unsuccessful, make sure to ask questions with options instead of yes/no.

Tell me about it



- What **type** of thing is this?
- What do you **do** with this?
- What does this **look like**?
- What are your **memories** of this?

What is the **first letter or sound**?

Gesture it



Look it up



REPAIRING CONVERSATION

I am talking about a...

New Topic

Same Topic

What happened?



I can't think of
the word



The wrong
word came out



I lost my train
of thought

REPAIRING CONVERSATION

I am...

changing the
subject



talking about
my emotions



explaining what
happened



telling you
a problem



asking a
question



asking for
something



ASKING QUESTIONS

WHAT?

clarify or label



WHERE?

place



WHEN?

day or time



WHO?

person or people



WHY?

reason



HOW?

tools or steps



Thank you!

Special thanks to Dr. Gary Robinaugh, Dr. Maya Henry, UT Austin's ARTLab, UCSF's Memory and Aging Center

Questions?



Personal website (with resources): www.zezzes.com