# Communication supports for People with Primary Progressive Aphasia

WHY use visual communication supports?

People with Primary Progressive Aphasia (PPA) benefit from visual support systems in order to help them understand language, events around them and express themselves. Visual supports are evidence based and there is research behind them. PPA is different from dementia or aphasia resulting from a stroke or other brain injury. With Alzheimer's dementia, memory loss is one of the first signs. With PPA, difficulty with language is the first sign, while memory and reasoning are usually not affected in the early stages. When helping clients with aphasia after a stroke, you expect to see improvements as they recover, however people with PPA have a degenerative disease that gets worse as time goes on. Nonetheless, there are many strategies and resources which can be used to support communication.

Communication books

Visual communication supports like communication books can be useful because using photos or pictures combined with the written word can support memory and help with word finding issues. There are many different types of communication books (e.g. size A4 or A5, number of phrases on the page, photos or symbols, etc), so it is important to get your speech-language therapist to help you find one that works for you. TalkLink have many templates, which you can customise to make it meaningful and functional for the person with PPA.
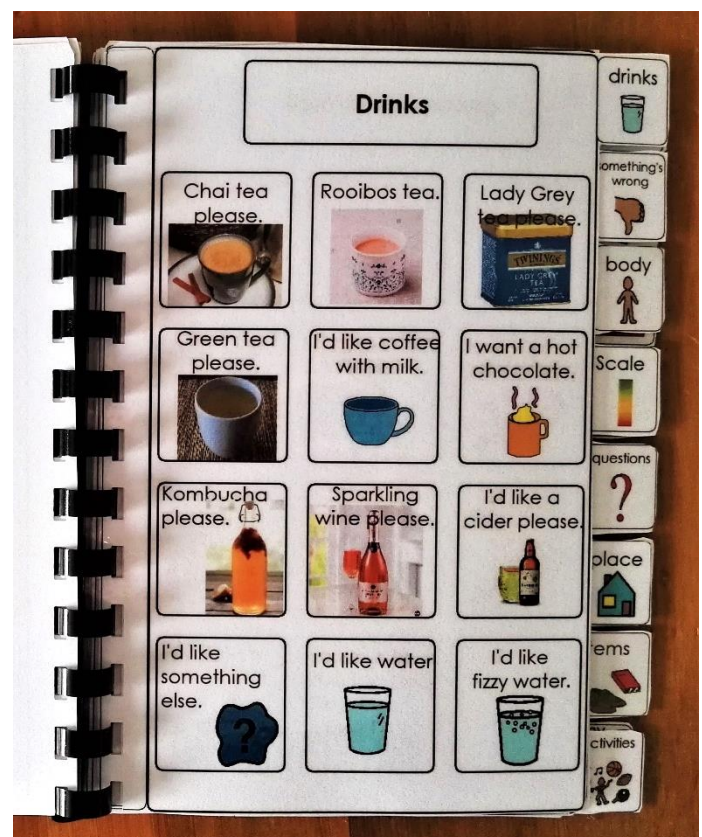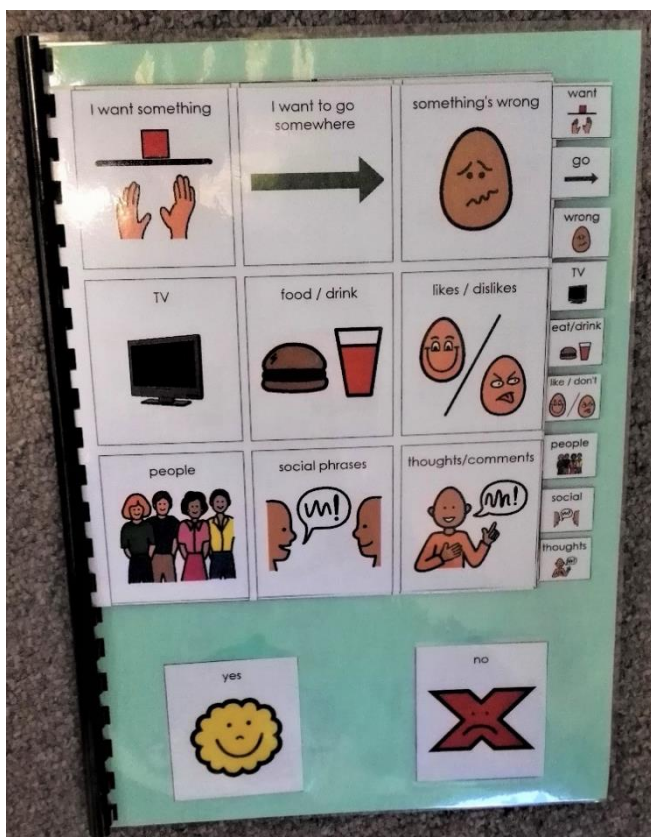
WHAT are visual communication supports?

There are many different types of visual systems which may help – ideas are listed below. It is important to remember that learning a new way of communicating can be difficult for a person with PPA, so any visual system must be functional, useful and must be used every day. Visuals displayed in this document can be found on the TalkLink website or by emailing your local TalkLink office with a request for a certain communication support.

Shopping lists – could be hand written or printed pictures. You could laminate the visual shopping list and circle (with a white board marker) the items you need to get from the supermarket and then wipe the circle off when you place each item in the trolley to visually show that you have got that item.

Menu boards – you could use Velcro or BlueTack to change the date and food options each day. The menu could also be written on a white board with the page number for a recipe book as a reminder of how to cook that meal.
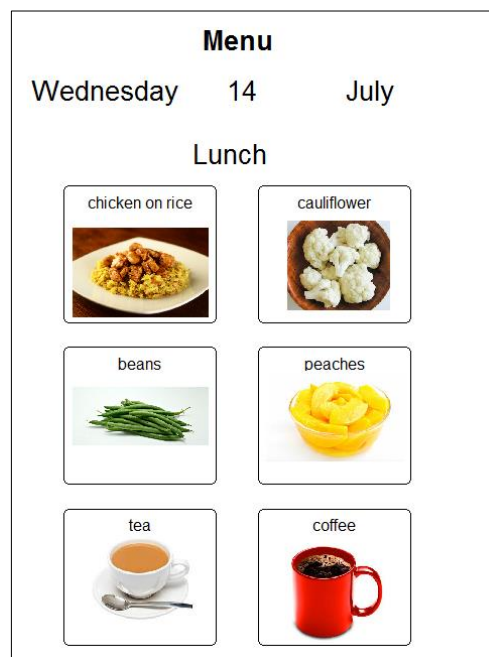
Yes/No visuals – sometimes people may say "yes" when they mean "no". Using a visual where a person can point to the visual of yes or no can reduce inaccuracy – these can be printed with pictures or handwritten on a piece of paper or white board.
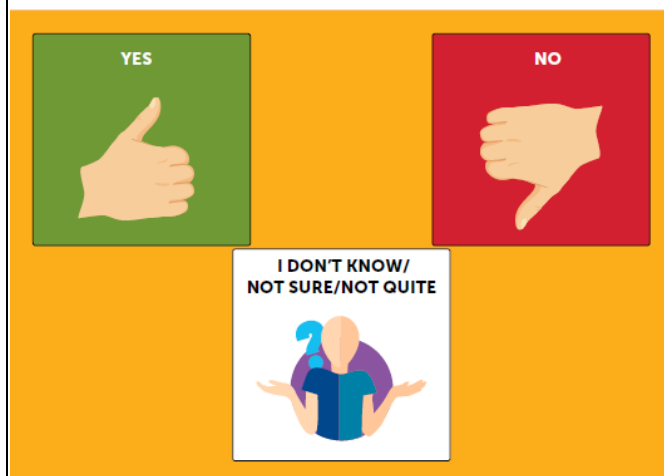
Phone lists - laminate a list with photos and name of important people and their phone number in large font right next to the phone – family members, medical professionals, friends, caregivers.

Identification card – Print a few of these and store them in a pocket, wallet, tied to walker or walking stick or attached to lanyard. The card can be shown to explain which communication strategies can help, how to contact in an emergency and a bit of information about PPA.

Name:
Address:
Phone number:
Emergency contact:

I have a communication disorder called primary progressive aphasia. It affects my ability to speak, read and write. Sometimes I get confused, you can help me by:
- Give me extra time to communicate and understand
- Speak slowly, use simple sentences
- Ask me to show you with a gesture, pointing or drawing
- Write down the main words for me
- Ask me simple yes/no questions
- Please do not shout

Daily Planner – it can be confusing remembering what day it is and what is happening that week. This can help to reduce anxiety about what is happening next or around forgetting important activities/ appointments. see Tip of the Month on Visual Timetables for more info

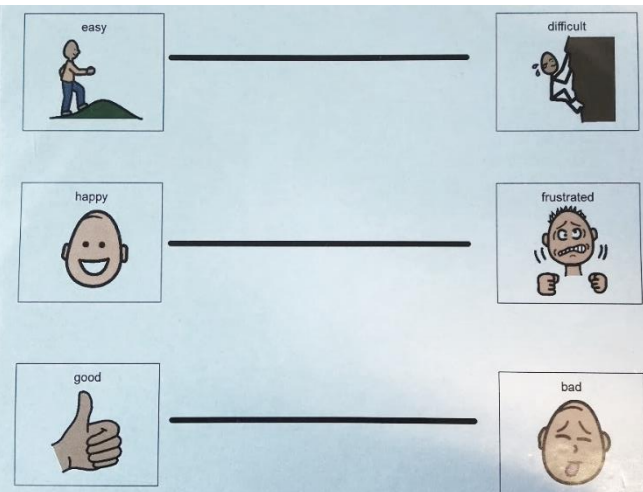**Cueing boards** – you could ask the person "what topic are you talking about?" and then "when did it happen" and then "could you tell me what letter the word starts with?"

Continuum lines – a scale to indicate how someone is feeling or the complexity of a task. You ask them a question and then they can point to a place on the line to show how they feel about that question.

Topic cuing boards – when the person with PPA is struggling to express themselves, ask them to cue you into what topic they are talking about before you start guessing. For example, if the person indicated they were talking about family, the conversation partner could then ask yes/no questions relating to family members to find out the intended message.

Communication boards – if the person is not keen to use a communication book, activity-specific communication boards can be used for a range of activities where remembering and naming specific items may be challenging such as gardening group (names of seeds, gardening tools, seasons, etc), book club, cooking, watching TV, ordering at a café, etc.

Person	Place	Thing	Something Else
• Family	• Home	• Looks like	• Important
• Friend	• School	• Used for	• Not Important
• Someone else	• Somewhere else	• Something else	• I don't know.

Feeling	Time	Medical	Problem
• Good	• Now	• Pain	• Health
• Bad	• Later	• Medicine	• Appointment
• Something else	• Past	• Something else	• Something else

Food Choices — Morning tea: fruit, nuts & raisins, crackers. Lunch time: sandwich. Drink: tea, coffee, water.
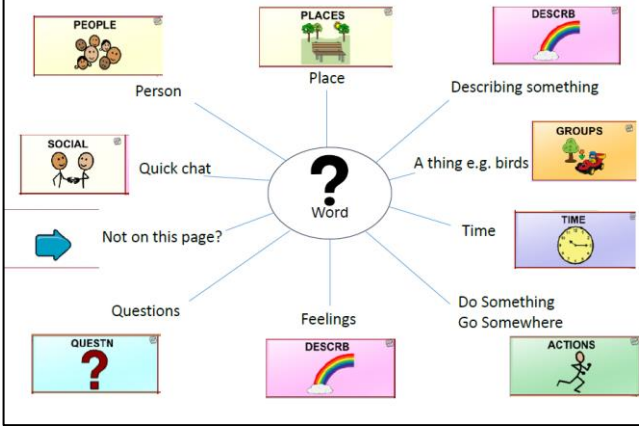
Cafe — I want, tea, flat white, hot chocolate, yum!; milk, sugar, sweetner, marshmallows, yuck!; sandwich, cake, muffin, please, good; bad.

Talking Mats – This is a commercially available resource that is a visual aid for supported decision-making and sharing opinions during conversations. It is interactive and uses three sets of picture communication supports - 1) a topic (meal times, activities that are important to you, etc), 2) visual options (pictures or photos or hand drawn images of each of the options) and 3) a visual scale (yes, no, maybe/don't know) – and a space on which to display them – this could be a white board or a carpet square or large piece of paper. After you have finished talking about that topic you can take a photo of the board as a record of the conversation. The individual with PPA is shown each topic one by one and asked whether they 'like' that activity or whether they are 'managing' to do that activity, for example. They place the visual under like', don't like' or 'maybe/not sure', etc. The visual presentation of Talking Mats helps comprehension as well as providing an effective way for people to express their views.
https://talklink.org.nz/talking-mats-courses
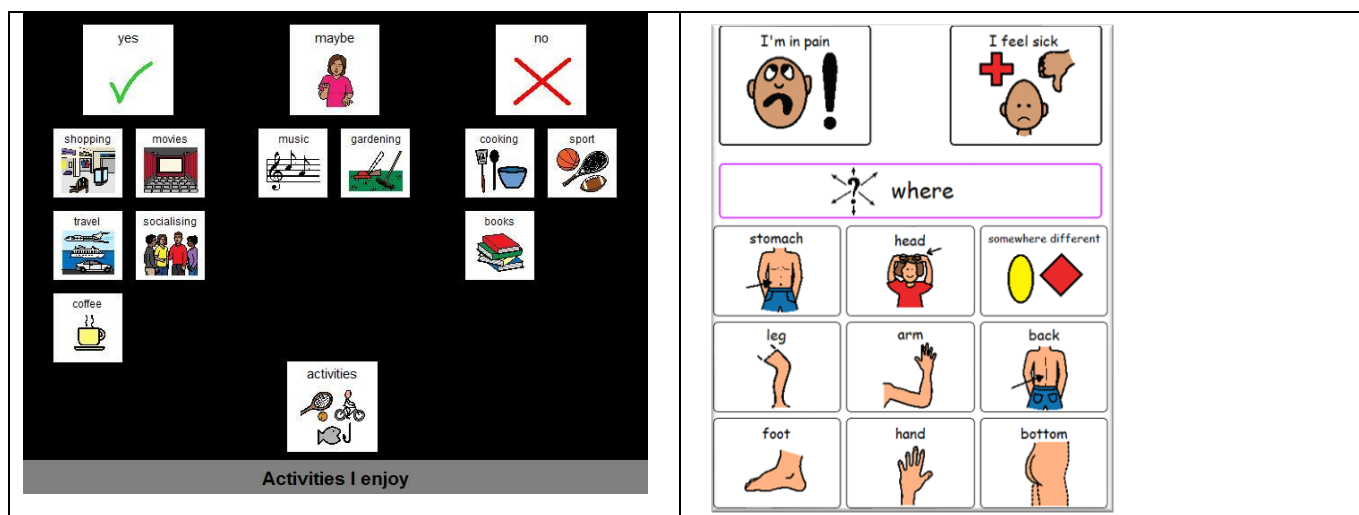
Pain board / something's wrong board – pain and illness can be difficult to identify and discuss verbally, so having a board with the most common issues, a rating scale to indicate how bad the pain is and some options for what to do about the pain can be helpful.

how much pain — ots of pain / no pain

what — go to bed, stretch, something different, massage, medicine

Other ideas:

- Large print **calendar** or **diary** to keep track of the day, as well as appointments and events – keep this in a very visible place like the front of the fridge
- **Labels** and **signs** - on doors or objects, e.g. place a label and photo on each door in a retirement village so that you know who lives where, or labels on the linen cupboard shelves to sort towels, sheets, etc
- **White board** or **paper & pen** - to write lists or write down instructions so that the person can refer back to them if they forget what they are doing half way through an activity
- **Memory book** – sometimes called "This is your life book" or "All about me book". See below section.
- **Memory wallet** – like a memory book but a smaller version
- **Photo albums** and reminiscence (generic) photos
- **Communication passport** – https://talklink.org.nz/resources/tip-of-the-month---april-2020---communication-passports on how to create a communication passport and a template you could fill in.

Free or cheap apps to support communication

- **Google Maps** or **Apple Maps** for showing places - sometimes visually showing a person the place you are talking about is easier than trying to name the place or describe it
- **Google Calendar** or **Apple Calendar** for reminders of appoints and reoccurring events, e.g. "caregiver coming in 15 minutes", "do your Multimodal Communication Therapy practice now", "take your blood pressure medication (blue bottle) now – 1 pill", "start getting ready to go out to your hair appointment – Driving Miss Daisy will be here in 30 minutes".
- Built in **Photo Gallery** app - have different folders within the app with picture to support communication, e.g. folder of photos of family members, folder of caregiver pictures, photos of most recent trip, photos of medical professionals. Most built in Photo apps allow you to click on the photo and then click "edit" and write the name of the person directly onto the photo, or the name of the place, etc.
- **Talking photo apps** – allow you to share memories. They allow you to record a sentence on each page of the story and add a photo. Then the person can look though them and remember special events and memories in their life. e.g. Little Story Creator, Pictello, Book Creator, All About Me Storybook, Talk'n Photos, Click n Talk
- Built in **Timer** app - set alarms throughout the day for reminders, e.g. 8am everyday "take medication", 9pm everyday "have a shower and get ready for bed", 6pm on Tuesdays "put the rubbish out on the road for collection" etc.
- A simple **white board/drawing app** can be used to draw pictures to support communication, e.g. Simple Draw on Android or built in Notes app on Apple
- **Visual time table app** – if a text based reminder on the Timer or standard calendar app is confusing, then adding a picture can help. e.g. Visual Schedule Planner, PictureRoutines, Symbol Calendar AAC Pro, What's Next (Visual Prompts)
- Built in **text to speech** on a mobile phone – This setting allows the person to press and hold text on the screen and then it will read the text out to them so they only have to listen rather than read it. Check the TalkLink website for a Tip of the Month on how to do this on Apple and Android phones – or call your local office.

- **SpeakText Free** is an [app](#) that will read any text or webpage if you are having difficulty with reading
- Built in **Notes** app - use the whiteboard feature to handwriting or draw something and then you can save the image into your gallery to view later or send in an email, Facebook/Whatsapp message or post it on Facebook.
- Simple **recipe app or blog** - Having pictures or a short video to accompany each step of a recipe can be helpful for maintaining independence during cooking. These apps/websites includes simple recipes and have sequenced visual supports you can print and laminate to go with each instruction. [Accessiblechef](#), [Tasty app](#) or [SideChef](#)
- Use **video calling** through Facetime, Skype, Facebook messenger, Whatsapp, etc, to connect face-to-face with video allows for use of facial expressions, gestures and visual supports, such as holding up your communication book to the camera to show the other person what you are talking about.
- Use **Pinterest** to create communication boards by visually bookmarking favourite movies, travel destinations, recipes, or unique interests. These can be used as topic prompts during conversations.
- Listen to **audio books** or **podcasts** rather than try to read them, by using [Audible](#) (paid), your local library audio book app, Apple Podcast app, etc
- **Meditation** has [been show to potentially](#) increase language recovery, decrease anxiety/stress/depression associated with having a language disorder, try [HeadSpace](#) (free with in app purchases) or free meditations on YouTube
- **TalkPath News** (free news source that reads the daily news to adults with aphasia/and language loss): [TalkPath News](#) for Apple, [TalkPath News](#) for Android devices
- **Big Launcher** (for [Android phones](#)) - replaces the home screen with this app and increases the size of the buttons and text and reduces the amount of navigation/remembering where apps are on the phone.

Multimodal communication

There are lots of different ways of communicating, such as speaking, writing, drawing or using a communication system. People with PPA often get stuck on saying a word and forget that there are other ways of expressing themselves. Sometimes having a visual like this and reminding the person "I can see you are stuck on that word, is there a different way you could tell me?" and then refer them to the visual to see if they can find the word in their communication book, draw it or write the first letter that the word starts with. Multimodal communication therapy has also shown some promising results in maintaining communication abilities. For more info see this [Tip of the Month](#).
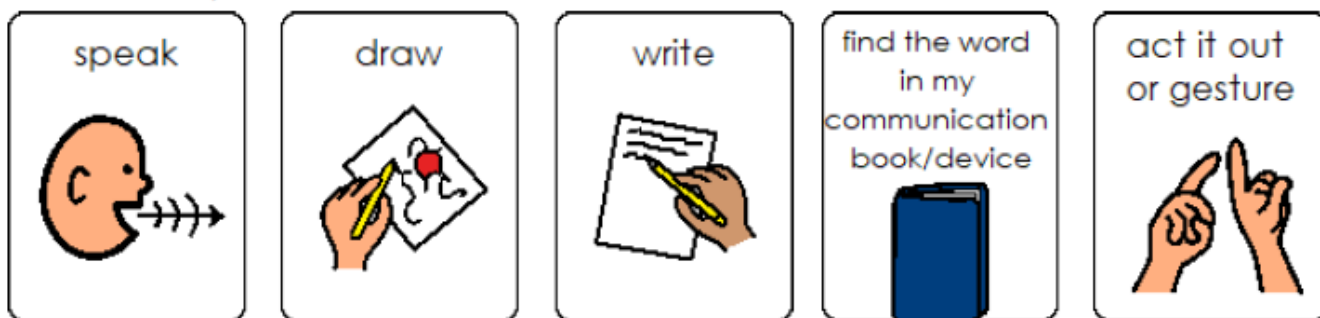

Scripting therapy

A script is a predictable sequence of sentences. A script can be a story that the person with aphasia tells, also known as a monologue. A script can also be between two people, such as ordering food in a restaurant. In either of those cases, the words the person with aphasia will use are easy to predict. Teaching scripts can improve topic content, speaking rate and can increase communication across a variety of situations and listeners. It can also increase confidence and maintain independence. Scripts can be taught verbally or using a communication book.
- Early in the progression of PPA, have the family and the person with PPA pay attention to routines and phrases used in everyday life. Ask a family member to write them down.
- Now you will have a list of what is important to the person's everyday life, and these phrases can be used as scripts to practice as PPA progresses.

- Scripts and Multimodal Communication Therapy can be used together, to practice as many different methods of communication as possible and introduce a communication book as early as possible so the person and their communication partners can familiarize themselves as much as possible.
- Vary the number and complexity of the scripts based on the stage of PPA – the more severe the PPA, the fewer and simpler the scripts.
- Focus on clarity and minimizing frustration – you aren't trying to teach something new, you are maintaining as much communication independence as possible.
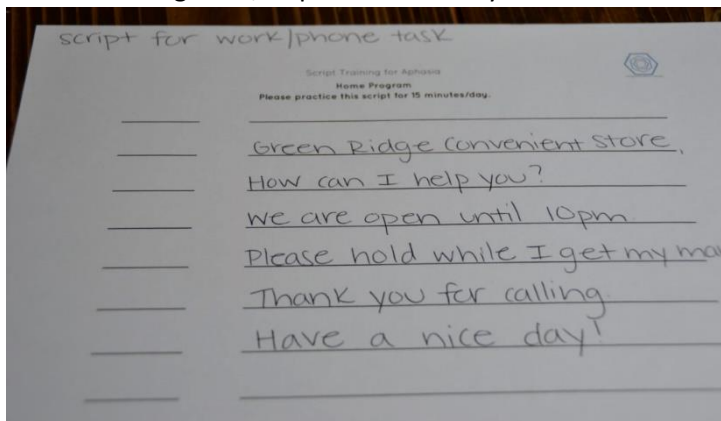
Memory book

A memory book is an external cognitive aid meant to assist with cognitive deficits, specifically memory and perhaps executive function. Most of the time it is used by an individual with memory loss alone and is not accessed by other people. Memory books differ from communication books because a communication book is an external communication aid, which is used between two people for the purpose of sharing a message. Pictures or written text in the communication book are a reference point between the individual with PPA and his/her communication partner. A memory book is a SELF-reference tool to orient an individual to what they have done in the past (e.g., retrospective memories) or things they need to do in the future (e.g., prospective memory). A communication book is "community" reference that aides communication.

- A memory book is one of the most important visual communication supports to create. It is a connection to the present and a bridge to the past. This contains information about the individual's life, history, hobbies, family, friends, holidays, etc.
- It can be used to 1) refocus the individual during word finding difficulties or times of frustration, 2) to initiate conversations about their life and interests, 3) to enhance self-esteem, 4) as a security tool when they are in an unfamiliar place (such as the hospital).
- Communication partners could ask the individual about 1) things they feel proud of in their life, 2) people who are important to them, 3) favourite memories, 4) hobbies, 5) places they have travelled, etc. If the individual does not respond to these

questions, flip through the book and read the annotations and comment on items included in the book to initiate conversation.
- A memory book can be created on paper using Microsoft Word or by handwriting next to photos in a scrapbook. It is best to keep the pages simple and uncluttered by having only the photos and some short and simple statements on each page. Memory books could also include remnant such as papers, or materials that remind someone of an event or experience. Ticket stubs, maps, seeds, dried flowers, etc can all serve as memories of special events. These items provide a visual and tactile way of sharing information and connecting with others.
- Here are some templates – Personal Life History, Life Story Book and All About Me Book.
- It could be created on the computer or an app. Book Creator and Pictello or All About Me are useful apps for creating memory books, electronic 'talking' photo albums and for sharing personal information/stories/memories with others.

WHEN should I use visual communication supports?

It is important to use them throughout the day. You may use a range of different supports (from the above list) during different times of the day. Use them to 1) warn the individual of what is going to happen (visual time table or calendar or diary), 2) to reduce anxiety about what is going to happen (visual time table or calendar or diary), 3) to reduce anxiety about word finding difficulties (memory book, communication passport, visual scenes, photo albums) and 4) to enjoy conversation (memory book, visual scenes, calendar, talking photo books).

WHERE should I keep the visual communication supports?

All of the visuals can be used at home, in residential care, at the shops and in other community locations. It is useful to stick the visual up where you would most commonly talk about that person/event/activity, e.g. have a visual timetable on the fridge (pictured beside), a shopping list on the pantry door, memory book and photo album on the coffee table or bedside table, identification card in their wallet or placed in their pocket each morning, pain board beside the bed or in the bathroom, photos of people by the telephone, etc. If it is available it will get used whereas if you have to walk to a different room to find the communication support, you probably won't use it.

HOW should I use visual communication supports?

- Use them in natural everyday conversations to add to your verbal communication. You don't stop talking when you use a visual communication support. The visual, added to your verbal communication, can increase the individuals understanding and memory recall.
- Be consistent in using the communication supports each and every day.
- Ensure that everyone communicating with the individual with PPA knows how to use the communication supports so that there is consistency. The focus is on maintaining communication as much as possible and compensating for any weakness, so use the person's personal priorities when setting goals, deciding what visual or therapy programmes to use and making plans for the future. Here is a list of 100 examples of really functional long term goals.

Tips for creating visuals for someone with PPA

Make sure that you:
- Have lots of white space around words and pictures
- Use less visually complex symbols or photos, i.e. make sure that people stand in front of a plain white background when you are taking photos to add to their communication book
- Use large standard fonts

Arial size 14/16 or above is good

These are recommended even when people don't have a visual impairment.
- Use simplified syntax and vocabulary, i.e. don't use multisyllabic long words
- Add visuals/pictures/photos to all text – the person might not need it right now but it is good to get used to the pictures and location of words for later as PPA progresses

Tips for communicating with a person with PPA

How you talk to a person with PPA is just as important as the visual cues you use. Tips for caregivers and communication partners:

- Ask simple questions – and only ask one question at a time and then wait for an answer before asking another question
- Give the person extra time to respond – count to 10 after you ask a question or make a comment before saying anything more
- Speak in short, concrete sentences, i.e. don't use metaphors
- Respond immediately to communication attempts
- Maintain eye contact and try to sit or stand at the person's eye level rather than hovering above them
- Redirect the person from frustrating problems to things such as photo albums, memory books or other activities
- Rephrase the conversation so far, to keep a topic focused when a person is confused
- Try to have a shared visual referent to look at together
- Avoid quizzing for the 'right answer'
- Encourage and validate the use of any communication techniques, even if they weren't used quite the way you were expecting

Progression of PPA and using visuals for communication

PPA is a progressive disease, meaning that communication and memory skill will deteriorate over time. Therefore, communication tools used in the initial stages may need to be adapted or simplified as PPA progresses. With PPA, don't expect the person to be able to generalise the skills to other activities or visual supports. This is why it is important to work on only things that are really important and practical for the person with PPA, e.g. if a person never orders coffees at a café, don't bother practicing scripts for ordering drinks. You might start out using a communication book with 12 phrases on each page but as PPA progresses, you might have to change to a communication book with only 6 or 4 phrases per page if they start to get overwhelmed with more visuals.

References:
https://rerc-aac.psu.edu/aac-for-persons-with-primary-progressive-aphasia-webcast/
https://tactustherapy.com/ppa-treatment-slp-primary-progressive-aphasia/
Research by Sarah Wallace https://www.duq.edu/academics/faculty/sarah-wallace
https://honeycombspeechtherapy.com/script-training/

Created by Jessamy Bell (TalkLink Speech Language Therapist) on April 2020