



Communication & Swallowing in PSP & CBD: A Speech & Language Therapist's Perspective

Gillian McKinley
Speech and Language Therapist

7th October 2026

Objectives

1. Recognise the impact of PSP and CBS on swallowing and communication.
2. Understand effective communication intervention approaches to enhance participation and connection.
3. Practical strategies to support safe swallowing and nutrition.
4. Understand alternative feeding options vs eating and drinking with acknowledged risk.

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Key characteristics of PSP

Different phenotypes, but they tend to converge in the more advanced stages.

Symptoms:

- Difficulties with eyesight / eye movement
 - Up and down more difficult
 - Sideways
 - Double vision
- Impulsivity - implications for eating and drinking
- Mobility / instability
- Executive dysfunction / cognitive changes / bradyphenia – more likely in PSP vs CBS
- Bulbar changes: speech and swallow changes

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Key characteristics of CBD / CBS

Cortico-basal Syndrome / Degeneration

May have different signs and symptoms from PSP. Many of the treatments for PSP are also helpful in CBS.

- Tends to be asymmetrical whereas PSP tends to be symmetrical.
- Cognition changes less likely in CBS than PSP.
- Speech / swallow changes may have a later median onset than in PSP.
- Apraxia
- Cortical sensory deficit
- Alien limb

In clinic – look at the outward presentation.

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Communication – what might we see?

Speech

- Mixed / hypokinetic / spastic dysarthria
- Apraxia
- Slow speech with pauses, or festinating / fast pace
- Voice changes
- Prosodic changes e.g. monopitch / monoloudness or bursts / difficulty controlling pitch and volume
- Dysfluency
- Palilalia or echolalia

Communication – what might we see?

Language

Limited research but cognitive or language changes might be an early symptoms for some people.

- **Comprehension:**
 - *Spoken word:* Limited evidence but we can see changes in comprehension at sentence level.
 - *Reading:* Impact on reading comprehension is unclear but visual difficulties within PSP also have a significant impact.
- **Expression:**
 - *Naming tasks:*
 - reasonably preserved in PSP.
 - Mild impairment in CBS - possibly related to retrieval issues as phonemic cues can help.
 - Verbs may be more difficult.
 - *Fluency tasks* – more difficult in PSP
 - Category fluency moderate impairment
 - Letter fluency severe impairment
 - Non-fluent/agrammatism and apraxia.
 - *Binary reversals:* significant feature of non-fluent PPA present in PSP and CBS e.g. yes / no responses. Important to check yes / no response is accurate.
 - *Writing:* Dysgraphia and micrographia.

Communication

CBS appears to be more language impairment based, whereas PSP may be more likely to be impacted by cognitive changes / executive dysfunction:

- Increased processing time or time to respond / bradyphenia
- Impaired initiation
- Difficulty with abstract thought
- Impact on verbal fluency
- Adynamic aphasia: sparse / reduced spontaneous speech and initiation, though word repetition, comprehension and naming may remain relatively intact.

The impact of communication difficulties



Difficulty communicating needs and wants and also initiating this.



Impact on social communication and increased responsibility on conversation partners: potential change in relationship roles.



Cognitive or language changes might be an early symptom for some people.



Impact on identity

Communication – what might we do?

Person centred and tailored approach - consider circumstances and impact of other symptoms e.g., visual and/or physical needs, cognitive changes.

Exercises:

- Can often be a hope for people but the impact of communication difficulties can be wider.
 - Direct therapy? Beneficial approaches in PD: EMST? LSVT? Little impact of low intensity 'LOUD' therapy.
 - Script training / non-fluent PPA approaches.

Strategies / Education

- **SLOP: Slow, Loud, Over-articulate, Pause**
- Pacing / pacing boards
- Conversation partner training / Better Conversations / total communication approaches
- Communication guidelines / passports
- Face to face conversation; reducing distractions; indicating topic / topic switching; allowing adequate time to respond; clarifying understanding.

AAC

- Low tech
- High tech
- Voice banking, message banking, voice cloning e.g. Speak Unique.

AAC – Points to consider

Familiarity with
technology

Cognition

Literacy

Physical needs –
access? Auditory
scanning?

Visuospatial
awareness

Echolalia, how do
they indicate yes
no.

Fatigue

Support needed

Visual difficulties

Vertical vs horizontal
High contrast
Font size / bold
Pictures / symbols / photos
Blepharospasm
Ophthalmology

Low Tech AAC

Alphabet charts

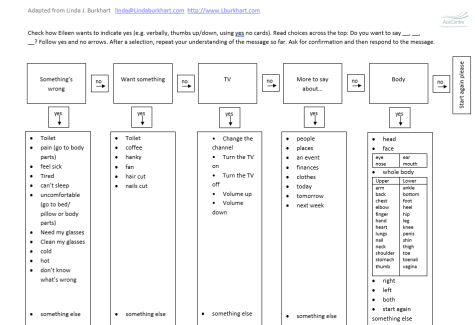
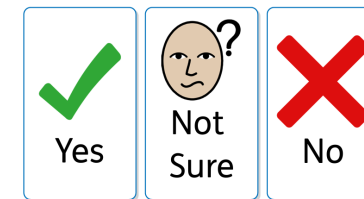
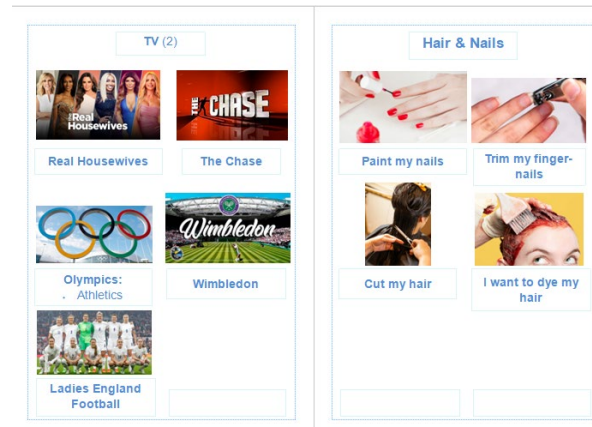
- QWERTY vs ABC
- High contrast

a	b	c	d	mistake	
e	f	g	h	SPACE	
i	j	k	l	m	n
o	p	q	r	s	t
u	v	w	x	y	z

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	.	?
YES	SPACE	NO	
stop	wrong	start again	don't know

A	B	C	D	.	Mistake
E	F	G	H	New word	Start again
I	J	K	L	M	N
O	P	Qu	R	S	T
U	V	W	X	Y	Z

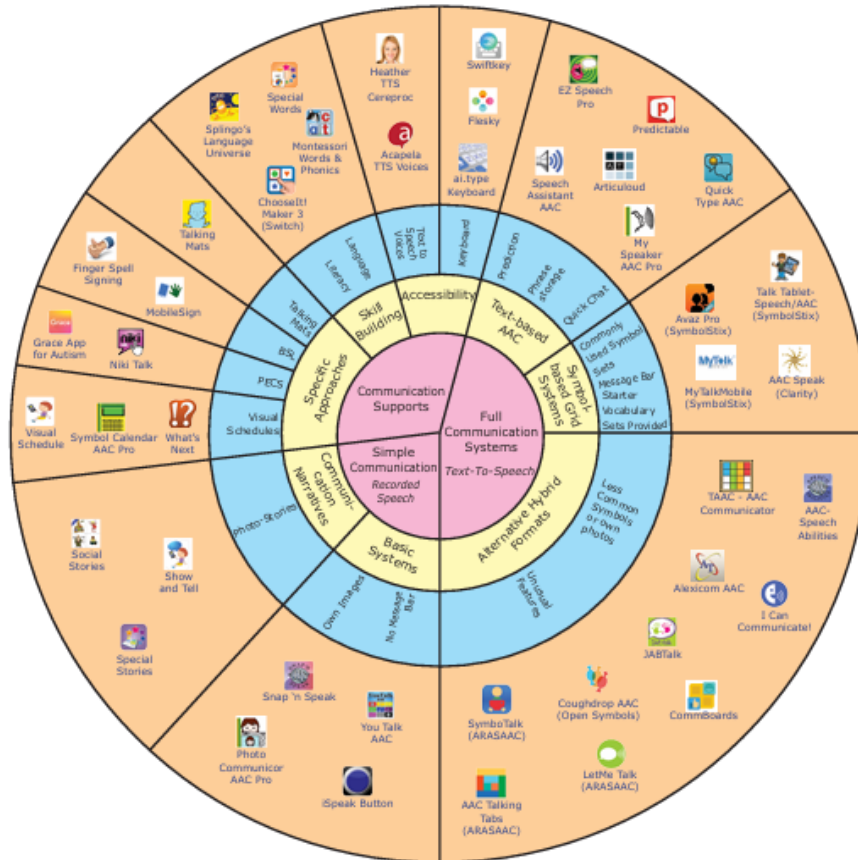
Communication charts / books



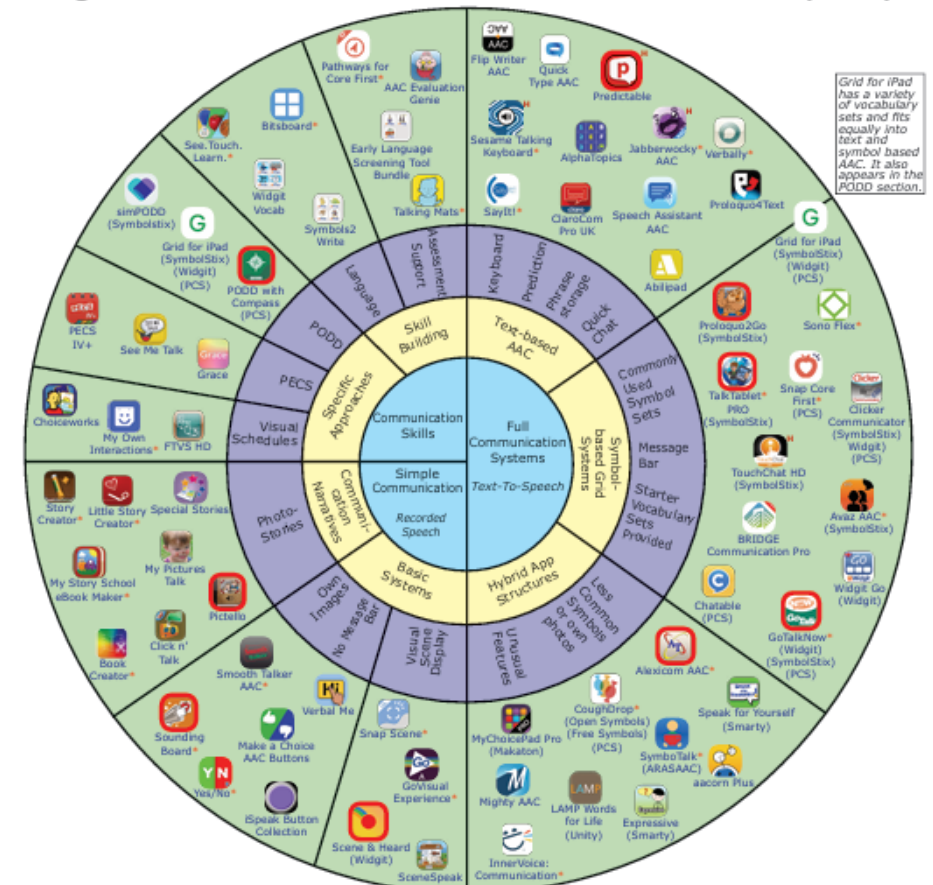
<https://acecentre.org.uk/resources>

High Tech AAC

Android Apps for Complex Communication Support Needs:
Augmentative and Alternative Communication (AAC)



iPad Apps for Complex Communication Support Needs:
Augmentative and Alternative Communication (AAC)



High Tech AAC

Apps, Amplifiers etc.



Access:

- Switch



- Stylus



- Eye gaze
(less common)



- Other e.g. head tracking, joystick

Note:

- Might want to think about both low-tech and high-tech options where applicable.
- Can tablet or iPad settings be adapted?
- Is an onward referral for regional high-tech support needed?
- Are there also environmental controls needs?

Voice banking and cloning

Recording voice to enable someone to create a personalised synthetic voice for use in high-tech AAC. This can support people retaining their identity and communicate using a voice that sounds like their own.

PSPA can fund one of three different SpeakUnique voice banking services for people living with a diagnosis of PSP or CBS depending on their speech needs.

<https://www.pspassociation.org.uk/information-and-support/pspa-voice-banking/>

Listen to me!



Voice banking and cloning

[About Us](#) ▾[Overview of Services](#) ▾[SpeakUnique for Clinicians](#)[Prices & Funding](#)[Using Your Voice](#) ▾[Resources & Support](#) ▾[Sign Up/Login](#)

Voice Build

With under 30 minutes of audio recordings, we can create a synthetic replica of your voice that sounds just like you.

[Learn More](#)[Get Started](#)

Voice Repair

A repaired synthetic voice, for people whose speech is impaired at the time of recording.

[Learn More](#)[Get Started](#)

Voice Design

Bespoke synthetic voices for people with no intelligible speech, or synthetic voices based on old recordings.

[Learn More](#)[Get Started](#)

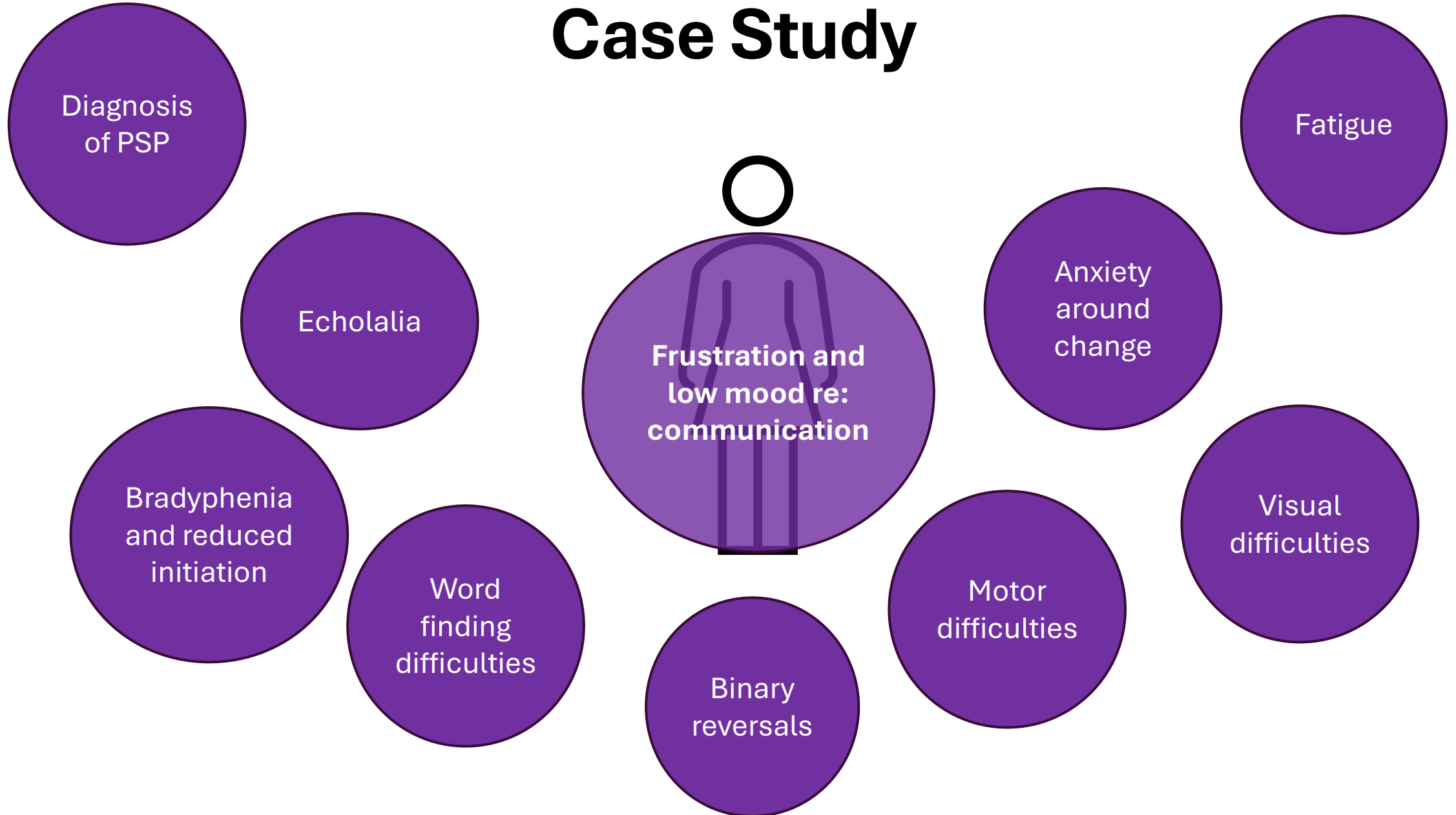
Prices & Funding

Learn about our prices and how our funding process works.

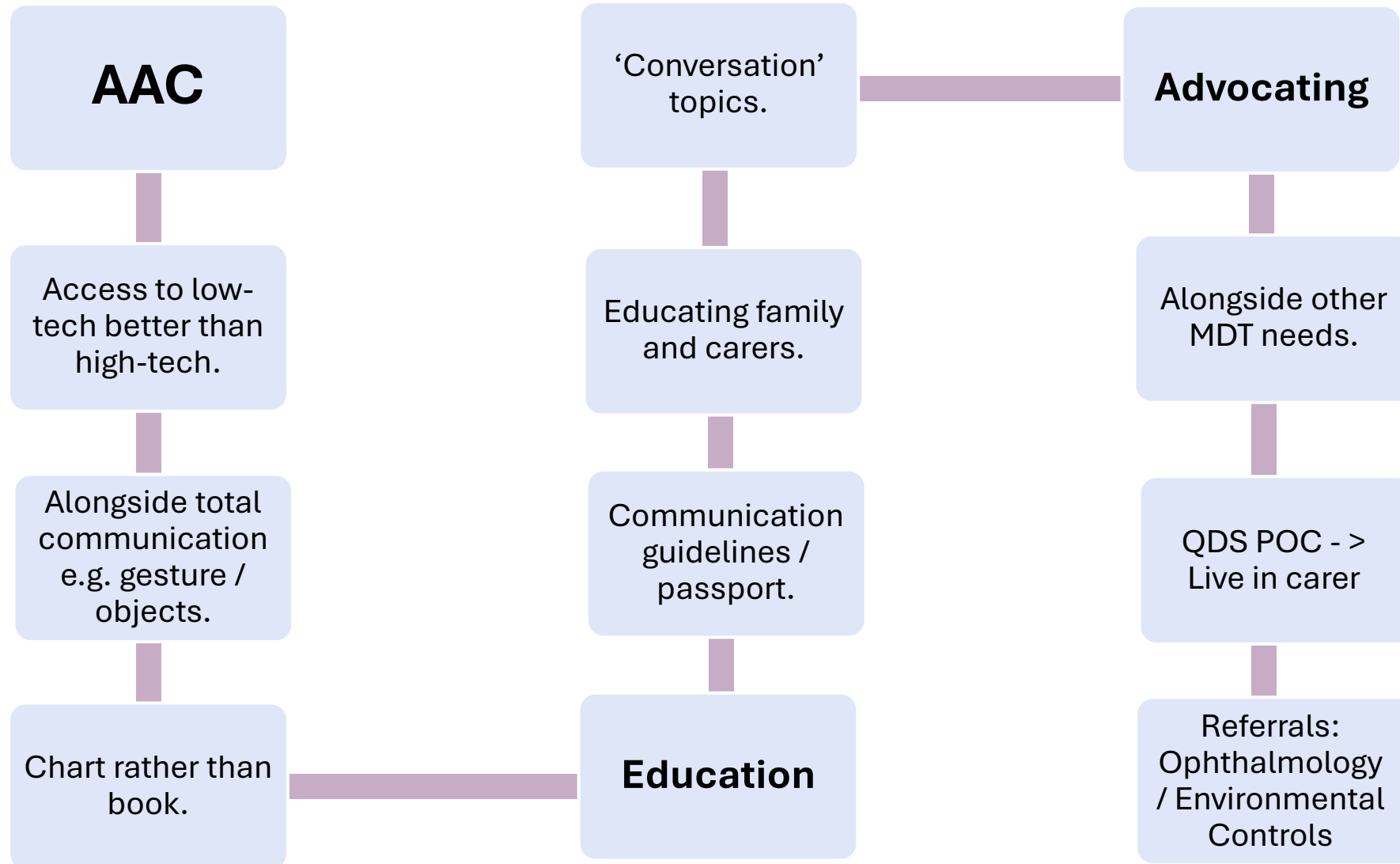
[Prices & Funding](#)

<https://www.speakunique.co.uk/>

Case Study



Case Study

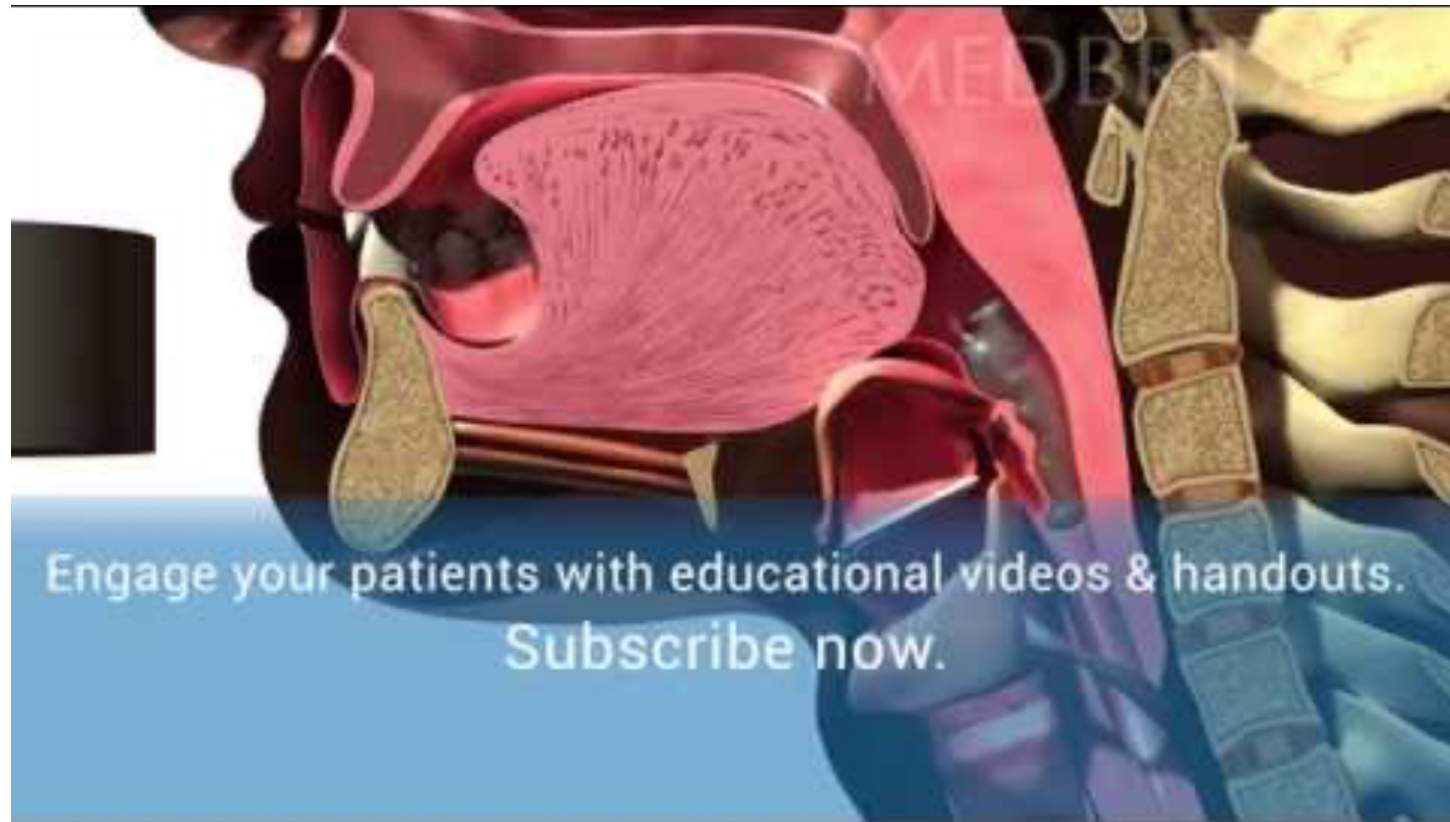


Eating, Drinking and Swallowing

**Signs and symptoms
might include:**

- Coughing
- Choking
- Problems chewing
- Delayed or effortful swallow
- Multiple swallows
- A 'gurgly' voice after swallowing
- Watery eyes, red face or trying to catch your breath when eating or drinking
- Taking a long time to eat
- Reduced food / fluid intake
- Difficulty with secretion management

What happens when we swallow?



PSP, CBD and Swallowing

More research for PSP than CBS. Swallowing difficulties are common and both are likely to develop impairment in both the oral and pharyngeal stages.

Oral phase: slower with prolonged chewing, disorganized / impaired tongue movements and poor transfer of bolus to the pharynx.

Pharyngeal phase: delayed swallow initiation, pooling, incomplete airway closure, reduced cough strength.

Issues with secretion management including sialorrhoea.

Piecemeal deglutition” (excessive lingual gestures causing multiple swallows required to clear a single bolus) is characteristic of CBS .

Dysphagia has a later median onset in CBS than PSP.

Risks and what can increase these?

Possible Risks:

- Choking
- Aspiration / silent aspiration
- Chest infections / pneumonia
- Dehydration
- Malnutrition
- Unintentional weight loss
- Constipation
- Difficulty swallowing medication
- Poor oral hygiene

Increased by:

- Impulsivity
- Being fed / needing assistance
- Positioning / Retrocollis
- Fatigue
- Difficulty seeing food on a plate – this might be due to visual difficulties but also retrocollis
- Difficulty completing mouth care– difficulty completing, assistance needed or given, can they access the dentist?

Strategies

- **Assistance:** Type of assistance required e.g. hand over hand, full, supervision, prompts. Education and e.g. pacing and mouthful sizes
- **Impulsivity:** pacing (small mouthfuls one at a time), smaller cutlery to reduce loading, explicit prompts to put cutlery down between mouthfuls
- **Timing:** Eat and drink when most awake e.g. swapping lunch/dinner
- **Concentration:** Reduce distractions, avoid talking while eating, turn off TV
- **Posture and positioning**
 - Sit fully upright and in midline where possible during oral intake and for 15–30 min afterward to reduce the risk of retrograde bolus flow and reflux.
 - Maneuvres such as chin tuck (may not always be successful!).
 - Retrocollis – liaise with MDT.
- **Onward referrals?** Note visual and perceptual impact (particularly with PSP) e.g. Ophthalmology referral– could items such as prism glasses help? Dietetics, support for positioning etc.



Strategies: adaptive equipment

- Adaptive equipment



Strategies: Modifying food and fluid consistencies

The IDDSI Framework

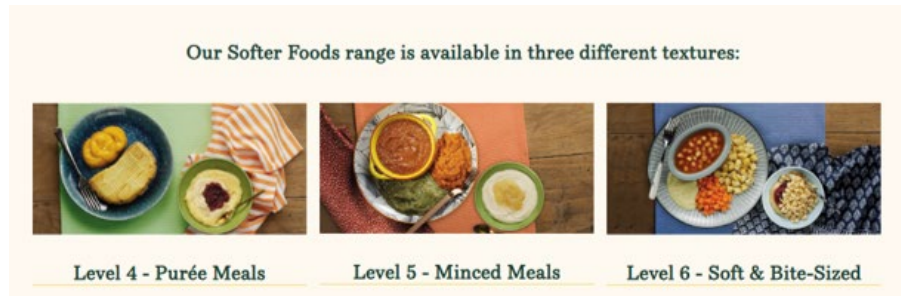
Providing a common terminology for describing food textures and drink thicknesses to improve safety for individuals with swallowing difficulties.



© The International Dysphagia Diet Standardisation Initiative 2019 @ <https://iddsi.org/framework/>
Licensed under the Creative Commons Attribution Sharealike 4.0 License <https://creativecommons.org/licenses/by-sa/4.0/legalcode>.
Derivative works extending beyond language translation are NOT PERMITTED.

<https://www.iddsi.org/>

Strategies: Modifying food and fluid consistencies



Meal provider companies who provided modified diet menus e.g.

- <https://www.wiltshirefarmfoods.com/about-our-food/softer-foods> (above)
- <https://www.apetito.co.uk/our-food/texture-modified>
- <https://www.oakhousefoods.co.uk/> IDDSI levels
- <https://www.itsmadeforyou.co.uk/idlsi>



- Not the panacea!
- Thickened fluids have risks as well as benefits which should be considered for each individual person.
- Thickened fluids are one of several interventions for dysphagia.
- Thickened fluids may be appropriate for some patients, but this decision is person specific.
<https://www.rcslt.org/>

Strategies – Secretions and Mouth care

Secretions

- Strategies e.g. regular flushes with drinks, prompts, apps.
- Signposting with medical team- medication reviews, botox, suction, ?radiation
- How do others access suction?

Mouth care

- Check mouth is clear of food after meals.
- Low/non foaming toothpastes.
- Adapted brushes e.g. handles, three-headed toothbrush, oralieve 360, electric vs manual.
- Is onward referral needed if they cannot access regular dentist.



Alternative nutrition/hydration vs eating and drinking with acknowledged risk

Potential benefits of non-oral feeding:

- Aid management of malnutrition / dehydration / weight loss – better outcome for tissue viability / sores.
- Reduce risks of choking / aspiration on oral intake.
- Less stress burden at meal times and on both the individual / carer.
- May aid constipation.
- May be able to eat / drink for pleasure rather than when they have to – enjoyment.

Consider:

- Procedure and infection risks.
- Digestive issues.
- Cannot prevent aspiration of oral secretions or refluxed material.
- Quality of life: Patients nearing the end of life may prefer to be fed orally and enjoy the taste of food.

Alternative nutrition/hydration options vs eating and drinking with acknowledged risk

It can be difficult to predict who will benefit from non-oral feeding. Iwashita et al (2023) identified strongest risk factors for discontinuation of oral intake include:

- Axial rigidity
- Cognitive decline
- Retrocollis

Alternative nutrition/hydration options vs eating and drinking with acknowledged risk



Principles



Early conversations: Cognitive changes in PSP and communication changes in both can mean early discussions are better rather than when it is 'needed'.



Combined Approaches: Non-oral feeding is often used alongside safe, modified, or small amounts of oral intake for pleasure rather than total restriction, whenever appropriate.



MDT working: Not isolated to a 'one off' discussion and usually involves wider MDT e.g. Neurology / Dietitian / Respiratory. Might look at written information, videos, pictures.



Capacity: Consider capacity / Mental Capacity Act if indicated – remember capacity is decision specific!



Patient-Centered: Promote person-centred decision-making. Primary focus should be on the individual's quality of life, comfort, and wishes. Some people might choose non-oral feeding, others EDAR, and some a combination.

Take aways

- Limited evidence base regarding communication changes and the benefits of SLT intervention but we can draw on similar client groups and clinical experience.
- The impact of communication difficulties is wider than 'just' speech changes.
- Individual needs may change as condition progresses. What works now may no longer meet needs as condition progresses.
- Impact of communication and potential cognitive changes - importance of early discussions where appropriate to support advanced care planning discussions.
- **There is no one size fits all approach to communication or eating, drinking, and swallowing intervention.**
- **Importance of a holistic approach and MDT working.**

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