Case study - Low tech outcome for a progressive condition

Background

Sarah has MS. She lives with her husband and has daily carers.

Sarah was referred as she was struggling to communicate verbally and had limited capability to express her needs and wishes to others.

Sarah uses speech when able, but her voice is very quiet and speech is limited to a few words at a time only. She rarely initiates conversation

Sarah's conversation partners are not always able to understand her. They tend to use yes/no questions when talking to her. Sarah's Yes/No responses are reliable via head nod/shake/vocalisations/speech

Sarah's husband had created 2 A4 page alphabet charts with some phrases and topics, and some colour coding following advice from the SLT at the local spoke service. He reported

these were not being used and they were not sure how to use them.

Breakdown in communication can occur when Sarah is fatigued and this can lead to frustration. Sarah's body language is limited due to her physical difficulties, but she makes good use of facial expression.

<u>Assessment</u>

Physical abilities

Sarah is currently bedbound due to a pressure ulcer. She is only able to sit out for very short periods at present, to allow her pressure ulcer to heal.

Sarah has a powered wheelchair which has recently been fitted with dual controls for her husband to operate due to her physical and cognitive changes. She also has a specialist armchair.

Sarah is unable to use her upper or lower limbs functionally.

Sensory

Sarah was able to scan to the left and right with enough reliability to eye point to objects at a suitable distance. She had difficulty tracking between 2 objects during assessment, overshooting both left and right, and her eye movement was not smooth. She was noted to have a Nystagmus affecting her right eye. Sarah tended to turn her head to compensate for reduced eye control (which could result in her fatiguing more quickly).

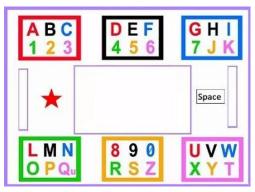
Cognition

Sarah has reduced attention and concentration, this appears to impact on her ability to learn, process and recall information. She had a basic environmental control system, but her husband reported she was no longer able to use it, as it was too cognitively demanding for her.

Language and Literacy

It was reported on referral that Sarah was literate, but her abilities were affected by her cognitive decline

An Etran frame and a Megabee were tried with Sarah, to see whether she had the potential to use them. However, Sarah struggled to use these, which is likely due to her visual (eye movements) and cognitive difficulties.



Etran Frame



Megabee

Outcome/ Recommendations:

High tech aids were excluded for a number of reasons, including:

- Sarah's limited physical and visual skills would limit her options in terms of access.
- Sarah has limited cognitive ability to take in, retain and manipulate information which would make most high tech systems difficult to use.
- This has been backed up by her inability to operate a relatively simple environmental control system.
- Sarah fatigues easily, and the effort of trying to access a high tech device with the movement she has would likely make this too effortful to be successful
- Any of the above is likely to frustration and abandonment of the technology.

Low tech (paper based) AAC was recommended to the spoke service to implement, as it promotes more of a partnership between Sarah and her conversation partner. Partner assisted scanning was recommended, whereby the listener systematically points and reads out the items, and Sarah indicates with a yes response which one she wants.

In addition, Sarah could use eye pointing to choose between two items (e.g. choice of DVD etc.) with the prompt – 'look at the one you want'.

Introduce a sheet of topics/phrases to help set the context. The content needs to be discussed with Sarah, her family and carers (examples below). These can be introduced gradually.

Problem with		I want/need		Talk about family		Something Else			- * ×
Body/comfort		Events/ Dates		People		Social		Spell it out/ Alphabet chart	
q	w	е	r	t	у	u	i	0	р
a		6 (d .	f g ł		n j ł		k I	
	z	x	С	V	b	n	m		•
Space									

If appropriate, then this can be developed over time with more messages, in particular the 'social' topic which could help Sarah engage more in conversation in a topic of *her* choosing.

It is highly recommended that the sheet is laminated or put in a display book so it is protected, and can be cleaned/ kept safe etc. This helps demonstrate it is a valued communication aid.

It also guides the listeners (family, carers, unfamiliar others) to think about the way they can communicate with Sarah, rather than just yes/no questions.

Encourage spelling for single words, as opposed to phrases and sentences, which takes more time and effort. A single letter or word can help to give a clue about the message.

Encourage conversation partner to use a white board or notebook to note down the letters or topics as they are are chosen to help Sarah and her partners have a visual record to keep track of where they are at in the conversation

A review is planned for 6 months time. Establish whether low tech AAC meets her needs or whether high tech AAC should be considered in addition to the low tech which will be implemented by the spoke service. Monitor whether Sarah's cognitive difficulties are impacting on her spelling and reading skills.