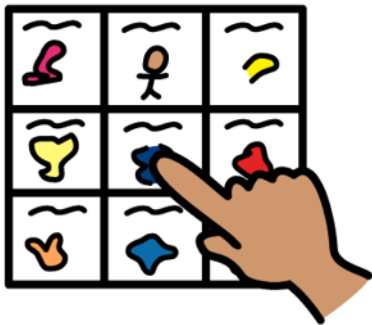




Royal Hospital for Neuro-disability  
A national medical charity



# A journey of communication for people with Motor Neurone Disease



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Therapist

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Royal Hospital for Neuro-disability, Putney



# Introduction

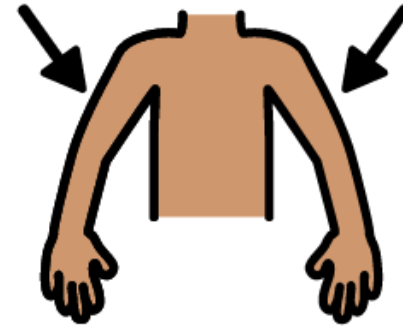
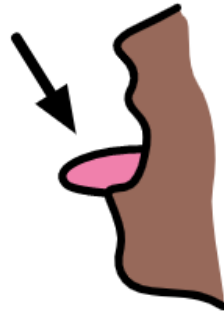
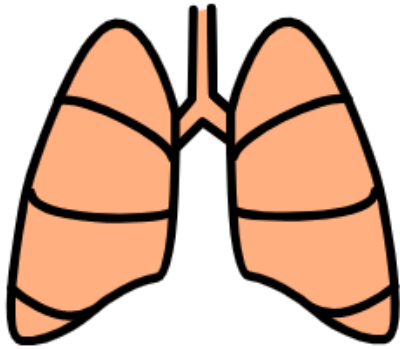
<https://www.rhn.org.uk/what-makes-us-special/services/compass/>



# NICE guidelines for MND 2016

- Assessment and review carried out by a speech and language therapist without delay.
- Consider face-to-face and remote communication
- Review the person's communication needs during multidisciplinary team assessments.
- Provide low and high tech AAC and EC equipment.
- Liaise with, or refer the person with MND to, **a specialised NHS AAC hub** if complex high technology AAC equipment is needed or likely to be needed.

# Communication difficulties in MND





# Early stages – how to help

- + Voice or message banking
- + Introducing AAC
- + Managing dysarthric speech

# Things to help dysarthric speech



SLOW SPEAKING  
RATE



EXAGGERATE  
SPEECH  
ESPECIALLY FINAL  
CONSONANTS



TAKE FREQUENT  
BREATHS.



INCREASE PAUSES



BREAK WORDS  
INTO SYLLABLES



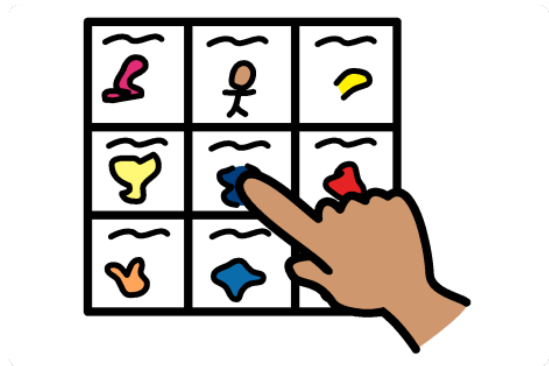
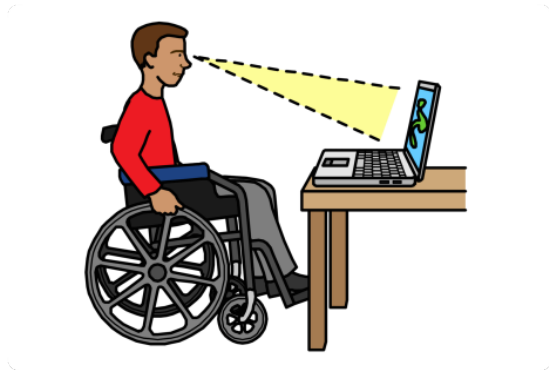
ENSURE LISTENER  
READY



MINIMIZE NOISE IN  
THE ENVIRONMENT



SPEAKER TO  
ESTABLISH TOPIC  
OF THE MESSAGE

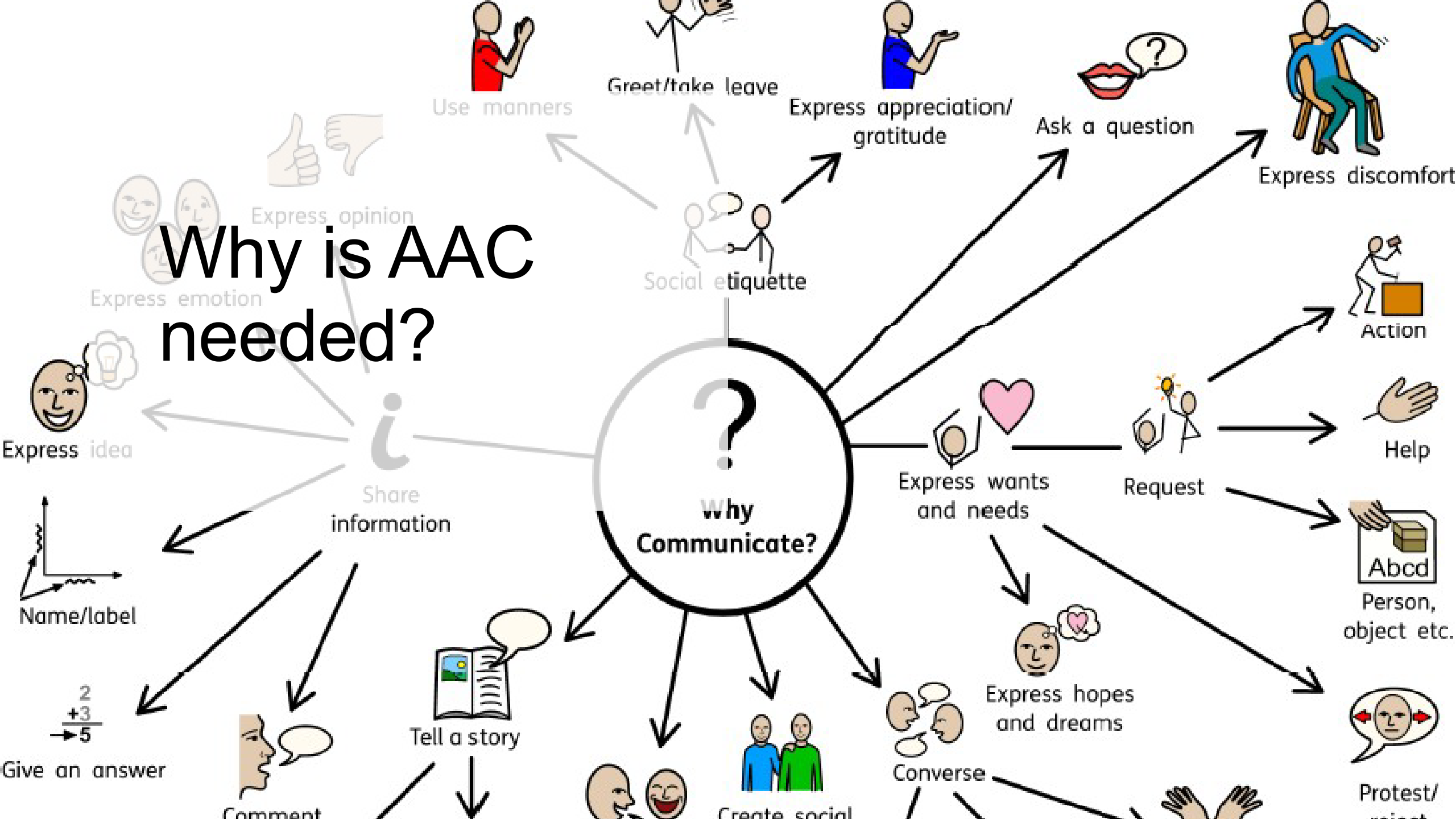


# What is AAC?

**AAC**= Augmentative and Alternative Communication=

- + **Augmentative**= supports/adds to speech
- + **Alternative**= instead of speech
- + **Communication**= in AAC this means using words or symbols to get the message across.
- + **EC= Environmental controls**- Enable people with significant disabilities to **independently access equipment in their environment** e.g. home or hospital e.g. **call bell, control lights, TV, curtains etc.**

# Why is AAC needed?





# Benefits of AAC for people with MND



AAC can support communication and interaction with family, friends and professionals when speech is difficult.



AAC can promote psychological and emotional wellbeing.



AAC can help to maintain autonomy and control over decision-making.



AAC can enable ongoing access to electronic communication, such as social networking and email.



AAC may help to maintain employment.

# Things to consider in AAC



Mobility: Positioning, Seating? Need chart/device mounted, can they carry it



Hand function: Able to point to device or chart, what is their range of movement?



Vision: Able to see letters, colours, do they need upper or lower case?



Cognition: Memory? Attention? Understanding?



Language: Can they spell? What is their first language? Can they read?

# Tools for assessment



Human Activity Assistive Technology Model (HAAT)

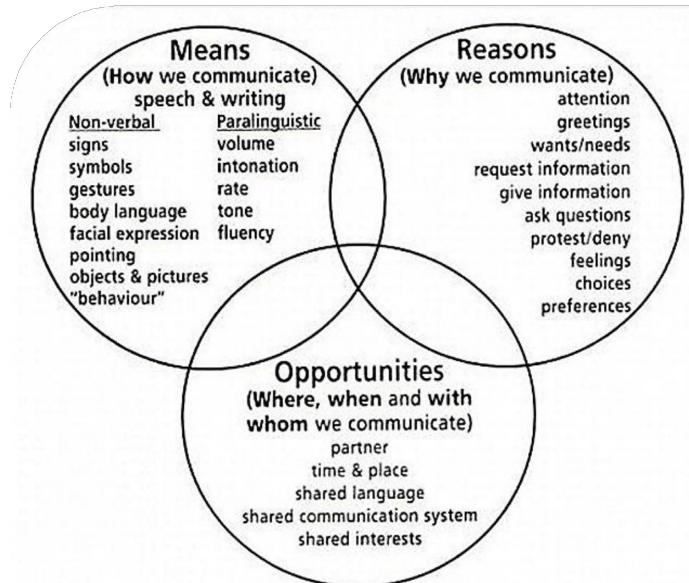
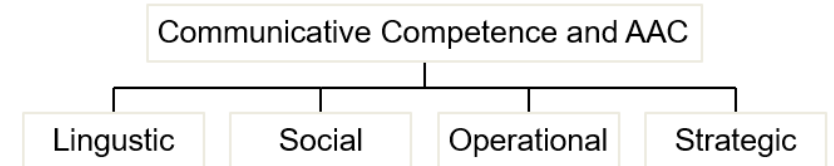


Figure 1  
Means, Reasons and Opportunities: The original model

Means, Reasons and Opportunities



Talking Mats



Light's Model of communicative competence

Please say/write each letter as I point to it. lowtechsolutions.org ©

1	2	3	4	5	6	7	8	9	0
Q	W	E	R	T	Y	U	I	O	P
A	S	D	F	G	H	J	K	L	'
Z	X	C	V	B	N	M	,	.	:
Message Code	Thank You	Start Over	Hold On...	Space	Delete Letter	\$	!	?	

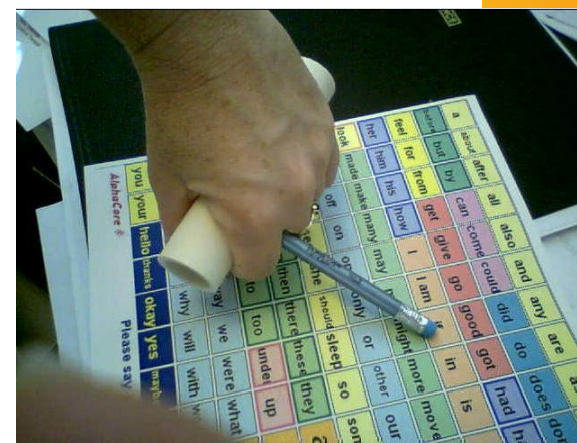
That's Not What I Meant Turn Board Over

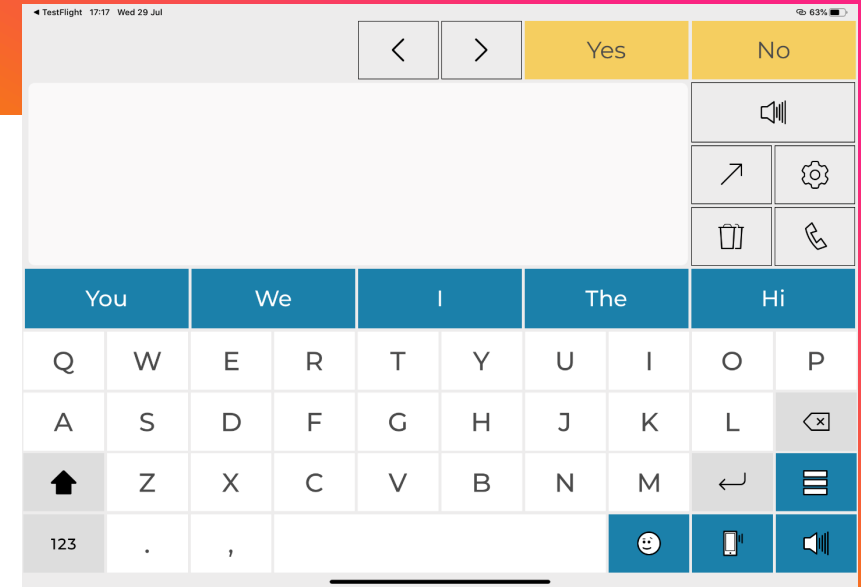
SUCTION	VENTILATOR	ANXIOUS/ SCARED	NURSE	DOCTOR	CALL MY FAMILY
PAIN	BREATHING TUBE	HOT COLD	REPOSITION	PROTECTIVE EQUIPMENT	WHAT'S MY STATUS?
MEDICINE	TROUBLE BREATHING	THIRSTY	LIGHTS ON / OFF	CHAIR	NO VISITORS
MOUTH CARE	BATHROOM	TIME / DAY ?	TV ON / OFF	BED	LETTER BOARD
MAYBE		DON'T KNOW		LATER	

WHAT IS HAPPENING TO ME?	WILL I GET BETTER?	AM I GOING TO DIE?	HAVE WE DONE ALL WE CAN?
WHAT ARE MY OPTIONS?	WILL I BE AWAKE?	WILL IT HURT?	I WANT TO TALK WITH MY FAMILY
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER
			NO

Early stages - low tech  
 -direct access finger or stylus  
 -text or symbols/photos

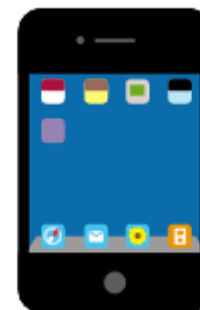
YES		END OF WORD	NEW WORD		NO					
A	B	C	D							
E	F	G	H							
I	J	K	L	M	N					
O	P	Q	R	S	T					
U	V	W	X	Y	Z					
0	1	2	3	4	5	6	7	8	9	10





# Early stages - high tech

Apps: Predictable, ClaroComm, TexttoSpeech!, Speech Assistant





1. Partner scanning

1. HOT	TEA	COFFEE	HOT CHOCOLATE
2. COLD	JUICE	SQUASH	COKE
3. EXTRAS	STRAW	ICE	BIGGER CUP
4. Sth ELSE			

DRINKS ROOM PEOPLE



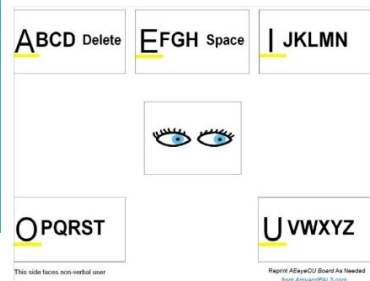
2. Eye pointing

# Late stages - low tech



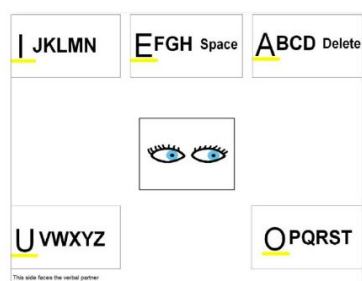
3. Bit of both!!

AEeyeOU Board

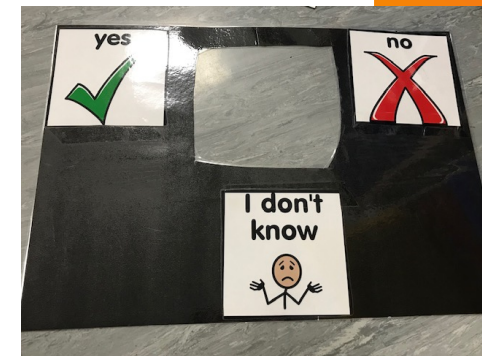


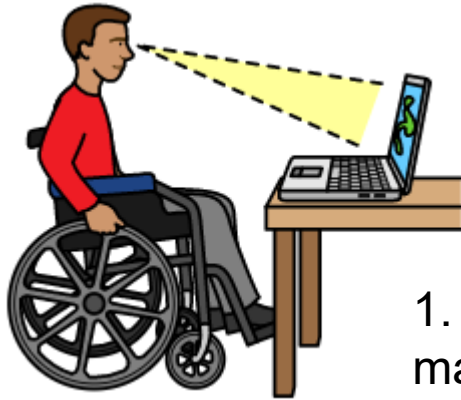
Download AEeyeOU Side 1

AEeyeOU Board Back



Download AEeyeOU Side 2





1. Eye gaze-  
many different  
cameras

2. Head mouse-if  
good head control



## Late stages - high tech

3. Switches-using  
hands.....



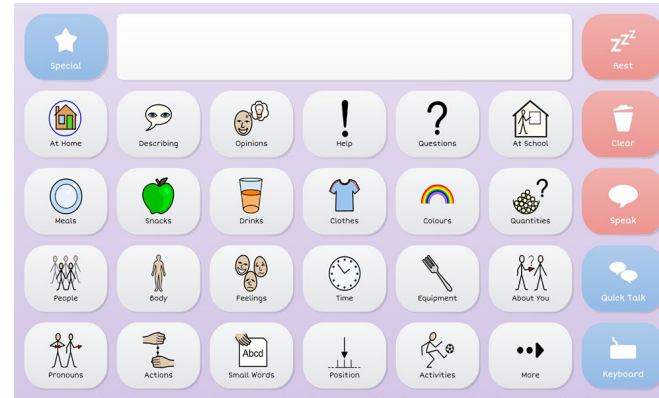
..or another part  
of the body....



# The software.....!



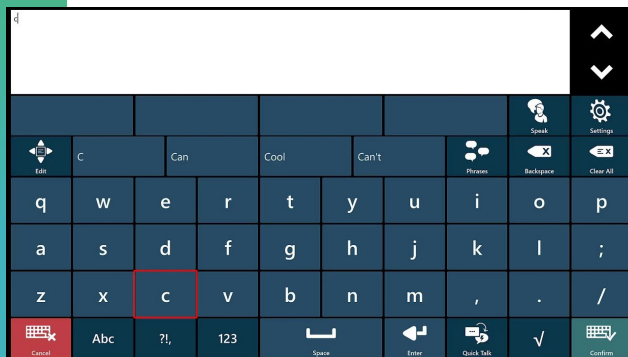
The Grid 3-  
Fast Talker



The Grid Symbol  
Talker A



Integration with  
Environmental  
Controls



Tobii  
Communicator

					F10	Speak as Select	F9	Attention	F11
					Speak & Clear	Save or Copy	😊	🚫	Undo
Greetings	Communication Tips	News & Current Topics	Questions & Continuers	Needs	My Phrases	More Topic Pages-->			
Hi	Good Morning.	Nice to meet you	I'm --name	Good to see you	You look... (Describing)	Want a drink? (Drinks)			
I have a question.	How are you doing?	What have you been up to?	Have you been...? (Activities)	How was your ...? (Event)	How is? (People)	How's it going?			
I'm doing OK.	I feel... (Feelings)	I've been feeling... (Feeling)	I've been doing... (Activities)	It's (Describing)	(Describing)	Tell me about it			
(Feelings)	Okay	Great	Good	So-So	Terrible	And you?			
Goodbye	Goodnight	I better be going	Great talking with you!	Nice to see you	Have a great day!	When will I see you again?			
AlphaCore		Keyboard		Return to Last Page	Yes/No/Maybe	Please/Thanks/Welcome			

Alphacore





# Tips from AAC users

- + Give me **time to communicate** - conversations will take longer using a communication aid of any kind.
- + Some people are happy for you to guess what they are trying to say...**but some are not** - check with me first if I am happy for you to do this.
- + Do not touch /grab my device/chart without permission –its my voice!
- + **Ask questions one at a time**, and wait for me to reply to the first question before asking the next one or for clarification. This is harder than it seems!

# Key points from today

Many individuals who have MND will require AAC to support their communication. There are lots of resources out there to help them.

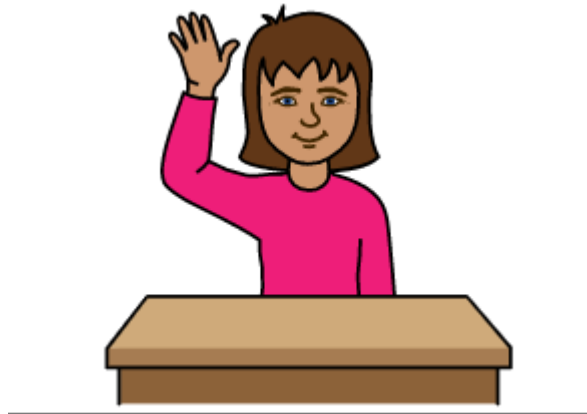
People who use AAC are not a homogeneous group. If someone has difficulties with access to a communication aid it is **essential that person has an expert assessment- from local SLT or specialist HUB**

Remember: AAC is not ONE system-many individuals use a **variety of systems to communicate**

**Don't be driven by technology**

**Person first!**

Thank you for listening!  
Any Questions?



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[compass@rhn.org.uk](mailto:compass@rhn.org.uk)

0208 780 4500 ext 5965

@HelenPaterson3

<https://www.rhn.org.uk/what-makes-us-special/services/compass/>

# Useful links

## MNDA and AAC:

<https://www.mndassociation.org/professionals/management-of-mnd/aac-for-mnd/>

## Voice and message banking:

<https://www.mndassociation.org/professionals/management-of-mnd/aac-for-mnd/voice-banking/>

## Models:

-HAAT: Cook, A.M., Polgar, J.M. and Encarnacao P. (2020) *Assistive Technology Principles and practice*, 5<sup>th</sup> Edition

-Light, J. (1989) Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication* 5:137-144

-Talking mats: <https://www.talkingmats.com/>

-Means, reasons and opportunities model: Money D. and Thurman S. (2002) Inclusive Communication. *Speech and Language Therapy in Practice*.

# Free AAC resources:

- + Charts-letter and picture:
- + <https://www.patientprovidercommunication.org/covid-19-tools/free-english-tools/>
- + <https://acecentre.org.uk/resources/>
- + Pictures only: Bungalow:  
[https://www.bungalowsoftware.com/blog/a/aphasia/communication-board/?fbclid=IwAR2LSChef2eBOMWw9yeE3E8NJ6lmg6dh3tGf\\_7WIPpU-bFcgtkA9cbMFmRU](https://www.bungalowsoftware.com/blog/a/aphasia/communication-board/?fbclid=IwAR2LSChef2eBOMWw9yeE3E8NJ6lmg6dh3tGf_7WIPpU-bFcgtkA9cbMFmRU)
- + Widgit: Has loads of medical related pictures and ones for hospital
- + <http://widgit-health.com/downloads/for-professionals.htm>
- + Scanning book: <https://www.childrenshospital.org/centers-and-services/programs/a-e/als-augmentative-communication-program/protocol-of-assessment-considerations/quick-access-and-low-tech-tools>
- + Speak book: <https://acecentre.org.uk/project/speakbook/>
- + Scan AEeyeOU: <https://amyandpals.com/communication-boards/>

# Charts in other languages

- + Patient-Provider website- 16 different languages on the charts- Yes/no, Pain, Basic needs:

<https://www.patientprovidercommunication.org/covid-19-tools/supporting-communication-with-patients-who-have-covid-19/>

- + Widgit-different language charts- bedside messages, hospital flashcards, A and E passport - 28 languages : <https://widgit-health.com/downloads/bedside-messages.htm>

- + <http://www.culturaldiversity.com.au/service-providers/multilingual-resources/communication-cards>

# Videos to help you/AAC users to learn low tech strategies

- + Barnsley AAC service:  
[https://www.barnsleyhospital.nhs.uk/assistive-technology/resources-and-information/?resource\\_type=HowTo%20Video&\\_page=2](https://www.barnsleyhospital.nhs.uk/assistive-technology/resources-and-information/?resource_type=HowTo%20Video&_page=2)
  
- + Compass:  
<https://www.rhn.org.uk/what-makes-us-special/services/compass/>

