

# Maintaining Identity in the Context of Communication Difficulties

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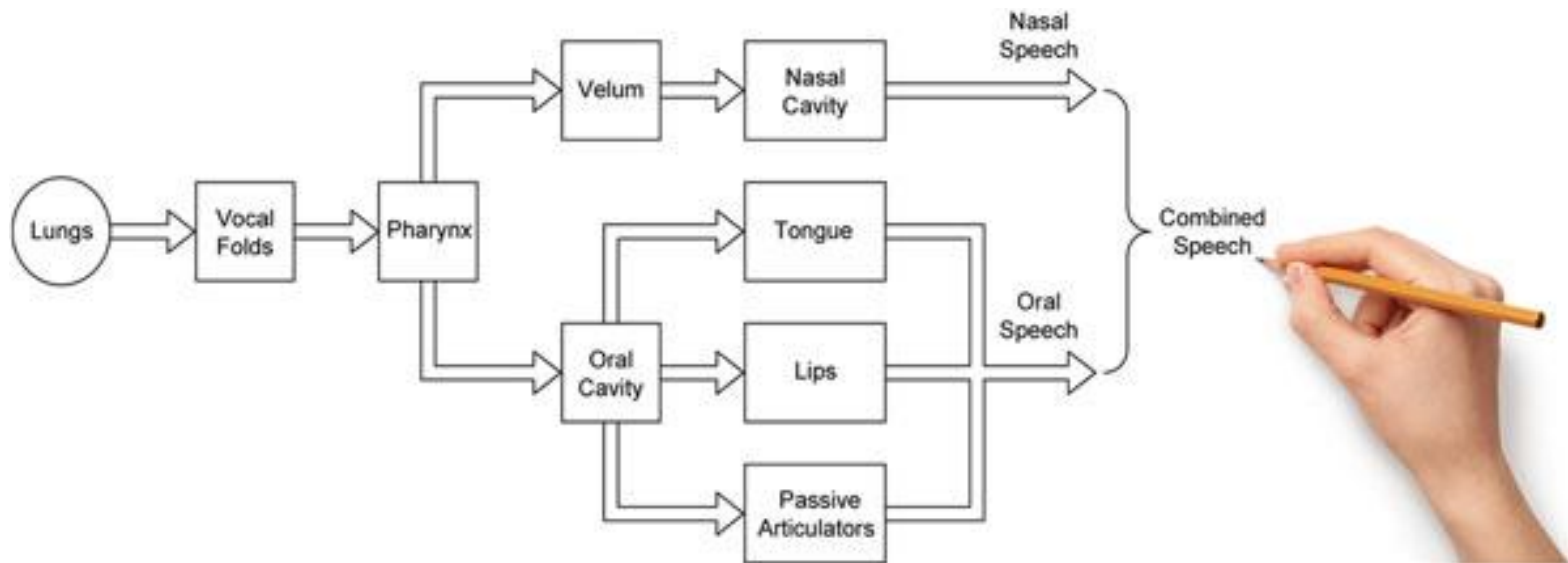
A Psychosocial Approach to Caring for People with MND in a Palliative Care Setting  
Study Day 19/05/14

# Plan to Cover

- How communication is affected
- Range of communication aids available
- What you can do to help a person with MND communicate
- How the attitude of the communication partner impacts on success
- Perspective of people with MND



# Speech Production



# Dysarthria

- A disorder of motor speech production systems:
  - » respiration
  - » phonation
  - » resonance
  - » articulation
  - » prosody
- Dysarthria type present in people with MND depends on the areas affected:
  - damage to upper motor neurones => spastic dysarthria
  - damage to lower motor neurones => flaccid dysarthria
- Therapy to strengthen the muscles not indicated due to the progressive nature of MND and fatigue effect

# How MND Affects Speech

## Poor movement of articulators

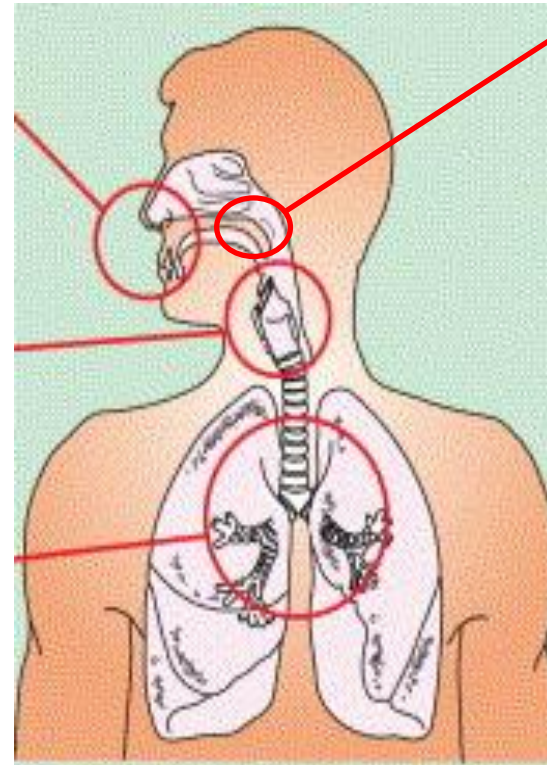
- Slow speech rate
- Reduced clarity of phoneme production

## Vocal fold issues

- Hoarseness
- Strained voice

## Reduced diaphragm/lung expansion

- Breathlessness when speaking
- Low volume speech



## Reduced soft palate movement

- Altered resonance leading to hypo/hyper-nasality

# ALS Severity Scale for Speech

(Yorkston et al., 1993)

## **Normal Speech Processes**

10 – Normal Speech

9 – Nominal change: only the patient or spouse notices

## **Detectable Speech Disturbances**

8 – Perceived Speech Changes: noted especially during fatigue

7 – Obvious Speech Abnormalities: remains easily understood

## **Behavioural Modifications**

6 - Repeats messages on occasion: rate is much slower

5 – Frequent repeating required: extensive repetition or a 'translator' commonly needed

## **Use of Augmentative Communication**

4 – Speech plus augmentation: intelligibility problems resolved by writing/spokesperson

3 – Limits speech to one-word response: otherwise writes or uses spokesperson

## **Loss of Useful Speech**

2 – Vocalises for emotional expression

1 – Non-vocal: vocalisation is effortful, and rarely attempted

# Moderate Speech Difficulty

If you have difficulty understanding a person's speech, you could ask them to try the following:

- Speak slowly
- Over-exaggerate mouth movements when speaking to stress the speech sounds
- Break longer words down into individual syllables
- Pause for breath frequently if straining for air
- Swallow down saliva if building up in the mouth

# Severe Speech Difficulty

If you have difficulty understanding a person's speech, you could ask them to try the following:

- State keywords if switching to a new topic
- Pause between each word
- Use phrase/short sentence when tired or short of breath
- Use gestures and facial expressions



# Things You Can Do

Set the scene:

- Make sure the person has their glasses and/or hearing aids in place if used
- Limit background noise: television/radio, equipment, noise on ward
- If appropriate, help to remove face masks for NIV
- Ensure the area is well lit
- One-to-one is easier than group, if group consider positioning
- Move closer to the speaker if their speech volume is low

# Things You Can Do

Monitor your communication style:

- Give the speaker your full attention – do not multitask
- Maintain eye contact at face-to-face level
- Do not interrupt while they are speaking
- Watch for non-verbal signs that they wish to speak
- Repeat back what you have understood and only seek clarification on what you missed
- Signal early if you are not understanding – establish method
- Verify that you have understood correctly – be honest if you have not

# Alternative Ways to Communicate

- AAC = **A**ugmentative and **A**lternative **C**ommunication
- Low-tech and high-tech options
- Allows people with MND to maintain autonomy and decrease dependence on others for communication (Nojboer et al., 2008)
- Communication through AAC becomes more important as a patient's disability increases as it provides a means to express fear, pain and grief related to the disease (Centers, 2007)

# Low-Tech AAC

- Includes any non-electronic communication aids
- Generally need little training or support
- Often first step into AAC
- Often used in combination with speech

# Writing

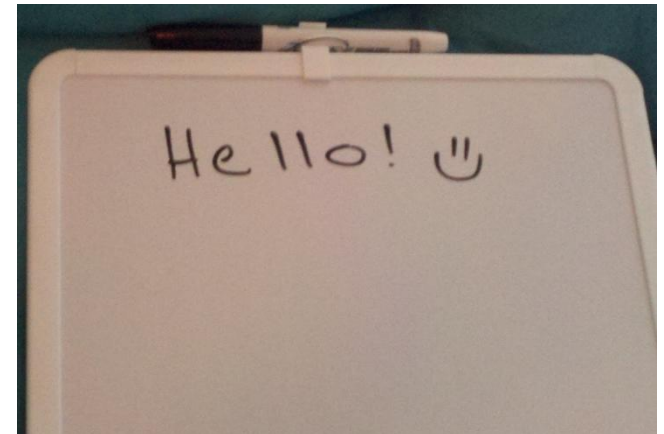
## Pen & Paper

- Fast if good hand function
- Depend on fine motor control
- May need grip aids
- Spiral bound notebooks useful



## A4 Whiteboard and Marker

- Easy to clean and portable
- Need to write bigger with marker



# Alphabet Charts

- Use to indicate the first letter of the word
- Use to spell out words
- Can customise with key phrases
- ABC or QWERTY
- May need to use pointing tool for clarity
- Partner assisted version if unable to point
- Could also use magnetic letters on board

I will point to the first letter as I say the word








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	Th	Ch	Sh

Who	And	Yes
What	You	No
When	Because	Maybe
Where	He/She	I don't know
How	The	Mistake
Why	They	Right/Wrong



# Sample Alphabet Chart

UNWELL 	ANGRY 	SAD 	SHY 	FUNNY 	LOVE 	HAPPY 	TOBY!CHURCHILL www.toby-churchill.com		
1	2	3	4	5	6	7	8	9	0
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	.	?	!
AND	YOU	THE		YES	(SPACE)		NO		

YOU CAN USE THIS CARD WHEN YOUR LIGHTWRITER IS UNAVAILABLE. PERSONALISE THIS AREA WITH YOUR OWN WORDS...

Download free from:

[www.toby-churchill.com/assets/downloads/alphabet\\_board\\_toby\\_churchill.pdf](http://www.toby-churchill.com/assets/downloads/alphabet_board_toby_churchill.pdf)

# Sample Alphabet Chart

YES	1	2	3	4	5	6	7	8	9	0	NO
It starts with...	a	b	c	d	e	f	g	h	i	j	I'm not sure.
New word	k	l	m	n	o	p	q	r	s		I made a mistake I'll start again
I'd like to ask you something	t	u	v	w	x	y	z	?			Thank you

Developed by Spectronics in collaboration with Scope [www.scopevic.org.au](http://www.scopevic.org.au)

Instructions for use: This Alphabet Board is designed for people who either cannot talk or have speech that is difficult to understand, but have literacy skills and can spell all or most words. If you think the person has something they need to tell you:

1. Place the board in front of the person
2. Ask the person to spell out what they want to say
3. Check how they are going to access the board i.e. with their fingers or by eye pointing
4. Clarify what was said by repeating back the word

  
**Spectronics**  
 Inclusive Learning Technologies  
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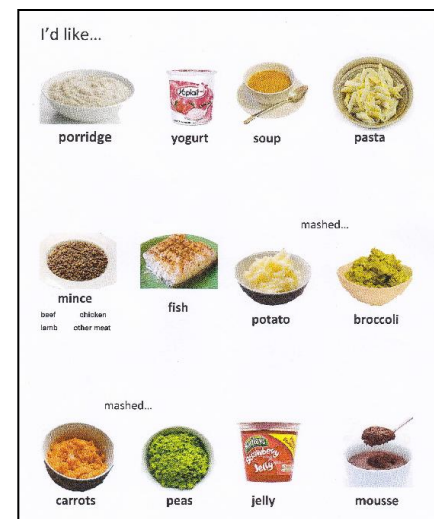
# Partner-Assisted Alphabet Chart

Red	A	B	C	D	Mistake							
Yellow	E	F	G	H	End of word							
Green	I	J	K	L	M	N						
White	O	P	Q	R	S	T						
Blue	U	V	W	X	Y	Z						
Purple	0	1	2	3	4	5	6	7	8	9	10	

- Hold where user can see
- Establish 'Yes' response
- Call out the row colours in order; keep the pace slow and consistent
- Once you have the row, call out the letters in that row
- Repeat back the letter selected to verify that it is correct, write it down if needed
- Repeat for the next letter

# Picture Communication Aid

- Useful for regular requests
- Backup when tired/electronic device not available
- Cannot use to generate spontaneous conversation
- Generic versions available but work better when personalised with chosen vocabulary



# High-Tech AAC

- Electronic devices
- Require batteries or charging to operate
- Often provide synthetic speech output
- Consider access options – how the user makes selections
- May not be suitable for:
  - people uncomfortable with computerised devices
  - people with literacy difficulties
  - people with significant cognitive changes

# Voice Amplifier

- Useful for people with low volume speech
- Easily portable
- Can use headset or lapel microphone
- Easy to use
- Feedback sometimes an issue



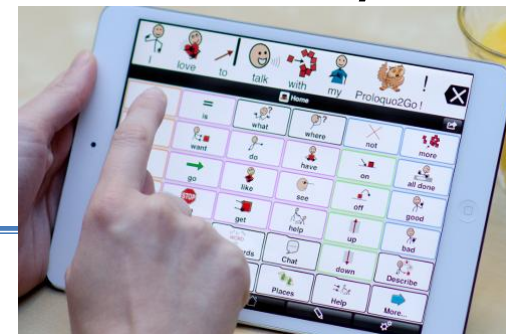
# Lightwriter

- Dedicated communication device
- Type message/select letter with switch
- Can save key phrases
- New version can accommodate SIM card



# Tablet/Smart Phone

- Mainstream device with multiple uses
- Can purchase communication apps
- iTunes apps for Apple devices
- Android apps for other brands e.g. Samsung
- Range in price and features
- Symbol selection vs text-to-speech
- High levels of social acceptance
- Touch screen selection not appropriate for everyone





# Smartbox Tablets



- Motion Tablet, SB10, SB8
- Dedicated communication device using Grid 2 software
- Windows-based touch screen system
- Bluetooth sound amplifier
- Instant on/off
- Gorilla glass – extra strong
- USB connection for alternative access/file transfer
- Can incorporate environmental controls



# Eye Gaze Device

- Computer access for people with severe physical disability
- Can incorporate communication software
- A camera tracks where eyes are focused on the screen
- Can type a message or select pre-programmed phrases
- Range of makes and models e.g. Tobii C12 with CEye





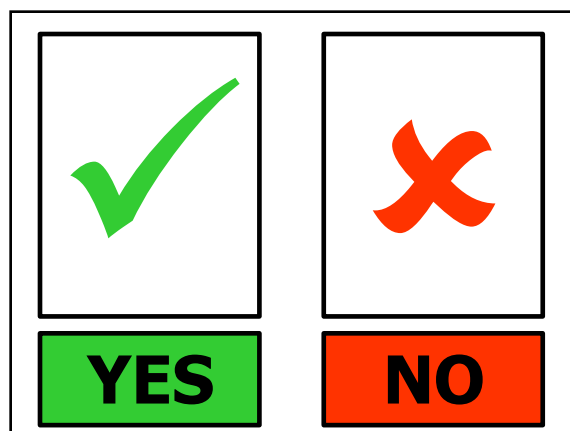
# Personalisation

- Choose core vocabulary
- Choose layout
- Choose ABC/QWERTY for keyboards
- Choose to use voice output; select voice, speak each word as typed or when all typed
- Choose to disable/hide features not desired
- Choose size of display

# Yes/No System

Most essential aspect of communication for people who can no longer communicate verbally

- Ensure signal for 'no' is as well defined as signal for 'yes'
- Ask closed questions requiring only a yes or no response
- Model for the person if necessary – use only one system with the person although this system may change over time as physical difficulties increase



Examples:

- » Head nod/shake
- » Thumbs up/down
- » Hand/foot movements
- » Eye movements
- » Yes/No chart



# Timing of AAC

- Sensitive due to psychosocial issues
- Generally accepted that too early better than too late
- People with MND and/or their family often not interested in facing the loss of their speech while it remains functional (Ball et al., 2005 & Nordness et al., 2010)
- People with MND may see acceptance of AAC devices as an indication that they are 'no longer the independent and verbal individuals of their past' (Doyle & Phillips, 2001)
- Many only accept AAC when speech is no longer intelligible

# Acceptance and Use of AAC

- Increased in recent years
- Acquisition – support of IMNDA
- As a society, moving away from only direct communication e.g. email, Twitter, Facebook, Skype; this can mean less resistance to AAC technologies and accessories when needed because of familiarity
- Attitudes of others significant factor in use of AAC
- Low AAC use often due to minimal training or follow-up (Murphy, 2004)
- In a 2004 MND study, 90% accepted AAC immediately, 6% after a delay and 4% rejected (Ball et al., 2004)

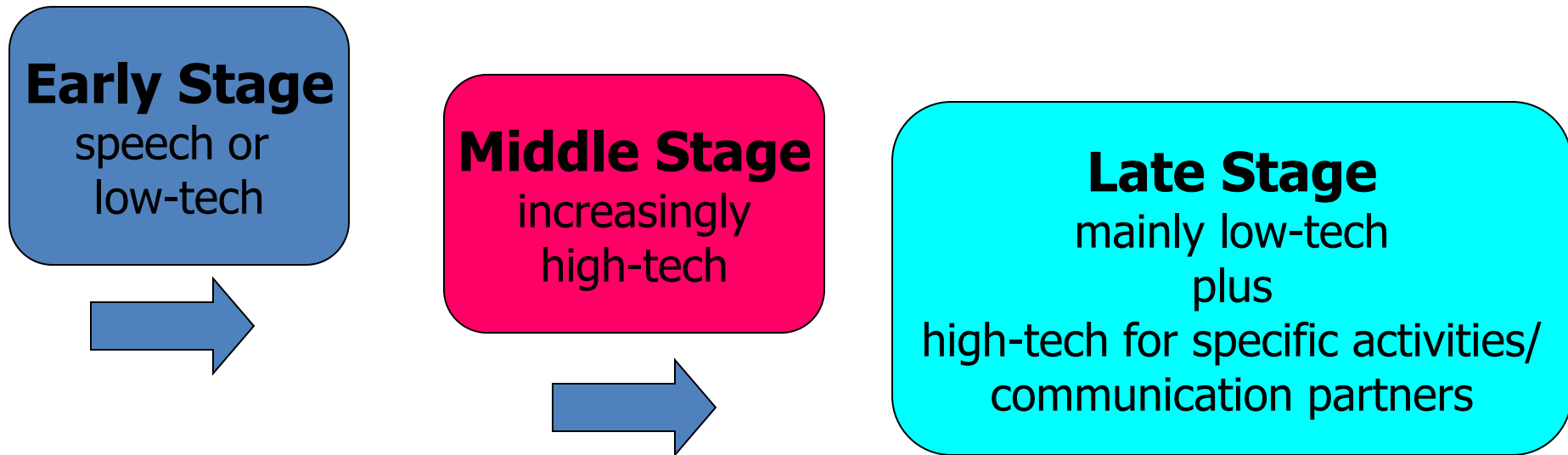
# High/Low Tech Preferences

- People who have experience with technology are typically more willing to consider high-tech AAC
- Use of AAC devices can change depending on the environment
  - may use high-technology devices with unfamiliar partners and low-technology devices with with familiar partners
  - may be a result of comfort levels and the familiar partner's ability to detect and even predict messages in typical contexts
- Men prefer high-technology devices while women more comfortable using low-technology devices

(Doyle & Phillips, 2001)

# Patterns of Use

Changes over time



During later stages, more concern with communicating basic wants and needs using yes/no responses or low-tech AAC that requires little effort  
(Doyle & Phillips, 2001)

## New technology for those living with motor neurone disease



Monday, March 24, 2014



Emma Miller Fitzpatrick at home in Kinsale, Co Cork, with her husband Jonnie, their two children, Rowan and Alannah, and Emma's Tobii eye-gaze-enabling device. Picture: Des Barry

"My 'eye-gaze' was sitting there for at least two months before I had the courage to use it. At a time when everything was changing in my body, I was desperately trying to cling on to 'normality'. Change was an ugly word to me then. So I preferred to stick with my little blue letter board and point out the words.

"Then, when I was no longer able to point I started to use the eye-gaze. What seemed daunting at first turned out to be a lifeline.

"I honestly don't think I would have survived this long without it because communication is the essence of life and it would literally break my heart if I was unable to speak to my family and friends." [Emma Miller Fitzpatrick](#)

# Uses for AAC

Not just for making requests – variety of purposes:

- Stay connected and interact socially
- Maintain employment
- Interact with AHPs to maintain control of their care
- Reduce anxiety
- Take care of basic needs especially when no longer able to do so independently

(Yorkston et al., 2013)



# What It's All About

"I love being able to explain myself instead of talking in words of one syllable. We had a meeting with a solicitor the day after I got it, and I was able to ask detailed questions.

"The voice is an upper class British one... I put in the dogs names but they ignore it.

"Three of [my husband's] granddaughters, ages 8, 9 and 12, came Easter Monday and they picked up how to use it very quickly.

They thought they had to write their part of the conversation, but I told them they could speak normally and I would answer them on the machine. It helped makes things relaxed instead of them being uncomfortable around me.

It's been great."

Email from Deborah McDonald to SLT on receipt of a Motion tablet from the IMNDA (quoted with Deborah's permission)

- Research has shown that those who have lost their ability to speak hold the ability to maintain social closeness with another person as the most important purpose of communication, above their desire to indicate wants and needs or to pass on information

(Murphy, 2004)

# “You don’t need speech to have a voice”

“For Betty, the loss of speech was one of the hardest things to deal with; however the IMNDA gave her a lifeline which allowed her to keep her voice & continue to communicate with her family and friends right to the end of her life.

“While Betty had been a stranger to iPads, and even mobile phones, before her illness, the iPad lent to her by the IMNDA became an extension of herself. The iPad also was linked into her email, so many of her family & friends would email her throughout the day... What the iPad did do, was allow Mom to continue to communicate with her family & friends, be involved in the community & still be one of the girls!”

Written about **Betty Rue O’Sullivan** by her children organising a charity cycle for the IMNDA - <http://liveyourlifecycle.com>

# Multimedia Functions

- Eye gaze devices offer extensive communication functions to people with MND (Ball et al., 2010):
  - face-to-face communication (100%)
  - group communication (43%)
  - phone (71%)
  - email (79%)
  - internet (86%)
  - other computer-based functions e.g., word processing, vocation-related software programs (43%)

# Shape Shifting Emma

<http://shapeshiftingemma.wordpress.com/2013/08/>



**“Why is This Happening?”**

Posted on August 14, 2013 by Shape Shifting Emma



“I nearly went out of my mind on Saturday last when this computer broke down. It just stopped working. Imagine the stress; Saturday morning, house in a chaotic mess, kids squabbling over TV and I planning writing this, texting and emailing for ireland! But none can be done. I can’t even vent frustration or contact a pal... I go into my bedroom and again, cry myself senseless... How could I possibly manage without my voice?

“...I was without the eye gaze for five days and I nearly went out of my mind... The worst part about not having it was feeling trapped, locked in what seemed like a prison in my head. All that awful stuff going on and not being able to say anything, no wonder I couldn’t stop crying.

It was hell.”

Emma Miller Fitzpatrick

# Try AAC out for yourself...



# Attitudes of Others

"I have also lost about 50 IQ points. Well, that may not be literally the case but it feels that way because that's how I'm treated. My son asked me if I missed work and I replied that I missed the respect.

"Of course it isn't true of everyone. Young shop assistants are great... the girl in Sports Direct (until then my most hated shop) who just treated me as *normal*."

Jo Harris

[www.theguardian.com/lifeandstyle/2014/mar/03/motor-neurone-disease-robbed-voice](http://www.theguardian.com/lifeandstyle/2014/mar/03/motor-neurone-disease-robbed-voice)

theguardian

Search

## Motor neurone disease has robbed me of what I value most – my voice

As a barrister and judge, I made my living by speaking. How do I cope now that such an integral part of myself has been taken away from me?

Jo Harris  
The Guardian, Monday 3 March 2014



'I give thanks for the genius of Steve Jobs.' (Posed by model) Photograph: Getty Images

"An entire room full of people with nothing to do but listen to me speak," is how I described my motive for becoming a barrister; even more so as a judge. I must admit the judicial art of keeping one's mouth shut was definitely best described for me as a work in progress – until I lost my speech altogether. What use is a judge who can't shout? What use is a mother who can't nag?

It's no accident I went into the senior branch of the profession. My three favourite activities were talking, drinking and eating ... and in that order. So what happens when you lose the ability to do any of that? I haven't gone mad. I haven't lost my mind. I have lost 40kg, though. It turns out Dorothy Parker was wrong. You can be too thin.

For more than 20 years, I have earned my living by means of the spoken word. I started to lose the ability to speak back in February 2012, although of course at the time I didn't know what was happening. It began with a sneaking suspicion on my part that I was slurring the occasional word, particularly when I was smiling. No one else noticed. In fact no one noticed for a very long time – although one friend did say to his wife one night when I rang, "What was wrong with Jo? Was she pissed?"

My speech progressed through the drunken-sounding slurring via virtually unintelligible into silence. From suspicion to silence took just over a year. I was diagnosed with pseudo bulbar palsy, a form of motor neurone disease, 10 months after the onset of symptoms. So now that I am silent when I've spent my life loving the sound of my own voice, how do I manage?

Well, I give thanks for the genius of Steve Jobs most days. Without a tablet, a smartphone, a mini tablet for going out and emails, emails, emails, my life would be hell.

I have also lost about 50 IQ points. Well, that may not be literally the case but it feels that way because that's how I'm treated. My son asked me if I missed work and I replied that I missed the respect. I cannot put into words how much I hate the constantly patronising, moronic twits who tell me to calm down when I was perfectly calm until that point.



# Our Attitude in Words

Can't communicate  
Can't speak  
Can't talk  
Has no voice  
Lost their speech  
Can only



Communicates using a...  
Helps to make the message clearer  
Makes it easier to communicate



## Apps help seriously ill TD communicate

Motor neurone sufferer Nicky's brave battle

By SEAN RYAN Published: 23rd June 2013



**A GOVERNMENT TD struck down with motor neurone disease can now only communicate using mobile phone apps.**

Nicky McFadden, 50, has lost her voice but still serves her constituents in Longford/Westmeath thanks to advances in technology.

Her sister Gabrielle, a councillor, has spoken of the Fine Gael deputy's brave battle with the incurable condition. She said: "While her movement has not been affected, her voice is completely gone.

"But she still holds regular clinics. Technological advances such as smartphone apps have made it easier for Nicky to communicate.



Condition ... McFadden



# Creating the Right Environment

- Invite the person to use communication aids
- Ask re personal preferences e.g. aids they use, should you guess words, do they prefer using a 'translator'
- Keep their aids within easy reach – don't tidy them away!!
- Plug them in to charge
- Help them to sit upright so they can see the aid
- Provide a flat surface/platform/stand for positioning the device
- In group situations, ask the person permission to read out their responses if no synthetic voice output
- When leaving, ensure the person has access to a call bell system to signal if they need help



# Creating The Right Environment

- Allow extra time – your body language should suggest patience and calm
- Do not ask another question/change topic while person still responding
- Recognise that at the end of life the person may only have short durations of energy – do not force communication outside of these times, help family to identify them
- If a relative 'interprets'/finishes phrases for the person with MND, continue to direct your response to the individual

# The United Nations Convention on the Rights of Persons with Disability (United Nations 2006)

Article 21: Freedom of expression and opinion, and access to information

B. Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions

# SARAH EZEKIEL

Saturday, 15 February 2014

## Life Without a Voice



The image above isn't pleasant. Living with motor neurone disease (MND) isn't either, but after 14 years I am used to my condition. I no longer feel disabled, I work voluntarily for two charities and I know that I work well. I have been bringing up two children on my own since 2003 and they are now kind, thoughtful teenagers. I'm an empowered patient and manage my condition very well, with the help of my hospice doctor. MND forced me to become an employer and I manage a payroll for five carers. Coordinating care isn't always easy but I do it because I want to choose who works with me. I run my home alone, pay bills and have bank accounts like everyone else. I use Tobii eyegaze technology to do most things online and I love being independent.

I'm not saying all of the above to blow my own trumpet or to boast. I'm saying it because, every now and then, a situation occurs that makes me feel like the woman in the photo. Yesterday was one such occasion.



Social Media Ad Campaign 2009

### Website

<http://www.sarahezekiel.com>



"I use Tobii eye gaze technology to do most things online and I love being independent... every now and then, a situation occurs that makes me feel like the woman in the photo.

"Increasingly we are expected to listen to computerised voices when we call government departments and big organisations nowadays. The problem is that the staff at these places are not prepared to speak to someone using a computer as their voice."  
Sarah Ezekiel

<http://sarahezekiel.blogspot.co.uk/2014/02/life-without-voice.html>

# Care Experiences 1

"Jenny and her stepmother were glad they were able to spend a lot of time with him in hospital.

Even in units where staff are trained to care for people with paralysis and communication difficulties she feels they do not have sufficient time, and sometimes make assumptions that someone is less aware than they really are.

Her message to the health service is that staff need to be able to spend much more time and effort communicating with patients, reassuring them, finding out more about them, and talking about more than just their physical needs."

<http://healthtalkonline.org/peoples-experiences/nerves-brain/motor-neurone-disease-mnd/jenny-interview-01#ixzz30r5dXxsn>

# Care Experiences 2

"She found the loss of speech frustrating. Roger became her translator, and she used a combination of word lists, a magnetic note board, sign language and a Lightwriter to communicate. Sometimes they felt staff tried too hard to keep communicating directly with Teresa, when in fact she preferred to communicate through her husband.

They knew this was well meant, because staff want to guard against carers intervening inappropriately against the patient's wishes, but felt staff also needed to be sensitive to individual preferences and recognise she might find it stressful."

<http://healthtalkonline.org/peoples-experiences/nerves-brain/motor-neurone-disease-mnd/roger-interview-41#ixzz31iiB6uK0>

# Questions to Ask

All: what helps/makes it more difficult for you to communicate

Verbal communication - if speech not clear:

- Do you prefer to prefer to communicate independently or to have an advocate speak for you/help 'interpret'?
- Do you use any aids to supplement speech?
- How should I signal if I don't understand?

No verbal communication:

- What communication aids do you use?; if electronic device, do you have a back-up low-tech device?
- How do you signal yes/no?
- If I can guess what you are typing, would you like me to say the word/phrase?

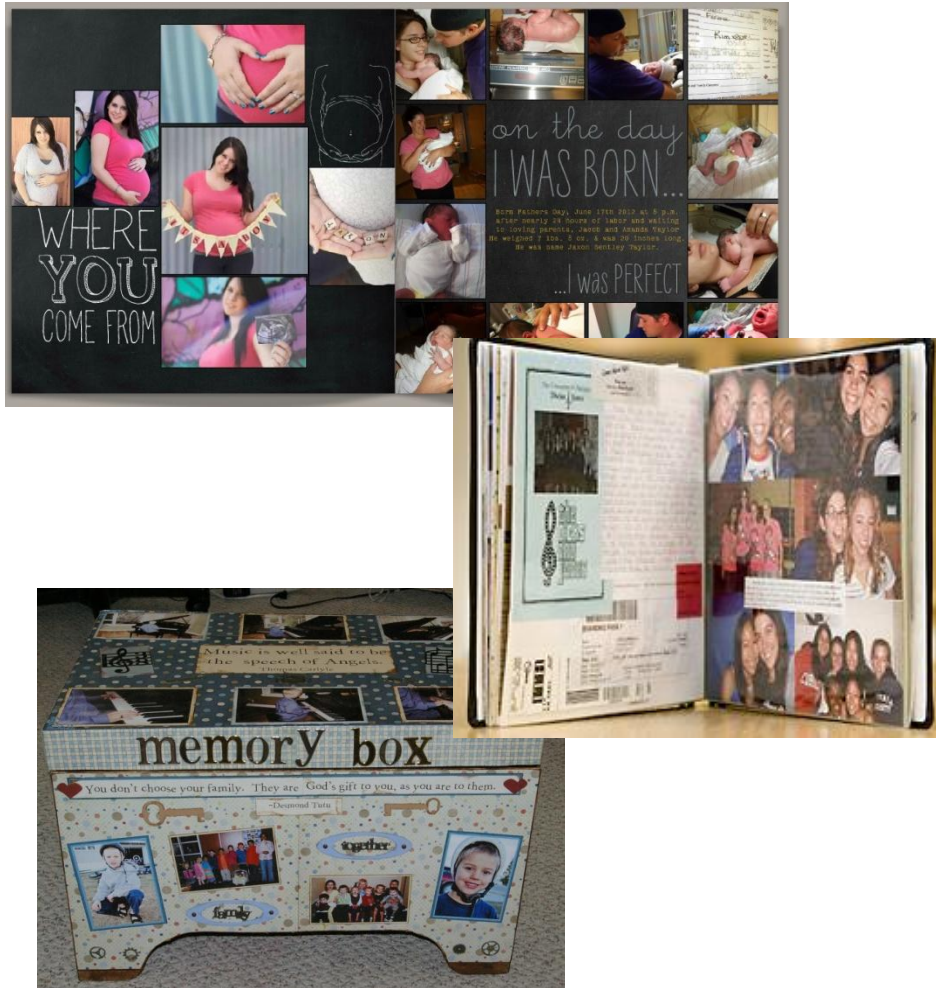
# Message Banking

- Record phrases while speech is still clear for potential use in the future
- Use for the speech output of pre-stored messages on AAC device
- Helps to maintain identity as a communicator
- Often 'trademark messages' such as a humorous remark the person frequently uses, affectionate names for family/friends, a unique greeting or a trademark delivery of a message
- Not compatible with all AAC devices





# Memory Books and Boxes



- Supporting a person with communication difficulties to collect memories:
  - helps to bring social closeness between person and family if assisting
  - help caregivers to understand person's personality and values
- Can contain anything the individual chooses – photographs, stories, mementos, letters etc.
- Becomes a legacy that is left behind for loved ones

# Eye Gaze Art



Sarah believes that  
technology gave her back  
the freedom of expression  
taken away by  
'this awful disease'

[www.eyegazeartists.com](http://www.eyegazeartists.com)

Sarah Ezekiel, who has MND,  
with her artwork created using  
a Tobii eye gaze device

# Dementia - What helps?

- Get the person's attention before you speak to them
- Don't rush around while you are speaking - face the person/encourage them to listen
- Always use their name and talk through daily events e.g. "Good morning John, breakfast time."
- Speak slowly and clearly
- Emphasise key words
- Use short sentences, keep things concrete
- Repeat important information
- Give frequent reminders of time, place and person e.g. "It's twelve o'clock, nearly time for lunch."

# Dementia - What helps?

- Give the person time to respond, they may need extra time to process what you said - don't ask another question immediately if there is a response delay
- Don't put the person on the spot e.g. "Are you hungry?" Instead, lead them e.g. "It's a long time since breakfast. I'd say you must be hungry. Let's have lunch."
- If the person goes off topic or starts to 'ramble', steer them back to the original topic
- If you are unsure what subject they are talking about, ask them to clarify or ask yes/no questions e.g. "Is this about where you are going today?"
- Use props, ask the person to point/write if it helps

# Summary

- No one communication system suits everyone – every person with MND has individual needs and preferences
- Choosing a system and customising it is part of maintaining control as MND progresses
- People accept AAC at different stages
- Attitude of communication partner has big impact on success and engagement – it's everyone's responsibility to make a person with communication difficulties feel 'normal'
- All AAC systems are slower than speech, all require extra time for communication

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