



Ray's Communication Journey

Challenges and Opportunities in the provision of AAC in Huntington's Disease

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Huntington's Disease

- A neuro-degenerative genetic disorder
 - affects muscle coordination – chorea (jerky, random, uncontrolled movements)
 - Problems swallowing & speaking
 - leads to cognitive decline
 - higher executive functioning initially
 - more noticeable problems with memory
 - dementia like symptoms.
 - Leads to psychiatric problems – can include
 - Anxiety / depression
 - Aggression
 - Reduced displays of emotion
 - Egocentrism
 - Compulsive behaviour – alcoholism, gambling etc.

- Typically referrals for AAC are not received until middle to late stage of disease process
 - Difficult to introduce AAC approaches and substantially decreases their potential effectiveness.
 - Early intervention means that AAC strategies can be implemented while learning ability is largely intact.

- Yorkston & Beukelman (2007) recommend:
 - Selecting simple systems that take advantage of previously learned skills.
 - Initiating training in AAC approaches early.
 - Avoiding techniques that require new learning.
 - Using strategies that provide opportunities to make choices and that employ memory aids.
 - Teaching yes/no systems and providing communication notebooks.
 - Relying on well-instructed communication partners.

Huntington's Disease & AAC

- Key principle in achieving effective communication is for the listener to consciously **accept the responsibility** for the conversation exchange.
- Person with HD often needs to rely on external cues and guidance from the listener to achieve communication.
- Whilst accepting responsibility for the exchange, the listener must not control the conversation.

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- Admitted to RHN from the Community - had been attending RHN Day Centre
 - Deterioration in balance, mobility and safety noted
 - Daily falls
 - House too small to use walker
 - Increasing use of wheelchair for long distances
 - Cognitive deterioration noted
 - Functional memory deficits
 - Impulsivity and reduced reasoning / judgement
 - Communication impairment
 - Moderate to severe dysarthria impacting on intelligibility

- However, many strengths:
 - Sociable individual
 - Highly motivated to communicate
 - Many social activities – highly motivated
 - Art
 - Pub lunches
 - Chapel
 - Regular outings and holidays
 - Music therapy
 - Orientated, able to recall daily routines

- Insight into his condition
- Responded well to physical and cognitive therapy
- Willing to use adapted equipment
- No evidence of depression

- Presents with a moderate-severe dysarthria (slurred speech)
- This has been gradually deteriorating – speech now approximately 30% intelligible.
- Understood well by those who know him well.
- Facial expression and gesture also affected by choreic movements which affect his communication further

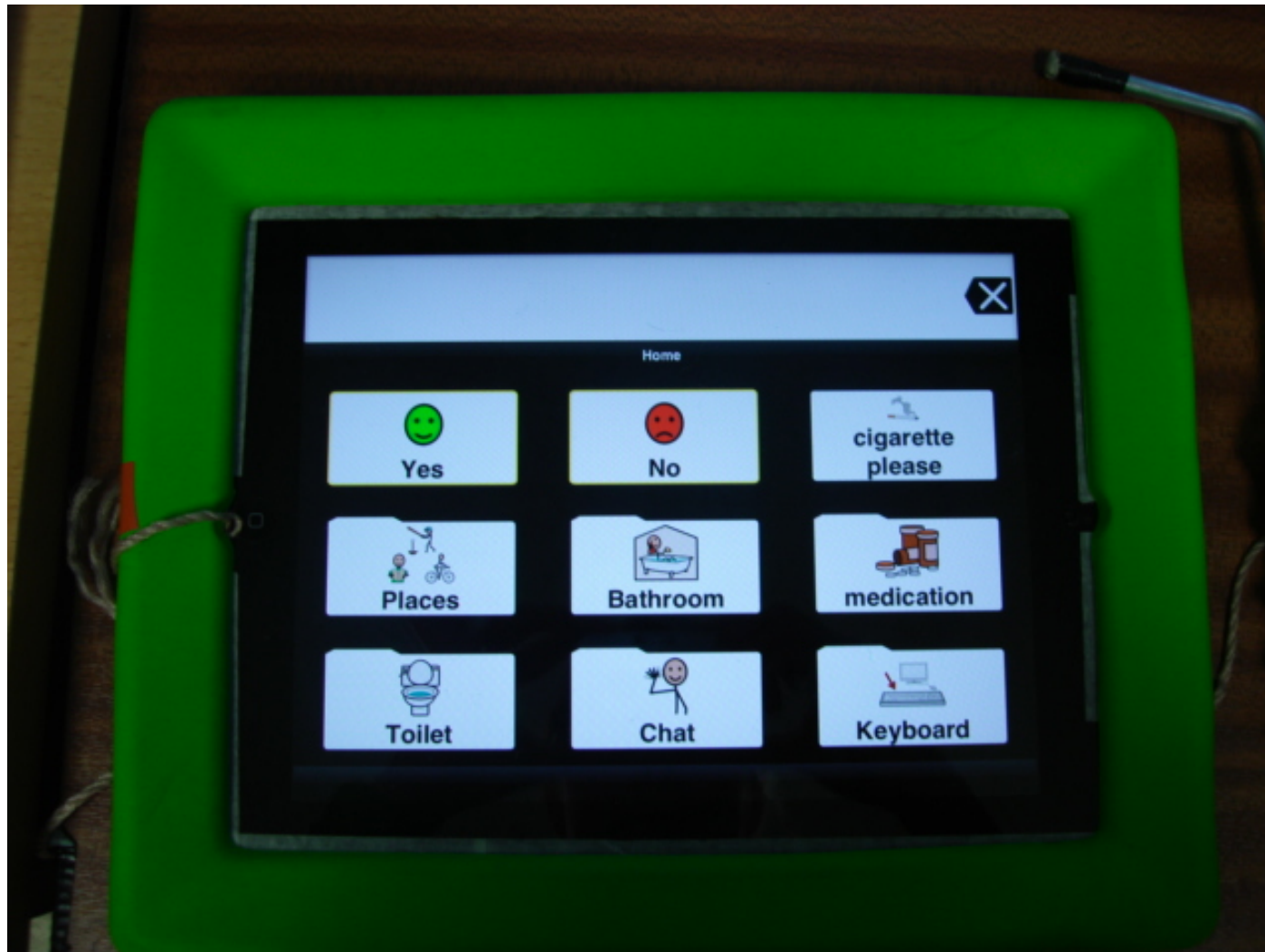
- Used increasingly at RHN
 - Recently been transferring these to high tech aids
 - Residents work with therapy team to develop

- Sahara Tablet – mounted on Daessy mount to manual wheelchair
 - Grid 2 design – alphabet and lifebook
- Issues
 - 8L – Mounting on to chair in a sensible location:
 - Interfered with self-propelling
 - Restricted access to footplates and brakes
 - Mounted on front upright bar of wheelchair chassis
 - Unable to move footplate out of way to stand transfer
 - Mounted on footplate hanger
 - Able to swing away but weight of device caused footplate to swing away violently – dangerous!

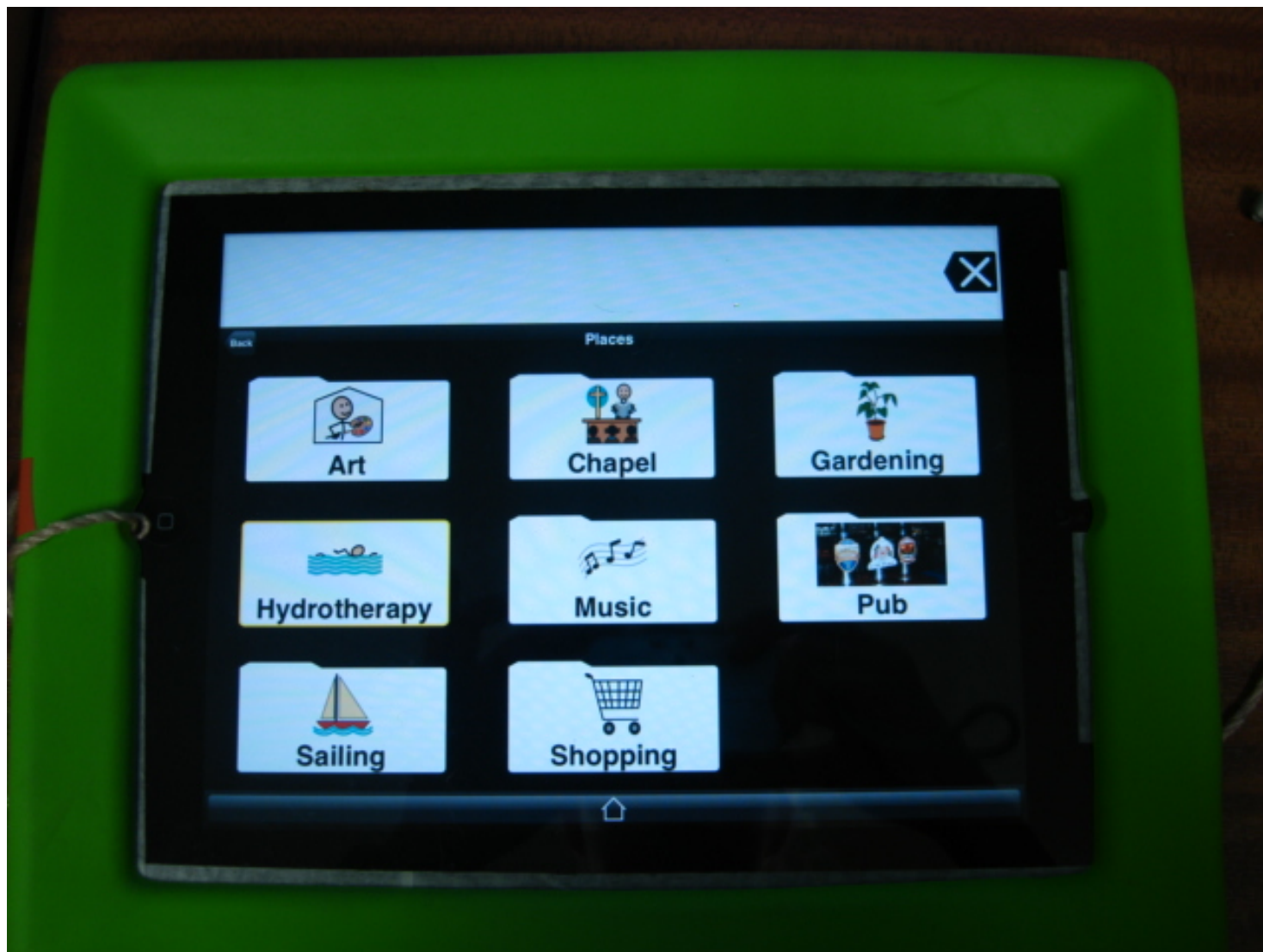
- Declined mounting so he could self transfer
- Rugged case on lap
- Prodder
 - Able to use fingers but reduced accuracy
 - Unable to hold standard prodder
 - RHN prodder – attached to case as falling on floor

- iPad
 - Design of Proloquo2Go grids
 - Uses 6 cell grid with sentences & short phrases
 - Vocabulary built up over time in joint sessions e.g. chapel, gardening, art.
 - Photos taken with iPad and added to life book cells – read a paragraph
 - Uses low tech book when iPad not available- exact copy of vocabulary in iPad, and contains alphabet chart
 - Difficulty swapping between apps
 - Passionate music fan
 - Tried Big Button App – not easy to access due to some small buttons (demo)
 - YouTube App with favourites used instead – does rely on Internet access.

Ray's iPad-homescreen



Activities page



- Issues
 - Impacted on by daily fluctuations in ability
 - Increased chorea and fatigue reduce accuracy and speed
 - Direct access may not always be an option
 - Funding – PCT refused
 - Would pay for App but not iPad because it provided more than just communication!!!

Video



- iPad
 - Increasing physical and cognitive impairment will impact on use
 - May require redesign of communication grids / interface
 - Continue to adapt prodder- issues with conductive material
 - ? Switch scanning

- Beukelman, D., Garrett, K. & Yorkston, K. (Eds.) (2007).
Augmentative Communication Strategies for Adults with Acute or
Chronic Medical Conditions. Baltimore: Paul H. Brookes
Publishing Co.