A Pilot AAC Programme

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Why Provide an AAC Service?

• Despite universal health care, there is no legal requirement to provide equipment for the communications impaired.

• Not only allows the user to respond to questions but allows them to INITIATE conversations.
  – Important for self esteem
  – More important for reporting changes to well-being, e.g. new symptoms, unrelated illnesses

• Suitable equipment and software can allow remote monitoring and remote consultations.
Dianne, 358 km away in Aberdeen.
The Challenge

• 400+ clients known at anyone time
• Deaths and diagnoses are approximately equal at around 180 per year

• How many need communication aids?
Known Facts

• Approximately 1.5% of caseload will have PLS
• Approximately 8% of caseload will have PMA
• Approximately 90% of caseload (360 people) will have ALS of which 25% (90 people) will have had bulbar onset and could possibly use a communications aid of some kind from diagnosis.
• 80% of those with limb onset, who live long enough, will require AAC help
Unknowns?

• How will a person’s abilities change as their disease progress?
• How many limb onset patients will require AAC?
  – i.e. Which limb onset patients will develop bulbar symptoms?
Averaged Data For Those Patients Who Died During The Period Of Study

Number of patients

Average Time from 1st Symptoms (months)

Diagnosis
- 13.5 months 1061 patients
- 17.7 months 980 patients
- 23.3 months 697 patients
- 27.7 months 341 patients
- 30.3 months 134 patients
- 42.3 months 50 patients
- 48.3 months 0

2nd Area Involved

3rd Area Involved

Gastrostomy
- 27.7 months 341 patients

Ventilation
- 30.3 months 134 patients
- 42.3 months 50 patients
- 48.3 months 0

Roche et al, Brain 2012: 135; 847–852
Estimated Requirements

• 90 bulbar onset + 80% of those who get to ventilation stage ~ 40 people

• Total ~ 130 people

Not everyone wants, or can use, AAC systems
Problems to Communicating and Using Communication Aids

- Lack of tongue/mouth control
- Poor breath control/weak voice
- Inability to hold writing implements
- Inability to use fingers or control arms to allow typing
- Posture
- The person’s abilities change with progression
- Progressive nature of the disease leading to people becoming locked in
Other Considerations

Previous knowledge and experience of ICT
Cognitive change
Fatigue

• These can influence ability to learn to use new equipment and software

• Therefore the earlier equipment is introduced the greater the chances of success.
Available Aids

• Voice Amplifiers
• I-Pads and other IOS devices,
• Windows/Linux devices e.g. desk top computers, laptops, tablets, netbooks
• “Pointing devices” Mouse, Headmouse, SmartNav
• Eye-gaze, e.g. Tobii PC EyeGo
Available Software

- The Grid 2
- Claro Software
- Tobii Software
- (E Z Keys much older and now superseded)
- Text to Speech programs and Apps
- Facetime/Cisco Jabber/Skype
Initial Inventory

- 18 iPads
- 6 touch-screen all-in-one PCs
- 4 laptop PCs
- 6 tablet PCs
- 5 SmartNav Pro4 cameras
- 1 Headmouse
- 7 Tobii eye-gaze units
Optimising Use

• Referral from SLT and CNS
• Assessment by specialist service
• Right voice and accent
  – Male or female
  – Most English language artificial voices have either Southern English or North American accents,
  – Completely alien to our client group
• Support while learning
Voices

• Standard voices are known as “SAPI” voices
• Acapella do a range of voices, but only 4 British voices – all English
• Cereproc has a number of UK regional accents available to purchase and download for all common platforms (IOS, Windows, Android)
• Offers a personalised voice synthesiser for £499.99
  – Important to many patients
Developments

• MND Scotland is actively participating in the development of assessment and referral pathways for people with MND
• Recently partnered with the MND Association at an All Party Parliamentary Group enquiry into AAC provision in the UK
• Continues to develop our own service and is recruiting a part time specialist to run the service.