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

4 Patients in Shetland

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

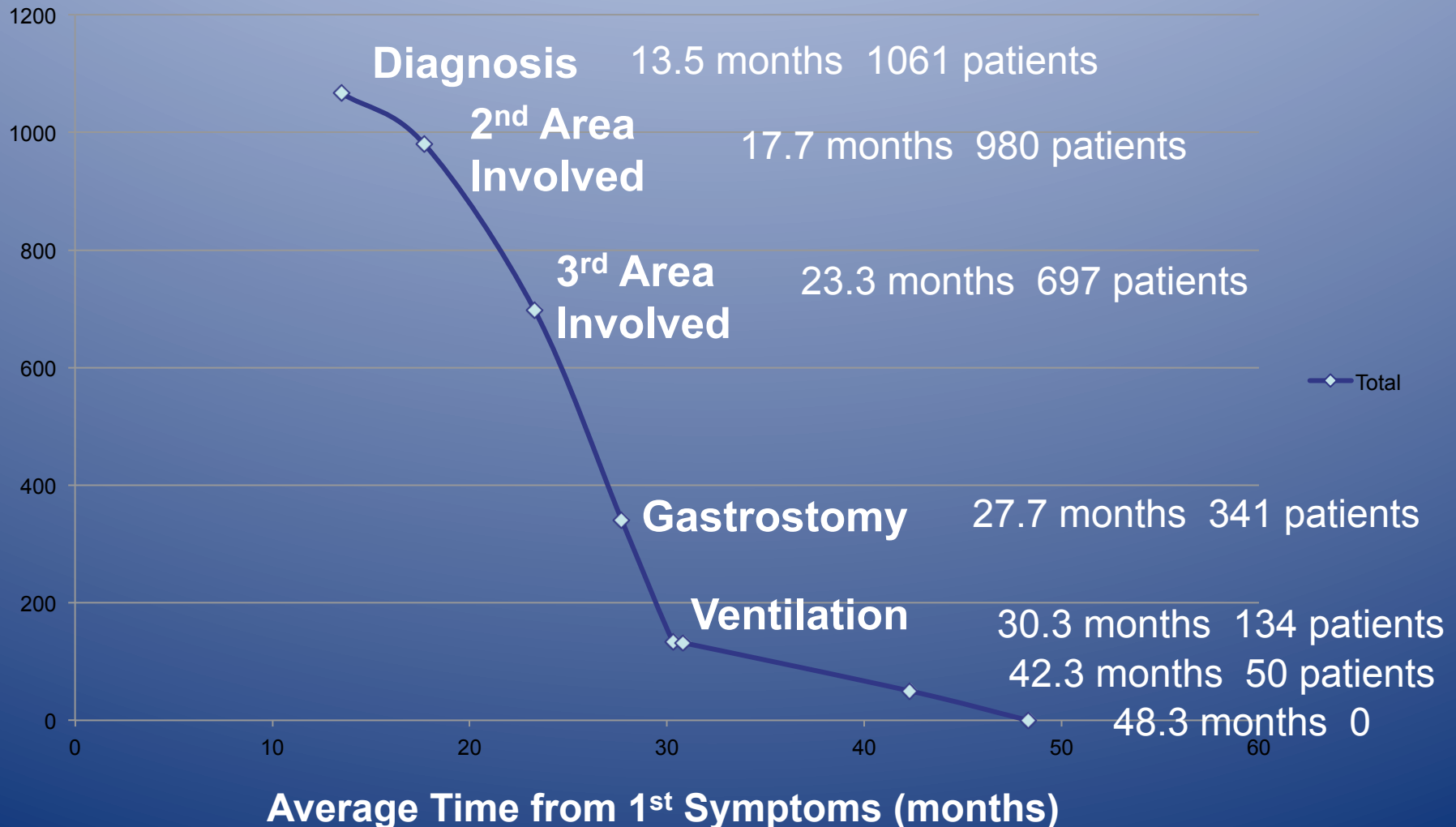- **How many need communication aids?**

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
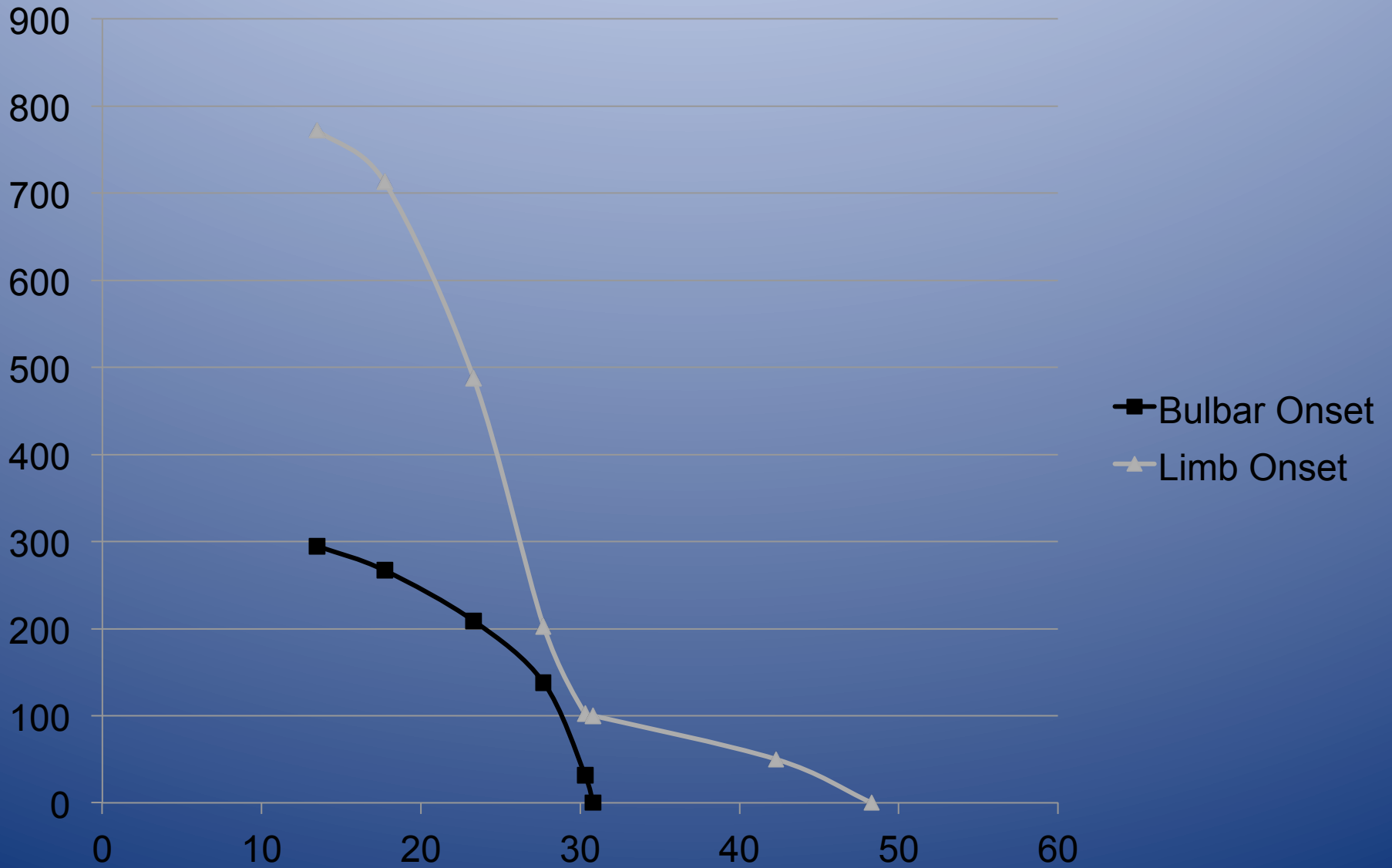
Unknowns?

- 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

Diagnosis — 13.5 months — 1061 patients

2nd Area Involved — 17.7 months — 980 patients

3rd Area Involved — 23.3 months — 697 patients

Gastrostomy — 27.7 months — 341 patients

Ventilation — 30.3 months — 134 patients

42.3 months — 50 patients

48.3 months — 0

Total

1200
1000
800
600
400
200
0

0   10   20   30   40   50   60

Average Time from 1st Symptoms (months)

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

After 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.