

A Collaborative Approach to Specialist Equipment Provision

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This case study outlines the iteration of equipment used by a 42-year-old gentleman with MND whose wish is to retain as much independence for as long as possible in order to spend quality and memorable time and experiences with his young family and friends.

This case study aims to share knowledge and experience of a number of different state-of-the-art technologies and how multidisciplinary teams, manufacturers and charities can work together to achieve this.

During the 4.5 years since being diagnosed with MND, our client's mobility and functional movement has gradually deteriorated. He has always been motivated to retain as much independence for as long as possible and this has been achieved through provision of a range of communication aids, specialist switches and state-of-the-art powerchair driving control systems.

Whilst initially working independently, our Wheelchair Service and the regional AAC Service started working together towards the end of 2023 to investigate alternative means of switch input. Our client's functional movement was rapidly deteriorating and both services needed to find alternative switch inputs to allow our client to retain independent use of his communication aid and powered wheelchair.

Due to the rapid deterioration, both teams have had to work hard and fast to secure funding for the specialist equipment and we have been grateful for the financial support of a number of charitable organisations. (MNDA, Challenging MND) Due to the nature of the disease, once a solution is found, it is often not in place for long before a further deterioration in function demands yet another change in equipment. (Brenan, Gardiner and Narasimhan 2022) He has progressed from simple buddy buttons to ultra-light switches and further to Electromyography (EMG) and gyro-tilt switches. Joystick choice started with a standard shaped knob, but was soon replaced with switch control, then the Vigo headset and more recently the Ability Drive eyegaze system. This happened within a period of 18 months.

There have been other challenges along the way which have influenced how the client was able to access these switches, having implications for both communication and powerchair equipment choices.

For example, the full-time use of a BiPAP machine, restricted switch and headrest placement, and an elective tracheostomy, which whilst benefiting the client with his breathing, meant he no longer had forwards/backwards movement of his head.

The current setup includes the following equipment

- TDX Powerchair (powered tilt, recline, lift, ELRs) [Invacare Ltd]
- Ability Drive (Rahana Life)
- Tellus i6 Communication Aid with Mind Express Software [Jabbla]
- G-Click switch [Celtic Magic]

Introducing new pieces of equipment into the Wheelchair Service has involved multiple risk assessments, working closely with manufacturers and other health professionals and completing many Linux programming changes.

Through each iteration of the control system, the risk assessment was reviewed and the client's driving skills re-evaluated to ensure safe driving around his home, whilst also maintaining the ability to use his communication device to communicate effectively with his family and carers and access computer control.

The client reports that the current setup with the Ability Drive software has enabled him more freedom and ease of driving in his home, in his garden and in the local community. Driving the wheelchair now uses less energy and exertion meaning he can stay seated longer in his chair and socialise with his family.

This journey has shown how quickly equipment needs change with progressive conditions, and the importance of specialist services working collaboratively and promptly to ensure provision is client-centred, time-appropriate and funding options explored thoroughly.

Our client commented that he wishes he accessed alternative switches sooner than he did; with lots more options in our arsenal and an increased awareness of available options on the market, we will now be better equipped to support future clients with similar complex needs.

Whilst the initial costs were high, we are confident that these setups will be used many times over and would advise other Wheelchair Services to make the investment now to benefit this group of clients.

References

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