Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill

Stage 2 Amendment on the provision of voice equipment: Call for Views

Parkinson’s UK

Parkinson’s UK strongly supports the principles behind this proposed amendment, which aims to ensure that people who require communication support are able to receive it without delay, and are effectively supported when learning how to use it. We welcome Scottish Government’s commitment to create a legal right to communication support.

We are also broadly supportive of the position laid out by the AAC Collaborative in their submission to the Committee, and the amendments proposed by the Royal College of Speech and Language Therapists (RCSLT) to ensure that the legislation gives effect to the AAC Collaborative’s views.

Parkinson’s UK would like to highlight the following issues:

Unmet need

A recent research report by the collaboration Communication Matters\(^I\) suggests that people with Parkinson’s account for over one fifth (22.7%) of all the people who could benefit from augmentative and alternative communication (AAC) in the UK.

Issues with communication are very common in Parkinson’s, with speech sometimes affected at diagnosis, and issues typically become more significant as the condition progresses.

Clinical guidelines state that people with Parkinson’s should have a speech and language therapy assessment at diagnosis, and at regular review appointments, in order to address issues with communication and swallowing.\(^{ii}\)

But there is unmet need in terms of access to SALT support, and AAC for people with Parkinson’s. In a large scale survey of over 750 people with Parkinson’s and carers in Scotland, about half had never seen a speech and language therapist.\(^{iii}\) Further, the Communication Matters report\(^{iv}\) identified that there was a large unmet need for AAC particularly in relation to people with Parkinson’s and those with dementia, which warranted further investigation.

We welcome legislation that will encourage NHS Boards and to examine their practice and the provision of AAC and communication support, as this could be a trigger for meeting needs that are currently unmet. However, the evidence suggests that meeting the duty to provide AAC and communication support will require resources in addition to those currently identified by the Scottish Government.
We would seek clarification that a legal duty on NHS Boards will have the effect of including services provided by Integrated Joint Boards in the post-integration landscape.

Support as well as equipment

Parkinson’s UK would like this amendment to include a clear right to support with communication as well as equipment.

Some people with Parkinson’s use AAC equipment to enable them to communicate. Commonly used aids include voice amplifiers, IT based systems and word boards. Technology is moving fast, but it is important that the legislation reflects the use of both highly engineered, powered ACC, and low tech ACC which currently accounts for most ACC use.

We welcome the recognition in the amendment that people using ACC often require support from speech therapists to be able to use equipment to its full potential, to build confidence in using it, and to work with families, friends and others to understand the equipment used and increase the effectiveness of their communication with the person using AAC.

Support is especially important for people whose cognition is affected, for example, people with Parkinson’s with dementia offered opportunities to communicate by using low tech solutions, such as Talking Mats, word and symbol boards.

But there are also evidence-based therapeutic approaches that can enable people with Parkinson’s to achieve improvements in their speech without using ACC, such as Lee Silverman Vocal Technique (LSVT), which is an intensive SALT intervention developed specifically for use in people with Parkinson’s. LSVT has been successfully used in Scotland, and we would like to see it made available more widely. We believe a greater emphasis on communication support in the amendment would help people with Parkinson’s to access essential communication support, with or without ACC.

Suggested Amendments: Parkinson’s UK believes that support should be highlighted more strongly, by adding text to the amendment as follows (additions in blue underline)

PART PROVISION OF COMMUNICATION EQUIPMENT AND SUPPORT

Duty to provide or secure communication equipment and support –
46A Provision of communication equipment and support
(a) communication equipment, and
(b) support in using that equipment, and /or
(c) speech and language therapy

to any person who has lost their voice or has difficulty speaking
These changes would have the effect of broadening the policy intention of the Amendment to ensure that people who can benefit from speech therapy can benefit from the right to communication support, as well as those who need to use AAC.

Support with swallowing as well as communication

Parkinson’s UK has some concerns that the Amendment’s focus on communication support may have unintended consequences for other parts of the Speech and Language Therapy services which are very important to the wellbeing of people with Parkinson’s and those with other conditions and impairments.

A recent study suggests that over 80% of people with Parkinson’s will develop dysphagia (swallowing problems) in the course of their condition\(^1\), and those with other progressive neurological conditions, dementia and stroke may have both swallowing and communication affected. SALT assessment, support and advice for people with swallowing issues have an essential role in preventing pneumonia and choking, and prolonging life.

It is essential that speech and language therapists are available to support people with swallowing issues as well as communication, so it will be important to make sure that service planners in NHS Boards and Community Health and Care Partnerships maintain the resource for dysphagia alongside the communication support needs outlined in the amendment.

About Parkinson’s

About 10,000 people in Scotland people have Parkinson’s. About one in ten of these people are classified by ISD as at high risk of hospital admission in the next year.\(^2\)

Parkinson’s is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson’s often find it hard to move freely. Their muscles can become stiff and sometimes they freeze suddenly when moving. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on peoples’ day-to-day lives. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden ‘freezing’.

Parkinson’s UK

\(^1\) Communication Matters (2013) Communication Matters Research Matters: an AAC Evidence Base research project – final report  
http://www.communicationmatters.org.uk/shining-a-light-on-aac

\(^2\) NICE (2006) clinical guideline 35, Parkinson’s Disease: Diagnosis and management in primary and secondary care.

\(^3\) Parkinson’s Disease Society (2009) Life with Parkinson’s Today: Room For Improvement  
http://www.parkinsons.org.uk/content/life-parkinsons-today-room-improvement
http://www.communicationmatters.org.uk/shining-a-light-on-aac


ISD SPARRA figures predicting a greater than 50% risk of hospital admission in the next year. ISD (2011) SPARRA database: Number of patients in Scotland at risk of emergency admission / readmission, in the period 1st July 2011 - 30th June 2012, by risk probability group, and those with an admission history of Parkinson's Disease. Unpublished data. Reference: /conf/sparralive/Ad Hocs/Parkinsons UK