

## Giving Voice to People Affected by Parkinson's - webinar Wednesday, 15<sup>th</sup> June 2016 13.00 - 13.45

### How can you support patient and family/carers when they are on denial in accepting person's deterioration on all areas of occupational performance?

#### **Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

Denial is a natural reaction of many people to diagnosis of a major health condition. It takes time to understand and to adjust. Explore what the person/family understands about the diagnosis and what it implies. There may be unfinished work to complete about education about Parkinson's and reflecting on implications for lifestyle and health.

Facing up to the reality of the progressive nature of Parkinson's can be equally challenging, especially if there was a honeymoon period when things didn't seem to change too much, drugs seemed to be helping, and no major changes to lifestyle were required. Explore and educate about how Parkinson's progresses, how each person can be different, how different symptoms change at different rates, about how there is always something that can be done to ameliorate the effects of changes.

You could discuss how they feel the person with Parkinson's managed with a range of communication situations/ tasks before they had Parkinson's, then compare that with a while after they received the diagnosis. Ask how the person manages now with the same tasks/ situations, and be realistic in describing how they are managing. Draw out the contrasts and discuss together why they might be so – but also highlighting what can be done to give support to help with the changes.

Talk through valid and reliable assessments you have carried out. Explain what they are meant to test/show and how people without Parkinson's would be expected to score. Discuss cut off scores and what a lower score would indicate.

Not all of this needs to fall to the speech language therapist – Parkinson's UK have the slogan that no one should face Parkinson's alone – via their website and via their network of education and support workers, Parkinson's nurses and so forth, they offer support precisely for people in this situation. The wider multidisciplinary team may also be able to offer support – especially where denial might also concern other motor, mood, cognitive etc. changes.

If the denial is specifically around occupational issues, then it sounds like dialogue with the employer may also be necessary, to talk about Parkinson's in general as well as implications for the individual concerned. Redeployment within the organisation or concessions around (some) working practices may be a positive step.

### Is there a Parkinson's Champion? I know there is a Dementia Champion

#### **Nick Miller, Professor of Motor Speech Disorders, Newcastle University:**

Not in exactly the same guise as the Dementia Champion. Parkinson's UK is the major champion at organisational level for people with Parkinson's. They have links to the Westminster and devolved parliaments as well as the Department of Health. There is an All Party Parliamentary Group for Parkinson's in the Westminster parliament. Parkinson's UK has regional and local workers who support education, advocacy for people with Parkinson's and links to other organisations within and outside the NHS.

#### **Clare Worrall Hill, Professional Engagement Manager, Parkinson's UK:**

Although there is not a full programme that mirrors the Dementia Champions programme, there are a small number of areas – mainly acute trusts, who have implemented a programme for staff to train up as Parkinson's Champions. These programmes are still in very early stages, and the Service Improvement Team

at Parkinson's UK will be working with the Parkinson's Nurses running these programmes so we can collate some information to share with the [UK Parkinson's Excellence Network](#).

In the meantime, there are [Parkinson's Nurses](#) in 80% of trusts and health boards across the UK. The nurses are vital in providing care, but also in educating other health and social care professionals about the specific needs of people affected by Parkinson's in different healthcare settings. [Parkinson's UK](#) have pump-primed these posts and our aim is that everyone affected by Parkinson's will eventually have access to a Parkinson's Nurse.

### **What therapy other than LSVT is offered by SLTs where LSVT is not available or suitable?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

In term of impairment directed therapy 'attention to effort' therapies have been used, long before LSVT came on the scene. It was from this approach that LSVT was derived/ systematised. So, focusing on the sense of effort applied when speaking is definitely a method that brings positive returns.

Rate control (in the direction of slowing rate, even if the person with Parkinson's already speaks slower than normal) has been successfully employed – alongside making sure that sounds/syllables are given their full weight (so combined with stress and intonation work) and word boundaries are clearly heard. For this reason some people have paired rate work with what has been variously termed 'clear speech', 'over articulation', 'overemphasizing sounds' – the key component being that exaggerating and putting full sense of effort into speech production is encouraged. Indeed the impression of speaking too fast may arise from an auditory illusion – the lack of stress and intonation changes and loss of word boundaries is associated by listeners with speeded speech.

This does not mean working through sound by sound, and certainly not sounds or syllables in isolation. Minimal pair work here can help though – practicing word pairs/ phrases where a key contrast has to be signalled – e.g. he picked up the bap vs picked up the bat; give me the big pea vs big piece; A long list vs long wrist; carry this bat vs this back vs this bag, etc. give me tea and sunshine any day vs sea and sunshine; lady vs lazy, shopping vs chopping; shave vs save, save vs safe etc. Prosodic contrasts are also important to practise – Yes? Vs yes! Do YOU like sugar vs DO you like sugar vs do you like SUGAR. He likes sugar? He likes sugar! A green house, a greenhouse etc.

Because a factor in Parkinson's is reduced awareness of sense of effort, then a lot of work on recalibrating this sense is required – visual, auditory feedback can be useful to give a target level to aim form and maintain.

The key components, certainly as regards impairment directed work, is that it should be regular and intensive in order to soundly fix new habits. After that regular review is still required to assure maintenance of gains through supporting the person to apply outside of clinic what they have acquired in the 1:1 situation.

There are various apps these days that can be used to aid transfer out of clinic for maintaining rate control, loudness control and similar.

### **My pupil with Parkinson's understands that speech and singing will be facilitated if he lowers his Larynx when speaking or singing. Is this standard practice with Parkinson's?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

This is a recommendation often used by singing teachers to increase range of pitch and loudness and improve resonance. It's not something that has been systematically examined in relation to voice loudness in Parkinson's. Raising and lowering of the larynx happens automatically when we speak/ sing/ swallow. Focusing attention on just one isolated part of the voice production process can prove negative (like asking someone learning to dance just to focus on one aspect of the posture of their right foot – ignoring the left one, the legs, body posture, movement etc.). Laryngeal movement is linked to respiration, so ideally the focus should be more on breath capacity and control rather than forcing the larynx down or up.

The research evidence for whether singing improves speaking in people with Parkinson's is mixed. There is

definitely a psychosocial gain, maybe some improvements in breath capacity, but whether there are lasting changes to loudness and intelligibility is unclear – some studies claim yes, others no.

**I am an LSVT practitioner operating in the Fens. Logistically it is extremely difficult for some of my patients to access therapy due to high mileage required for every session. What is the RCSLT's position on telepractice?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

There are several studies from Britain and other countries demonstrating that equally good results can be obtained delivering speech and language therapy/ LSVT for people with Parkinson's over the internet as are obtained face to face. The same applies to carrying out assessments/ reviews of speech performance across the internet.

See the RCSLT's information on technology and telehealth:

[https://www.rcslt.org/cq\\_live/resources\\_a\\_z/tecnology\\_for\\_slts](https://www.rcslt.org/cq_live/resources_a_z/tecnology_for_slts)

**How to support voice in Parkinson's without being trained in voice disorders, what is best practice?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

The voice changes in Parkinson's are not the same as those which come from say vocal nodules, laryngeal inflammation, muscle tension dysphonia etc. They are neurogenic and so the interventions of choice are those that modify the neuromuscular aspects and planning/ initiation for voice. The basis of the voice changes in Parkinson's is the under-scaling of effort for subglottal driving force and balance of this with vocal cord tension. Thus therapies that focus on the sense of effort and internal monitoring of effort and outcome (loudness) are ones that are likely to work best and for which there is strong evidence that they do indeed work. You don't need specific training as a voice coach to carry this out. If you are carrying out the branded LSVT programme then you are supposed to have undertaken a recognised LSVT training course.

**I work for a memory service and we have increasing referrals for people with Lewy Body or Parkinson's type dementia. Are there any strategies that can help given their impaired cognitive function?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

On the one hand strategies need to be applied that are in common with anyone with a form of dementia. Then there are the strategies directed at the specific characteristics of Lewy body dementia (e.g. the very wide fluctuations that can occur; relatively spared memory early on but great difficulties with attention; auditory and visual hallucinations etc.).

As regards speech and voice, what is likely to work better are therapies that rely on one simple clear instruction – so think louder, focus on your voice effort as opposed to 'don't forget to keep your lips closed, remember to take a big breath in and start phonating when you breathe out' etc. The more complex the instruction, the more there is to remember to do, the less likely the success that can be expected.

**Clinical question - what advice/strategies are clinicians offering to their PD patients who have trouble initiating conversation/freezing/losing train of thought as this is often a worry expressed by my PD patients?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

Attention to effort, making a conscious effort to begin phonation/speaking, is a help. Many people though are helped by cuing of one form or another e.g. a regular beat to entrain to help start movement. There is plenty of evidence from physiotherapy that this helps and evidence too from speech studies. Cues might be delivered visually or auditorily or tactilely.

Two strategies that might help with train of thought are:

a) If this is for a known, predictable challenge – e.g. a doctor's consultation, sorting something out with the bank – then preparing/rehearsing beforehand what is likely to be needed by way of questions/ answers, words and sentences may help.

b) As part of the problem in keeping up with conversations is speed/complexity of processing, then education

of interlocutors around giving time to the person with Parkinson's and advice around what intervening strategies (giving them the word, completing or definitely not completing sentences) are preferred or work can also be explored.

Advice/ work with interlocutors around giving of information in small manageable chunks with check backs about comprehension vs avoiding long rambling complex narratives can also assist.

### **At what stage in the development of Parkinson's is voice distortion likely to occur? What percentage of Parkinson's patients suffer significant distortion?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

People with Parkinson's may notice changes to their voice from the earliest stages – it may even be the first sign that something is amiss, long before diagnosis with Parkinson's. In large scale surveys up to 90% of people with Parkinson's report their voice has changed. When the alterations turn into a problem is of course a different matter. There probably isn't a simple answer – a) because rate of deterioration is different for different people; b) different individuals are able to compensate to a greater or lesser degree; c) it depends very much on what they use their voice for, where, when and how much and how central it is to daily living.

On the plus side, modification of voice production is one of the easier goals to achieve in rehabilitation for Parkinson's, so even when it does start to pose a problem, improvement is possible.

A couple of references that may be of interest here:

Miller, N., Allcock, L., Jones, D., Noble, E., Hildreth, A. J., And Burn, D. J., 2007, Prevalence and pattern of perceived intelligibility changes in Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry*, **78**, 1188–1190.

Ho, A., Iansek, R., Marigliani, C., Bradshaw, J. And Gates, S., 1998, Speech impairment in a large sample of patients with Parkinson's disease. *Behavioral Neurology*, **11**, 131–137

### **How can we address the needs of this population in a more integrated way?**

**Clare Worrall Hill, Professional Engagement Manager, Parkinson's UK:**

Communicating (within the boundaries of confidentiality!) with the multi-disciplinary team around a person is vital in providing a better, integrated approach to addressing the needs of people affected by Parkinson's. As well as the health and social care professionals, ensure that the Third Sector is integrated into your approach, if it is not already. Organisations, like Parkinson's UK, can often provide support and services that might not be readily available through other channels, for example, dedicated [Local Parkinson's Advisers](#) who can work with people to provide information and support in their own homes.

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University:**

In a broad sense, by making sure the multidisciplinary team is joined up and moving in the same direction, and that within the team the voice of the person with Parkinson's is heard and provides the direction for the team's efforts.

On an even broader stage, at societal level, then clearly the answer is around education about Parkinson's and provision in daily living for people with Parkinson's as a natural course of events – something the Disability Movement has been aiming to achieve for decades, not just for people with Parkinson's.

Focusing more narrowly on communication, better management will come from realising that communication changes and challenges in Parkinson's are more than just a quieter voice. Changes to nonverbal aspects of communication, difficulties with attention, attention switching, speed and complexity of processing are all factors suggested to be key to address too. Getting into and staying in conversations needs to be addressed. The awareness of the person with Parkinson's for what changes have taken place (e.g. their voice is quieter) is key to integrating speech interventions too. And, gains in clinic are likely to be in vain unless a programme of transfer and maintenance of gains outside of clinic is implemented.

Because the picture evolves over the course of Parkinson's, then a regular (at least 6-12 months) review policy is recommended to make sure that any communication problems emerging are tackled before they get out of hand.

To chart change, and plan intervention, valid and reliable assessments of key communication variables are essential. Surveys suggest some of the assessments that speech language therapists routinely employ are either not the most appropriate as regards measuring what should be measured or/and do not measure in a valid and reliable way; also, assessments need to go beyond the narrow focus on voice.

### **Are different SLT interventions used for speech as opposed to swallowing difficulties in Parkinson's patients?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

Yes.

There is little evidence to date to support carryover between speech and swallowing therapies in Parkinson's. This is not surprising – they are functionally completely different tasks. Even though they might employ some of the same muscles they employ them in a completely different fashion.

Further, there is little evidence specific to Parkinson's on which swallowing therapies are most effective.

Expiratory muscle strength training has good evidence to support its efficacy for airway protection in Parkinson's. rTMS has some preliminary positive indications too. Timing meals to coincide with peak dose effects for medication is also advantageous for some people.

Speech treatment, at the impairment level, focuses on the attention to effort and recalibration of what a loud (enough) voice feels like to produce.

### **Is there an alternative therapy to LSVT for people affected by Parkinson's?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

See questions 3, 6, 8 above

### **How can Parkinson's UK and the Excellence Network support Parkinson's research?**

**Clare Worrall-Hill, Professional Engagement Manager, Parkinson's UK**

Parkinson's UK is the research and support charity for Parkinson's. Our [research team](#) is very proactive and carries out and supports research and clinical trials into Parkinson's; and new and better treatments and therapies. The [GDNF Trial](#) is the most recent example of a major clinical trial. As well as funding research projects, we also support a [community of Parkinson's researchers](#) at all levels from student upwards, and coordinate a vibrant [Research Support Network](#) of people affected by Parkinson's who wish to contribute to or get involved in research.

Several leads and members of the UK Parkinson's Excellence Network have worked with us, or been supported by us in their research; and the Excellence Network also has a Research Thematic Working Group to take forward this area within the network.

Another research study that Parkinson's UK will be keeping updated about is the PD COMM trial currently being recruited for by Birmingham Clinical Trials Unit (BCTU). This study will compare LSVT with standards NHS SLT, and a control group. BCTU are keen to hear from SLT departments who are interested in taking part in this trial: [PD-trials@bham.ac.uk](mailto:PD-trials@bham.ac.uk)

### **How can we better support people with Parkinson's and dementia?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

See questions 7 and 10 above.

### **What kind of support can a patient get from Parkinson's UK?**

**Clare Worrall-Hill, Professional Engagement Manager, Parkinson's UK**

Parkinson's UK work to ensure that no one faces Parkinson's alone. We aim to get people the right support when they need it, and to take control by getting informed, staying positive and keeping connected. There are a number of ways that we can support people affected by Parkinson's and the people around them, including a [helpline](#) (0808 800 0303), [Peer support](#), [Parkinson's Local Advisers](#), [Local Branches](#) (including Young Parkinson's groups), a [self-management programme](#), [Parkinson's Nurses](#), [information resources](#) and also a well-used [online forum](#).

**You mentioned it is important to include strategies for transfer and maintenance of gains into therapy. What are some of the barriers to this and can you suggest any ways of supporting transfer and maintenance?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

Make sure that all barriers to communication have been assessed and addressed in the first place – not just the quiet voice, but intelligibility, receptive and expressive prosody, language and pragmatic issues too, getting into and staying in conversations, nonverbal as well as verbal communication.

Assure that practice has covered how speech/ voice will be employed in day to day situations with day to day speech/language content, and not been relying on drills that have no or tenuous relationship to speech in daily living. Make sure therapy has trained speech alongside competing tasks – e.g. walking and talking, talking and thinking – and in multi-talker contexts, not just one to one.

Make sure that methods in therapy employed the tenets of motor learning that are known to facilitate maintenance and generalisation – issues around intensity, frequency of practice, schedules of feedback, feedback on performance, internalisation of monitoring etc.

Have regular tasks and goals outside clinic after intensive therapy has finished. Have top up groups. Have buddies 'on the outside' who are trained to listen out for and remind the person with Parkinson's if they not remembering skills learned. Use apps that can monitor and give reminders, e.g. if loudness level is dropping below a certain threshold. Have regular phone reviews, or spot checks phoning up the speaker to see if they are employing their new voice/speech.

**You said swallowing can change right from the earliest stages in Parkinson's, but that it may not be noticeable to the person with Parkinson's or their family for a long time. How should one best go about assessing if an underlying swallowing problem is affecting daily living and possibly the person's health?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

Even though swallowing changes can be detected from the earliest stages the person with Parkinson's may not notice them – partly because of the same underlying issue as not noticing speech/voice changes or other changes to their performance; partly as the brain does spontaneously compensate for some changes for a while, partly as the person with Parkinson's may be unconsciously making adjustments to the slowly altering status – e.g. by eating more slowly, chewing more, taking smaller mouthfuls, avoiding certain food etc.

Asking the question 'do you have any swallowing problems' is therefore unlikely to elicit a reliable answer. Instead questioning should be around the extent of other behaviours likely to disclose deteriorating swallowing, even if the person is not aware of these changes or does not link them immediately to swallowing:

- Do you feel you have to be careful when swallowing thin liquids? (e.g. tea, coffee, juice, beer)
- Do you feel you have to be careful when swallowing thick liquids? (e.g. yoghurt, custard, thickened gravy)
- Do you feel you have to be careful when eating soft foods? (e.g. mash potato, scrambled egg)
- Do you feel you have to be careful when eating hard foods? (e.g. tough meat, raw fruit or vegetables)
- Do you feel you have to be careful when eating dry foods? (e.g. biscuits, toast)
- Do you have to specially prepare food before you can eat it? (e.g. liquidize it or mash it up)
- Do you have to avoid some foods because you find them difficult to eat or drink?
- Does food ever 'go down the wrong way' or make you cough when you are eating or drinking?
- Do you find food left in your mouth after you have finished eating?
- Do you ever have problems keeping food or drink in your mouth?

Is chewing of food a problem for you?  
Are you less happy now about eating in public?

These questions and the scoring guidelines can be found in Noble E, Jones D, Miller N (2015) Patient reported changes to swallowing in Parkinson's disease, *Int J Therapy & Rehabilitation*, 22(12), pp573-581, but there are several similar questionnaires around.

As regards health related quality of life and swallowing the key features to look out for are unexplained or increasing number of chest infections, dehydration, weight loss, malnutrition. Reports of regular cough on drinking/eating or after eating are also behaviours to monitor.

#### **What are the most suitable outcome measures for speech therapy with people with Parkinson's?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

As the central aim of therapy is to increase intelligibility and participation in society then the central ones have to be a validated, reliable diagnostic intelligibility assessment (so not brief rating scales or other methods with poor inter- and intra-rater reliability) and valid measure of participation and communication related social quality of life. Examples of the latter might be the Dysarthria Impact Profile (Walsh et al) or the CPIB (Baylor et al).

#### **Can you mention any language assessments that might highlight possible changes to language as opposed to speech and voice?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

People with Parkinson's manage well on standard offline aphasia tests. They don't have aphasia.

Problems mount with increasing speed and complexity of processing.

Switching mental sets is also an issue. Name as many animals as you can think of, the person with Parkinson's probably doesn't do too badly. Name an animal then a food (dog, beans, tiger, sausage, cow, peaches etc.) in succession or words starting with F then with S, and disproportionately more difficulties can emerge.

Some studies report more difficulties with literal vs metaphorical meaning – he's a real fighter, leading someone up the garden path.

Differentiating meaning by prosody may prove problematic – they're hunting dogs (the hunters are out looking for dogs; vs they are using dogs to hunt), psychiatrists should not be disturbed (don't interrupt them, they need to be of balanced mind), very funny spoken with laughing vs ironic tone.

So, assessments that tap these factors would be the ones to choose.

#### **Does deep brain stimulation improve speech outcomes?**

**Nick Miller, Professor of Motor Speech Disorders, Newcastle University**

No. At best outcomes for speech are neutral, at worst speech deteriorates. Clearly though DBS can be of benefit for limb control/ balance. There is a discussion to be had therefore with patients about the balance they would wish to achieve between improved limb control vs possible negative effects for speech.