

Report for Berkshire West Neuro Local Implementation Team

Living with speech, language, swallowing and communication impairment in Berkshire West, for those affected by Stroke, MS and MND.

Findings from a focus group held at Padworth on 22nd October 2012

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1. Executive Summary

Only three of the many conditions that may require SALT services are covered by this report. Reduction in or loss of ability to swallow or communicate can arise suddenly or progressively. This requires a diversity of specialised services, sometimes needed over a long period of time. The care pathway is not necessarily clear and some service is in short supply.

For those experiencing sudden loss of swallowing or speech function, for example following a stroke, prompt and continuing access to SALT service is often important and can be very helpful. No particular problems were identified in patients securing an initial referral, but concerns abound that the communications therapy service stops too early and there can be problems in continuity of support if health fluctuates. Inappropriate assumptions are sometimes made that carers will take over when NHS therapy stops. Some carer training is either missed, not planned effectively or is insufficient. Once NHS care has ceased individuals continuing with voluntary sector or private therapy can experience significant progress, consistent with the view that some NHS service stops too soon for some patients. Improvements can continue over long time periods and sometimes be very significant. Peer group support, voluntary sector provision and private therapy all received positive mentions, but for some individuals these have not been an automatic part of the pathway, which appears either to be incomplete or perhaps not always followed.

Those experiencing progressive loss of function described a range of experiences and needs, some finding their own coping methods, some seeking professional advice, others not acknowledging their situation or needs. In some cases family and friends have to work out their own solutions. Some have little wish to know what lies in store should their speech deteriorate, while others identify strongly the need to plan ahead so as to be able to maintain communications when their speech finally fails. Concern exists that some equipment costs are very high and funding is sometimes short, with some funding pathways also uncertain. Concerns were expressed that the local SALT service has developed too much of a focus on

swallowing. Swallowing is important but the service needs to address speech and communication needs with similar priority.

Individual needs are sometimes met fully by NHS provision and sometimes only partly, experiences being variable. The reasons should be investigated to ensure better equity and consistency of outcomes. The care pathway is probably unclear to many patients and may need some review, followed by an awareness program.

2. Recommendations

1. It would be helpful to review with the SALT Service Manager how complete and clear is the care pathway and the extent to which it is followed.
2. It would be helpful to raise awareness of the care pathway with clinicians, Social Care staff, at-risk patients and the voluntary sector, so that all who may be in need are in a position to access relevant services in a timely way.
3. It would be helpful to review how frequently patients discharged from the service can confirm that their needs have been met and that discharge is appropriate to them, and 'if not, why not?'
4. Following that, it is recommended to review what resource would be needed by the SALT Service to bring the rating of its communications service to at least the same satisfaction rating as its swallowing service and to adjust budgets accordingly.
5. It would be helpful to review how much the SALT service improves the relevant performance of patients between first assessment and discharge and to compare against performance at 12 and 24 months after discharge, to determine which factors contribute most to post-service improvement. This information could be used to update advice on 'best practice for patients after discharge' and to ensure that an appropriate mix of non-statutory sector services is available, affordable and accessible. Such services may or may not require or benefit from an amount of statutory sector support.

3. Limitations of this consultation

SALT services are needed by some MS, MND or post stroke patients, but are also needed by many others including clients with head injuries, Parkinson's, hearing loss, Learning Disabilities, mental health, dementia, autism and other conditions that were not represented at this event. Most SALT resources are devoted to children's services, also not represented at this meeting. Therefore this review covers only a small part of the overall SALT Services need.

The 10 attendees had a bias as regards age, (all in the range 30-75 yrs), and a feminine bias, (3M, 7F). There were more carers (5) than patients (3). Most but not all attendees were in communication with several others experiencing similar problems. Delegates live in and receive(d) services in locations across Wokingham, Reading, West Berkshire and North Hampshire.

There were no service providers, commissioners or statutory sector personnel present, although one delegate is both a patient and a social worker and one former carer is also a trained OT. There were no delegates to represent the situations of

patients with no improvements to report. One delegate represented a patient who is now deceased. Two carers of a patient who was not present were his wife and his daughter. Their needs and perspectives were similar but not identical. Each present had a unique story to tell, such that on one hand there was a wide diversity of experiences discussed, but also a likelihood that the discussions may not have included other circumstances that the SALT service meets and should serve.

The purpose of the meeting was circulated in advance and attendees were asked to prepare, which all had done. Neurological Alliance volunteers led the discussion and two sets of notes were taken of the proceedings, (combined into one set of notes as appended). Care was taken to avoid use of leading questions and attendees determined most of the direction of the discussions.

Those taking part should not be thought of as being 'generally representative' or 'typical'. They volunteered to take part and to talk about challenging matters of personal and wider importance. Despite the different personal experiences, there was considerable common ground as regards successes, frustrations and opportunities. The extent of the opportunities arising is difficult to quantify from the limited data collected.

4. Profile of those present:

Ten people were present. The conditions represented were MS, Stroke and Motor Neurone Disease. Noting the multiple roles of some, there were 5 carers, 3 patients, 2 family support workers, 2 trained OTs, 1 facilitator and 2 people taking a record of proceedings.

5. The pre-advised agenda

1. Welcome and introductions

The local Trust Head of Scheduled Care, Adult SLT service wrote prior to the meeting: 'I would like the participants to tell me how they would like the service to be designed – from the point of access/location and what service they feel they need. We are already on Choose and Book so GP's can discuss with them where they would like to be seen and we don't have long waiting lists to access the service.'

2. Purpose and focus group 'rules'

3. Open discussion on experiences about:

- impact of impaired speech, language, swallowing and communication skill
- obtaining information and advice
- obtaining suitable products and services
- leading an active and fulfilled life
- managing when things change or go wrong

4. What makes a good speech, language and communication service?

5. Recommendations for the statutory, private and voluntary sectors

The delegates determined their own priorities for discussion within the above.

6. Themes that emerged

- The care pathway is not particularly clear.
- Some services are too time-restricted and can stop sooner than appropriate.

- There is insufficient emphasis on communication, compared to that given to swallowing.
- Funding restrictions can limit the supply of equipment and some professional staff find it a challenge to secure appropriate funding.
- There are sometimes uncertainties on leaving the service:
 - some patients may feel too much 'left to themselves',
 - some carers may need training or may not be able to provide help,
 - as regards getting the most from voluntary sector and other services.

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West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition

Appendix

Notes taken during the meeting

One MS carer referred to his wife's deterioration in swallowing where she does not recognise that she has a problem. He has found ways of helping her, including not allowing her to eat alone, but has not sought any professional help.

One participant had a stroke 6 years ago, where speech was badly affected initially. The local SALT provided some rehab help, which was time-limited. When this came to an end he used a private SALT for over 5 years. He now has the confidence to help other Stroke survivors with their communication at a locally run Stroke Group in Woolhampton, which is a rewarding experience. The private help was expensive and very effective. 'NHS provision stopped too early.'

An MND participant was diagnosed in October 2011. Lip and tongue movements had changed dramatically. This was particularly significant because her husband is deaf and he depends on lip reading to be able to converse with her. She heard a programme on the radio about recording your voice for use when you could no longer speak. She contacted a SALT at Reading University who has links with a centre at Oxford. Over a period of time, she has recorded 1,610 phrases, all downloaded onto Grid 2 software. She needed to acquire a Fujitsu tablet PC to hold the recordings. She was going to apply to the NHS for the £1,200 necessary to fund this equipment, but her employers agreed to buy the equipment instead. She regards speech as being hugely important; without it she loses her personality. She needs the equipment now, before she loses her speech altogether, so that she can practise. In effect, she is pioneering the equipment and a local NHS Consultant has asked her to write a paper on her experiences when she has mastered it.

Another participant gave an account of an MND patient's recent experience with the SALT service. The patient is profoundly disabled as a result of her condition and was given a chin operated device which was very slow and frustrating – just positioning her correctly so that she could operate the switch took a very long time – so slow was it that she preferred to struggle making sounds that were sometimes understood by her family and friends, but not always. The local SALT asked the Oxford Centre for Enablement for advice, and, after assessment, they suggested an Eyegaze device, C12, which was trialled with the patient over a period of 10 days. It made a dramatic difference to her ability to communicate successfully with all those around her, but the cost was £11,000 plus VAT. The NHS should pay but could only offer 50% of the cost with the result that the patient was told she could only have this piece of equipment, which could make such a difference to her quality of life, if she raised over £6,000 herself, which is unrealistic when her husband cannot work as he is her fulltime carer and there is no money coming into the household. (The story does have a happy ending because the MNDA has been able to renegotiate the price with the supplier and got the cost down substantially, and there has been sufficient fundraising in a short time to enable the equipment to be purchased.) She wanted to have this system before losing her speech completely so that she could practice using it. She has no control over her saliva.

A participant who has had MS for 30 years and has slowly deteriorated. He has swallowing problems and did see a SALT once for advice, concluding with 'but if you don't keep up the contact you go off the system'. 'Thick and Easy' is helpful product.' A carer, whose husband had a stroke six months ago, followed by therapy, described how this led to an improvement. Then her husband was diagnosed with Type 2 diabetes and suffered another stroke, resulting in speech problems and comprehension difficulties. A SALT was involved and visited him at home at first. Low targets were set and achieved but he was nowhere near back to normal and his family thought he would have benefited from more SALT input. He was encouraged to attend the local Stroke Group, which he did, but it is only once a month. This has been excellent.

The daughter of the above stroke patient said that the initial intensive therapy that was provided was good but it didn't last long enough and he was then left to 'do his own thing'. She wondered if an iPad could be used to help her father communicate better. The family need advice on what sort of application would be suitable, if any, but are no longer in touch with the SALT service. Others present advised her to get back in touch with a SALT and ask if a referral to the Oxford Centre for Enablement would be appropriate. 'What programme could be used with an iPad?' 'The Oxford Enablement team can give advice on equipment.'

A participant said that it was very frustrating that her husband had professional help for such a short period of time and too much of that time seemed to be taken up in assessment and administrative matters. She felt the targets had been set too low. She stressed that individually all the SALTs had been excellent when working with her husband but that time was too short – 'there aren't enough of them'.

One participant stated that for the first year after his stroke he couldn't speak much at all. The crucial thing for him was getting someone to come in and help on a regular basis. It was slow progress and therefore disheartening because it was so slow. But he has learned to develop strategies to get around communication problems. He valued speech as being 'the most important thing for me'.

A participant stated that one-to-one therapy leads to tiny improvements all the time. She stated that the SLT service 'manipulates' her as a carer 'to accept that she can be the therapist'.

A carer responded to a question by stating that 'the SALT has given some advice but training could only be given on a certain day and in effect had said that it was too bad that I couldn't make that day'.

Another participant suggested that all carers are entitled to training and the carer concerned should ask to go on a free S&L communication-training course. 'All carers and subsidiary carers should be entitled to training.'

One participant lives on the Hants/Berks border and expressed uncertainty as to which county should give him Social Care. Answer: 'Social Care comes from where you pay your Council Tax'.

The group expressed generic concerns about the two subjects of 'access' and 'forward planning'. 'We need to be aware of what the referral access routes are.' 'The general Public don't know where to go – how do people living on their own

manage?’ ‘Where do they turn?’ ‘Services tend to be re-active not pro-active.’ ‘You have to have a crisis before action happens – there’s not enough advance planning.’

‘Singing for the Brain can help brain repair in people with stroke, although this is not relevant to MND which is a deteriorating condition.’

‘Health needs to make a massive investment in the SALT Service.’

‘The local service has become more of a swallowing service than a communication service – there should be equal investment in both.’

‘SALTs should learn how to apply for funding and not just expect the voluntary sector to fill the gaps.’

‘There should be better information in signposting people who have stroke etc. Perhaps there are a lot of people who have never had the help they need.’

A participant described her experiences 20 years ago when her father had MND. He had it for 7 years and was diagnosed after 3 years. He had such serious swallowing problems that he had to have a PEG fitted. He was given a typewriter but eventually could not use it and had to use an alphabet board. He asked his daughter to help him ‘end it’. He kept getting chest infections and eventually refused treatment but took 6 weeks to die. His problems communicating had increasingly devastating effects on him and on his family. If the situation had happened in more modern times, the pro-active use of the technology now available would have made a big improvement to the quality of life for all concerned.

Another delegate expressed concern that the MS Society was asked recently to fund 50% of the cost of a very expensive item of equipment (nothing to do with S&L services). The group expressed concerns that the statutory sector is not fulfilling its normal obligations towards funding essential equipment.

‘There is no system for returning equipment.’

One participant knew a patient who had no speech and could only use his eyes with ‘1 eye-closure for yes and 2 for no’. The participant expressed concern that he had been unable to identify any other meaningful way to communicate, which he found distressing. He could not imagine the feelings of the person who could not speak.

One participant communicates with the one she cares for, finding a topic and then asks him what he wants by speaking to him or pointing.

‘Berkshire Health Care Trust is not the same as Berkshire Hospital Foundation Trust.’

‘The Neurological Alliance needs to find out where the money is for the help that is available. When there is a crisis, a patient does not know where to go for help.’

‘When a diagnosis is first made, the patient should be told what help is available and which includes the voluntary sector. This should be repeated when the patient is next seen.’

'An OT will not recommend extra gadgets until you are past needing it, e.g. a replacement shower.'

'Patients do not necessarily want to know what the prognosis is.'

'The professionals should be more proactive.'

'Health services need to make a massive investment into speech, language and swallowing services.'

'Patients can apply for funding but it will be taken back if it is not all spent.'

'What is the requirement of need in the general community?'

Ends