



# **Securing a better future for people with communication and/or swallowing needs**

## **Policy statement - 29 April 2020**

### **Introduction**

As COVID-19 and non-COVID-19 policies develop across the United Kingdom (UK), this policy statement highlights the principles that will guide the Royal College of Speech and Language Therapists (RCSLT) as we work to influence nationally and locally for better lives for people with communication and/or swallowing needs.

Since the outbreak of the COVID-19 pandemic, the RCSLT has been very proud of how our members have responded to the unprecedented challenge facing the UK.

As with all other health, social care, education and justice professionals, the working lives of our members have changed, in some cases very significantly. We salute how speech and language therapists in England, Scotland, Wales and Northern Ireland have adapted to this situation so they can continue supporting people with communication and/or swallowing needs. These new ways of working have included greater use of telehealth, the training of other staff to support their work and adapting their usual working.

The lives of people with communication and swallowing needs have also changed and speech and language therapists across the UK are helping those people understand and adapt to these changed circumstances. Speech and language therapists are producing information that is accessible so people with communication needs understand what COVID-19 is, what they need to do to keep themselves and others safe and what to expect when accessing health and social care and education services.

This statement covers:

- People with COVID-19 - section 1
- People who do not have COVID-19 - section 2
- The future - section 3
- Rehabilitation and recovery of COVID-19 patients - section 4
- Specialist support for people who do not have COVID-19 - section 5
- Next steps - section 6
- Reducing the risks associated with children and young people's communication and/or swallowing needs - Appendix A
- Reducing the risks associated with adults' communication and/or swallowing needs - Appendix B

### **1. People with COVID-19**

Throughout the UK, speech and language therapists have worked tirelessly to ensure that people with COVID-19 receive as much support as possible. They are promoting people's physical and mental well-being, using their specialist skills to provide interventions and rehabilitation, both within and beyond intensive care units, to support communication, swallowing and respiratory management.

Speech and language therapists have also been redeployed to other roles across the health and care system to help contribute to supporting people with the virus and respond to the national emergency.<sup>1</sup>

## **2. People who do not have COVID-19**

At the same time, speech and language therapists have continued to support those people with communication and/or swallowing needs that are not related to COVID-19. There are many such people in the UK.

### ***Communication needs in children and young people***

- Over 10% (1.4 million) of children and young people in the United Kingdom have long-term communication needs.<sup>2</sup>
- In areas of social disadvantage, around 50% of children start school with delayed language or other identified communication needs.<sup>3</sup>
- 81% of children with social, emotional and mental health needs have significant unidentified language deficits.<sup>4</sup>

### ***Communication needs in adults***

- 20% of the adult population may experience communication difficulties at some point in their lives.<sup>5</sup>
- 50%-90% of the learning disabled population have communication difficulties<sup>6</sup> and 89% of people with learning disabilities need speech and language therapy intervention.<sup>7</sup>
- About 90% of people with Parkinson's report changes to their voice<sup>8</sup> and up to half of people with the disease are affected by unclear speech.<sup>9</sup>
- Speech problems (dysarthria) occur in more than 80% of people living with motor neurone disease progresses<sup>10</sup> and approximately one third of people experience bulbar motor neurone disease, a particularly aggressive form affecting speech and swallowing muscles early in the disease process.<sup>11</sup>
- Around a third of people will have some level of communication difficulties (called aphasia or dysphasia) following a stroke.<sup>12</sup>
- Studies have found between 35% and 56% of people with multiple sclerosis have speaking difficulties (dysarthria) which can affect their quality of life.<sup>13,14</sup>

### ***Swallowing needs***

- In addition, people of any age, from neonates to children and young people and adults, may have some difficulties with eating and drinking safely. This includes people with learning disabilities, those recovering from a stroke or living with head and neck cancer or a neurological condition (such as Parkinson's disease, motor neurone disease, and multiple sclerosis) and people with dementia.

## **3. The future**

As the UK turns to planning for the future, it is important that policies and strategies reflect both the rehabilitation needs of COVID-19 patients and the ongoing support of people who do not have COVID-19 related needs.

Those policies will need to ensure that people newly referred to speech and language services receive the support they require, whether they have had COVID-19 or not; and that those without COVID-19 who may have missed out on being identified and/or supported during the pandemic also receive the support they need. This must include the identification and appropriate support for all those who have communication and/or swallowing needs.

Speech and language therapy services will have an important role to play in supporting these people, their families, carers and the other professionals working with them to have a better future. This may involve services being delivered differently for a period of time, for example a greater use of tele-health.

All of this could place significant extra demands on speech and language therapy services not only to manage the backlog of existing and new non-COVID-19 people, but also to incorporate additional COVID-19 referrals.

It is vitally important, therefore, that sufficient resources are provided to ensure that *these* services are able to respond in as timely and appropriate way as possible. This may also include the need for additional speech and language therapy resource and training for colleagues to provide the support COVID-19 patients with long-term rehabilitation and recovery needs require.

If these potential extra resources are not made available, there may be negative consequences for the physical and mental health of people with communication and/or swallowing needs and their families which in turn may result in greater costs to the public purse.

At the same time, it is likely that the way the future speech and language therapy workforce is taught, trained and prepared for work may have to change, including through virtual lectures, innovative placements and learning about COVID-19. The RCSLT will be working closely with the Higher Education Institutes on these issues.

#### **4. Rehabilitation and recovery of COVID-19 patients**

While the communication, swallowing and respiratory rehabilitation needs of people recovering from COVID-19 are emerging, early indications suggest that for some there will be a prolonged impact on their quality of life.

In particular, people affected more severely by the COVID-19 virus and those who required intensive care treatment may suffer from a whole range of associated problems lasting for months and even years. The consequences of life saving interventions such as sedatives, mechanical ventilation, oxygen therapies and tracheostomy may lead to a myriad of problems:

- voice disorders;
- swallowing muscle weakness with a need for restricted diets or artificial feeding via a tube;
- chronic respiratory compromise impacting on the coordination of swallowing and breathing which carries an increased risk of chest infection and further lung complications;
- cognitive communication disorders potentially limiting return to work and daily life;
- psychological trauma and post traumatic stress disorder; and

- chronic upper airway narrowing or stenosis requiring complex multidisciplinary team management

People may face any of the above issues to differing degrees.

Speech and language therapists will have an important role to play in supporting these people. The rehabilitation of their communication and/or swallowing disorders needs will require careful planning and speech and language therapy input into the multidisciplinary approach will be essential. Speech and language therapy delivered in the community will be vital in order to prevent any negative health consequences and to optimise long-term outcomes.

## **5. Specialist support for people of all ages who do not have COVID-19**

While ensuring the rehabilitation and recovery of COVID-19 patients, it is also essential that people who do not have COVID-19 related issues, but acquire communication and/or swallowing needs (for example through having a stroke or being newly diagnosed with a progressive neurological condition or cancer) receive the specialist professional support they require. Equally, it is essential that children with delayed language or other developmental delays have their needs identified and supported. If they do not, both children and adults are at significant risk of negative outcomes, including on their mental health with potential extra costs to the public purse.

For the same reasons, it is critical that people of all ages with long-term communication and/or swallowing needs continue to have their needs met. These people include those with:

- autism;
- brain injury;
- cerebral palsy;
- cleft lip and palate;
- craniofacial conditions;
- dementia;
- developmental language disorder;
- Down's syndrome;
- hearing impairment;
- head and neck cancer and other cancers;
- learning disability;
- mental ill-health;
- progressive neurological conditions, such as Parkinson's disease, multiple sclerosis and motor neurone disease;
- respiratory conditions;
- selective mutism;
- sensory impairment;
- speech disorders;
- stammer;
- stroke;
- visual impairment;
- voice disorders.

## **6. Next steps**

It is not yet clear what future COVID-19 and non-COVID-19 policies for people of all ages and stages of their life with communication and/or swallowing needs will look like.

As those policies and services are being developed, the RCSLT will work with members and partner organisations across all four nations of the UK to influence them to ensure that health and social care, education and justice policies take account of and provide appropriate support to everyone who has communication and/or swallowing needs.

## **APPENDIX A**

### **Reducing the risks associated with children and young people's communication and/or swallowing needs**

Children and young people face a range of negative outcomes if they do not have their communication and swallowing needs identified and met.

#### ***Communication needs***

Communication is a fundamental and foundational life skill, central to understanding, expression and social relationships (social communication). The development of communication and language skills impacts directly on children's ability to learn, their mental health and wellbeing and their future employment prospects and life chances. As identified above, many children and young people have some form of long-term communication need and children in areas of social disadvantage are at much greater risk, with around 50% of children starting school with delayed language or other identified communication needs.

During the pandemic, children and young people with long-term needs will receive less support due to the closure of education settings and redeployment of speech and language therapists. Some of these children and young people will have a statutory plan or statement which gives them a legal entitlement to support because of their identified special educational needs and disabilities, additional learning needs, or additional support needs.

At the same time, many children and young people will not have their needs identified, meaning they miss out on the chance for early intervention. This includes young children with delayed language, as well as children with long term needs such as developmental language disorder or stammering.

In England, for example, we know from our own report, Bercow: Ten Years On, as well as external reviews such as those by the Children's Commissioner and the Education Select Committee, that even prior to the current crisis many children and young people were not able to access the speech and language therapy they needed. It is critical, therefore, that those children and young people's needs are not forgotten both now in the immediate response to the pandemic and in the future. This is particularly important given that children and young people with communication difficulties are at increased risk of social, emotional and mental health needs, and early indications are that the COVID-19 pandemic is already having a negative impact on children and young people's mental health.

Children and young people must continue to have any speech, language and communication needs identified and must continue to receive the appropriate level of support, including any speech and language therapy, they require. If they do not, they, their families and carers, and the country will be at risk of negative long-term outcomes which might increase costs to the public purse.

Therefore, national and local recovery plans must specify how children and young people with speech, language and communication needs are going to be identified and supported, including those with a statutory entitlement to speech and language therapy because of their identified needs.

#### ***Eating and drinking needs***

Some children and young people may also have difficulties swallowing. Speech and language therapists play a crucial role in supporting them, their families and carers, to ensure safe eating and drinking.

Speech and language therapists also have a crucial role in neonatal units across all levels of care, both as autonomous practitioners and as part of the multidisciplinary team. They work with families through use of various mediums to support safe feeding, prevent persistent early feeding difficulties, enhance and support developmental outcomes and promote earlier and safe discharge home.

It is vital that babies', children's and young people's feeding and swallowing difficulties are identified and supported to ensure the risks of malnutrition, chest infections and choking are reduced.

## **APPENDIX B**

### **Reducing the risks associated with adults' communication and/or swallowing needs**

As with neonates, children and young people, adults with communication and/or swallowing needs are at risk of a range of negative outcomes if their needs are not identified and met.

#### ***Communication needs***

Communication is central to our ability to learn, work, form and maintain relationships and to participate in society. Everyone needs to be able to communicate to be able to be involved in daily life. However, as shown above 20% of adults experience communication difficulties due to stroke, cancer, progressive conditions, Alzheimer's disease or other types of dementia or a learning disability.

Failure to support people's communication needs will deny them the means to communicate their most basic needs and wants, to express their wishes and to reach out to their family and loved ones at this most difficult time.

Supporting communication during the pandemic is critical. Failure to support communication needs can result in withdrawal and social isolation as communication is essential to building relationships, interacting and participating in family life, making friendships and being part of the wider community.

As access to health professionals decreases, an expectation of self management increases. However, without good speech, language and communication people are at risk of taking incorrect medication, failing to follow health and public health advice and ultimately taking health decisions which could make their overall health deteriorate.

During the pandemic, resources are being redeployed to support the acute frontline and community health services and social services are being scaled back. Many adults and older people living in the community with underlying health conditions who would normally receive speech and language therapy will only receive support if their needs are classed as 'urgent'. Therefore, there are many adults and older people who will not receive any speech and language therapy support.

Many speech and language therapy clients are classed as vulnerable and are shielding, avoiding all contact to keep themselves safe and well.

After the pandemic there will be much unmet need from existing clients either who have received no service, new clients diagnosed and referred and COVID-19 patients for speech and language therapists to balance and manage.

### ***Eating and drinking needs***

Many adults and older people will have eating, drinking and swallowing difficulties. These difficulties have potentially life-threatening consequences. They can result in choking, pneumonia, chest infections, dehydration, malnutrition, weight loss and in some cases death. They can also make taking medication more difficult.

During the pandemic, people with COVID-19 are developing swallowing difficulties for a variety of reasons, including intubation, tracheostomy, sedation, ventilation and/or fatigue.

Mouth care is extremely important for these patients and speech and language therapists add huge clinical and advocacy value to their care. Recovery from COVID-19 may take a long time so these people will need ongoing assessment, advice and management by speech and language therapists to eat and drink safely.

At the same time, those with non-COVID-19 swallowing difficulties will need also support and ongoing monitoring to ensure there is no deterioration in their condition so resulting in their needs do not escalate and require unnecessary hospital admission.

Speech and language therapists support people with eating, drinking and swallowing need in intensive care units, acute hospitals and in community settings such as people's own homes and care homes.

### **REFERENCES**

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