

# Impact of COVID-19 on the stroke rehabilitation pathway: multidisciplinary team reflections on a patient and carer journey from acute to community stroke services

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## SUMMARY

A 62-year old man attended accident and emergency in June 2020 with dense right sided weakness, aphasia and confusion. Investigations revealed a left middle cerebral artery infarct, and he was admitted under the stroke team for ongoing inpatient rehabilitation. He was discharged home in September 2020 and received community stroke rehabilitation from physiotherapy, nursing, occupational therapy and speech and language therapy. He is now working towards a graded discharge from the Community Stroke and Neuro Rehab Team, after achieving his rehabilitation goals. In this case, the multidisciplinary team adopted different ways of working to accommodate the patients' priorities while also negotiating the COVID-19 pandemic. This included taking a transdisciplinary approach to rehabilitation and considering alternative supported self-management strategies. This case highlighted several learning points, particularly the potential benefits of shared goal setting for patients with communication difficulties and transdisciplinary approaches to community stroke rehabilitation.

## BACKGROUND

The impact of COVID-19 on core National Health Service (NHS) services and patients seeking care during lockdown have been widely documented.<sup>1,2</sup> However, the impact of the pandemic on patients, their families and care givers throughout the stroke rehabilitation pathway is lesser known and warrants discussion. Stroke affects more than 100 000 people per year in the UK<sup>3</sup> and often requires substantial, coordinated input from the multidisciplinary team (MDT), both in acute services and the community, which integrates family and caregivers as part of the rehabilitation process.<sup>4</sup> The impact of COVID-19 on this pathway is discussed in detail in this case report, focusing on the patients' rehab journey from hospital to home and the impact of COVID-19 on his partner and her involvement in the rehabilitation process. This report will evaluate the MDT approach to rehabilitation and goal setting with a patient with complex communication difficulties. It will also reflect on the challenges of supported self-management (SSM) and discharge from community rehabilitation during the pandemic, from the perspectives of the health professionals involved in this case.

## CASE PRESENTATION

A 62-year-old man with a history of atrial fibrillation attended accident and emergency in June 2020, presenting with dense right-sided weakness, aphasia and confusion. He was assessed by the medical stroke team and transferred to the acute stroke unit for therapy assessments and ongoing medical care. He remained an inpatient for 3 months, making variable progress in therapy. He was discharged home with input from the Community Stroke and Neurological Rehabilitation Team (CSNRT). On initial assessment, he presented with dense right upper limb weakness and pain, with some activity in his right lower limb. He used a hoist for all transfers, and due to apraxia, he required assistance with all activities of daily living. He was discharged from hospital with a communication book to aid functional communication at home. However, on initial CSNRT speech and language therapy assessment, he was unable to reliably use it due to his dyspraxia and aphasia. He had difficulty using gesture such as thumbs up/down for yes/no, and verbal yes/no was also unreliable, consequently leading to frustrations when he was unable to be understood by his partner and CSNRT therapists.

The pandemic introduced several challenges to this patients journey through the stroke rehabilitation pathway, as outlined in [table 1](#). Due to COVID-19 restrictions, the patients' partner was unable to visit or be involved in his inpatient rehabilitation. Her only form of contact had been FaceTime, however, due to his receptive and expressive aphasia, communicating in this way was challenging. Without involvement during the rehabilitation process, the initial transition to life at home was difficult for both the patient and his partner. This would normally have been supported through CSNRT in-reach prior to discharge but was suspended to reduce potential transmission of COVID-19 within the hospital. His overall presentation from a CSNRT therapy perspective was that of a complex medical and social case following a large, left hemisphere stroke requiring coordinated, multidisciplinary working, supporting the patients' priorities and those of his partner.

## TREATMENT

The patient received inpatient care on the stroke rehabilitation unit between June and September 2020. Following hospital discharge, he was seen



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## Case report

**Table 1** A table to show the impact of changes to normal practice resulting from COVID-19, on the rehabilitation process and on the patient and his carer

Change to normal practice because of COVID-19	Impact on rehabilitation	Impact on patient/carers
Visitation to hospital suspended, replaced with virtual contact using iPad	<ul style="list-style-type: none"> <li>▶ Unable to involve family/carers in rehabilitation process</li> <li>▶ Fewer family meetings with carer and wider family therefore less opportunity to provide education and support around adjustment to life after stroke</li> </ul>	<ul style="list-style-type: none"> <li>▶ Patient unable to engage in virtual contact due to aphasia</li> <li>▶ Carer felt isolated and unable to gauge the extent of communication difficulties</li> </ul>
Restrictions on community staff accessing hospital wards	<ul style="list-style-type: none"> <li>▶ No in-reach to support discharge and consider medication management/early liaison with GP. May have avoided rehabilitation breaks due to unmanaged pain and low mood</li> </ul>	<ul style="list-style-type: none"> <li>▶ Difficulty adjusting to life at home following discharge from hospital which team could have supported through in-reach</li> </ul>
Use of PPE—facemasks and visors	<ul style="list-style-type: none"> <li>▶ Eliminated therapist directed visual articulation cues during apraxia of speech rehabilitation and multidisciplinary rehabilitation tasks</li> </ul>	<ul style="list-style-type: none"> <li>▶ Increased burden on partner to be involved in multidisciplinary rehabilitation as she was not required to wear a mask in the home</li> <li>▶ Increased frustrations when the patient was unable to understand therapists</li> </ul>
Community clinic spaces closed	<ul style="list-style-type: none"> <li>▶ Limited opportunity to progress difficulty of rehabilitation in home environment</li> <li>▶ Reduced access to equipment and group classes to facilitate social interaction and communication strategies</li> </ul>	<ul style="list-style-type: none"> <li>▶ Patient was limited to home environment but due to progressing quickly wanted to increase the intensity and difficulty of his rehabilitation. Being unable to do this increased his frustration and impacted his mood</li> <li>▶ Increased carer stress supporting patient with low mood, unable to have breaks for self-care</li> </ul>
Local lockdowns and public health restrictions closing local community resources	<ul style="list-style-type: none"> <li>▶ No access to local facilities and groups to support discharge planning which increased length of stay</li> <li>▶ Unable to practice functional and higher-level tasks outside of home environment</li> <li>▶ Increased requirement for team to support patient and carer as wider family not able to visit during lockdowns</li> </ul>	<ul style="list-style-type: none"> <li>▶ Unable to access local groups (patient and carer groups) for peer and carer support</li> <li>▶ Unable to practice speech strategies outside of therapists and partner</li> <li>▶ Unable to access personal assistant support through social services at start of rehabilitation, increased carer stress/burden</li> </ul>
Virtual support groups	<ul style="list-style-type: none"> <li>▶ Technical issues often limited access to virtual support groups</li> <li>▶ Increased team involvement to provide additional support to patient and carer in the absence of functioning local groups</li> </ul>	<ul style="list-style-type: none"> <li>▶ Patient mostly excluded from these groups due to communication impairment</li> <li>▶ Neither patient nor carer use technology so could not see the value in accessing these groups. Eliminated valuable peer support</li> </ul>

GP, General Practitioner ; PPE, personal protective equipment.

jointly, within 48 hours, by a physiotherapist and occupational therapist. He was also referred for speech and language therapy and nursing input. To provide a greater intensity of therapy, he was referred to the technical instructor who provided multidisciplinary rehabilitation based on a structured rehabilitation plan. Rehabilitation was approached collaboratively between the professions and involved significant joint working between physiotherapy, occupational therapy (OT) and speech and language therapy in the early stages, to align with the patients' priorities, support his partner and to avoid communication and carer breakdown where possible. Functional speech was integrated into physiotherapy and OT interventions in line with his rehab priorities, allowing him a greater sense of control. His ongoing therapy included upper limb pain and spasticity management, improving functional mobility in all environments, increasing independence in activities of daily living, and working towards effective communication strategies using a total communication approach. However, with the use of personal protective equipment (PPE), including a facemask and visor, therapy for his apraxia of speech was more challenging as visual articulation cues were eliminated, thus placing increased pressure on his partner to support his communication and rehabilitation. [Figure 1](#) shows a timeline of this patients' rehabilitation, from arrival at accident and emergency to discharge planning in the community. It includes standardised outcome measures used within stroke rehabilitation in line with the Sentinel Stroke National Audit Programme,<sup>5</sup> demonstrating improvements in the Barthel Index and Modified Rankin Scale. Onward referrals during

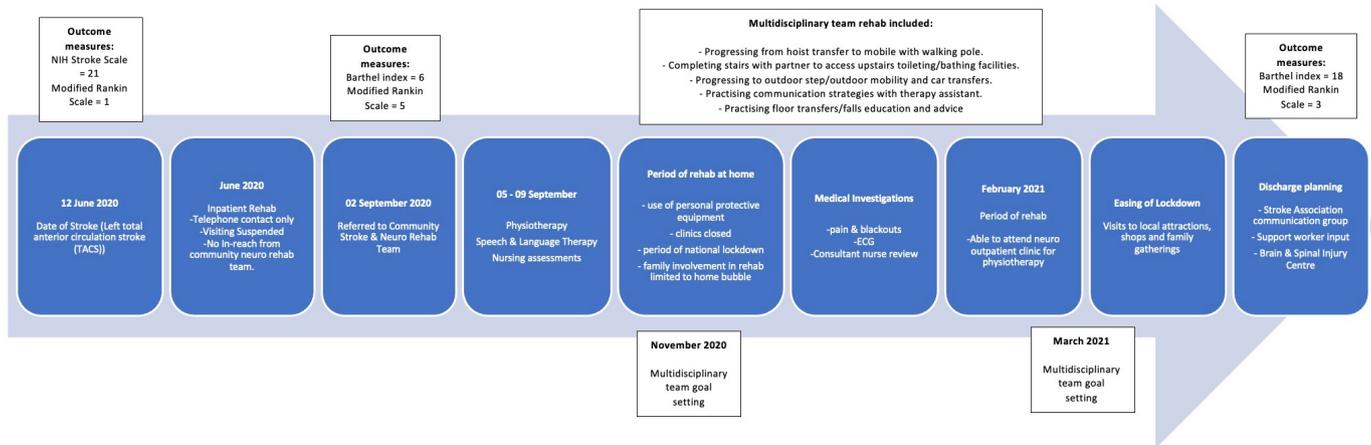
his rehabilitation included orthotics, orthoptics, his General Practitioner (GP) and psychology.

### OUTCOME AND FOLLOW-UP

The MDT is exploring suitable options to support discharge from CSNRT after achieving his rehabilitation goals. He is independently mobile unaided, accessing bathing equipment upstairs, accessing the community and continues to develop effective communication strategies with his communication partner. His discharge from CSNRT will be graded to avoid feelings of abandonment after a prolonged period of rehabilitation, and while community services start to resume after the pandemic. Examples of community services include Stroke Association communication groups and the Brain and Spinal Injury Centre.

### DISCUSSION

The National Clinical Guideline for Stroke provides recommendations for the delivery of stroke rehabilitation in acute and community settings, including involvement of family and carers to offer information, advice and support, particularly for those taking the role of communication partner.<sup>6</sup> Stroke rehabilitation is considered specialist rehabilitation, defined as 'the total active care of patients with a disabling condition, and their families, by a multiprofessional team who have undergone recognised specialist training in rehabilitation'.<sup>7</sup> The patient in this case report required specialist rehabilitation for physical, sensory, communicative and cognitive problems relating to his



**Figure 1** A timeline to demonstrate the patients' journey from accident and emergency, through to discharge planning in the community during the COVID-19 pandemic. NIHSS, National Institutes of Health Stroke Scale; TACS, Total Anterior Circulation Stroke.

stroke. Evidence supports multidisciplinary working as the mechanism for delivering poststroke rehabilitation.<sup>8</sup> However, this patient challenged this as his priorities differed to those of the therapists, whereby he prioritised his physical functioning over his communication and often lacked engagement with communication strategies. This was difficult for his partner for several reasons. As she had been unable to visit the ward and be involved in his acute therapy, she did not feel adequately prepared for the challenges surrounding his communication impairment and consequent frustrations when he was unable to make himself understood. Early poor engagement with speech therapy and psychology lengthened the time in which effective communication strategies between the patient and his primary communication partner were established, often leading to carer stress and breakdowns in communication. To accommodate this, therapists adopted a transdisciplinary approach to integrate speech therapy and psychology strategies into his physical rehabilitation, particularly in the earlier stages. There is limited research evidence on transdisciplinary working in stroke rehabilitation and even less that focuses on community stroke settings. However, in inpatient facilities, this approach contributes towards improvements in the quality of rehabilitation through better team dynamics, communication and the development of shared goals.<sup>9</sup> This case demonstrates the success of transdisciplinary working and adopting a shared approach to treatment planning based on the patients' needs.

In this patient example, joint goal setting was integrated into joint treatment sessions as detailed in figure 1. Following clinical reflection for the purpose of this report, shared goal setting was discussed as a key learning point, leading to the exploration of more appropriate goal setting for patients with aphasia, who rely on a communication partner. A recent review<sup>10</sup> suggests that evidence to support accessible goal setting with patients with stroke and with aphasia is lacking, proposing a model to support this process. A key component being combining supportive conversation strategies with a modified physical environment, with these elements working synchronously, to be successful.<sup>10</sup> The responsibility for communication access, including goal setting, is the responsibility of all rehabilitation staff; therefore, service-level training and support are required to improve in this area.<sup>10</sup> Following this case review, strategies to support shared goal setting for patients with aphasia in CSNRT have been considered and include values-based approaches through supported

conversations using Talking Mats. Current evidence suggests that stroke survivors with communication difficulties often feel powerless and abandoned when discharged from community services, with emphasis on providing support before and around the point of discharge to build confidence and skills for long-term management.<sup>11</sup> This case has highlighted the need for more considered, early conversations around long-term management and discharge planning, grounded in appropriate and accessible goal setting to empower patients and their carers. A key learning point for the remainder of his intervention will be to ensure this patient and his partner feel adequately prepared for discharge from the service, particularly considering the extensive rehabilitation provided so far.

Building confidence and skills for long-term management relates to SSM, constituting part of the NHS Long-Term Plan's drive for delivering personalised care by 2024.<sup>12</sup> SSM has been a priority for CSNRT following a quality improvement project linked to the NHS England Personalised Care Plan. However, the impact of COVID-19 on SSM has been challenging, particularly for people with communication difficulties. Being supported to trial communication strategies in different settings, to build confidence and manage the impact of stroke-related communication difficulties in day-to-day living, constitutes a key aspect of SSM strategies for people with aphasia.<sup>11</sup> However, with the transition to virtual support in the absence of face-to-face contact, this patient has been excluded from supported communication groups that would normally facilitate long-term management in the community. Due to his apraxia and a historical limited interest in technology, he and his partner have been unable to access support that would ordinarily be available, such as through Speak Easy and Stroke Association. Ongoing involvement of his partner in the rehabilitation process and in determining SSM strategies will be key to a successful discharge from CSNRT and the patient's ability to manage the long-term impact of his stroke. Spouses of stroke survivors often feel lonely, sad, lost, burdened and guilty and need support in their own role and emotional management.<sup>13</sup> In this case, the national lockdowns have contributed towards increased isolation for the patient and his partner, reduced availability of external support services and inability to create peer support networks. Consequently, they have had limited opportunity to explore and develop creative and meaningful strategies to manage the long-term consequences of stroke.

### Suggestions for future improvement

- ▶ Collaborative, transdisciplinary working integrating all aspects of rehabilitation may reduce length of stay and enhance patient experiences through stroke services. This supports person-centred care and provides a holistic approach to poststroke rehabilitation.
- ▶ Service-level training and development, across inpatient and community stroke services, around supportive conversation strategies to form collaborative, shared goals with patients with aphasia and their families.
- ▶ More accessible virtual support for patients with communication and/or cognitive difficulties poststroke. This could include training or involvement of formal carers where possible.

### Multidisciplinary specialist perspectives on the case

#### Occupational therapy

The role of OT after stroke is to facilitate and maximise return to functional tasks. This includes assessment and treatment of affected upper limb and cognitive functioning. There have been many challenges to therapy during the pandemic with no access to clinics, carer strain and lockdown limiting this patient's access to meaningful activities in the community. Ordinarily, this patient would have accessed in-reach OT to support the transition from hospital to home, which was not available due to hospital restrictions. This reduced the opportunity for inpatient education to help manage expectations and support adjustment to life at home. Had the patient and his partner been able to access further Stroke Association support once home, they may have felt less reliance on visiting therapists and had other means of outlet and shared experience. The process of assessment and intervention is patient focused and goals led, which meant that this patient often prioritised physiotherapy work through eagerness to walk. He challenged us to take a more transdisciplinary approach to rehabilitation, incorporating speech therapy and upper limb rehabilitation into mobility-focused work, aligning with his rehabilitation priorities and reducing the risk of COVID-19 transmission within the household (Ruth Heyes, Ellen Upton).

#### Speech and language therapy

Speech and language therapists work with patients and families poststroke, on impairments and to establish compensatory strategies and functional communication. Approximately, one-third of stroke survivors experience communication difficulties, impacting on the whole MDT. Supporting the MDT with training, facilitating communication in function and supporting goal setting is an important role of the speech and language therapist. In this case, providing support to the MDT to set collaborative patient-centred goals was invaluable and assisted with expectation management. Our typically holistic options to facilitate reaching these goals were impacted by the changing nature of services due to COVID-19, such as non-face-to-face communication groups. Virtual opportunities over telephone or videoconferencing are a fantastic resource but remain inaccessible to those with certain cognitive or communication difficulties, excluding our patient from tools he would typically be able to access to facilitate his independence. The impact of COVID-19 was evident in this case, as the use of facemasks in apraxia of speech treatment reduced the visual articulation cues the patient was able to access, resulting in additional burden on his partner to provide this aspect of his rehab. Being supported by the MDT and learning

from their reflections allows us to provide holistic, patient-centred approaches to help our patients achieve their rehab goals (Sophie Gordon).

#### Physiotherapy

The role of physiotherapy after stroke supports patients to achieve long-term rehabilitation goals. This includes regaining independence through improving physical function or introducing compensatory strategies, including reintegration back into meaningful family, social and community roles. In this case, COVID-19 presented many challenges. We would normally consider adjuncts to therapy, such as hydrotherapy and gym-based rehabilitation, to improve function, manage spasticity and increase rehabilitation stimulation. Experience suggests this can have positive effects on mood, engagement in rehabilitation and can facilitate the development of self-management strategies. However, due to the national lockdowns and restrictions in the hospital and community, this patient was unable to access these resources. Coordination of care between services was also challenging during the pandemic. Medical interventions delayed rehab progress as they were required to continue physiotherapy safely, in turn impacting on the patient's mood. Despite these challenges, this patient exceeded his goals and is now in a position, as postpandemic life slowly starts to return to normal, to explore and develop meaningful self-management strategies with his partner (Lauren Lucas, Emily Townend, Emma Higgins)

#### Nursing

The role of nursing following stroke is to provide secondary prevention education to avoid further strokes, often including home blood pressure monitoring and medication management. We take a holistic approach to care, including coordinating Stroke Association support, and make onward referrals to more specialist services based on patient needs. In this case, the nursing role has predominantly been to support the patient's partner. As she was unable to be involved in his rehabilitation while in hospital, she was underprepared for the challenges associated with life after stroke on his return home. Due to COVID-19, face-to-face visits were limited, and the patient's priority was rehabilitation. Therefore, support was provided remotely, which reduced opportunities to build strong therapeutic relationships, which underpin the nursing role. Due to hospital restrictions, we were unable to provide an in-reach service to build this relationship with the patient and his partner prior to returning home. Despite COVID-19 challenging, our way of working and reducing opportunities for in person contact, this has not been of detriment to the patient due to collaborative and successful MDT working and communication between all professions (Eleanor Monteith, Joanne O'Meara)

#### Technical instructor

The role of technical instructor (TI) following stroke takes a holistic approach to support the MDT to increase intensity of rehabilitation input. This often means that technical instructors have more opportunities to build relationships and gain trust. In this case, an important part of the TI role was to reduce the number of people going to house, therefore reducing the risk of COVID-19 transmission. The biggest challenge was around providing speech therapy intervention and engaging with general communication because of wearing PPE, in particular, wearing face masks. This increased the need for his partner

## Patient's perspective

Due to his poststroke communication difficulties, this statement was written by the patients' partner, who facilitated his perspective using communication strategies implemented during his rehabilitation.

One of the first challenges was when he was taken into hospital in an ambulance, and I could not be with him. This was distressing for him as I was not allowed to be there even just to hold his hand. I was told over the phone that he had had a massive stroke because of a blood clot. I did not find out about his speech difficulties until much further down the line. Our only communication was over the iPad, which was challenging, mostly because he did not want to speak due to his communication difficulties, but I did not know that at the time so often felt upset. Not being able to visit the ward was difficult because I could not see how he was improving or properly understand the impact of his stroke. We had two or three family meetings on the ward, which gave an update of what he had been doing, but it was hard to see this progress having not being allowed to visit.

After 3 months of being in hospital, he just wanted to get home. When he first came home, it was lovely, hard at times but good to have him back. It has not been easy since he is been home, but it was good to see how he improved so quickly. Emotionally and physically, it was hard work but worth it to have him home. It is been hard for him coming to terms with a lot of things, with low mood and trying to find his fight. But there is a light at the end of the tunnel for both of us. If it was not for the community team coming, we would not have got to this point. They have been both of our support for months since he got home. Because of the lockdowns and family not being able to visit, it is been very lonely for both of us. We probably would have got more support it was not for the lockdown. I have had to do all the shopping, cleaning and caring for him. Whereas, if we would be able to have visitors when he first came home, I would have had support with this. Even if they had been allowed to visit in the hospital, he would have had my family and his family visiting, so more people would have been able to understand the impact of the stroke and the responsibilities I have caring for him. This has meant that I have not had a break in 10 months, it is like going to work for 10 months without a day off and it is been hard.

The masks have been hard to manage especially during speech therapy. I am not properly trained for speech and sometimes felt that I may not have been doing things correctly when helping him and the speech therapist. COVID-19 has had a massive impact on every part of managing life after his stroke. We have not had support from other services as they have not been allowed to visit, for example, the social worker and the stroke association. We may have been further in his recovery if we had had this support. I feel like there is still a long way to go, but we will have to take baby steps, while COVID-19 is still around to make sure we are both safe. Seeing family is enough for us for now. My biggest fear is for him to get COVID-19 after everything else he is been through.

to be involved in rehabilitation, often causing frustration and anger when he was unable make himself understood, leading to communication breakdowns and carer strain. As the most frequent person in the patients' home environment, a strong relationship was developed providing opportunity to support

## Learning points

- ▶ Transdisciplinary working ensured that the patients' priorities were considered while integrating communication strategies into his physical rehabilitation, supporting person-centred care and increasing engagement in therapy.
- ▶ Shared goal setting could facilitate supported self-management approaches from the beginning of a person's rehabilitation in the community.
- ▶ Virtual support has been inaccessible for this patient with communication difficulties, limiting his opportunities to explore and develop strategies to manage the long-term consequences of stroke.

both the patient and his carer at their lowest points. The pandemic emphasised the importance of regular and consistent communication between the MDT. Without COVID-19, it is likely that this patient would have progressed more quickly. He would have had opportunity to socialise and communicate with family and friends, therefore supporting his rehabilitation progress. COVID-19 has posed significant challenges to the quality of this man's rehabilitation recovery and quality of life (Clair Bennett).

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