Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar rhyddhau cleifion o ysbytai ac effaith hynny ar y llif cleifion drwy ysbytai

This response was submitted to the Health and Social Care Committee consultation on Hospital discharge and its impact on patient flow through hospitals

HD 29

Ymateb gan: | Response from: Multiple Sclerosis Society Cymru

Hospital discharge and its impact on patient flow through hospitals

About Multiple sclerosis (MS)

MS is the most common disabling neurological condition affecting young adults. More than 130,000 people in the UK have MS, the equivalent of one in every 500 people across the UK, with approximately 5,600 of these living in Wales.

MS is a progressive condition and symptoms often present in a person's 20s and 30s. Symptoms often fluctuate, many are invisible, and they vary greatly between individuals, including: loss of balance, fatigue, pain, bladder and bowel problems, visual and memory impairment, and issues with speech.

Around 85% of people with MS are diagnosed with Relapsing-Remitting MS. People with this kind of MS have distinct attacks of symptoms which then fade away either partially or completely. Many go on to have secondary progressive MS. It means they have a sustained build-up of disability, completely independent of any relapses. Primary progressive MS affects about 10 to 15% of people diagnosed with MS. Symptoms gradually get worse over time, rather than appearing suddenly.

The MS Society is the largest charity for people living with MS in Wales, with 16 volunteer-led groups, and is the largest charitable funder of research into MS in the UK.

MS Society Cymru welcomes this opportunity to respond to the Health and Social Care Committee consultation on hospital discharge and its impact on patient flow through hospitals.

Avoidable admissions;

People with living with MS and other long term neurological conditions sometimes have acute episodes of illness that may necessitate hospital admission.

Studies from the UK and elsewhere have shown that a number of people living with MS are admitted to hospital, and/or remain in hospital when their needs (for assessment, observation and/or intervention) can be met more effectively elsewhere.

The age, health and functional status of the person living with MS and the speciality of care admitted to have all been shown to be associated with inappropriate admissions. Living alone, absence of family support and the requirement for home nursing following discharge or entry to an institutional care facility, contribute to an increased likelihood of adult and older patients remaining in hospital unnecessarily.

A growing number of people living with MS are being admitted to hospital for emergency care; yet many of these admissions could have been avoided with earlier intervention.

An analysis of hospital statistics [2017/2018] in England of the numbers of people living with MS who accessing hospital in an emergency and associated costs found that common reasons for admission were; respiratory issues at a cost of £6 million and emergency bladder and bowel problems at a cost of £5 million.

Aside from the cost of these admissions to the NHS the distress to people living with the conditions is enormous. If each MS service was able to proactively manage respiratory, bladder and bowel problems there could be significant savings.

NHS capacity and infrastructure;

A lack of capacity and infrastructure within the NHS in Wales is leading to people living with MS making unnecessary visits to Accident and Emergency Departments.

The Association of British Neurologists guidelines for prescribing Disease Modifying Treatments (DMTs) recommends that decisions about treatments should be jointly taken by the person with MS and their neurologist, with treatment starting as early as appropriate after diagnosis. For people living with relapsing forms of MS, treating it early and effectively can suppress the disease and presents the best chance of preserving brain and spinal cord tissue during the course of the condition.

By preventing relapses and disability progression, people living with MS should be able to take greater control of their condition and their lives, directly and indirectly improving physical, economic, emotional and social outcomes. Access to treatment and services helps people living with MS manage their condition, and to identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions.

Timely and equal access to services and treatments across the country was a significant issue before the pandemic.

With the increasing number of treatments options, it is more important than ever that people living with MS are supported to make choices about their treatment, and can access the best treatment for them, regardless of where in Wales they live.

Prior to the pandemic, MS Specialists in Wales told us that timely follow up was becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks. They felt as though they are ‘always behind the curve in providing appropriate treatments’.

With this added pressure on MS Neurologist and Specialist Nurse case-loads, people living with progressive forms of MS were being pushed further down the waiting lists with little or no support.

The All Wales Medicines Strategy Group recommendation in December 2019 that the drug fampridine should be made available in Wales was greatly welcomed, especially by those people living with MS who are not eligible for a DMT.

Fampridine is effective as a treatment option for the improvement of walking in adult patients with MS with walking disability (Expanded Disability Status Scale [EDSS] 4 to 7). It is a symptomatic drug that requires prescription, often by a consultant following a face to face consultation. Face to face consultations are necessary to allow assessment of a patient's eligibility by way of a 25m walk assessment.

Whilst the pandemic has played a significant part in preventing face to face assessments from taking place, the lack of infrastructure and capacity to see patients has been a decisive factor also. In some LHBs, fampridine clinics have started slowly, in others not at all.

For many people living with MS, the consequences of such delays in receiving a treatment like fampridine are immense as their balance and walking ability has been impacted thereby putting them at risk of falling / hospital admission.

People living with MS need a flexible blend of care, comprising disease modification and also proactive symptom management and neurorehabilitation, delivered by multidisciplinary teams.

Preventative care strategies for people living with MS must be reviewed in order to tackle problems, such as respiratory and urinary tract infections, at an early stage to try to avert the need for emergency care. This would not only be of huge benefit to people living with MS, it would also reduce pressure on struggling A&E departments.

The MS Multi-Disciplinary Team based in Morriston Hospital (Swansea Bay University Health Board), have been at the forefront of delivering innovative services and this includes the appointment of the first Advanced MS Champion in Wales. This much needed specialist and community based support has reduced the need for emergency hospital care for people living with MS.

Recommendations;

- Preventative care strategies for people living with MS must be reviewed and supported
- The appointments of Advanced MS Champions in each local health board area would significantly reduce the need for emergency hospital care for people living with MS across Wales.

Discharge and delayed transfers;

There are a number of complexities surrounding discharge and delayed transfers for people living with MS.

A systematic review that examined delayed discharge in people living with MS showed that: poor communication between hospital and community services; lack of assessment and discharge planning; inadequate notice of discharge; inadequate consultation with patients and their carers; over-reliance on informal support and lack of (or slow) statutory service provision; and inattention to the special needs of vulnerable groups are problems that characterise delayed hospital discharge.

Greater understanding among health and social care professionals about MS is a priority in Wales. For example, people living with the condition who are admitted to general wards in hospital have repeatedly told us that staff are not aware of MS symptoms and there is no communication with their MS team.

In particular, there is a need to significantly improve understanding of the cognitive impact of neurological long term conditions such as MS. Many of those living with cognitive impairment are unable to identify their own needs, nor articulate those needs or use means of communication to make them known to anyone:

"##### developed an abscess on her bottom and was prescribed medication to help with this, however, the side effects caused raised her blood pressure and the GP admitted her to the Princess of Wales hospital. At the hospital #####'s case was passed from consultant to consultant no-one really taking responsibility to improve her condition.

'So many anti-biotics were pumped into her that it affected her liver and kidneys and her condition worsened. ##### needed help to be able to eat and drink and this was not forthcoming on the ward. The staff failed to keep her hydrated and they didn't feed her. I took in a special cup with a long straw for her to try and drink herself but this was often on the floor when I visited. There were no records either on fluid intake.

'There was no understanding of Multiple Sclerosis on the ward and no input from the Multiple Sclerosis team. They did not keep up to date records and there was little or no communication. We occasionally would see the doctor and he would speak to us but they just didn't give her the care that she needed'.

Many people living with and affected by MS say that health and social care professionals often display a lack of knowledge and understanding of the cognitive impact of MS, nor that it can affect the person's ability to communicate in a social environment, often leading the person to appear rude and aggressive. This can lead to a failure to give optimum high standard care as social relations are compromised.

Recently (January 2022) we have spoken with the family of a man living with Progressive MS who is currently in hospital undergoing treatment for Leukaemia. Whilst he is receiving the very best of treatment for this condition, a number of staff have displayed a significant lack of understanding about his MS symptoms which is resulting in them providing inappropriate procedures and not engaging with his community nursing team. Consequently, this is lengthening his stay in hospital and preventing early discharge home.

Access to Social Care

Social care is vitally important to enable many people with MS to live healthy, full and independent lives and have equal opportunities.

MS Cymru has been concerned that people living with MS have not been able to access the social care support they need both during and after the pandemic.

Prior to the outbreak, there was significant unmet need. One in three people with MS in the UK struggled without the support they need to do the basics like getting washed, dressed and eating. This prevented them and their family members and friends providing unpaid care from living dignified, independent lives. This is not fair and it is unsustainable.

Social care funding in the Wales has not kept pace with increasing demand and we now face a significant shortfall, with too many people living with MS shut out of the system.

Action was taken in Wales to improve access to social care through the Social Care and Wellbeing Act 2014. However, the system is still failing people living with neurological conditions including MS.

People living with MS are disproportionately likely to require social care services at some point in their lives. However, there is a significant number of people who have not been offered a formal assessment or receive any services from a local council as a result of a care plan.

The Coronavirus Act gave local authorities powers to temporarily suspend duties in the SSWB (Wales) Act if pressures on social care got too high, during which time some people did not get the care and support they would normally have been entitled to.

We understand that some local authorities reduced care in response to funding and demand pressures. Also, the lack of Personal Protective Equipment (PPE) for care workers caused some people to decide to cancel their care in order to protect themselves from infection. Together, this situation meant that some people’s health and wellbeing deteriorated without support, or that of their unpaid carers had to take on increased responsibilities.

MS Cymru knows of people living with MS for example #### who has secondary progressive MS. He faced several days during the pandemic when his carers refused to attend because both he and his husband had Covid-19 symptoms and they didn’t have access to PPE equipment. #### is in his 40’s and more recently, he has been forced to live in a residential home for the elderly because due to the crisis in social care, the local authority was not able to provide sufficient carers.

Discharge of people living with MS who are medically fit to be discharged from hospital is being delayed due to a lack of available social care support in the community.

Without adequate investment during the pandemic, and investment and long-promised reform afterwards, social care will continue to let people with MS and other disabilities down, limiting their ability to live independent lives and avoid unnecessary hospital admissions.