

# Setting up an infusion service



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With the advent of more experimental and aggressive drug therapies, MS nurses are being asked to work in different ways. MS nurses have to set up and operate new services so that people with MS have access to the expanding number of treatments for MS. In the following article, MS Specialist Nurse, Caroline D'Arcy, shares the knowledge and experience she acquired in setting up a natalizumab infusion service at Charing Cross Hospital and explores the pivotal role of the MS nurse in facilitating access and safe implementation of new MS treatments.

## Introduction

The role of the MS specialist nurse has changed dramatically in the 15 years since its inception and is continuing to do so with alarming pace. The first MS nurses in the UK were recruited to support the provision of the first licensed disease modifying drugs for MS; at the time this was limited to four self-injected drugs. In more recent years extensive research into new drugs; and into the potential of drugs currently used in oncology and haematology, has broadened the treatment horizon for people with MS. In delivering these new treatments MS nurses have had to acquire additional clinical knowledge, skills and expertise. MS nurses increasingly recognise the need to adapt service design and service delivery and to embrace innovative therapies to ensure people with MS get access to the best available treatments for them.

Several treatments that are used in MS are delivered by intravenous infusion; including intravenous steroids and sometimes intravenous immunoglobulin for the treatment of MS relapses; and mitoxantrone – a chemotherapy treatment that is used off-licence in MS in some centres. But it wasn't until natalizumab (Tysabri) was approved for the treatment of highly aggressive relapsing remitting MS that the need for a specialist infusion area for MS was recognised. Natalizumab was licensed and approved by NICE for the treatment of this subtype of MS in 2007. The introduction of Tysabri required a new level of education for MS nurses and people with MS eligible to receive the drug. With further intravenous drug treatments for MS on the horizon, it will be imperative that MS nurses have their own area for infusions; have the expertise to deliver these treatments safely, and can communicate the risks and benefits of new drug treatments to individuals effectively.

## Starting up an infusion service

When an intravenous treatment is introduced at a site, protocols and pathways need to be established. These should clarify the roles and responsibilities of each member of staff and department. Written protocols and pathways should be drawn up to facilitate appropriate patient selection and to provide guidance for both health professionals and patients on timescales for preliminary clinical investigations and treatment initiation. Patients will also need to be informed about on-going

monitoring and stopping criteria where appropriate and effective communication will prove key to ensuring patients understand how their treatments work and what they can realistically achieve for them.

## The importance of a coordinated approach

When setting up an infusion service it is important to take a coordinated approach. The treatment pathway might include the input of health professionals across medical departments including radiology, pharmacy and neurology and effective communication between these departments will be necessary to ensure a smooth transition between stages along the patient pathway.

## Designated space and specialist equipment

Managers are responsible for allocating space and resources so their input will be crucial to the success of the service. Adequate space is essential for the safe and effective implementation of a new specialist treatment service and appropriate furniture and facilities such as comfortable seating for patients and access to telephones and computers for health professionals should also be considered. Other equipment such as drip stands, infusion pumps, equipment for taking vital sign observations, trolleys for cannulation and venepuncture, may seem obvious, but are essential. Rescue drugs and a crash trolley should also be easily accessible.





## Training and development

To meet the expanding treatment options available to people with MS, MS specialist nurses need training on an on-going basis. Nurses need to demonstrate a broad spectrum of skills and knowledge including practical expertise such as clinical certification in cannulation and venepuncture; administrative and organisational skills to ensure accurate documentation and appointment scheduling; as well as effective communication skills to ensure people have a clear understanding of where they are in terms of the patient pathway. A patient should understand how their treatments are working, how they appear to be responding to the treatment, and what their treatment goals are. Nurses also need to be able to communicate appropriately with a patient's GP, family and carers where applicable.

## Benefits of designated space and resources

When the challenges of setting up such a service are set aside, there are many benefits associated with dedicated space and resources in the delivery of a treatment service including the flexibility to accommodate standard and new treatments as part of routine practice. Patients will receive continuity of care and assessment from the same team of nurses and consultants once the service is established and the team may be able to address other aspects of the patient's care such as symptom management. A permanent service location and regular treatment schedules also encourages patient interaction, allows patients to share their experiences and potentially form new friendships with people in a common environment.

## Challenges

As with the establishment of any new treatment service, there will be problems and challenges. Increasing patient numbers can present a major problem to an infusion service as space becomes inadequate and organisation increasingly difficult. When an

increasing workload is drawing on static resources it is important for health professionals to prioritise their responsibilities. Unrealistic patient expectations is another challenge MS nurses providing new treatments are often faced with. Some new treatments are hailed by some as 'miracle treatments' but the reality can often be very different and patients can be faced with disappointment. Patient expectations can be difficult to manage and warrant clear communication about treatment goals, and potentially, treatment failures. In cases where the treatment fails, patients need to have been prepared for the potential failure and know whether there are alternative treatment options available to them.

As an example, where patients fail to respond to natalizumab, the only treatment alternatives are experimental or drugs that are licensed for conditions other than MS, but may be prescribed off-licence. The risks and side effects of experimental treatments can cause great anxiety in patients and their families and it is the nurse's role to explore their concerns and ensure they have a clear understanding of all of the potential outcomes of proceeding with a new treatment. Patients sometimes do their own research and draw on the wealth of information available online. MS nurses are expected to be able to judge the validity of this information and to be up-to-speed with the latest evidence base for the respective treatments.

## Conclusion

The role of the MS nurse is constantly evolving to meet the promise of newer and more effective treatments. The safe and effective use of these new treatments relies on the clinical knowledge, understanding, practical expertise, and effective organisational and communication skills of MS nurses. The approval of natalizumab for the treatment of MS necessitated the establishment of a new model of service delivery within the MS nursing profession. MS nurses have risen to the challenges of this new mode of treatment delivery and with the possibility of new intravenous MS treatments on the horizon, including alemtuzumab and rituximab, it is likely that infusion services will become a defining feature of future MS services.