

Eight steps to improving your relapse service

A guide to best practice for MS specialist nurses

Step 1: Educating health professionals

Step 2: Educating people with MS

Step 3: Ensuring a responsive first point of contact

Step 4: Providing timely, effective triage and assessment

Step 5: Providing timely treatment if required

Step 6: Following up relapses consistently

Step 7: Reviewing disease modifying drug management

Step 8: Auditing your service

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Introduction

Why is this guide needed?

The majority of people with multiple sclerosis (MS) will experience a relapse at some stage and many people will have several relapses over time. Relapses vary hugely in their impact; they may be little more than a nuisance or they can be devastating, take months to recover from and leave people with some degree of permanent disability.

People who are having a relapse, or who think they may be, need help and support to manage the impact. As well as managing the symptoms of relapse, it is important that the MS team also consider treatments to help reduce the chances of that individual having more relapses in the future by reviewing their disease modifying drug (DMD) treatment.

MS specialist nurses in the UK play a vital role in relapse care. There has been an increase in nurse-led relapse services, particularly since oral steroids (which can be prescribed by non-medical prescribers) have been shown to be similarly effective to intravenous steroids in treating relapses¹⁷. At the same time, however, we know that there is room to improve the quality and consistency of services across the country¹.

Rapid diagnosis and treatment of relapse is included within the 2014 NICE Guideline on MS² and associated 2016 Quality Standard³, and in the Neurological Health Services Clinical Standards for Scotland⁴. But, in addition to meeting national standards, delivering a responsive, high quality and effective service for people who may be having a relapse underpins the delivery of responsive services for people with all types of MS experiencing acutely deteriorating symptoms.

Who is this guide for?

This guide is primarily aimed at MS specialist nurses, though any health professional working with people with MS should find it useful. It is important that anyone working with people with MS understands what a relapse is, the significance of relapses in terms of overall clinical management and the importance of a speedy assessment of the individual by the local specialist MS service. This guide provides a blueprint for relapse management in any MS service, urban or rural, acute hospital or community based, and will help MS teams to measure the quality of their services.

How is the guide structured?

The guide is split into three parts.

Part 1 explains what relapses are, what causes them and why they matter.

Part 2 discusses the clinical management of a relapse.

Finally, **Part 3** sets out eight steps needed to deliver an effective relapse service.

The guidelines here are based on evidence and national recommendations wherever these exist, and where they do not, on the consensus opinion of a group of health professionals with expertise in MS who are listed in the Acknowledgements section at the back.

To go alongside this guide, on the MS Trust website you will find a selection of example resources such as template letters and leaflets to download and adapt for use in your own service, further reading and useful links. These are available at www.mstrust.org.uk/relapse-guide.

1. Understanding relapse

What is a relapse?

An MS relapse is defined as the onset of new symptoms or the worsening of pre-existing symptoms, attributable to demyelinating disease, lasting for more than 24 hours and preceded by improving or stable neurological status for at least 30 days from the onset of the previous relapse, in the absence of infection, fever or significant metabolic disturbance⁵.

In practice it can be difficult both for people with MS and for health professionals to identify relapse until the pattern of deterioration and recovery becomes clear over time. MS symptoms may worsen for a number of different reasons and it can be difficult initially to distinguish relapse from other potential causes. Just knowing what to call a relapse can be a problem; words such as 'exacerbation', 'flare-up', 'attack' or 'blip' are often used to describe a deterioration of MS and people may not always associate these episodes with relapse.

A relapse typically presents with symptoms that people notice over a period of a few days. Individuals can experience an increase in their existing symptoms; a reoccurrence of symptoms they have had in the past or new ones. Common symptoms include **weakness in one or more limbs**, problems with **vision**, increased **fatigue**,

altered **sensation** (which may include **neuropathic pain**) and **cognitive problems**, though any other symptom which can be associated with MS may occur. Classifying relapses, based on symptoms and neurological examination, is an advanced skill which MS specialist nurses should work towards. Understanding, recording and communicating the phenotype of a relapse helps other members of the healthcare team to pinpoint the site of MS lesion(s) and can inform prognosis and DMD management for the individual. There is more information about the different phenotypes of MS relapse in Appendix 1.

People with relapsing remitting MS are most likely to have a relapse but people with both progressive types of MS may also experience occasional relapses. Relapses are sometimes more difficult to diagnose in people with progressive MS although their impact is no less significant. It is just as important to treat a relapse in someone with progressive MS who has lost upper limb function as it is to treat someone with relapsing MS who has developed ataxia.

Relapses can be sub-divided into **clinically significant** and/or **disabling** relapses (Box 1) as defined by NHS England⁵. These definitions are relevant both in terms of assessing the impact of the relapse on the individual and in establishing which (if any) DMDs may be indicated.

Box 1: Definition of MS relapse

A **clinically significant relapse** is defined as any of the following:

- any motor relapse
- any brainstem relapse
- a sensory relapse if it leads to functional impairment
- a relapse leading to sphincter dysfunction
- optic neuritis
- intrusive pain which lasts more than 48 hours

A **disabling relapse** is defined as any relapse which fulfils one or more of the following criteria:

- it affects the patient's ability to work
- it affects the patient's activities of daily living as assessed by an appropriate method
- it affects motor or sensory function sufficiently to impair the capacity or reserve to care for themselves or others as assessed by an appropriate method
- the individual needs treatment/hospital admission as a result of the relapse

What is happening when someone has a relapse?

Relapses are the outward sign of increased inflammatory activity within the central nervous system (CNS) which results in demyelination. Myelin is a substance produced by oligodendrocyte cells which wraps around axons within the CNS. The thickness of the myelin and the distance between the nodes of Ranvier along the axon determine the speed at which impulses are transmitted along it and so ultimately the speed and efficiency with which that part of the CNS communicates with the peripheral nervous system.

For reasons which are not yet fully understood, T cells in the peripheral circulation of someone with MS become activated such that they bind to myelin. These activated T cells express adhesion molecules which allow them to pass through the normally impermeable blood brain barrier.

Once the T cells are circulating within the CNS, antigen presenting cells such as macrophages, microglia or B cells stimulate the T cells to produce cytokines, a broad group of molecules which act as signals between cells. The production of cytokines causes other cells in the vicinity to also become activated, a process is also known as 'bystander activation' or 'inflammatory cascade', and the affected area within the CNS enlarges. Within the area of inflammation, proteins such as interferon gamma and tumor necrosis factor (TNF α) are produced which result in damage to the myelin. As the myelin along the axons in the affected area is attacked, the efficiency with which the axon conducts impulses is impacted and they may become delayed or completely blocked, leading to symptoms of relapse. The symptoms caused depends on which part of the CNS is affected. For example if the optic nerve is demyelinated then the individual's vision will be affected.

For reasons that are not yet understood, the inflammation within the CNS resolves after a time and repair of the damaged myelin can take place providing there are enough oligodendrocytes in the vicinity. These areas of remyelination are what form the plaques that show up as enhancing white regions on T2 magnetic resonance imaging (MRI) scans. Although the new myelin can work effectively, it tends to be thinner than unaffected myelin and so the transmission of impulses through the affected nerves may not be as fast as before the relapse⁶.

If a nerve axon is affected by repeated relapses, the amount of remyelination along the axon is reduced and the nerve cell may be lost altogether. Over time this contributes to the brains of people with MS losing more nerve cells than people with healthy brains and so decreasing in volume at a faster rate than a healthy brain. Loss of brain volume is also called brain atrophy. Healthy adults experience brain atrophy as a normal part of ageing at a rate of approximately 0.1-0.5% per year. People with MS, however, will typically experience brain atrophy at a rate of 0.5-1.35% per year if untreated⁷. The mechanisms which cause this increased rate of atrophy often occur early in the disease process and the atrophy is irreversible once it has occurred.

Human brains have an inbuilt neurological reserve (or neuroplasticity) which means that when an area of the brain is damaged, nerve pathways can be 'rerouted' through undamaged areas to enable normal or near-normal functioning. This explains why early MS activity can be undetected for some while⁶. Over time, as increasing numbers of nerve cells are lost as a result of the disease process, the neurological reserve available becomes less and less, and the capacity of the brain to compensate in this way is reduced or lost. It is this process which underpins the accumulation of permanent disability over time.

Inflammation of the central nervous system is a key part of the disease process in MS and can occur without causing any clinical symptoms. This means that an MRI scan may show several areas of inflammation within the brain of someone with MS who otherwise presents as being well. The difference between a relapse and ongoing inflammation is one of presentation rather than causation (see figure 1). The process and the long-term effect are the same, the difference is that the inflammation which causes a relapse occurs in a part of the brain which impacts directly on function.

Figure 1: MS relapse: the tip of the iceberg^{5,8,9}

Relapse – the tip of the iceberg of active MS

Relapse:

"The onset of new symptoms or the worsening of pre-existing symptoms, attributable to demyelinating disease, lasting for more than 24 hours and preceded by improving or stable neurological status for at least 30 days from the onset of the previous relapse in the absence of infection, fever or significant metabolic disturbance."⁵



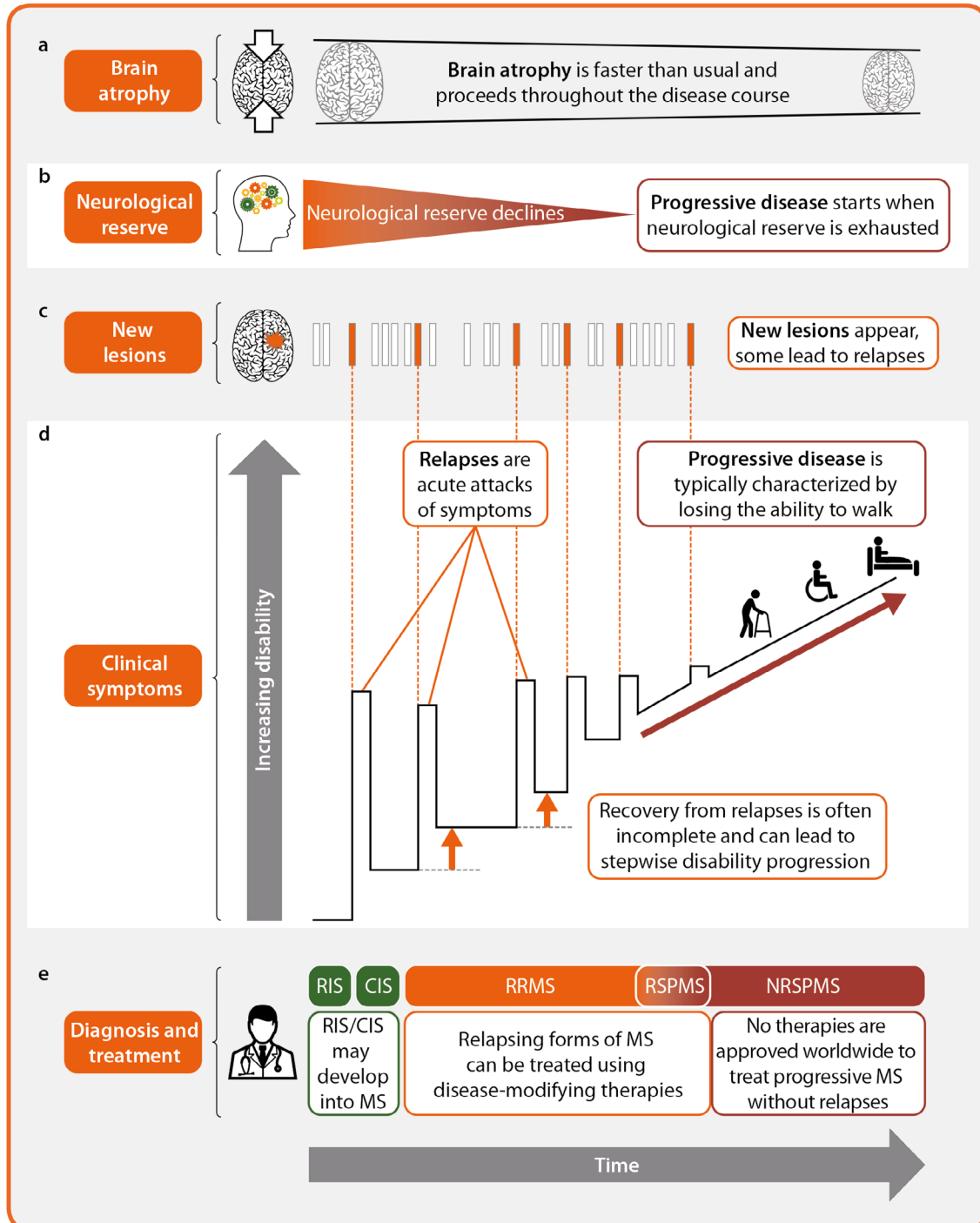
Sub-clinical activity:

For every clinical relapse there are known to be an average of 8-10 T2 (white matter) lesions occurring as well as more diffuse white matter changes, grey matter atrophy and cortical lesions.⁷

Figure 2 illustrates the different processes which are happening within the central nervous system of someone with MS. It also shows how people develop new lesions over time only some of which will result in relapses, depending on where the lesions arise. The long-term impact of ongoing lesions on neurological reserve is the same, whether or not they cause symptoms of relapse.

Figure 2: The impact of inflammatory episodes and demyelination on long-term outcomes

The brains of people with MS atrophy more quickly than healthy brains as a result of damage caused by MS (a), the brain compensates for this using its neurological reserve (b). When the neurological reserve is used up progression of the disease becomes more evident (c). Lesions may or may not cause a clinical event or relapse though are still significant (d). A typical MS disease course involves relapses followed by progression (e)



NB: CIS, clinically isolated syndrome; NRSPMS, non-relapsing secondary progressive multiple sclerosis; RIS, radiologically isolated syndrome; RRMS, relapsing remitting multiple sclerosis; RSPMS, relapsing secondary progressive multiple sclerosis.

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Why do relapses matter?

Relapses provide clinical evidence of MS activity. No matter how seemingly insignificant the relapse may appear, they are an indication of active disease. We know that a higher frequency of relapses early in the course of MS is associated with less favourable, long-term outcomes¹⁰. By monitoring all relapses in people with MS, MS neurologists are better placed to optimise DMD treatment with a view to preserving brain volume and slowing progression of disability over the long-term⁷.

Relapses impact on people with MS and their family and friends in many different ways (see box 2). They typically occur indiscriminately with no precipitating factors and the time and extent of recovery is hard to predict. This uncertainty adds to people's concerns. Women are at increased risk of relapse during the first three months following pregnancy¹¹, at what can already be a challenging time.

The impact of relapses on individuals can be profound; 67% of people in paid employment reported having to take time off sick and 66% needed additional support to undertake routine daily tasks during their relapse¹². MS specialist nurses working every day with people experiencing relapses will be familiar with their impact and know that prompt and effective action helps to reduce the burden for the individual. It is important to take the necessary actions to mitigate the impact of a current relapse and to reduce the frequency and severity of future relapses.

Box 2: The impact of relapse

Physical: Increased dependence on others is a common feature. People are often unable to function fully and independently during a relapse. Fatigue is often much worse and people may experience increased weakness, spasms, pain or visual symptoms. Mobility may be reduced as may upper limb function, making everyday activities much more of a challenge than usual.

Emotional: People often feel more anxious during a relapse and feel that they have less control than they would like over their body and their life. People may also worry about the 'damage' the relapse is causing and the long-term implications of this for them.

Family: Partners or other family members may have to take time off work to provide additional support or extra child care. People having a relapse find that their roles often change within the family and work environments during a relapse as they become less able to carry out their usual activities and relationships can be affected as a result.

Work: Some people will reduce their working hours during a relapse, whilst others may have to stop work temporarily or permanently depending on the extent of recovery they experience. The uncertainty around recovery time can make employer relationships difficult.

Financial: Having a relapse can result in loss of income for working people who don't receive sick pay, such as the self-employed, and there can be additional costs (for instance, the need for taxis or extra childcare).

Disease modifying drugs are used in people with relapsing MS with the aim of reducing the number and severity of relapses, slowing the rate of progression and, in some instances, slowing the rate of brain atrophy. The ABN¹³ and NICE² recommend that an MRI scan should be considered as part of an annual MS review in order to monitor the efficacy and safety of DMDs and to assess the extent of sub-clinical inflammation within the brain or spine of someone with MS at that point in time. Greater use of MRI scanning in people with MS over the last 15 years has improved our understanding of the nature of the inflammatory process which causes damage to the myelin around the axons of the CNS and contributes to long-term neurodegeneration or brain atrophy. A systematic review of 45 different studies concluded that MRI based measures provide the most useful and sensitive guide currently available for predicting long-term outcomes¹⁴.

Relapses give a clear indication of ongoing neuro-inflammation⁹ and, when clear relapse records are combined with information from an MRI scan, this gives the MS team a fuller picture of the extent of inflammation and a better understanding of whether the individual is on the right treatment.

In summary, an effective relapse service is an integral part of effective DMD management and as such central to overall disease management, helping to improve short and long-term outcomes for people with MS.

2. The clinical management of relapse

This section explains best practice in diagnosing, treating and following up people experiencing MS relapse.

Diagnosing relapse

Diagnosing a relapse can be difficult. Each relapse is different and there are many other factors which can cause a similar presentation (at least initially) in people with MS. It is often only with time that the pattern of deterioration and recovery typical of relapse becomes clear. It is vital to determine whether the symptoms are a true MS relapse or whether the deterioration has some other cause. This ensures that the individual is given the right treatment and that genuine MS disease activity is recorded.

Figure 3: Typical pattern of a relapse

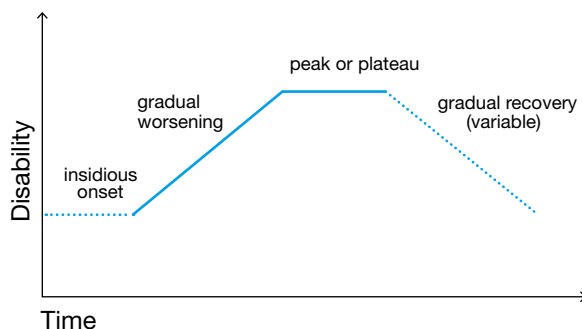


Figure 3 shows the common pattern of an MS relapse. Onset typically occurs over a few days or perhaps a week or so. Symptoms then tend to continue to worsen and will then plateau before the individual begins to see some recovery. Usually, the recovery begins within a few weeks of onset though this may extend into 2-3 months. If the deterioration in symptoms is caused by a relapse an individual will typically experience a degree of recovery, regardless of whether or not they receive treatment. If their symptoms are caused by progression of MS they are unlikely to see any sustained or significant recovery. The timeline of changes is very important in helping to understand what is happening and to aid diagnosis.

When someone with MS first contacts the service with a possible relapse, the MS specialist nurse should explore the changes the individual reports and look for any obvious cause. Questions which may help with this initial triage discussion, which

may well take place by phone, are shown in box 3.

Box 3: Questions to ask during initial triage of someone contacting the service with acutely deteriorating symptoms

- What has changed? What can you not do now that you could do last week/2 weeks ago?
- When did you first notice your symptoms were getting worse and what has been the pattern of your symptoms since?
- Are these new symptoms present all the time or do they fluctuate in severity?
- Can you identify anything that caused the changes - for example have you been doing any strenuous exercise, working long hours, experienced a major stress or been exposed to unusual levels of heat?
- Do you have any signs of infection? (feeling hot/cold/shivery; recent changes to bladder function; feeling systemically unwell)
- When was your last relapse? How was it treated and how soon did you recover?
- Are you currently prescribed a DMD? How many doses have you missed over the last 4 weeks?
- What other medications are you currently taking? Has anything changed with these recently?
- Are you or have you been pregnant during the last few months? (if appropriate).

Initial questions such as these can help the MS specialist nurse to decide on the urgency for full assessment and/or treatment and allow any referrals (eg to social services or physiotherapy) to be made quickly. Drawing a simple timeline on paper with the person can be a helpful way to clarify the pattern of symptoms.

At this point the MS specialist nurse may decide 1 of 4 things:

- A possible relapse is suspected and a full assessment is therefore required
- The person does not seem to be having a relapse of their MS. They should be encouraged to contact the service again if the symptoms don't resolve within a few days. If they have new MS symptoms which are not consistent with a relapse, consideration should be given to booking them into an MS clinic or bringing forward their next review
- The person has signs of infection and should be fully assessed and treated for this first, usually via their GP. A follow up call a few days later

to make sure they have seen their GP and that their symptoms are beginning to resolve should be scheduled

- The individual has experienced an acute deterioration of their MS (possibly a relapse) so severe that the MS specialist nurse thinks admission is required. The MS specialist nurse should discuss this urgently with the neurologist

A full, face to face assessment should be carried out as soon as possible after the initial contact if it is thought there is a possibility the individual may be experiencing a relapse. A thorough history of the individual's signs and symptoms should be taken including an indication of the time periods over which these have changed and any new symptoms which have developed. This should include whether their symptoms have continued to worsen since triage. The history should also consider any impact on mood, cognition and function as well as social role, such as within the family or at work, for example. Objective measures of changes should be made where possible and appropriate to the individual's symptoms - these should be compared with the individual's baseline when such records exist (see box 4 for some examples of the type of objective measures which can be relatively easily undertaken in clinic or on a home visit). These objective and subjective records of changes help describe the overall impact of the relapse and help with diagnosis and treatment planning.

Box 4: Objective measures to assess possible relapses

- **Visual problems:** Visual acuity can easily be tested in each eye using a Snellen chart and/or problems with colour vision using an Ishihara test (online versions available). Remember to use corrected vision when carrying out these tests
- **Problems with mobility:** Timed 25 foot walk. Self-assessment of changes in function are also useful such as the time taken to walk a specified distance (eg from their gate to the end of the road) or inability to complete specific tasks requiring fine motor skills
- **Reduced upper limb function:** 9 hole peg test
- **Cognitive dysfunction:** simple cognitive testing such as BICAMSⁱ should be considered where recent cognitive changes are reported
- **Ataxia:** There are different tests for ataxia depending on which part of the body is affected. Observing the individual's gait when they are walking, asking if they can tandem walk, performing a Romberg test or finger-to-nose testing can all be helpful

Once the full assessment is complete, the assessing MS specialist nurse should discuss their impression with the individual and check their understanding. Even after a full assessment, it may not be clear whether or not someone is experiencing a relapse or whether the changes are indicative of sustained disease progression. It is sometimes only as someone's symptoms improve, remain or worsen over time that it becomes clear. Whatever the conclusions, they should be discussed with the person with MS who should then be provided with clear information about the next steps.

Differential diagnosis of relapse

When deciding whether someone who presents with a sudden or recent deterioration in symptoms could be having a relapse, it's important to consider other possible causes and these should be either ruled out or managed.

- **Heat/stress:** Excessive heat or stress can cause a temporary exacerbation of symptoms. Careful questioning can help to determine whether the changes could be due to triggers such as these. If this is the case, symptoms should ease within 24 hours of the trigger being removed
- **Infection:** If someone with MS has an infection, such as a urinary tract infection (UTI), the first symptoms they notice may be a worsening of their MS. Careful questioning may reveal symptoms such as a raised temperature, shivering, feeling hot and cold, new symptoms of burning when passing urine etc. which may indicate infection. High dose steroids are clearly contraindicated in the presence of infection so it is important to carry out an infection screen before prescribing high dose methylprednisolone to treat a relapse.

As a minimum, screening should involve a urine dip stick test and ensuring there are no clinical signs or symptoms of infection. A blood test to check ESR (erythrocyte sedimentation rate) or CRP (C-reactive protein) can also be useful in ruling out any underlying systemic infection. If the urine sample tests positive for blood, protein, nitrites or leukocyte esterase and/or the clinical suspicion of a UTI is high then a mid-stream specimen of urine should be sent for further analysis¹⁵ and antibiotics prescribed if indicated. Some centres have more stringent protocols in place for establishing whether or not an infection is present and these should be followed. An infection can predispose an individual to an increase in symptoms they have previously experienced, but it does not generally produce new MS symptoms never previously experienced. If this is the case, the MS specialist nurse should discuss the situation with a neurologist.

ⁱ Brief International Cognitive Assessment for Multiple Sclerosis – see www.bicams.net

- **Change in medication:** Current medication, medication adherence and any recent changes to medications should be discussed and recorded. If the individual has recently started (or stopped) a particular medication, this may be responsible for the change in their symptoms – for example anti-spasticity medications may increase fatigue and weakness
- **DMDs:** If the individual is being treated with a DMD where there is a risk of developing immune related disorders or PMLⁱⁱ then urgent consultation and review with a neurologist experienced in MS is strongly recommended. Whilst the most likely explanation for a deterioration in MS is a relapse, potentially serious side effects caused by DMDs cannot be ruled out and expert review is needed to make sure that nothing significant is missed
- **Progression of MS:** This can be very difficult to distinguish from a relapse in the first few weeks or even months. Typically, progression of MS occurs more gradually than a relapse but not always. The main differentiator between relapse and progression is the speed and extent of recovery. Someone who is having a relapse will experience full or partial recovery from their symptoms within a few weeks (even if they do not have any treatment for the relapse). If someone is experiencing progression of their MS any recovery is likely to be transient even if treated with high dose methylprednisolone
- **Menstrual cycle/menopause:** Many women report cyclical changes in MS symptoms and feel that their symptoms deteriorate 2 to 3 days prior to the onset of their menstrual period and improve once bleeding has started¹⁶

Treating relapses

Once a diagnosis of relapse is made it is important to discuss the treatment options with the individual. NICE recommends that treatment should be offered for relapses of MS which ‘affect the person’s ability to perform their usual tasks’².

Routine treatment options are:

- **No treatment** – given that methylprednisolone does not have any impact on long-term outcomes, not every relapse needs to be treated
- **Symptomatic treatment**, such as a course of physiotherapy or other interventions from the multi-disciplinary team (MDT) where required
- **‘Wait and see’** ie treatment with high dose steroids (methylprednisolone) will be given if relapse symptoms worsen over the next few days
- **Oral high dose methylprednisolone** (500mg daily for 5 daysⁱⁱⁱ)
- **Intravenous high dose methylprednisolone** (1g daily for 3 days)
- **Plasma exchange** may be used occasionally to treat severe relapses which have not responded to high dose methylprednisolone
- **Assessment of the need for short-term support** from local services such as social services, community rehabilitation teams or voluntary agencies should also be made

If steroid treatment is required, this should be given during the inflammatory phase of the relapse, ie as early as possible and within no more than 2 weeks from the initial patient contact if possible. In the majority of studies examining the effect of steroids on relapses in MS the steroids were administered within 2-4 weeks of the onset of symptoms. Based on this, the NICE clinical guidelines recommend early use of steroids in relapse and advise that if someone presents with symptoms with onset more than 2 weeks ago, they should be reviewed by a neurologist before being prescribed methylprednisolone².

Using high dose methylprednisolone

Treating a relapse with high dose methylprednisolone does not affect long-term outcomes or prognosis. The steroids serve solely to speed up recovery from relapse and hopefully ease acute symptoms. This can mean that the individual is able to continue working or caring for their family or can avoid a hospital admission.

Methylprednisolone can be given either orally or intravenously. A Cochrane review¹⁷ concluded that there is no difference in terms of effectiveness between oral and intravenous (IV) forms. Oral methylprednisolone is easier to administer and avoids the necessity of an admission.

Oral methylprednisolone should therefore be the default option, and NICE recommends that people should only be prescribed IV methylprednisolone:

- if they have **failed to respond to oral steroids** in the past
- if they **cannot tolerate oral steroids**
- if they **need to be admitted** due to the severity of their relapse symptoms

ii PML stands for progressive multifocal leukoencephalopathy which is a rare, viral disease of the brain. More information is available from the MS Trust website (www.msstrust.org.uk/a-z/pml)

iii A paper published in 2015 recommended twice this dose, ie 1000mg oral methylprednisolone daily for 3 days (LePage E, Veillard D, Laplaud DA. Oral versus intravenous high-dose methylprednisolone for treatment of relapses in patients with multiple sclerosis (COPOUSEP): a randomised, controlled, double-blind, non-inferiority trial. *Lancet* 2015; 386 (9997): 974-81.

- if they **require close monitoring** whilst taking the steroids (for example if they have unstable diabetes or a prior history of psychosis)²

The decision should be made based on the individual's clinical history and presentation.

Prior to any treatments being prescribed, there should be a full discussion with the individual about the pros and cons of high dose methylprednisolone treatment, including how steroids have previously affected them (see box 5).

Box 5: Pros and cons of treating relapses with steroids

Pros:

- Steroids can shorten relapse recovery time
- Steroids may ease the acute symptoms - some people find steroids make them feel much better

Cons:

- Steroids make no long-term difference to the course of their MS – managing expectations is key
- Treatment with methylprednisolone will reduce any enhancement of active lesions which would be picked up on MRI for up to 7-9 weeks¹⁸. This may be relevant if an MRI is indicated to inform prescribing of DMDs and will require the MRI to be done before steroids can be taken
- Many people experience significant side effects when taking steroids (see box 6). People who have previously experienced particular side effects when taking high dose methylprednisolone often seem to have similar side effects each time
- The likelihood of developing side effects increases with increasing frequency of prescription. It is good practice to limit the number of courses of high dose methylprednisolone taken by an individual in any 12 month period to no more than 3¹⁹

Potential side effects need to be balanced against the impact of the relapse and the person with MS may decide that they do not wish to take steroids and prefer to let the relapse run its course or opt for other treatment options (see below).

Box 6: Common side effects of methylprednisolone

Side effects of methylprednisolone can include^{iv}:

- Insomnia
- Altered mood (high/low)
- Anxiety
- Increased appetite
- Headache
- Myalgia
- Acne
- Gastrointestinal distress/heartburn
- Flushing
- Palpitations
- Metallic taste
- Hyperglycaemia if diabetic

Rarer side effects include:

- Osteoporosis
- Osteonecrosis
- Avascular necrosis of the femoral head
- Psychosis
- Gastrointestinal ulceration

Simple actions which can be taken to minimise problems with side effects include:

- Taking the steroids with food and preferably in a morning can help to minimise problems with gastric irritation or insomnia
- Prescribing an H2 antagonist such as ranitidine or a proton pump inhibitor such as omeprazole can reduce gastric irritation, though any prescribing must take account of local policies

It is important that anyone close to the person with MS understands the potential side effects of the steroids so that they can support their loved one. This can be particularly helpful if they experience mood changes which they may not have full insight into at the time.

Once a treatment plan is agreed this should be implemented without delay. If oral steroids are prescribed the prescription should be given with clear instructions as to when and how to take them and how to manage any side effects. The aim should be for the individual to start their medication within 24 hours, provided any infection screening is clear.

^{iv} A full list of side effects which have been reported in people taking methylprednisolone can be found within the summary of product characteristics (www.medicines.org.uk/emc/medicine/25693)

Other treatment options

Symptomatic medications may be helpful for people who are having a relapse, though it is advisable to monitor the effect of the steroids first and assess the need for symptomatic treatment at a follow up consultation.

Regardless of whether a relapse is diagnosed or not, the MDT should consider the need for symptomatic management and support for functional ability and safety and ensure referral to any members of the MDT who may be helpful. There is evidence²⁰ that recovery from relapse is improved if people are treated by a specialist multi-disciplinary team as well as with steroids. Additionally, referral to a neuro-specialist physiotherapist and/or occupational therapist should always be considered when assessing someone in relapse.

Plasma exchange to treat relapse

Plasma exchange or plasmapheresis is occasionally used to treat severe relapses which have not responded to treatment with high dose methylprednisolone²¹.

Plasmapheresis involves taking whole blood from the individual and passing it through a continuous flow machine (as used in kidney dialysis). The plasma in the blood is separated out, removed and replaced with donor plasma and the 'cleaned' blood is then transfused back into the individual. The process usually takes between 2-4 hours. People can find that their blood pressure drops during the procedure and so can feel light-headed as a result. There is also an increased risk of infection and a small risk of a blood clots forming.

Recording relapse

Relapses are not always recorded accurately in the medical notes¹². Future opportunities to fully assess disease activity may be missed if a complete history of potential and confirmed relapses isn't available.

A record of the history, objective measures, discussions with the patient and other professionals and agreed next steps should be made in the medical notes. This also allows continuity of care for the individual should any other colleagues speak to them in the future.

Follow up after a relapse

Follow up is an essential part of relapse management. It allows the MS team to assess the pattern of relapse and recovery – indeed, it may only be at this stage that the MS specialist can be sure that the individual has experienced a true relapse rather than progression as the pattern of recovery and response to steroids (if taken) is reviewed.

The follow up review may take place face to face or over the telephone and should be planned for 6-8 weeks after assessment. People with MS should, of course, know how to contact the MS service at any time before then if they need to.

The follow up appointment provides an opportunity to discuss:

- The person's **pattern of recovery** (or otherwise). Any objective measures such as the 25 foot walk, neurological examination or BICAMS should be repeated. The results of these should be compared with the results at their previous appointment and recorded
- Any **concerns** the person with MS or their family may have, for example if their recovery is slow or incomplete
- The need for **symptom specific interventions** including medication or referral to appropriate members of the MDT (if not already done)
- Any **side effects** the person has had from steroids (if taken) and how they managed these; this will be helpful when making prescribing decisions in the future
- The **need to review DMD management**. Relapses are seen as indicators that the individual's MS is active and are a principal factor in determining whether or not someone should start, switch or perhaps stop DMD treatment. If referral to the DMD clinic is required this should be made quickly and expedited if needed. If there is any doubt then the individual's case should be discussed with the local neurologist responsible for prescribing DMDs

Most people can be discharged from the relapse service back into routine MS care. However people should be able to access the MS team for advice at any time via the telephone helpline and should understand how to contact the MS specialist nurse team if they need to.

As always it is important to keep clear and accurate records throughout - a summary of the episode should be sent to the neurologist, GP, any relevant members of the MDT and the individual for their records.

3. Eight steps to providing an effective relapse service

MS specialist nurses play a key role in establishing services to manage MS relapse and this final section offers a practical guide to what the components of a responsive, high-quality relapse service should be.

The way that relapse services are configured varies widely across the UK. Some services are based in specialist neuroscience centres, others in community settings; some cover urban areas whilst others have a more rural geography. Each has their own challenges. The way in which services deliver care also varies widely. Some teams may deal with most people who are relapsing over the phone, in collaboration with GPs, whilst others have dedicated relapse clinics. Most services deliver care using a combination of telephone and clinic consultations. The case studies in this section highlight how different service models can work provided they include the features outlined in this guide: rapid telephone triage, face to face assessment with MS specialist involvement, timely treatment, follow up and DMD review.

MS specialist nurses are often the people within the team who drive improvement in services as they are the health professionals who have an understanding of what people with MS need and of how their services are meeting, or failing to meet their needs. MS specialist nurse prescribers have the additional ability to manage the whole episode of care for someone with MS - from triage and assessment through diagnosis of relapse, prescribing treatment and follow up. This can improve continuity of care for people with MS through what is often a very difficult period for them. Whether prescribers or not, the MS specialist nurse role is key.

Step 1: Educating health professionals

Every health professional who works with people with MS needs to ensure they fully understand MS relapse. GPs in particular need to have a good understanding of relapse management. Whilst every health professional is responsible for their own professional development, it is also the role of the MS specialist nurse as an expert in the area to ensure that local practitioners know what MS relapses are, their presentation, differential diagnosis, management and the importance

of involving the MS team when a relapse is suspected.

There are a number of educational resources which can help health professionals to improve their own knowledge and to teach others (some are listed in Appendix 2). Whilst reading journal papers provides a theoretical understanding, there is no substitute for spending time with knowledgeable colleagues (for example an experienced MS specialist nurse or neurologist) in order to learn about the clinical aspects of relapse management.

Courses in relapse management are not widely available. However, the MS Trust, in partnership with Birmingham City University, provides foundation training for MS specialist nurses and this includes training on relapse management.

Goal: The healthcare team working with people with MS understand what a relapse is, what to do if a relapse is suspected, diagnosing relapse, potential treatment options and the configuration of local services.

- Everyone working in the multi-disciplinary team should have sufficient understanding of relapses and their differential diagnosis to be able to advise people with MS who they think may be having a relapse. This may be simply advising the person with MS to contact their MS specialist nurse and providing the individual with some information about relapse in the interim
- MS specialist nurses should take every opportunity to make sure that GPs in their local area understand what a relapse is, how it should be treated and the importance of communicating quickly with the MS team if they see someone with MS who they suspect may be having a relapse
- MS specialist nurses and therapists should have undertaken training on relapse management. This is likely to take a combination of forms including reading, working with more experienced colleagues and participating in face to face meetings relevant to relapse management. Skills and knowledge in relapse management should be refreshed annually

Step 2: Educating people with MS

Many people with MS are unsure of just what a relapse feels like. It can be very difficult for them to know when a change in their symptoms constitutes a relapse and when it is just part of the normal fluctuation of their disease or due to some other cause, such as infection. Making sure that people understand what a relapse is, what they should do if they are worried they may be having a relapse and how to cope should a relapse happen can help to ease anxieties and to help them feel more confident about reporting problems quickly should they occur.

Many people with MS do not report all their relapses to their MS team¹². Reasons include:

- insufficient knowledge about relapse, for example not realising that it is important to report every relapse even if they don't want treatment or just not understanding that the symptoms they are experiencing would be classed as a relapse
- concern that their disease modifying treatment may be stopped or changed
- thinking their symptoms aren't 'bad enough'
- feeling that there is 'no point' because 'nothing can be done'

Education about relapse – what it is, what to do about it and why – is key, and should start at diagnosis and continue at regular intervals. The comprehensive annual review recommended by NICE², self-management courses, and of course any contact by people with MS asking for advice when they think they may be having a relapse, are all opportunities for reviewing their understanding and providing further information.

There are a number of resources available to people with MS to help with this, including information on the MS Trust website^{vii} and a booklet available from the MS Society (Appendix 4). It is recommended that, when providing information to people in advance of having a relapse, you include the following points:

- What a relapse is and why it is important to let the MS team know quickly if they think they are having one, even if they don't want any steroid treatment
- What local relapse services are available, who they should contact and what to do if they are worried about their symptoms outside the MS team's working hours

- The sort of symptoms that they may experience including the possibility of cognitive symptoms occurring or worsening during relapse
- Other possible causes of a deterioration in symptoms including the most common signs and symptoms of infection
- Treatment options should they have a relapse

There should also be some discussion with the individual about the importance of recording symptoms at times when they feel they are experiencing an acute deterioration. These periods may or may not be subsequently identified as relapses, however being able to view a record of symptoms and their impact over time can be very useful for the neurologist and MS specialist nurse in terms of identifying the treatment options.

Ways in which people can record their symptoms include symptom tracking apps such as SymTrac^{viii} whilst other options include making a simple note of how they are feeling on a daily basis in a notebook or diary. There is more information available about keeping a symptom diary on the MS Trust website^{ix}.

Goal: People with MS should understand the need to report all possible relapses and the MS team need to ensure that relapses are recorded accurately in the patient's medical notes.

- People with MS should have a clear understanding of when and how to contact their MS team if they suspect they may be having a relapse and what to expect from the team
- Information about relapse should be given to people at (or soon after) diagnosis and should be available in written form to take away or download
- People's understanding of relapse and what to do if they experience deteriorating function should be reviewed and updated when opportunity presents and as a minimum during their comprehensive annual review
- At each review appointment, people should be asked about recent symptoms which could indicate relapse, and a comprehensive record of all possible and confirmed relapses should be made in the notes.

vii www.mstrust.org.uk/a-z/relapse

viii www.symtrac.com

ix www.mstrust.org.uk/a-z/diary-symptoms

Step 3: Ensuring a responsive first point of contact

People with MS need to know who to contact if they experience a deterioration in their MS or think that they may be having a relapse. Offering people a simple card with signs of relapse and contact details to call can be an effective way to make sure they have this information to hand – an example of such a card is available on the MS Trust website. NICE recommends that people with MS should have a single point of contact to enable them to access the multi-disciplinary team². When someone is diagnosed they should be seen within 6 weeks by a health professional with expertise in MS, such as an MS specialist nurse, who should ideally be their point of contact from then onwards.

Goal: There should be a responsive, single point of contact for people to call if they are experiencing acutely deteriorating symptoms.

- The local contact number which people with MS are given to use in case of a deterioration in their symptoms should connect them with someone they can speak to who is able to take their details, record the nature of the problem and explain to them what the next steps will be. Anyone who may answer the phone should be trained in what to ask about: a simple call recording template can help
- If it is not possible for calls to be answered in person, an answerphone should ask the caller to leave a clear message summarising their problem and should be checked at least daily. The message should clearly say when the individual can expect a call back
- For anyone calling to report acutely deteriorating MS symptoms, an MS specialist nurse or another MS specialist should aim to respond to the individual within 2 working days

Case study: Derriford Hospital, Plymouth – a daily, neurology-led assessment service

The MS team in Plymouth serves a caseload of 1100 people with MS. The hospital's neurology ambulatory care unit runs a daily clinic staffed by a consultant neurologist to deal with acute problems and they keep 2 slots each day for people with MS with acutely deteriorating symptoms.

People with MS phone the MS specialist nurse helpline and are triaged by an MS specialist nurse. If the nurses are not available, the secretary knows to find one as quickly as possible for a call back if possible relapse is mentioned.

If there are signs that the cause of the problem is infection-related then the MS specialist nurse directs the patient to contact their GP for an infection screen and antibiotics if appropriate. If an MS relapse is suspected, the person is booked into the ambulatory care unit the following working day. There, they are examined by a neurologist (an MS specialist on 2 days of the week, but otherwise one of the other neurologists) and, if appropriate, steroids are prescribed and the patient booked for an MRI.

All patients who have been treated for a relapse are discussed at the weekly multi-disciplinary team meeting to explore options for any changes to DMD treatment, and then followed up in clinic 4-6 weeks later.

Current nurse staffing levels do not allow for a nurse to be present at the relapse assessment, but the fact that a person with MS can be seen within a day of contacting the service makes for a rapid, responsive service which receives positive feedback.

Step 4: Providing timely, effective triage and assessment

Triage is a vital first step which helps to decide the degree of urgency with which the individual needs to be seen and allows immediate advice to be given.

Assessment is a more involved process where the nature and extent of the presenting problem is investigated and treatment options discussed. Ideally, assessment should take place face to face with the MS specialist nurse. By seeing the person with MS, watching them walk, hearing them speak, talking to them and undertaking any relevant objective measures, the nurse will gain a much more complete picture of the problems the individual is experiencing. Some larger services offer a dedicated weekly relapse clinic where

patients can be seen by an MS specialist nurse and/or neurologist and ideally also have rapid access to other members of the MDT. In other services, a small number of appointment slots are held open each week in regular MS or neurology clinics so that relapse assessments can be slotted in. The MS Trust GEMSS programme¹ teams found that, on average, 21% of their caseload contacted them in any given year about a suspected relapse. This information should help guide the number of appointment slots which would need to be planned in for assessments: for example a service with 600 people with MS on the caseload might consider keeping 126 appointments a year available (2-3 per week) for assessments.

Where face to face assessment is not possible, either because of capacity constraints or the geography of the service, assessment may be carried out by the MS specialist nurse over the phone in collaboration with the patient's GP who can undertake urine screening for infection and prescribe treatment for the relapse, if indicated. In this instance, triage and the elements of assessment which can be done over the telephone may take place within the same call. It is vital that the MS specialist nurse speaks with the GP and backs up the discussion with clear written information to email or fax across summarising the local MS protocol. An example of this documentation is available on the MS Trust website.

Goal: Triage should be carried out as part of the conversation when someone first contacts the service to report symptoms and should take place within no more than 2 working days of the first contact from the person with MS. Assessment should be provided within 1 week of the initial patient contact. This should be carried out face to face if at all possible by an experienced MS specialist nurse or neurologist.

Triage:

- The individual should be asked about their level of concern and the impact on function of the changes they are reporting (including fatigue and cognition)
- The MS specialist nurse should ask the individual about any signs or symptoms which may indicate infection or other possible causes of deteriorating function
- Having determined the urgency or otherwise of the problems next steps should be clearly communicated and discussed with the individual (or their carer)

Assessment:

- During the assessment, objective measures of function should be made and recorded
- If a relapse is diagnosed, the pros and cons of treatment with high dose methylprednisolone should be discussed with the person with MS and a decision regarding whether to prescribe high dose methylprednisolone made
- The MS specialist nurse should make accurate notes in the medical records
- The treatment plan should be clearly communicated to the patient and further appointments given to them in writing

Case study: Sussex Community MSSN service – a community based relapse service

Katrina Orchard is the community MSSN for West Sussex managing a caseload of around 380 people with MS. *'It's all about education', she says. 'Every time I see a patient I do a lot of education about recognising relapses and the importance of recording symptoms – keeping a simple paper diary is a great help when it comes to a neurology review and you can look back and summarise what's happened since the last appointment'.*

The first point of contact for people with MS experiencing potential relapse is to telephone Katrina's mobile for triage. Where possible, she will fit them into one of her community clinics, but more often she will visit them at home within a couple of days of the call for a face to face assessment, carrying urine testing sticks and assessment tools. If needed, she can request community phlebotomy for blood testing if the patient is unable to get to a hospital.

Katrina is a nurse prescriber but often works with the patient's GP to obtain steroids when a relapse is confirmed. The local neuro-specialist physiotherapy team also step in if someone is having difficulty with walking and can usually respond within a week to a referral in this situation. *'If there's one thing which I have learned with experience it's to step back and assess the whole person when a relapse is suspected'.*

Katrina emails a brief summary of the relapse to the patient's neurologist and this triggers a neurology review which includes their DMD treatment or consideration for treatment with DMDs if not on treatment. Recent relapse

case studies are discussed at the 6 weekly Peer Group Supervision meetings held with the other MSSNs across Sussex and attended by MS neurologist Dr Waqar Rashid.

Following assessment, Katrina will phone the patient after a week and usually weekly to track their progress and recovery from the relapse. An ongoing record is kept and each patient has a relapse summary sheet in their notes where all relapses are listed and can be seen 'at a glance' – this is useful for reviewing the person's relapse history and the number of times they have been given steroid treatment.

By providing rapid home-based assessment for people who may be too unwell easily to get to a hospital, Katrina believes that she prevents people with MS turning up in A&E.

Step 5: Providing timely treatment if required

Goal: Treatment which may be required for people experiencing a relapse should be offered within 2 weeks of the onset of their symptoms and ideally within 48 hours of the assessment.

- Treatment options should be discussed by an MS specialist nurse or neurologist with the individual. They should provide information (written and verbal) about the pros and cons of steroid treatment including potential side effects and their management. The individual's expectations of treatment should be clarified and discussed
- Once a treatment plan is agreed this should be implemented without delay
- The MS specialist nurse should assess the need for multi-disciplinary team support and refer the individual if indicated
- Clear information about follow up and about how and when to contact the MS team in the meantime should be provided to the person with MS in writing
- A record of the discussion and any interventions should be recorded in the medical notes and a letter sent to the neurologist, GP, any relevant members of the MDT and the person with MS

Step 6: Following up relapses consistently

Goal: People who have received any treatment or have experienced a clinically significant deterioration should be offered a face to face follow up appointment within 6-8 weeks of the assessment. The appointment should be booked and given to the individual at the time of their assessment. They should also be advised how they can contact the service in the meantime if they have any concerns or questions.

The follow-up should include:

- Discussion and documentation of the individual's pattern of recovery (or otherwise) – repeat any objective measures
- Discussion of any side effects of prescribed treatment which should be documented
- A review of any ongoing symptoms and discussion about options for symptom management and any further need for multi-disciplinary team support
- Discussion of the requirement, or not, for a DMD review, outside of any scheduled review
- Information on how to access the MS team for advice at any time in the future

Case study: Dumfries and Galloway Royal Infirmary – joint MSSN–neurology assessment via a weekly relapse clinic

Liz Clark is the MSSN for 350 people with MS living in Dumfries and Galloway in south west Scotland. Around 2 years ago she established a weekly relapse clinic by preserving 2 emergency slots on the end of a nurse-led MS clinic into which she can book people directly following telephone triage. Consultant Neurologist Dr Ondrej Dolezal and Liz assess the patients together and make a plan of action including infection screening and blood testing. An MRI will be ordered to establish whether a change to DMD treatment is required.

Liz follows patients up and ensures that any necessary steroid treatment is prescribed without delay. Oral steroids are prescribed via the GP, who will receive an electronic copy of the letter requesting this the following day,

or IV steroids can often be commenced the same day on the ambulatory care unit.

Liz telephones the patient after a week to assess improvement, and then after 2-3 weeks and a month later, and they will have been booked a follow up appointment in a neurology clinic when assessed. *'With the new treatment options now available, relapse is a prompt to think about where you are going next with treatment – that's why you want to see them. Education is critical – right from the start people with MS need to know that if they are getting unexplained symptoms, even if they aren't sure if it's a relapse, they need to phone you. If in doubt, phone. We emphasise this both verbally and in a book about MS and our service which everyone gets on diagnosis'.*

Occasionally, if people with MS really can't get to clinic then relapses are managed over the phone with the GP. GPs rely heavily on guidance from the MSSN to know what to test and how to treat relapses. But a vote of confidence in the service is that people will travel as much as 80 miles to attend the clinic in order to get the specialist expertise of the team at the time of a relapse.

Step 7: Reviewing disease modifying drug management

Goal: Relapses are a signal of disease activity and should serve as a flag for review of the individual's current DMD management.

There should be a pathway which allows timely review of DMD management for people who have had a relapse.

- The MS specialist nurse should discuss the individual's current treatment with them at the follow up appointment with a view to identifying any issues with adherence, side effects etc
- The MS specialist nurse should feel confident to discuss the pros and cons of the different DMDs as they apply to each individual, including the risks associated with untreated or poorly treated MS
- The MS specialist nurse should liaise with the neurologist and arrange for a DMD review if required. Any appointment should be communicated to the patient in writing
- An accurate, clear record of any discussion should be recorded in the medical notes

Step 8: Auditing your service

Auditing your service allows you to pinpoint which aspects of the service are meeting standards and which (if any) are not. This allows you to focus on the aspects of the service which would most benefit from improvement. Repeating the audit after you have made the changes will allow you to demonstrate whether the changes have worked and/or to identify where further change is needed.

Audit can also be a very useful way of demonstrating the effectiveness of your service to managers, commissioners and other stakeholders.

If you have not previously audited your relapse service or you are planning to overhaul your service then you should consider implementing a baseline audit. This should look at the whole service including any policies and protocols which are relevant. Once you have completed a baseline audit you should continue to audit the service on a regular basis although this need not be on the same scale as a baseline audit. Some teams collect data about their relapse services on an ongoing basis whilst others prefer to collect data for a short period (typically 2-4 weeks) once or twice a year. You should decide which approach suits your resources and needs best.

The results of each audit should be written up into a short report about the service and shared with your team, your managers, and other key stakeholders as appropriate. A brief commentary explaining the data and outlining any changes you have made or plan to make to the service will also be very helpful.

Resources to help you learn more about auditing your relapse service are listed in Appendix 3. Box 8 gives a list of suggested key process indicators (KPIs) which you could consider including in a regular audit of your relapse service. Achieving good performance on the KPIs will ensure that you are meeting the NICE Quality Standard on multiple sclerosis statement: 'Adults with multiple sclerosis (MS) who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms'³. Importantly, it will also mean that the service offers the same level of responsiveness to people with all types of MS (not just those who may be experiencing a relapse) who experience acute deteriorating symptoms.

Incremental service development can result in huge improvements in patient care and service provision.

Box 7: Audit checklist of staff, processes and information in place

Local protocols and treatment pathways for relapse services have been reviewed in the last 12 months and are known to all members of the MS team (including administrators who may take incoming calls from people with MS)	
<p>Written information for people with MS is routinely given at the time of diagnosis and available at all regular review appointments and this includes:</p> <ul style="list-style-type: none"> • What MS relapse is, what can trigger it and the importance of reporting it • The potential for cognitive problems during relapse • The importance of recording MS symptoms and suspected relapses, even if not seeking help from the MS team • How to get in contact with the MS team in the event of deteriorating symptoms or suspected relapse 	
Written information for people with MS is available at the time of relapse diagnosis, and this includes information about steroid treatment (this may be a separate leaflet)	
MSSNs can access expert advice when required (eg from a more experienced MSSN or MS specialist neurologist)	
In the event that the service is managed by a single MSSN, back up arrangements for responding to people with MS during times of holiday and sickness are in place	

Box 8: Key process indicators

% of people reporting deteriorating symptoms who are triaged by an MS specialist within 2 working days of the initial patient call	
% of people who require assessment who are offered it (ideally face to face) within 1 week* of the initial contact	
% of people who require treatment with high dose methylprednisolone who receive treatment within 2 weeks of the onset of symptoms	
% people who are offered treatment with high dose methylprednisolone who complete an infection screen in accordance with local policy	
% of people prescribed methylprednisolone who are offered a follow up appointment (face to face or telephone) 6-8 weeks post assessment	

x NHS Scotland Clinical Guidelines for Neurological Conditions recommend that assessment should take place within 5 days of the initial call.

Appendix 1: Further information on relapse phenotypes

Depending on which part of the CNS is affected during a relapse the individual will experience different symptoms. Relapses can be classified by phenotype:

Relapse phenotype	Example of symptoms
Visual	Blurred vision, blindness
Pyramidal	Spasticity, hyperactive reflexes, loss of fine motor movements
Sensory	Numbness, neuropathic pain, dysaesthesia
Cerebellar	Ataxia, nystagmus, intention tremor, vertigo
Brain stem	Diplopia, oscillopsia, unsteady gait, vertigo
Bladder/bowel (Sphincter)	Incontinence
Cognitive	Difficulty multi-tasking or word finding, reduced concentration and problem solving skills

In practice it can be difficult to attribute a phenotype to a relapse without neurological examination and possibly an MRI scan. Neurological examination and understanding an MRI scan reports are skills which MS specialist nurses who are or who wish to deliver whole episodes of care around relapse management should seek to acquire. There are training courses available (see further reading) to support MS specialist nurses who want to develop their practice to include neurological examination. It is also recommended that MS specialist nurses should discuss relapses with an MS neurologist when opportunity presents with a view to understanding how to better differentiate the phenotypes in practice.

A study which collected data from nearly 50,000 relapses has established that people are significantly more likely to experience the same type of relapse as their preceding one regardless of the number of relapses they have experienced in total¹⁰. The authors suggest that the structural damage which occurs during a relapse may impact on the neurological reserve in that area of the CNS which enhances the impact of any future inflammatory activity in the same area.

The results of the study also showed that relapse patterns vary according to people's age, sex, MS

course and duration. For example visual and sensory relapses are more common in younger people with a shorter duration of disease whereas pyramidal and bowel/bladder relapses are more common in older people with longer disease duration.

Other work examining the use of relapse phenotyping as a prognostic tool is ongoing²². Another recent study provides evidence that a motor system relapse with poor recovery at any point in the course of relapsing MS increases the risk of transition to secondary progressive MS²³.

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Further reading

MS Nurse Professional: an online training resource: www.msnursepro.org/

MS Trust: information and downloadable resources for health professionals at www.mstrust.org.uk/relapse-guide

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Appendix 4 - Resources for people with MS

MS Society: information for people with MS at www.mssociety.org.uk/what-is-ms/treatments-and-therapies

MS Trust: information for people with MS at www.mstrust.org.uk/a-z/relapse

Symtrac symptom tracking app at www.symtrac.com

Appendix 3 - Resources to help with service development and audit

The Royal College of Nursing website has a useful section on guidance and tools for quality improvement and clinical audit at www.rcn.org.uk/professional-development/quality-and-safety

Useful articles and papers:

Burgess M. Improving relapse management in multiple sclerosis: a nurse-led model. *British Journal of Neuroscience Nursing*. 2011;7(1):441-4.

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About the MS Trust

The MS Trust is a charity which works to make a difference today for the more than 100,000 people living with MS in the UK.

We work to make sure everyone affected by MS can access good quality care from specialists with an interest in MS, and offer education and professional development.

Through our innovative GEMSS programme, we support evidence-based service improvement in MS care. Our approach is always to work in partnership with health professionals and people affected by MS to improve MS services now and in the future.

We also produce practical, reliable information, online and in print, and offer a telephone and email enquiry service to anyone who needs to know more about MS. Our materials are widely used by MS services across the UK.

We rely on donations to fund our vital services.

To find out more about our work, how we can help you and how you can get involved

Visit www.mstrust.org.uk

Call **01462 476700**

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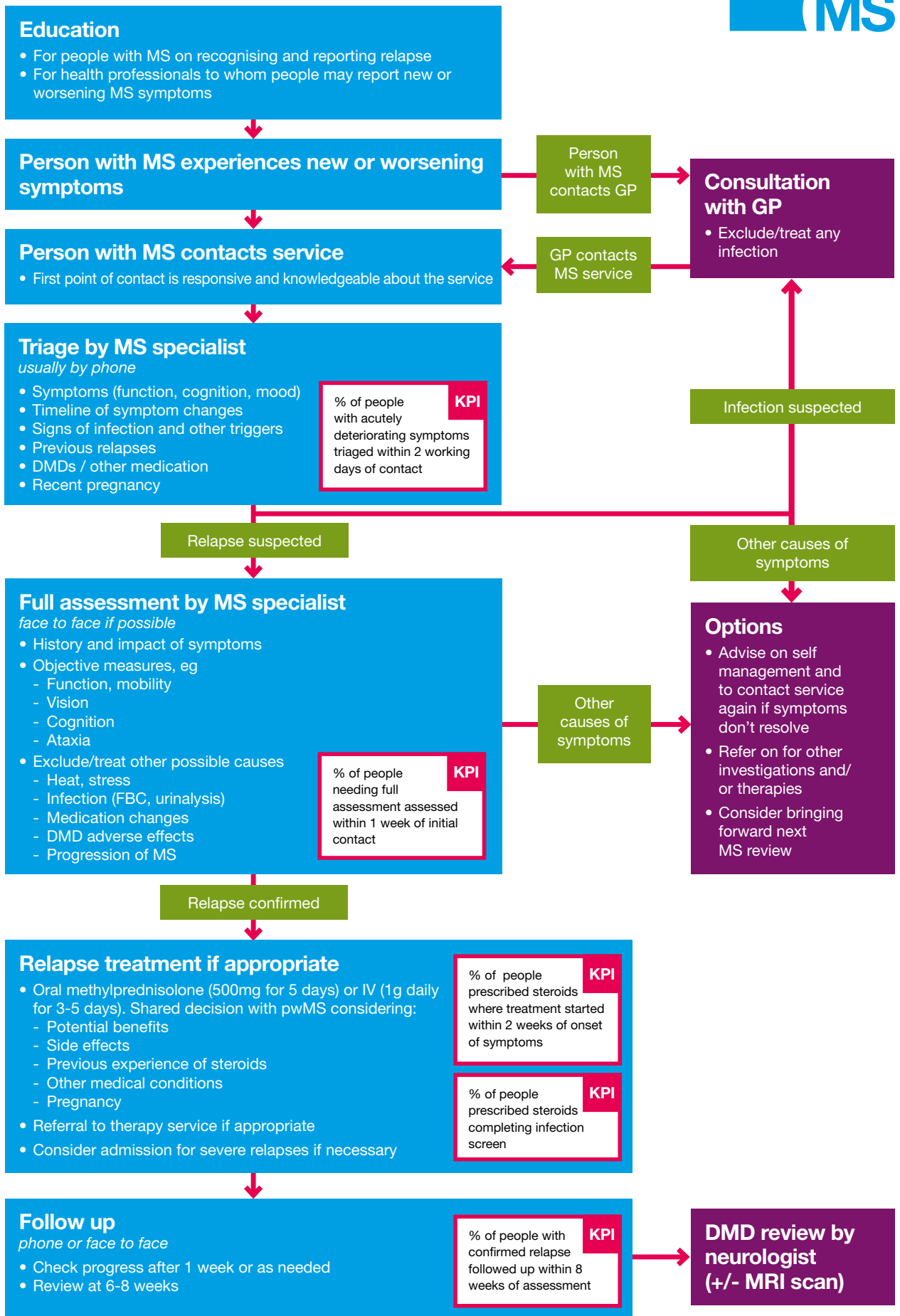
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Managing relapse in MS

From *Eight Steps to Improving your Relapse Service* (2016)

Record keeping, communication and regular audit of service responsiveness and outcomes



KPI = key process indicator to be audited regularly