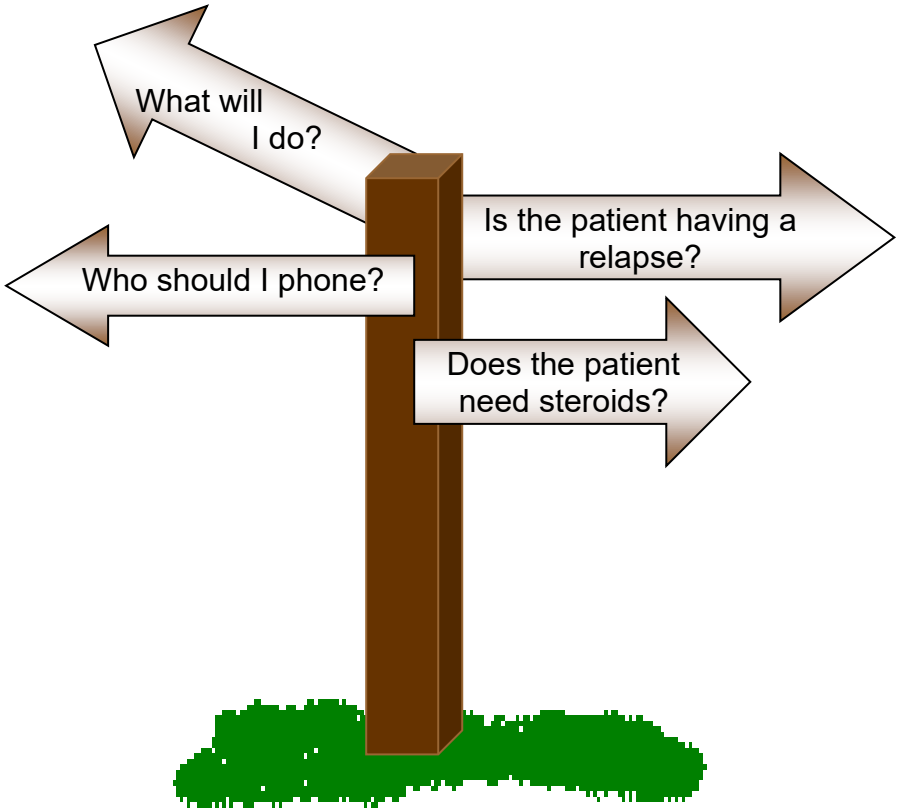
RELAPSE MANAGEMENT TOOLKIT



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Relapse Management Tips
A Guide for Completing Relapse Assessment Form

An MS Relapse can be defined as the rapid onset of new neurological symptoms or worsening or re-occurrence of pre-existing symptoms lasting more than 24 hours in the absence of infection, fever or significant metabolic disturbance, after a stable period of at least 1 month.

This pathway has been produced to assist you to understand what a relapse is and the importance of prompt assessment. This local guide will assist all healthcare staff to follow best practice in the management of relapses for our patients.

When a patient reports any change in their MS or are concerned they are having a relapse, a detailed assessment should be carried out to investigate and to offer an appropriate treatment plan. Possible causes for a person to deteriorate include:

1. Triggers/exacerbating factors such as infection, heat, stress, change in medication, changes in menstrual cycle/menopause.
2. Natural progression of disease
3. Definite relapse of MS

Each point requires a different treatment plan.

Assessment Tips

Identify and document what the new symptoms are, how long they have been present and if they came on suddenly rather than insidious. Observe for marked lifestyle changes leading up to deterioration.

Consider if the person may have underlying illness other than always assuming it is the MS causing the deterioration. Think about a differential diagnosis throughout assessment.

A relapse assessment form can be found in this document which can assist to record the correct information during an assessment or assist to discuss this with the MS Team/patient.

Trigger/Exacerbating Factors

Health promotion focuses on the MS person keeping as well as possible despite having a chronic illness. Taking a balanced diet, stopping smoking, participating in exercise and fitting in rest and relaxation are encouraged to try and minimise symptoms or complications such as infection and excessive fatigue. Infection or excessive fatigue can mimic symptoms similar to that of an MS relapse. Other 'trigger' factors include trauma, vaccinations and stress. Part of the assessment therefore is to explore the presence of these causative/trigger factors when a person reports deterioration in their MS. This presentation is commonly called a pseudo-relapse. The treatment plan is to manage the triggers that caused the deterioration in

the first instance. In this situation you would expect the person to improve following treatment for the particular trigger.

Infection

It is recognised that a person with MS can deteriorate when they have an infection. The most common infections seen in MS are as follows;

- Urinary Tract Infection (often patients have few signs or symptoms therefore send specimen to labs for testing prior to prescribing antibiotics or steroids, this has been confirmed by microbiology)
- Chest infection
- Common colds/influenza
- Viruses

Investigate and treat any underlying infection promptly. You would expect the symptoms to improve once the infection resolves. Treat infection first, if no improvement in symptoms after infection treated, you may need to re-screen prior to discussing use of steroids. Steroids should not be used without screening for infection. Steroids can suppress the immune system and compromise a patient further, causing further deterioration. Consider referral to MS Nurse to identify risk and provide preventative advice. For example if a patient had a urinary tract infection it may be the result of incomplete emptying which can be assessed easily with a bladder scanner and treated appropriately. Chest infections may be due to silent aspiration therefore the person may need screened for this.

Fatigue

Fatigue is one of the most common symptom of MS affecting up to 85% of people with multiple sclerosis. It is however poorly understood. There are different types of fatigue. When poorly managed and allowed to escalate, the symptoms of fatigue can look as though the person is having a relapse. However the treatment plan is very different. Steroids given to someone who has extreme fatigue are not advised as they mask the symptom giving the person a false sense of energy and improvement. This is a side effect they are experiencing. Unfortunately this leads to a worsening in their symptoms once the side effects of the steroids have worn off making it look like they are having another relapse and they think they need steroids again thus entering into a poor management cycle.
Assessing for the following signs will assist in deciding whether the person is having a true relapse or if it is an exacerbation of fatigue that requires symptom management.

- Evidence of poor self management of fatigue – the person may be overdoing things regularly, have no rest periods in their day, suffering from stress, taking on too much, not listening to their bodies when they get messages telling them to rest etc.
- Poor sleep pattern
- Exposure to excessive heat
- Differential Diagnosis –Anaemia or depression

Consider referring back to Fife Rehabilitation Team for advice on Fatigue Management.

Medication

Record all drugs on prescription as well as recent changes. Discontinuing or commencing medication may exacerbate symptoms similar to that of a relapse.

For example, in some individuals baclofen can cause reduced tone in large muscle groups giving the patient a feeling that they have deteriorated as they can no longer stand unaided or walk any distance. Some antispasmodics cause an increase in fatigue symptoms making it look as though they are having a relapse. Side effects from Disease Modifying Therapy can be similar to relapse symptoms.

Post partum

There is a 1 in 3 chance of having a relapse in the first 3 months following child birth. Patients in this category should be pre-warned of this risk so as they can put in place a management plan. Organise help at home, express milk for when on steroids, and liaise with GP/MS Nurse for quick access to an infection screen and prescription of steroids.

Conclusion/Summary

Consider all information gathered in order to recommend a treatment plan. Discuss thoughts with patient. If the cause for the deterioration has been assessed as a true relapse then the decision to treat with oral steroids versus conservative treatment will need to be discussed with the patient. Please refer to steroid information sheets when considering steroid therapy. Refer to Fife Rehabilitation Service if required for conservative treatment. The patient will be assessed for a rehabilitation programme by relevant members of the team.

Discuss with patient if they feel they can manage at home during the relapse phase or if they need support. Consider best person to assess home circumstances. If relapse severe, patient may require hospital admission. Consider other possibilities – emergency respite, hospital at home, emergency increase in care package.

In the longer term the patient who relapses needs to consider whether their house is suitable on these bad days as well as good days. Refer onto social services for assessment for living independently at home, as there may be a need to look at housing adaptations versus re-housing, respite, homecare, equipment etc. Consider appropriate follow up.

Patients may need referred back to FRS for period of outpatient rehabilitation. They would participate in an active rehabilitation programme, specifically aimed at achieving their goals.

Aspects of rehabilitation include

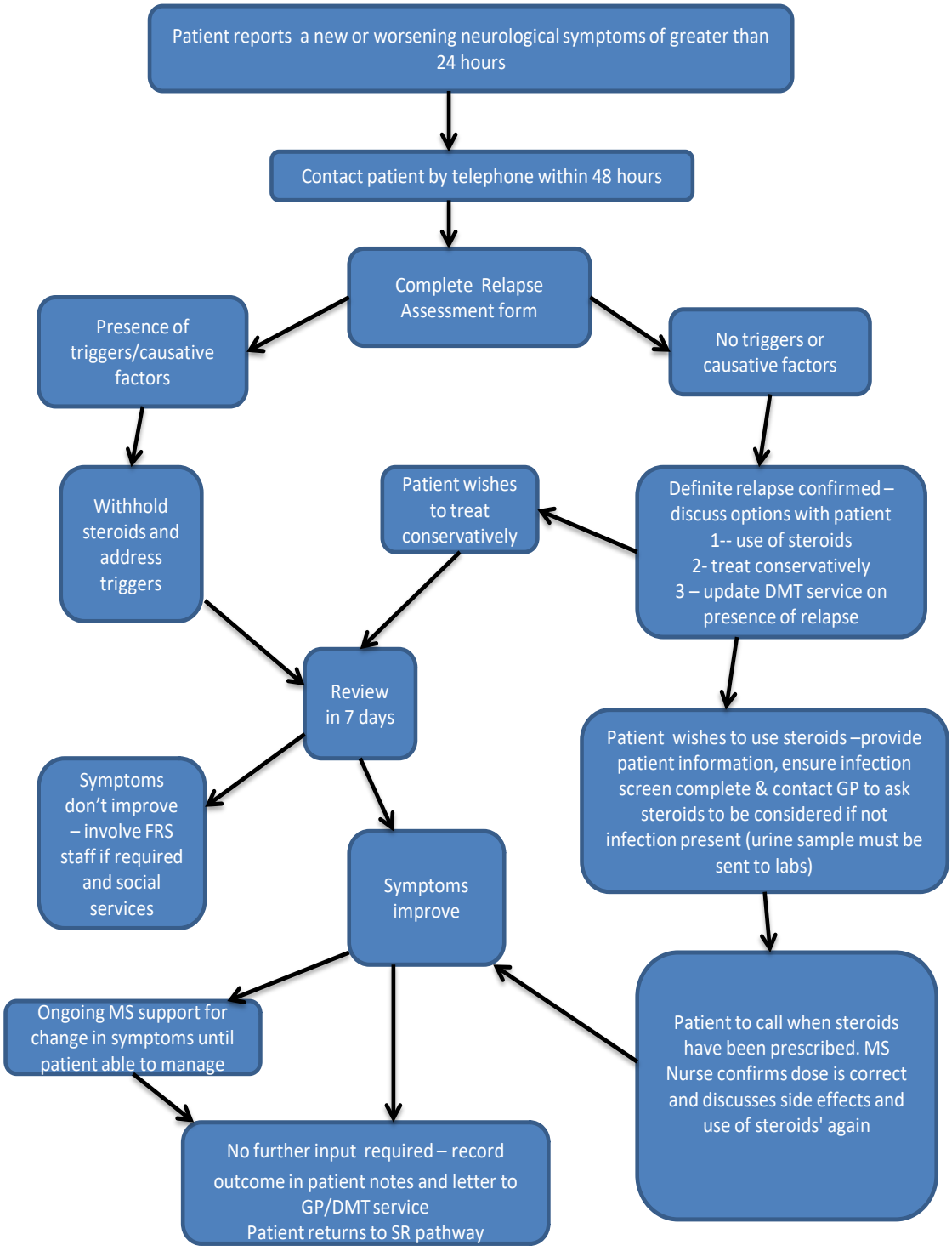
- team assessments
- vocational activities-employment and education
- leisure and social interaction
- mobility; activities of daily living
- equipment, adaptations and personal support
- symptom management advise
- emotional support.

See also relapse review – page 14

Copy assessment form to MS Nurses for continuation of pathway if required and for documenting definite relapse in patient's notes.

Patients who are having active relapses should be referred to the Disease Modifying Therapy (DMT) Service for initiation of treatment or assess for escalation of existing DMT.

MS Relapse Management Pathway



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Relapse Assessment Form

Assessor .....

Patient ID Label

Type of Multiple Sclerosis .....

Date of Diagnosis .....

Current medication .....

Any recent changes to medication .....

.....

On Disease Modifying Medication? Y/N……. Which drug…….

When started……

History of Presenting Problem/Relapse (*date symptoms started/worsened & list of symptoms)*

Date of last relapse ..... Were steroids use? Y/N

Side effects ..... Type & Dose…….

Outcome .....

.....

Contraindications to steroid use .....

Presence of any trigger/contributory factors

Infection Screen

Summary/Conclusion

Copy to GP ☐ Copy to MS Nurse Fife Rehabilitation Service ☐

Contraindications for Steroid Use

Current systemic infection
History of psychosis
Severe depression
Osteoporosis
Unstable IDDM (May require monitoring as inpatient if given steroids)
A recent live vaccine
More than 3 steroid courses in previous 12 months
Minimum or no response to previous steroid courses
Previous severe reactions to steroids
Active Gastric Ulceration
Exposure to chicken pox
1st trimester of pregnancy
Breastfeeding
Patient requires to shield for 2 weeks post steroids during COVID pandemic

*If in doubt consult BNF or community pharmacist

Steroid Management Tips

- Patient should be informed of the side effects of steroid treatment, verbally and in written format (see patient information sheet).
- Patients considered suitable for steroids should be advised that steroids may give a boost in energy levels. However this is a side effect and masks what the body should be feeling. Advise the patient to rest despite these feelings in the first few days of starting steroids.
- Oral versus IV steroids should be discussed with the patient in terms of convenience of oral treatment versus day case admission. Recent research highlights both treatment modes have similar expectations therefore decision making should be based on patient convenience and previous results with steroid therapy.
- Assess impact of relapse on individual's lifestyle when deciding on steroid use versus conservative treatment.
- A realistic explanation of how steroids can assist with relapse management should be given emphasising that they are not a cure and that they cannot change the overall course of the disease but steroids can assist to shorten the duration of a relapse.
- Consider the individuals previous outcomes with steroids when deciding on a treatment plan.
- For patients who have a history of gastric ulceration or gastric irritation with previous steroids, prescribe Omeprazole 20mgs daily throughout course.
- Low dose steroid therapy is no longer indicated.
- Prolonged steroid use (longer than 3 weeks) is no longer indicated.
- A second course of steroids for a single relapse should not be given without discussion with Neurologist/ MS Nurse/Consultant in Rehab Medicine.
- Steroids should not be given without screening for infection. Always send urine for laboratory testing and wait on result before considering steroids.
- Steroid therapy should be avoided during the 1st trimester of pregnancy. When treatment is deemed necessary, it should only be initiated on advice from neurologist/obstetrician.
- If a patient has taken large cumulative doses of steroids, their risk of osteoporosis should be considered.
- Diabetic patients should be monitored closely during steroid treatment and requires input from diabetic team if the diabetes is very unstable.
- There is low incidence that short courses of steroids can cause an interruption of blood flow to the hip(femoral head).

Taking Steroids For Relapses In Multiple Sclerosis – Patient Information

Your doctor/nurse feels that you are having a relapse of your MS and that treatment with steroids is indicated. Symptoms due to relapse usually settle after a few weeks but may or may not leave persisting problems. Steroids have been shown to help relapses settle more quickly but do not alter whether or not any problems will persist in the long-term. Not all relapses require treatment with steroids and therefore should be reserved for symptoms which are distressing or result in a limitation of your usual activities.

Possible Side Effects

All drugs can cause side effects. You are more likely to have problems if you take steroids for a long time or are on very high doses.
Side effects do not happen to everyone. However it is important that you know about them. Generally side effects subside after the treatment is completed.

These are the side effects that have been reported when taking steroids:

- Weight gain/increased appetite
- Altered sleep pattern
- Indigestion
- Metallic taste in mouth
- Slight reddening or flushing of the face
- Swelling of the ankles
- Mood alterations

Management Tips

- Infections should be ruled out as a cause for a relapse before taking steroids as steroids can make the infection worse and therefore can exacerbate the MS further.
- If taking steroids in summer you should wear sunscreen to protect your skin from burning as the steroids can make you photosensitive.
- If you have severe indigestion when taking steroids you need to tell your doctor treating you or the MS Nurse as this may mean that you need to either be prescribed appropriate medication to reduce the burning or stop steroids.
- Repeated courses of steroids can lead to thinning of the bones (osteoporosis).

Other Points

Some drugs interact with steroids and you should always tell your doctor treating you if there has been any changes to your medication that he/she isn't aware of, or if you are on any 'over the counter' tablets.

You should avoid immunisation injections which involve any live vaccines such as polio and rubella whilst on steroids.
Whilst on steroids it is not a good idea to take alcohol. Alcohol and steroids together both upset your stomach.

Dosage of Oral Steroids recommended for a relapse in Multiple Sclerosis

Remember

Always discuss with your doctor before commencing any steroids.
If you suffer from any side effects whilst on steroids – **let your doctor know**

- High-dose oral methylprednisolone 500mg daily for 5 days & oral omeprazole 10mgs to cover during oral steroid use. (NICE guidelines updated 2019)
- During COVID19 – there is now recommendations from the Association of British Neurologist (5/11/2020 advising that patients will require to shield for 2 weeks post steroids due to their immunosuppressive effects)

(please note methylprednisolone comes in 100mg tablets)

Relapse Review

Following Steroid Use

- Provide patient with a telephone contact person – this can be the MS Nurse at Fife Rehab Service.
- Good practice to assess patient 7 days following completion of steroid course by person who prescribed steroids or MS Nurse – this can be done by telephone review or face to face contact.
- Record outcome to date – improvements made, presence of side effects during course of steroids.
- Decide on suitable review appointment thereafter – 1month, 3 month, 6 month, yearly depending on need, document in notes and give patient appointment.
- If concerned about recovery following relapse, refer back to Fife Rehabilitation team if not already attending for
    - reflection of relapse to identify trigger factors etc and to look at strategies to minimise this risk for future relapses
    - provision of any mobility aids
    - assess improvement - may need course of physiotherapy to assist with recovery
    - provision of independent living aids
    - fatigue management advice if required
    - emotional support
    - symptom management
    - update records
- Update the Disease Modifying Therapy Service if they have had a relapse and are currently on a DMT which may require review of the effectiveness of this treatment
- Refer to the Disease Modifying Service post relapse if not already on a DMT for an assessment

Useful Contacts

MS Nurse Service
Sir George Sharp Unit
Fife Rehabilitation Service
01592 226754

- Debbie McCallion
  MS Clinical Nurse Specialist – Lead Nurse for MS Service at FRS
  Debbie.mccallion@nhs.scot

- Fiona Sneddon
  MS Nurse
  Fiona.sneddon@nhs.scot

- Louise Long
  Trainee MS Nurse

Fife Rehabilitation Service

- Dr Lance Sloan
  Consultant in Rehabilitation Service
  01592 226812

Disease Modifying Therapy Service
Victoria Hospital
Kirkcaldy
01592 643355

- Dr Uwe Spelmeyer
  Consultant Neurologist
- Lynda Kearney
  MS Clinical Nurse Specialist/Parkinsons Nurse – Lead Nurse for MS DMT Service
- Emma Gabellone
  MS Nurse Specialising in DMT

References

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