



GUILLAIN BARRÉ SYNDROME



Physiotherapy

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What does a Physiotherapist do?

Physiotherapists are healthcare professionals who work with patients and their families to identify individual problems, strengths and weaknesses and maximise a patient's ability to move and function. Therefore the physiotherapist plays a key role in enabling people to improve their health, wellbeing and quality of life following illness and injury or when living with the consequences of a long term health condition such as Guillain-Barré syndrome (GBS).

Guillain-Barré syndrome and it's consequences

GBS is a peripheral neuropathy with an acute onset that rapidly deteriorates to a plateau phase at the point of worst symptoms, prior to a recovery phase. Symptoms during the early and recovery phases of the condition include muscle weakness, altered sensation, pain and other symptoms. The disease is very variable in severity and can range from mild tingling and weakness in the extremities that recovers within weeks, to widespread paralysis of muscles and loss of sensation requiring emergency medical attention. In a minority of cases this may require admission to an intensive therapy unit for support of breathing and patients may take many months to recover. Recovery, whilst good in the majority of cases, is not always complete and residual symptoms include loss of sensation, muscle weakness and fatigue. These can result in difficulties in carrying out everyday activities that may interfere with an individual's normal lifestyle, mood and well being. In a minority of cases recovery is less complete and a few people with GBS may require a wheelchair for mobility. About one third of patients will experience severe long term difficulties requiring ongoing care.

Further details about GBS can be obtained from other documents *Guillain-Barré syndrome* and *GBS and Intensive Care*.

Physiotherapy in GBS

The role of the physiotherapist is to work with the healthcare team, the patient and their carers from the early stages during hospital admission through recovery and rehabilitation to returning home and managing any residual problems long term.

In the early phase, when patients are usually in hospital, the physiotherapist works with nurses, doctors and other health care staff to monitor symptoms to detect any changes in function. This might include checking muscle strength and areas of altered sensation as well as monitoring patients breathing in case it deteriorates and requires more intensive treatment. Symptoms typically reach their worst point within four weeks after onset and patients usually enter a plateau phase where symptoms stay the same for some days or weeks before recovery of function occurs.

During this time the aim of physiotherapy is to help the patient maintain as normal function as possible, prior to recovery. This includes stretching weak muscles, advising on positioning and assisting with everyday activities. It is important to carry out regular stretches to minimise pain associated with damaged nerves as well as to prevent weak muscles from becoming stiff and shortened. The physiotherapist will also advise family and friends on how to help with this safely. Pain is a common symptom in GBS and since pain arising from damaged nerves (or neuropathic pain) can sometimes be severe it is important that the physiotherapist times any stretches or exercises appropriately with the patient's pain relief regime.

If patients are receiving mechanical support for breathing

or where breathing is affected the physiotherapist will also undertake specific manual techniques, teach breathing exercises and coughing techniques as well as advise on lying positions in bed, encourage the patient to sit up in bed or in a chair to maximise lung function.

Once recovery begins

Once the patient is medically stable and recovery is underway the physiotherapist will help the patient to join in with everyday activities as much as they are able and also give specific exercises for them to practice alone or with family and friends. Therefore, as soon as is feasible, patients will be encouraged to sit or stand, to stretch stiff muscles and joints where this is possible, stimulate balance and normal blood pressure responses to moving around. Even a short time spent immobilised in bed can affect balance and this may be exacerbated where patients also have muscle weakness, sensory loss or involvement of the autonomic nerves that control blood pressure, leading to postural hypotension. Postural hypotension is where the patient may experience dizziness and nausea when sitting upright or standing due to a drop in blood pressure when moving into the upright position.

Therefore the physiotherapist will monitor the patient's blood pressure when initially helping them to sit up in bed, out in a chair or to stand with support where possible to minimise this and gradually increase the time spent upright. If a patient is immobile in bed then a specialised bed or tilt-table can be used to help them gradually stand whilst safely supported, despite weak muscles. The benefits of standing during a period of immobility include effects on maintaining bone strength, muscle length, assisting with drainage of the bladder and alleviating constipation as well as the psychological benefits of being upright and able to see and communicate more effectively with visitors, family and staff.

Even from an early stage, patients are encouraged to be

assessment, prescription and support for exercise and the physiotherapist can also advise on safety whilst exercising. This is particularly important for patients with severe weakness around joints that may make them vulnerable to damage during exercising and special splints may be needed to protect such joints.

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exercise then the physiotherapist should advise the patient on fatigue management. This is best achieved with the support of a specialist physiotherapist or occupational therapist since patients respond differently to fatigue. Some are determined to carry on regardless and suffer from a cycle of bursts of activity followed by prolonged fatigue (boom and bust) and others are concerned that fatigue is damaging and may avoid activity altogether resulting in deconditioning that may in itself contribute to further feelings of fatigue. Therefore advice on pacing encourages patients to identify what level of activity or exercise brings on their fatigue and to then tailor their daily activity accordingly.

This may include reducing the amount of overall daily activity initially until fatigue settles. Once an acceptable level of fatigue is established then the total amount of activity or exercise can be gradually increased by increasing the number of shorter bouts of activity throughout the day. In this way the total amount of activity or exercise can gradually increase but individual bouts do not produce fatigue. In this way patients can pace their daily activities to manage fatigue and begin to incorporate exercise into their lifestyle.

Finally

Once the patient has been discharged from formal medical care, they should contact their GP for further assessment or advice. If needed, the GP can refer a patient to the community physiotherapist or a private physiotherapist for further rehabilitation or advice about exercise.

Patients wishing to begin general exercise to improve fitness should also seek the advice of their GP or consultant to check that there are no medical reasons to prevent this. Referral to a physiotherapist will allow expert

involved in everyday activities as far as possible, without causing undue fatigue. For instance, whilst assistance from nurses and physiotherapists will still be required for many tasks, patients can be encouraged to use their recovering strength to join in with turning, getting in and out of bed, standing and walking with support to strengthen muscles, rehabilitate balance and re-educate functional activities. The distance walked will be gradually increased to improve endurance and assistance or aids for walking gradually reduced as muscles strengthen.

Patients are also encouraged to join in with feeding, washing and other activities requiring upper limb strength, co-ordination and dexterity. Nevertheless, in the plateau and early recovery phase, splints or adaptive devices may be required to help prevent joints becoming damaged due to weak muscles and loss of sensation or to help patients be more independent with everyday activities such as walking, using cutlery and washing.

Strengthening exercises can also begin whilst the patient is still in bed and should include the major muscles affected and those where the signs of recovery are evident. Depending on the severity of the muscle paralysis, exercise may begin with only gentle assisted movements initially. As strength returns, exercises and every day activities such as sitting balance, sit to stand and standing and walking are progressed by reducing assistance, increasing the number of repetitions or by changing the exercise. Once the patient can safely exercise alone and carry out activities without support, usually in a rehabilitation setting or gym, then active exercise with increasing external resistance should be encouraged. External resistance exercise might involve using free weights, elastic resistance bands, exercise equipment or their own body weight as in sit to stand or step ups. However, since recovery does not occur in all muscles at the same time the therapist will also need to adapt exercises or provide splints for support of weaker muscles, to help the patient get the most benefit. It is also

important that the physiotherapist advises on the amount and intensity of exercises to avoid overwork during recovery.

Once the patient can sit and stand independently the physiotherapist will progress the time spent in balance activities and increase the difficulty using reaching for targets and regaining balance, standing on one leg and balancing using a wobble board or large inflatable exercise ball.

Rate of recovery

During the recovery phase, physiotherapy plays a vital role in aiming to maximize functional ability. Recovery may be rapid or alternatively, progress may be slower and patients may become discouraged. The physiotherapist will explain the rate of progress and adapt exercises and activities accordingly. Many patients return to full functioning, including stair climbing, running and full fitness but others have residual weakness or altered sensation and pain that affect the extent of recovery of function. However, most patients are able to walk although some may require a walking aid or assistance for balance or a splint to prevent the feet dragging whilst walking.

A minority of patients will not return to walking and will require prescription for a wheelchair. This may be self-propelling or a powered chair and a specialist assessment of the patients needs will be undertaken, often by an occupational therapist.

Once patients are able to manage at home they will be discharged from hospital. In some cases, a small amount of support is available through the community therapy team to ensure patients are safe at home.

Long term consequences and ongoing rehabilitation

Even some considerable time after apparent recovery of affected nerves in GBS, many patients experience ongoing symptoms and difficulties with everyday activities including fatigue, as well as problems experienced by people living with other long term conditions. Research with healthy adults, older people and people with other long term conditions shows that undertaking regular exercise is beneficial and may reduce the risk of several health conditions as well as improve mood and wellbeing. Whilst only limited research is available in GBS it suggests that patients with GBS can also safely exercise alone and be advised to use local health and leisure facilities. It is recommended that a programme is set up in conjunction with a physiotherapist.

Fatigue and exercise

Fatigue is commonly experienced by patients with GBS and this can either be due to weak muscles having to work harder than usual or a more generalised fatigue described as an overwhelming feeling of weakness and lethargy. Fatigue can be experienced at any stage or by patients who may otherwise appear symptom free. On returning home from hospital, fatigue may become evident as patients take on more of their normal everyday activities and responsibilities. If muscle fatigue is present then the physiotherapist should tailor exercise accordingly, It is important to note that some fatigue and muscle ache can be experienced 1 - 2 days after commencing new exercise and this is true of healthy individuals also. Therefore the physiotherapist should monitor fatigue to provide advice on whether it is a normal consequence of increased activity. If for instance muscle fatigue is severe after exercise then the patient will be advised to reduce the intensity of the exercise by either reducing the amount of resistance or the number of repetitions. Alternatively, if generalised fatigue is making it difficult for the patient to carry out their everyday activities or undertake regular