

# Inside Guillain-Barré Syndrome: An occupational therapist's perspective

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ABSTRACT

*Occupational Therapists working with patients with Guillain-Barré Syndrome (GBS) are tasked with collaborating with the patient to achieve maximal functional recovery. Although much has been published about recovery after GBS from a scientific perspective; this article combines occupational therapy principles with the personal experiences of an occupational therapist who herself suffered from GBS. This commentary outlines important considerations for providing intervention to patients with GBS and offers insights into the emotional and psychological aspects of coping with GBS.*

**Key words:** Guillain-Barre Syndrome, personal experience

## INTRODUCTION

As occupational therapists we are faced with the unique challenge of enabling patients to adapt to altering life circumstances after contracting disabling health issues and to improve their level of adaptive functioning. We are trained not to be sympathetic by telling patients that we *know how they feel* because without any firsthand experience, there is no way that we could understand their situation<sup>1</sup>. I contracted Guillain-Barré Syndrome (GBS) after returning from an overseas holiday and within 6 days from my first symptom I was completely paralyzed; requiring maximal nursing care in the ICU. I believe that my personal experience with this condition has given me insight into being a patient; extended my understanding of GBS; and improved the quality of my intervention as a therapist.

GBS is an auto-immune condition with an average incidence rate of between 0.35 and 1.8/100 000 people per year<sup>2-4</sup>. GBS is an acute demyelinating peripheral polyneuropathy characterised by a symmetrical progressive muscle weakness and sensory loss<sup>2</sup>. Research on the causes of GBS include preceding gastrointestinal or respiratory infections in 40% to 70% of cases. Trauma, surgical procedures and childbirth preceding only a small percentage of incidents<sup>3-6</sup>. Viral infections and inoculations have also been cited as potential causes<sup>6</sup>.

The condition typically has a rapid, symmetrical progression that reaches a plateau eight days to four weeks after initial onset<sup>4,7,8</sup>. The rate and extent of recovery is variable but better outcomes have been associated with younger age at onset, slow disease progres-



sion, no axonal involvement, prompt medical treatment and no need for mechanical ventilation<sup>5,7,9</sup>. While the mortality rate for GBS is between 2-12%, between 15-20% of patients experience persistent disability and approximately 70% experience complete recovery or have small residual deficits<sup>6-9</sup>.

My experience with GBS has afforded me certain insights as an occupational therapist which I describe below. Although it is important to recognise that each person's experience of disability in general, and of GBS in particular, is completely unique; I believe that what I have learnt has improved the quality of care that I have since been able to offer patients with GBS. By extension, I believe that other occupational therapists who apply what I have learned to their work will also be able to offer more comprehensive and better quality care to GBS patients and their families.

## ACCESS TO INFORMATION

Occupational therapists should not underestimate the importance of their role in providing information to the patient and family and of being available to answer their questions. Without clear information about the condition, its progression and prognosis, family members may become fearful and experience high levels of emotional stress<sup>10</sup>. They may also turn to the internet which may provide inaccurate or conflicting information. In my case, my family was not offered any information and relied on the internet for answers to their questions. Contradictory and sensationalist articles ultimately caused them to become more scared and confused than they had been before doing any research. In contrast, by giving families clear, comprehensive information they will be better equipped to make decisions about the patient's medical care and rehabilitation which ultimately will afford them a greater sense of control.

Patients and family members may also have difficulty in processing all of the information given to them at this traumatic time which may cause them to forget some of what they have been told by doctors, nurses and therapists<sup>11,12</sup>. While I was in ICU, therapists would often describe a series of exercises to me very quickly in a session and then fail to repeat or re-explain these in subsequent sessions. It was only because I was familiar with the type of exercises that would be appropriate that I was able to continue with these as ward and home exercise programmes. Occupational therapists should thus ensure that they take the time to re-explain ward and home exercise programmes and be prepared to answer the same questions on more than one occasion. To meet the families' information needs, printed information about GBS and addresses of appropriate websites can also be given to families to answer their questions and concerns.

## EMOTIONAL SUPPORT

Although the entire process is quite an emotional one, in my experience certain specific events were particularly catastrophic. The first event occurred when I realised that I could no longer walk, even with assistance, and the second was the day when I needed both thumbs to press the keys on my cellphone. It was at these times that I realized just how serious the situation was becoming. Therapists should expect patients to experience emotions associated with the grieving process as they try to adjust to their lost abilities and body functions<sup>13,14</sup>. Also, one should remember that each member of the patient's family will experience unique emotional reactions towards the patient during this time<sup>15</sup>. I believe that providing patients and their families with emotional support, honest information and encouragement is especially important when they experience similar significant losses.

In terms of emotional support, therapists should strike a balance between allowing the family time and space to process the situation and knowing when to refer specific people to a psychologist. In my experience, this aspect was largely neglected. Although I was coping fairly well, my father was not coping at all. He didn't know what to say or do, he couldn't concentrate on having a conversation with me and became obsessive about asking what each number on the bed chart meant every time he visited. Still to today he battles to discuss my experience with GBS without becoming emotional. I

believe that he would have benefitted from professional help while I was in ICU – at a time when my other family members could not provide him with the type or amount of support that he needed. This type of emotional support would have enabled him to cope better, which would have allowed him to participate more actively in family decisions and planning. One should therefore ensure that each family member is coping well and in this way we can enhance the entire family's functioning; thereby indirectly increasing the support they are then able to offer to the patient.

## FAITH

Spirituality is one of the seven performance contexts that influence a patient's overall occupational performance<sup>16</sup>. Occupational therapists should therefore know their patients' religion and values and determine how important these beliefs are to them. This is noteworthy because faith and religion influence how patients perceive their disability and how they cope with it. Therefore, in intervention we should endeavour to respect and support the patient in his spirituality; irrespective of whether this matches our own religious convictions. Beyond spiritual benefits; religion can be effective in relieving stress, offer patients a sense of control and hope and provide various other physical health benefits<sup>17</sup>. Some patients may benefit from being referred to a psychologist or pastor; however most patients simply require support and an opportunity to share their concerns, hopes and fears – as was the case in my situation<sup>10,14</sup>. Most professionals avoided mentioning faith or religion when talking to me, except for one nurse. These interactions may have influenced my perception of her as she subsequently became the one professional that I came to trust more than anyone else.

## MAINTAIN JOINT AND MUSCLE FUNCTION

Another important consideration is to maintain the patient's muscle length, strength and joint range of motion<sup>10</sup>. While this may seem obvious; this is important even while the patient's condition is worsening – before he reaches the plateau phase. Right from the time that I was admitted into ICU I received regular passive range of motion stretches – especially of my ankles – and recruited family members to perform these stretches during visiting hours. This maintained my muscle length, which was starting to diminish very quickly, and gave my family something concrete to do in a time when everyone felt so helpless and useless<sup>13</sup>. Occupational therapists should explain the importance of physiotherapy and of passive range of motion stretches but should also caution patients that overstretching and overexerting their muscles may increase the rate of peripheral nerve demyelination or impair their rate of recovery<sup>10,18</sup>.

## INTERCOSTAL AND ABDOMINAL MUSCLE FUNCTION

As the patient's condition worsens, he begins to experience weakening of his intercostal and abdominal muscles<sup>10,18-20</sup>. Although respiratory care falls primarily in the scope of physiotherapy, the occupational therapist should also address the patient's weakening intercostal muscles as part of functional activities. In my experience my core stabilising muscles weakened considerably during the initial phase of GBS. As a result, it took significant effort for me to regain strength in these muscle groups when I was recovering. Preserving muscle function becomes especially important later on because lung function, core muscle strength and physical endurance affect the speed and extent of a patient's physical recovery<sup>8,19</sup>. In my experience, controlled deep breathing, bridging and dissociated rolling exercises were initially useful to preserve the remaining function that I had in these muscle groups. Later on in rehabilitation, however, occupational therapy should include activities that target sitting and standing balance, core muscle strength and muscle endurance; even after the patient has regained the ability to sit or stand independently<sup>18</sup>. When I started standing and taking a few steps again, it was my abdominal muscles, not my legs, that got tired the fastest from trying to maintain an upright position.



## FATIGUE

Many patients with GBS experience persistent fatigue in the recovery stage, making even simple Activities of Daily Living (ADLs) such as bathing and toileting very tiring<sup>18,20,21</sup>. In my case, I knew that I had to plan my bath time routine very carefully because if I had to add extra steps to the activity – such as fetching the towel I had forgotten on the bed – I would not have had enough energy to transfer myself out of the bath afterwards. Intervention should include teaching patients to plan how to use their energy; energy conservation techniques and the importance of taking regular rest breaks during activities. Well graded activities with rest breaks will enable the therapist to improve the patient's muscular and cardiovascular endurance from early on in the intervention process<sup>8,19,22-25</sup>.

## INTRINSIC HAND MUSCLES

My intrinsic hand muscles were the last to recover function owing to the proximal to distal pattern of recovery in GBS. Although I was still determined at this stage of my recovery, it has been my experience with other GBS patients (especially those who recover slowly) that they become despondent or disinterested by the time their intrinsic hand muscles start to regain strength. By explaining the functional importance of these muscles, we can hope to motivate patients to persevere with therapy<sup>21</sup>. It is also wise to explain to patients that even though they may recover good intrinsic muscle strength they may continue to experience temporary weakness or slowness during cold weather, when lifting heavy items or after prolonged hand use, as is still evident in my case.

## FUNCTIONAL ACTIVITIES

The practice of occupational therapy is grounded in the principle that involvement in functional activities is motivating and rewarding<sup>26-29</sup>. Encourage patients to perform their ADLs as independently as possible for as long as possible<sup>30</sup>. As my condition worsened it became increasingly difficult to perform various actions such as using a fork and rolling over. Despite the extra effort to perform these tasks, doing these activities gave me a sense of hope and accomplishment<sup>16,26</sup>. Because some patients may accept more assistance than they actually require; encourage nursing and allied staff to allow patients to perform their ADLs as independently as possible; only providing supervision or assistance when necessary<sup>13,30</sup>.

## INTRINSIC MOTIVATION

Another core principle of occupational therapy is enhancing the patient's intrinsic motivation by creating opportunities for him to experience success while performing functional activities<sup>26,29</sup>. It was devastating for me to lose a large proportion of my body function and to become completely dependent on others to care for me. Simple, functional activities such as working out an adapted method for eating with a fork and opening a Tupperware container provided me with a sense of accomplishment much greater than one would expect by objectively evaluating the motivational potential of the task<sup>26-30</sup>. These achievements, in turn, fuelled my intrinsic motivation to continue with rehab activities. Upon reflection, these experiences reminded me not to underestimate the powerful effect that a well-selected and graded activity can have on one's motivation<sup>16,26,29</sup>. Conversely, other less successful experiences reminded me how demotivating an activity can be when it is too difficult and when it magnifies one's lost abilities and skills<sup>13,31</sup>.

## REALISTIC GOAL-SETTING

The occupational therapist as part of the rehab team should facilitate an open discussion with the patient and his family about his long-term prognosis, rehabilitation goals and possible functional outcomes<sup>30-32</sup>. Through collaboration, we can convey respect, acknowledge the patient and his family as equal rehabilitation partners and ensure that their priorities are met<sup>16,32-34</sup>. When setting goals, families should be guided to formulate realistic expectations based on the patients' specific prognostic factors, current level of functioning and rate of recovery<sup>21,34,35</sup>. Discuss the potential long-term effects of GBS on the patients' ability to perform their ADL;

participate in community activities and return to work and how these factors may influence the family as a whole<sup>16,36</sup>.

So often, occupational therapists are determined to ensure that a patient achieves complete independence when performing a task that we deny the patient the opportunity to experience some measure of success in the meantime<sup>16,21,30,31,35</sup>. Since having GBS myself, I have treated a patient with GBS whose biggest priority was to hold and breastfeed her newborn infant. Initially this meant finding ways to compensate for her lack of strength and function but the joy that she experienced from this motivated her to continue with her rehabilitation so that she could eventually hold her son without any compensation.

Furthermore, challenge patients to achieve rehabilitation goals but ensure that they are aware of their own physical and functional limitations<sup>25,32,36</sup>. Be sure to warn highly motivated GBS patients that over-exertion is ineffective and it may delay their functional recovery<sup>18</sup>. Be available to problem-solve with patients but allow them opportunities to do some of the problem-solving themselves. One of the greatest personal achievements I had while recovering was being able to bath myself independently for the first time again – and part of that joy was being able to problem-solve how to do that by myself.

## LONG-TERM OUTCOMES

Recovery is a long process. Even though improvement from GBS can be dramatic; recovery usually takes between 3-6 months on average, and up to 2 years in total<sup>4,5,9</sup>. Establish a strong therapeutic relationship with your patients and their families and prepare them for the many hours of rehabilitation that lie ahead<sup>21,30</sup>. The quality and strength of the relationship you establish with them ultimately influences the extent to which they value your input and continue with rehabilitation<sup>32</sup>. Outpatient therapy sessions can be used to develop the families' problem-solving skills so that they can address some of the difficulties they experience more independently in the future<sup>30,31,33</sup>.

Even though it is impossible to know for certain how much function the patient will recover or how long this will take; prepare the family early on to discuss topics such as wheelchairs, home adaptations and return to work. Although this may be a lot to cope with, it helps to be mentally prepared and it gives the family time to adjust their schedules or save money for assistive devices if these continue to be necessary. Lastly, collaborate with patients to develop their ultimate long term goals – whether this is walking ten metres or returning to work, each patient's ultimate goal will motivate him to persevere no matter what<sup>34,36</sup>.

## CONCLUSION

Although this commentary offers guidelines for working with people with Guillain-Barre Syndrome it is important to remember that each person experiences disability in a completely personal way. Collaborate with patients and their families to establish goals that are important to them. Be careful not to assume how patients are feeling or that what worked for one patient will work with every other patient with the same diagnosis. To assume these things is to lose sight of the fact that we are all unique individuals with our own personal goals and aspirations. Therefore, as an occupational therapist on the rehabilitation team, your ultimate role should be to enable patients to regain function so that they can live as independently, productively and meaningfully in the future as possible.

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