



*Kathy Eggers' experience 'on the other side' as a patient has given her valuable insights to share with other nurses. After 18 months of hospitalisation and rehabilitation she returned to work, where she is pictured here with patient Desmond Renete in the dialysis unit at Hawke's Bay Hospital.*

## NURSING A PATIENT V

*Guillain-Barré syndrome is a very frightening condition for patients and their families. Excellent communication from nurses and medical teams can provide much needed reassurance.*

*By Maria De Cort*

Hospital's emergency department, Bronwyn Snodgrass.

Eggers was diagnosed with CIDP in 2007 and her experience "on the other side" as a patient has given her valuable insights.

Snodgrass offers a carer's perspective. Her mother, Marilyn Turnwald, was hospitalised in early January just after arriving in Australia on holiday. She was intubated later that month and flown back to Waikato Hospital, still on life support, in March.

Eggers said the medical care she received while an in-patient was very good overall, yet the care she received from the nursing team "was varied, ranging from exceptional quality nursing care to having only minimal basic cares provided – probably due to the nurses' limited knowledge of GBS/CIDP".

She admitted feeling torn as a CIDP patient. During her illness, she relied completely on her colleagues to provide total care for many months, particularly when her condition meant she was fully quadriplegic for a period. But as a nurse, she knew the difficulties and limitations currently experienced in the workplace.

"I believe the main message to those involved in the nursing care of GBS or CIDP sufferers is their continual commitment to practising core nursing values – empathy, care and advocacy," Eggers said. "GBS/CIDP is potentially life threatening and definitely life changing. It can affect anyone, and no two patients ever experience the same symptoms, rate or extent of deterioration, or progression of this neurological illness. Main symptoms can include muscle weakness (often leading to paralysis, and mechanical ventilation/intensive care unit – ICU – support), pain and fatigue.

"Excellent communication skills are required to relay empathy, accurately assess pain and recognise patients' capabilities. A patient may be able to hold a spoon and feed him/herself breakfast, yet be unable to perform this task four hours later. Nurses need to continually assess patients and update their care plans accordingly. As highlighted during this year's conference, regular communication and involvement between family/whānau and nursing staff can ensure the sufferer remains safe and well cared for. GBS/CIDP is a very frightening condition

**G**uillain-Barré syndrome – GBS – has, for many patients of this debilitating disorder, come to mean "getting better slowly". And on that often slow road to recovery, the nursing care a GBS patient receives can make a world of difference.

In a survey conducted by the GBS Support Group of New Zealand (GBS NZ) in April 2010, members were asked how they felt about the nursing care they received when in hospital with GBS. Eighty percent said nurses had done a good job.

"The bulk of the 20 percent who were not so happy said it wasn't about the nurses themselves – just that they had no knowledge of the special needs of a GBS patient and so caused unnecessary discomfort or stress to the patient," said GBS NZ secretary Tony Pearson.

GBS is a rare autoimmune disorder, where the body's own immune system turns on itself and attacks the peripheral nervous system. This causes temporary muscle weakness, sometimes to the point of severe paralysis, sensory loss and pain. Often triggered by a preceding illness, GBS has an incidence of one to two people per 100,000 or about 40-80 New Zealanders a year. Chronic inflammatory demyelinating polyneuropathy (CIDP) is a chronic or ongoing neuropathy that closely resembles GBS.

At the fifth GBS NZ biennial national conference in April this year in Wellington, more than

60 delegates, including current and former GBS/CIDP patients, their families and caregivers, and representatives from the medical fraternity, benefited from the chance to hear about the latest research, quiz the experts, plus connect and share experiences with others who had battled this frightening and debilitating illness.

Professor of health law and policy at the University of Auckland and former Health and Disability Commissioner, Ron Paterson, was one of the keynote presenters. His talk honed in on the specific needs of GBS/CIDP patients and their support people, covering key issues such as the right to information and effective communication, the concept of duty of care, the question of competence and the importance of compassion.

Paterson encouraged his audience to share their stories of what great care looked like. This prompted me, as GBS NZ publicity officer, to issue a call to members to share their experiences of nursing care, in order to raise awareness of this illness within the nursing profession. Nurses have the most daily contact with a hospitalised GBS patient so can really make a huge difference to both their physical comfort and emotional well-being.

Two of the people who have had significant input into this article are nurses themselves – haemodialysis nurse at Hawke's Bay Hospital, Kathy Eggers, and senior staff nurse at Waikato

# WITH GULLAIN-BARRÉ SYNDROME

for both the patient and family, and excellent communication from nurses and medical teams can often allay fears and provide much needed reassurance."

Getting better slowly described the experience she went through, Eggers said. "With quality nursing care, this can be achieved in a dignified manner. On a personal note, each day I am truly thankful to all the many staff involved in my care. Experiencing life as a quadriplegic and 'on the other side' as a patient has highlighted how I, and many other nurses, can undervalue the care we provide. I now truly appreciate a patient's sincerity when they thank me for the care I have given. We are not just doing a job – we are affecting someone's life!"

At the end of May, Marilyn Turnwald was transferred from Waikato Hospital's ICU to the high dependency unit, moving to a ward about a month later. Last month, she still had very minimal movement in her limbs, was

"People need to understand that GBS patients are still as sharp as a tack," she said. "GBS is a roller coaster and a good day may not always mean a patient is 'on the mend' or on the up and up.

"When my mother was in ICU I struggled with the staff not seeming to comprehend that GBS patients are nothing like any other patient. I felt my mother was being pushed to make improvements too quickly, such as getting off the ventilator.

"I don't think the staff understand she is fighting this disease – a disease they can't see. Some days she is so tired and just wants and needs to rest. GBS patients recover more slowly than other patients and cannot be assessed within normal parameters."

Above all, the most important lesson Snodgrass has learned while accompanying her mother on her road to recovery is patience.

"No matter how frustrated I get, she is ten

patients need "lots of enrichment, stimulation and distraction".

GBS NZ support group medical advisor, Gareth Parry, is medical director of the Clinical Neuroscience Research Unit at the University of Minnesota in the United States. The New Zealand-born neurologist has studied GBS and its variants for the best part of four decades, and is considered a world authority. He gave two keynote presentations at this year's conference – one on pain and fatigue, which he describes as "very common but much under-appreciated features of GBS and CIDP" and the other about atypical forms of GBS and CIDP. Above all, he emphasises the critical importance of communication in nursing care.

"When patients are on a ventilator or heading in that direction, the focus is, understandably, one of life-saving," he said. "In this situation, patients often cannot communicate adequately and a system of communication should be developed and applied frequently. For example, even severely paralysed patients can usually blink or move their eyes. A system of 'blink once for yes and twice for no' can enable the nursing staff to ask about their pain and explore how severe and where it is."

For more information about GBS, visit the support group's website at [www.gbsnz.org.nz](http://www.gbsnz.org.nz). The group exists to provide information to the public and health sector; to educate people and raise awareness of this rare illness; to sponsor research into the causes and effects of the illness, as well as research into methods of treatments and possible cures; and to provide support and information for GBS sufferers and their support networks.

If you ever have a patient in your care with GBS or CIDP, please tell them about our support group, as it is the initial stages of these illnesses that are the most frightening and when a visit from a recovered patient and information about the illness are most valued. As there is no automatic system of notification from hospital organisations, GBS NZ relies on the patients, their families, carers and friends to make the initial contact and health professionals to let them know of our existence. •

**Maria De Cort** is publicity officer for GBS NZ. Her husband Roy was diagnosed with GBS mid last year. She is grateful for the support GBS NZ gave her and her family during the months of his recovery.



Bronwyn Snodgrass (right) sits with her mother Marilyn Turnwald in the Royal Brisbane and Women's Hospital intensive care unit, while nurse Jessica Brown checks on her patient.

unable to sit up unassisted, was talking and eating, but still had a tracheostomy tube. Snodgrass has reflected on what she has learned at her mother's bedside and has a few key points to raise. One of the "don'ts" on her "dos and don'ts" list would be that hospital staff shouldn't treat a patient like s/he is "deaf, dumb, blind or stupid", just because they are in ICU and may be on a ventilator.

times more frustrated than I am and she can't get up and walk out. I have learned to cherish, love and support her in any way I can. The staff have been great and let us (the family) spend a lot of time with Mum, as they can see her improvement when we are around."

Snodgrass has read books to her mother on most of her visits, as she believes it is important to encourage people to understand that GBS