Chapter 7

A patient’s journey:

Acquired Brain Injury

Ik lijk weer heel wat
zo even bekeken
rest nu enkel nog
mijn verborgen gebreken

(Poem of Gerrieke Pas, partner of man with Acquired Brain Injury’)

Linda Kat
Karen Schipper
Jeroen Knibbe
Tineke A. Abma

Linda Kat was 40 when surgery left her with acquired brain injury. She tells of her initial shock, her frustrations, and her need to make her own choices.

My problems began eight years ago, when I was 40 years old. I lived with my husband and 2 year old daughter. Because I had problems with my eyes I visited my general practitioner. I suffered diplopia and, after examination, my general practitioner sent me to a neurologist. I had a number of examinations, including magnetic resonance imaging, a scary experience. Shortly afterwards, the neurologist asked me to come to see him immediately as they had found a brain tumour. I was shocked. I had never thought about this possibility. An operation was necessary. I was told I would definitely die without it. But the operation was not without risks. The doctor told me that I would “never be the same again after the operation” and that “my life expectancy wasn’t that high if the tumour proved to be malignant.” I felt, however, that I had no choice and that I understood the risks and consequences. The information didn’t really get through to me. I was just trying to survive. There was no room for doubt.

The shock of having an acquired brain injury

The operation caused severe acquired brain injury. Shortly after the operation I was unable to walk, talk, smile, or eat, and I had problems with my sight. Nowadays I need a wheelchair. My face is also paralysed, so I can’t express my emotions. I can’t laugh or kiss anymore, and I have problems with eating. I also have problems with talking, so I can’t express myself well. As a result, people often fail to understand my conversations. They pretend to understand me. That’s the most awful thing; it makes me feel frustrated and angry when people don’t understand me or pretend they understand me. The only way to express my feelings at these moments is by screaming and yelling, and when I do that people walk away because they find it annoying. Besides these problems, I have cognitive and other impairments. I have problems with my memory and concentration, and I feel terribly tired. I don’t have enough energy to do the things I really want to do.
Struggling against myself and my environment

After being in hospital I went to a rehabilitation centre, where they taught me how to fold up my laundry, and other skills, to make me independent. But for me such things were never the most important in life. After a year in the rehabilitation centre I moved to a nursing home where I lived with old people. It was awful, but as my house wasn’t adapted to my impairments and as my relationship wasn’t stable enough, I couldn’t go home. Gradually I realised that my life had changed dramatically and that I would never be the same again. My husband decided he wanted a divorce. This felt like rejection and the divorce made me feel miserable. Now I realise that it was a good decision. Our relationship was already on its last legs before I got the brain tumour. It hurt me tremendously that, initially, my little daughter didn’t want to see me. That felt like another rejection. Thank goodness my friends and family turned out to be loyal. They were a great support to me.

From the nursing home I moved into a home for people with acquired brain injury. My early period in the home can be characterised by fighting. I struggled to become the same person as I was before. I am not and never will be able to take care of myself and my daughter anymore. This makes me very sad as my daughter is the most important thing in the world to me. She makes me feel happy, but her situation makes me sad. I can’t take care of her. When she visits me she gives me energy and hope, but afterwards I am totally exhausted and can’t do anything for a day. Finding a balance between doing something and doing too much is complicated; I have to make choices constantly, depending on my level of energy at that moment. My energy level changes during the course of the day, which is typical of acquired brain injury. One day I can do small things, the next day I cannot. This leads to incomprehension. People don’t understand me and sometimes they think I try to mislead them, and then they sometimes respond, “I am not going to help you. I know you are able to do that. Yesterday you did it, so now you have to do it also.” Sometimes they say: “We are not going to do that, because you are able to do it by yourself.” The staff often say that they are trying to stimulate me to do the things that I can still do myself. However, it is important for me to make my own choices, and these choices can differ from those of the staff. I know myself best, better than anyone knows me, so I want to make my own decisions and stay in control as much as possible. For me it is not that important to wash my own clothes, or always to put my teabag into my mug. For me it is much more
important to have a phone call with a friend. I value my friendships highly and the loyalty of my friends. I can’t do everything, and I want to choose for myself what is most valuable to me at that particular moment. Sometimes this leads to struggles with my environment. I know people are well intentioned when they try to help, but their kind of support doesn’t always fit my needs. This makes it hard to ask for help, to be responsive to care, and to accept that I am dependent. Yet I realise that I can only continue the life I value when relying on others for support.

**Having to change my dreams and having to go on**

The brain injury forced me to change radically my perspective and dreams for the future. Most of the things I wanted and did in the past are impossible now. Step by step, I have acknowledged my restrictions and gradually learned to focus on the things I can still do and enjoy. I have also learned to take care of myself and to make more choices of my own. I always say, “the smaller, the better”: when you have to live a lazy life, you automatically learn to appreciate small things. I like to listen to music, do some yoga, sit outside my apartment just listening to the birds and looking at the beauty of nature. By focusing on small things, doing the things I want to do, making my own choices, and taking care of myself, I am able to live my life as best I can.

**Helping hands during my journey**

- Seeing my daughter, talking to friends on the phone, sitting outside watching birds: these are the things in life I have come to value and that make me happy.
- The support of friends and family. They helped me to accept my new self and my situation.
- Telling my story, and having someone listening to my story patiently in a quiet environment.

**A medical specialist’s perspective**

Acquired brain injury is damage to the brain that is acquired after birth and can result from traumatic brain injury (caused by, for example, a car crash or a fall) and non-traumatic brain injury (caused by, for example, cerebrovascular events
and brain tumours). Acquired brain injury should not be confused with intellectual disability. The damage can be focal or diffuse, and the brain injury can range from mild to severe, leading to mild or more severe symptoms. Brain injury has extremely varied effects, and no two people can expect the same outcome. Cognitive deficits such as memory problems, concentration problems, and problem solving deficits or perceptual problems can occur, as can motor deficits such as paralysis or spasticity, and communication problems such as aphasia. Patients may also develop problems with understanding and responding in social interactions, and they can become self centred. Most patients report extreme tiredness. Personality changes or neuropsychiatric symptoms such as apathy, emotional lability, irritability, anxiety, and depression can also occur. Even a mild injury can sometimes result in serious disabilities that will interfere with a person’s daily functioning for the rest of their life. Although the outcome of the injury depends largely on the nature and severity of the injury itself, appropriate treatment will play a vital role in determining the level of recovery. The treatment starts with a period of clinical observation, mostly in a rehabilitation centre. The approach is multidisciplinary. Information about the premorbid physical condition (of the head) and about the patient’s personality is important for understanding the patient and his or her behaviour better. The treatment focuses on improvement of physical condition and mobility, teaching the use of aids for daily living (such an adapted spoon for eating or a walking frame), training in practical skills, cognitive training, reintegration into work or school, and helping the patient to adapt to and “accept” their losses. Linda’s story shows, however, that the feelings of loss and sorrow are not resolved during the treatment period. Professionals have to be alert to signals of sorrow during the chronic phase. Understanding the premorbid factors, neuropsychological profile, and cognitive impairments is necessary for the treatment of neuropsychiatric problems such as apathy, depression, aggression, and anxiety. Many of these problems can be minimised by early intervention based on the neuropsychological profile. Additionally, as patients find it difficult to accept the changes in their life, a system of care involving support, information, and instruction plays a crucial role in patients’ rehabilitation and reintegration. A gradual return into society follows the clinical phase. However, personal factors (such as cognitive impairments and feelings of insecurity) and external factors (such as a lack of facilities and unforgiving environments not suited to people with acquired brain injury) can substantially hinder reintegration. Some patients need
professional support for the rest of their lives in the form of specialised nursing homes or day care centres. The medical policy in such places will be focused on the prevention and treatment of chronic problems caused by brain damage, such as decubitus ulcer, retention of the bladder, obstipation (severe and intractable constipation), epilepsy, hypertonia, swallowing problems, infection of the bronchial tubes, becoming overweight, visual problems, cognitive impairments, and neuropsychiatric problems.

What can medical professionals do?

- Show empathy. ABI often implies radical changes in all the domains of life and in the identity of the patient.
- Help the patient find a balance in energy levels; inform other healthcare professionals that energy levels may fluctuate daily and that care should be tailored to the daily changing situation of the patient.
- Pay attention to the feelings of patients during the chronic phase. After the rehabilitation phase, when the patient is at home, he or she will feel and realise the impact of the brain injury, which may evoke emotions.
- Give clear information about medical examinations and interventions, checking whether the patient really understands the information and supports the decision making process.
- Ensure that rehabilitation does not centre just on learning skills. It’s just as important that patients learn to cope with their limitations and the changes in their life, and to discover their strengths.
- Respect and take notice of the patient’s needs and perspectives without imposing ideas on the patient.
- Support the expression of emotions and communication with the patient. Not every patient is able to express emotions facially and verbally. Do not pretend to understand the patient. Listen to the patient: be honest and listen carefully.
- Accept the patient’s identity and values and his or her view on autonomy; not everyone is or wants to be self sufficient and independent all the time.
- Support the patient in directing his or her life even if this conflicts with the vision of care held by the institution where the patient lives.
- Give support and information to the patient’s relatives.
Jeroen Knibbe, physician specialising in persons with (intellectual) disabilities and acquired brain injury

Contributors: LK told her story to KS during two interviews and a series of group training meetings; because of her brain injury LK cannot read or write but can speak in quiet surroundings. KS recorded LK’s experiences and used LK’s words to draft the article in the first person; KS read the article to LK repeatedly until LK recognised it as her own story. TAA helped KS with the writing process and commented on and edited the text. JK, the doctor at LK’s residential home, compiled the two medical boxes. KS translated the article into English, with TAA’s help.