Walking into Darkness

The Experience of Spinal Cord Injury

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Preface

For many years, the onset of disability has been viewed as a personal tragedy, and consequently the disabled person has been seen as a victim of such an unfortunate happening. Spinal cord injury has often been seen in such terms: the sudden nature of its occurrence—as the result of a road accident, a fall or a sporting injury—rendering someone who was previously fully fit and well, completely paralysed. The physical consequences of such a happening are best described in the words of Sir Ludwig Guttmann, pioneer in the development of a spinal injury service in the United Kingdom:

It must be remembered that the spinal cord, that big nerve trunk within the vertebral column, is one of the most important organs in animals and man. For it is the main mediator of all impulses from and to the brain. For instance, any volitional isolated muscle movement initiated from the brain is only possible if the spinal cord is intact, and vice versa—all forms of sensory impulses originating from the skin, muscles, joints and internal organs have to travel through the spinal cord to be consciously appreciated. Moreover, in addition to these vital functions, the cord contains in itself nerve centres for controlling bladder, bowel, sexual and respiratory functions.

Therefore, if the spinal cord is severed or crushed—by a knife, bullet, vascular catastrophe (thrombosis) or a fracture of the spine at any level—this immediately results in a paralysis below the level of the injury, with loss of most essential functions. This involves all voluntary motor functions, appreciation of all forms of sensation, and results in loss of posture and control of bladder and bowels. Sexual function in men is abolished. Women lose sexual sensation but can have intercourse and still conceive. The higher up the spine the level of the injury the more parts of the body are cut off. In injuries of the cervical cord, the respiratory function as well as the blood circulation are greatly impaired, especially in very high cervical lesions, the involvement of the blood circulation leading also to a reduction of the tone of all tissues, especially skin and muscles. This in turn results in a lowering of their resistance to pressure, which is one of the most important causes of the development of pressure sores. All forms of sensation are cut off and the patient does not feel the

discomfort of pressure, such as non-paralysed people do in the form, let us say, of pins and needles.

The victims of war, road, industrial and sporting accidents did not establish a social problem in the past, as their life expectancy was very short, two to three years at the utmost as a rule. Complications such as sepsis from ascending infection of the bladder into the kidneys, and pressure sores, were considered inevitable. Therefore, any attempt to restore such a person to his or her former social activities seemed to be out of the question, and the view generally held was the sooner they died the better for all concerned.

(quoted in Goodman, 1986:96–7)

Given this description, it is not surprising that spinal cord injury is seen as a catastrophic event in someone's life. However, largely as a result of the work of Sir Ludwig Guttmann at Stoke Mandeville Hospital, attitudes to recovery and rehabilitation, and a new approach to spinal cord injury, emerged:

The basic principle of this new philosophy was to provide a comprehensive paraplegia and tetraplegia service to rescue these men, women and children from the human scrapheap and return most of them, in spite of permanent, profound disability—by clinical measures and psychological readjustment—to a life worth living, as useful and respected citizens in the community.

(quoted in Goodman, 1986:101)

Partly as a result of this new approach, many people with spinal cord injury emerged from Stoke Mandeville, and later other hospitals, keen and eager to rebuild their lives or continue their existing ones with the least possible disruption. Not all, of course, made it, but many did and reappeared in society, working, marrying, enjoying a whole range of leisure pursuits and sporting activities, thereby challenging the stereotype of spinal cord injury as a personal tragedy.

The purpose of this book, therefore, is to describe the lives of people with spinal cord injury: to look at what happened to them at the time of their injury, on discharge from the spinal unit and at the time of the interview. Seventy-seven male ex-patients from Stoke Mandeville who had been disabled for between 2 and 15 years were traced and interviewed. The material from the interviews is presented in chronological order, tracing the 'disability career' of those interviewed.

This is not the first study to use the idea of a 'disability career' as a means of providing a chronological or temporal ordering of the data to be presented (Goffman, 1961; Safilios-Rothschild, 1970; Blaxter, 1980). Carver sets out the rationale for such an approach:

A career in disability refers to the course or progress through life of any disabled person insofar as he encounters problems or handicapping conditions related in any way to his disabilities. A person's progress may be affected . . . in practical ways and/or in the ways he thinks about himself or others. This concept of career is a broadly comprehensive one and implies that the individual is actively and repeatedly involved in the definition of his own problems and in the search for solutions, and, like any other career, it will comprise a succession of interactions with his environment, both physical and social.

(Carver, 1982:90)

These interactions, at the points in time already mentioned, are described in the words of the people with spinal injuries themselves, giving a sense of authenticity to the disability career.

The first chapter provides a brief history of the medical treatment and rehabilitation of people with a spinal injury, along with an outline of the medical consequences of such an injury and a description of the kinds of treatment facilities available in the United Kingdom. This discussion is located within the context of changing ideas of what are appropriate services for people with a spinal injury and historical changes in the patterns of community support. The second chapter then provides a conceptual framework for the study, seeing spinal cord injury as a 'significant life event' rather than a personal tragedy, and the operationalisation of the concept of social adjustment is also discussed. A short account of the development of the study is provided, together with a description of the methods used to collect the data. Finally, a brief description of some of the characteristics of the people interviewed is presented.

The next three chapters utilise the concept of the career. Chapter 3 focuses on the medical consequences of spinal injury, looking at the nature of the accident, immediate post-accident treatment at both general and specialist hospitals, the rehabilitation process and the medical problems that may arise after discharge and for the rest of the person's life. Chapter 4 then moves away from the immediate medical and physical impact of spinal injury, and focuses on the impact on the injured person and his family. The concept of social adjustment is crucial here, and it is suggested that personal and family responses to spinal injury can only be understood in the light of a whole range of personal, social and economic factors, and not simply as a function of the extent of residual disability. Chapter 5 then broadens out the discussion and looks at the effects that spinal injury has on interpersonal relationships, and the restrictions that it may create for leisure and the pursuit of various hobbies and interests, as well as examining the issues of personal mobility and public transport.

Social adjustment and a successful career in disability are not,

however, solely dependent on medical and interpersonal factors: a range of external factors, such as the availability of suitable housing, the prospects of keeping or finding a job and the kind of income support that is available, are also critical. Chapter 6 is pivotal in relation to these issues, for it looks at the roles of various professionals, both within the hospital and in the community. It suggests that while these professionals should provide access to the range of support services, information and benefits available to people with a spinal injury, in practice these roles are inadequately fulfilled.

The next three chapters, therefore, look at the services available. Returning to the concept of disability career, Chapter 7 examines the range of accommodation available, the process of adapting existing properties for someone confined to a wheelchair, and the issue of personal choice about where to live and, indeed, with whom to live. Chapter 8 discusses the effects that spinal injury has on the prospects of keeping an existing job or finding an alternative one, on the capacities and capabilities of those so injured, and on the desire, or otherwise, to resume work. Chapter 9 then describes the financial circumstances of our interviewees and their families, the nature of financial hardships that some of them suffer, and the whole issue of compensation and disability income.

The final chapter then attempts to pull together the many themes that have been raised throughout the book. It summarises the key issues that have arisen; it considers and suggests improvements in the planning and delivery of services, both hospital- and community-based, and it argues that there is urgent need for action by all concerned if the 'disability career' of those with a spinal injury is to be significantly improved.

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