

Chapter 1

The Patient's Journey

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INTRODUCTION

A person is on a journey through life which runs from the ante-natal period to the time of death. It is to be anticipated that, through experience, a person can manage obstacles in their pathway and continue on their journey in a productive and positive manner. This life journey contains a number of pathways. These pathways, such as financial circumstances, interpersonal relationships and health, do not always run smoothly and may lead to various deviations. The health pathway is a continuum of wellness, illness, recovery or death and includes all occasions of ill-health.

Primary prevention is an important aspect of the patient's journey. Preventing disease or ill-health through early education will decrease morbidity and mortality. A particular pathway along the patient's journey commences once the patient has been diagnosed with a particular health condition/problem. Unfortunately, due to the nature of neurotrauma, there is seldom a pre-arranged plan in place as there is for elective surgery. This part of the health journey usually comes as a shock and 'emergency resources' may need to be called upon to be able to continue the journey. It is important to provide a smooth route throughout the patient's journey in order to ensure that quality care is provided, decrease stress, increase compliance and decrease deviant or destructive behaviour. The patient's journey takes place within a particular environment and involves the patient, family and the wider community. It is a journey that needs to be patient-centred and focused on the patient's perspective, expectations, motivation and

behaviour. When considering the journey the patient's life experience, their strengths, abilities, capabilities and any fears or weaknesses must be considered. The patient's health journey, interrupted by the neurotrauma, is influenced by a number of existing factors:

The patient:

- Age.
- Gender.
- Pre-existing conditions.
- Social practices.
- Health status.

The factors:

- Peri-natal care.
- Environment.
- Education.
- Family support.
- Community support.

Planning the patient's journey may be referred to as 'process mapping' whereby the team and the patient work out the pathway a patient is expected to follow. This requires taking into account all aspects of holistic, person-centred care that the patient may require, as well as the resources needed to achieve the proposed plan. The team is then able to examine the patient's situation in terms of patient outcome and consider and identify potential challenges that may occur along the pathway that may hinder achievement of the patient's goals.

CARE PATHWAYS: POLICIES AND GUIDELINES

Numerous care pathways have been developed to ensure cost-effective, efficient patient care to help create a seamless journey through this episode of altered health. Internationally, specific policies and standards have been developed that focus on neurotrauma throughout the patient's journey (Espinosa-Aguilar *et al.* 2008; Seeley *et al.* 2006; Sesperez *et al.* 2001; Zampolini *et al.* 2012). The National Institute for Health and Clinical Excellence (NICE) (NICE 2007) has developed guidelines for the management of head-injured patients. The National Service Framework for Long-term Conditions (DH 2005a) has a particular focus on the needs of people with neurological disease and considers some of the generic issues, including rehabilitation, that are of relevance to people with long-term conditions and disabilities. The introduction of these policies addresses some of the inequities for patients requiring rehabilitation (Pickard *et al.* 2004).

Guidelines have been produced by a number of sources, nationally and internationally, to assist in clinical decision

making, prevention, diagnosis and management, including rehabilitation, of patients with neurotrauma. Guidelines make specific practical recommendations based upon rigorous and available scientific data (RCP 2010).

The health professional is responsible and accountable for the quality of care a patient receives. Basic care in today's climate is often protocol driven, particularly as many basic tasks are undertaken by non-professional personnel under the direct or indirect supervision of registered personnel.

INTEGRATED CARE PATHWAYS

Internationally (Espinosa-Aguilar *et al.* 2008; Seeley *et al.* 2006; Sesperez *et al.* 2001) and nationally (BSRM 2002; BSRM 2008a; 2009; NICE 2007; Royal College of Physicians [RCP] and BSRM 2003) interprofessional, integrated care pathways have been developed to improve the management of patients with neurotrauma and are useful in managing specific issues such as depression (Turner-Stokes *et al.* 2002).

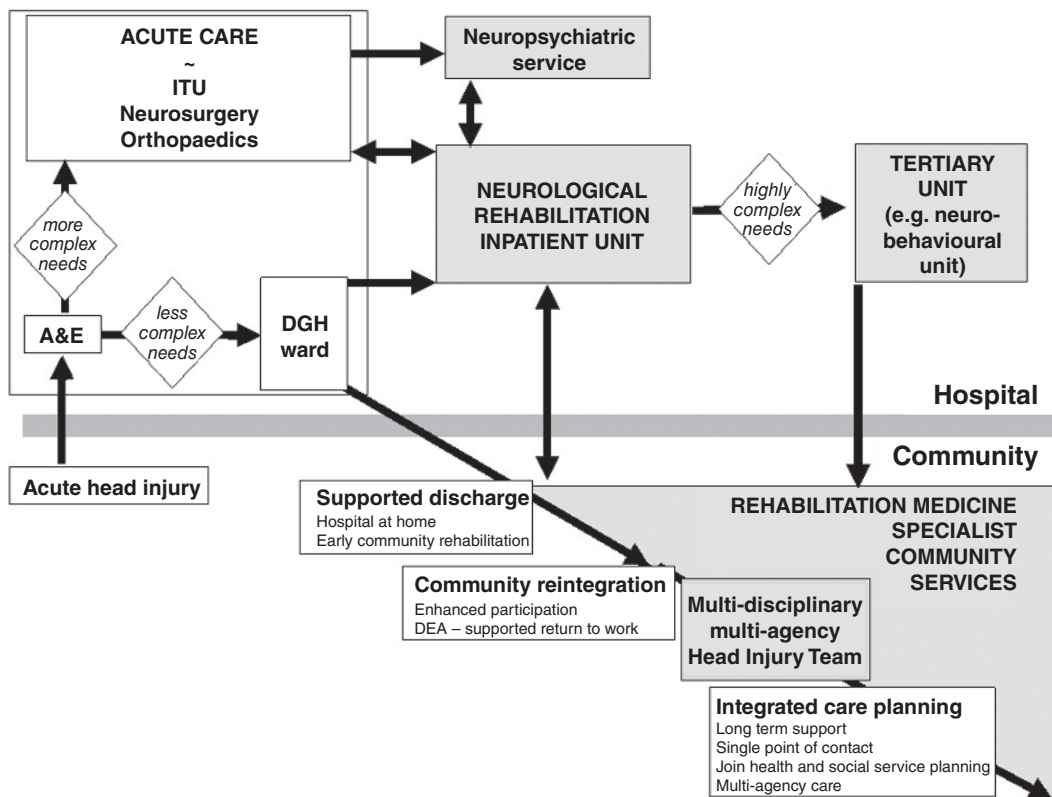


Figure 1.1 Care pathway for traumatic brain injury (RCP 2010: p. 28). Reproduced from: Royal College of Physicians. Medical rehabilitation in 2011 and beyond. Report of a working party. London, RCP, 2010. Copyright © 2010 Royal College of Physicians. Reproduced by permission.

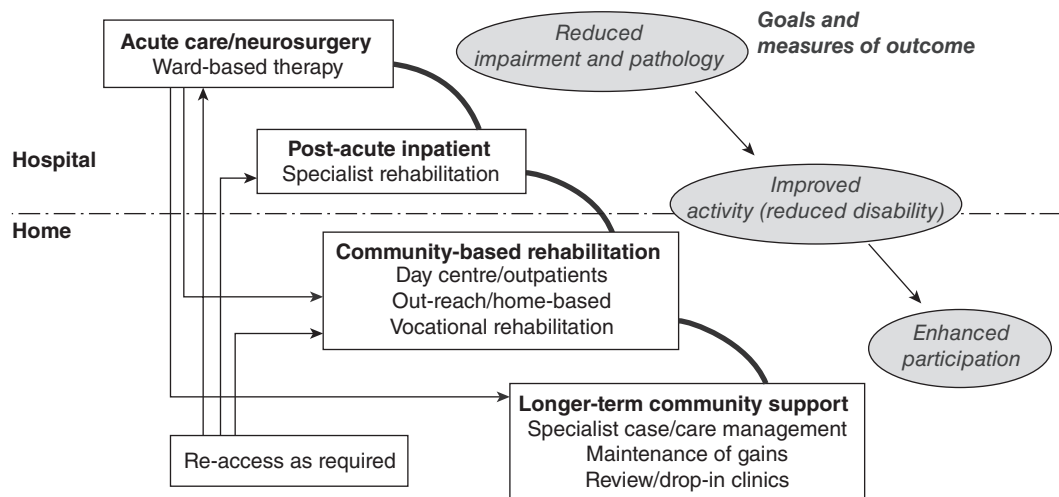


Figure 1.2 The 'Slinky' model of phased rehabilitation (RCP and BSRM 2003: p.10). Reproduced from: Royal College of Physicians and British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: National clinical guidelines (Turner-Stokes, L. ed). London, RCP, BSRM, 2003. Copyright © 2003 Royal College of Physicians. Reproduced by permission.

The National Service Frameworks stress the importance of integrated care pathways in the development of quality healthcare. These pathways, if developed and implemented effectively, will increase interprofessional co-ordination, efficiency of healthcare, reduce sequelae of head injury and reduce healthcare costs (Coetzer 2009; Singh *et al.* 2012; Vitaz *et al.* 2001; Zampolini *et al.* 2012).

Patients able to access these recommended pathways should experience a seamless transition from incident to home or final destination.

Activity 1.1

Scenario

An 18 year old boy was admitted with a GCS of 14/15 with a scalp injury that required suturing after a skate boarding accident in the park.

Exercise

1. Interview the patient and his mother to gain a picture of the patient's life journey thus far.
2. Plan a session with the mother and son to decrease the risk of further head injuries.

Activity 1.2

- 1 Select a patient in the unit who has had neurotrauma (GCS 5/15) and plot the patient's journey.
- 2 Are there any aspects related to professional practice that you need to consider in the patient's journey?
- 3 Develop a communication plan for patient.
- 4 Develop a communication plan for family and carers.

Activity 1.3

- 1 Do you use an integrated care pathway in the unit?
- 2 If yes, see Chapter 16, Activity 16.1 and describe a possible pathway for Trevor.
- 3 If no, why does your organisation not use an integrated care pathway?
- 4 Would you consider developing such a pathway with a team of colleagues?