

# **Unit 39: Supporting Families who are Affected by Acquired Brain Injury**

**Unit reference number: R/616/7377**

**Level: 3**

**Unit type: Optional**

**Credit value: 3**

**Guided learning hours: 30**

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## **Unit summary**

Families who live with an individual with an acquired brain injury may find that their lives have changed completely. This unit will explore the types of change experienced by families and the support they may need.

In this unit, you will consider the impact on families who are dealing with an individual in either a state of minimal responsiveness or a vegetative state. You will look at working in partnership with families, in order to provide holistic packages of care that meet the needs of individuals, carers, families and friends. You will consider the type of long-term adjustments that families may need to make and the support they may need.

You will investigate the different aspects of the impact on families living with an individual who has an acquired brain injury. You will look at the emotional and socio-economic aspects and changes to the individual's personality caused by the injury.

You will explore the legislation and policies relevant to carers, together with the key principles and values that underpin them.

You will have opportunities to demonstrate competencies in assessing the needs of carers and in evaluating the outcomes of support for carers and families of an individual with an acquired brain injury.

## Learning outcomes and assessment criteria

To pass this unit, the learner needs to demonstrate that they can meet all the learning outcomes for the unit. The assessment criteria outline the requirements the learner is expected to meet to achieve the unit.

Learning outcomes	Assessment criteria
<p>1 Understand the impact on families who care for an individual who is in a minimally responsive or vegetative state</p>	<p>1.1 Explain the impact on family of caring for an individual in a minimally responsive or vegetative state</p> <p>1.2 Describe how theories of loss and grief provide a framework for practice</p> <p>1.3 Describe the long-term adjustments families and friends may need to make</p>
<p>2 Understand the long-term effects of acquired brain injury on family</p>	<p>2.1 Explain the emotional impact of acquired brain injury on families</p> <p>2.2 Compare the difference for families between caring for an individual with mild to moderate brain injury and an individual with severe brain injury</p> <p>2.3 Describe the socio-economic impact on the family of the long-term effects of acquired brain injury</p> <p>2.4 Explain the impact on families of personality changes in the individual</p> <p>2.5 Describe changes that may occur in relationships as a result of acquired brain injury</p>
<p>3 Understand legislation that is relevant to carers of an individual affected by acquired brain injury</p>	<p>3.1 Describe legislation and policy specific to carers of an individual affected by acquired brain injury</p> <p>3.2 Explain the key principles within legislation and policy that are applicable to carers of an individual</p> <p>3.3 Outline the obligations on social care organisations as a result of legislation</p>

Learning outcomes	Assessment criteria
<p>4 Be able to assess the support required by families who hold the primary caring role</p>	<p>4.1 Assess, with primary carers, the support they require</p> <p>4.2 Demonstrate that a plan of support has been agreed with the primary carer</p> <p>4.3 Identify support that can best be provided by others</p> <p>4.4 Report, using agreed procedures, where there are unmet needs</p>
<p>5 Be able to work in partnership with other professionals and agencies</p>	<p>5.1 Explain the role of other professionals and agencies working with individuals with acquired brain injury</p> <p>5.2 Work in partnership with other professionals and agencies to support families</p> <p>5.3 Evaluate outcomes for families of partnership working</p>

### What needs to be learned

#### **Learning outcome 1: Understand the impact on families who care for an individual who is in a minimally responsive or vegetative state**

##### **Individual**

- The individual is the person with the acquired brain injury.

##### **Minimally responsive.**

- Definition – the individual is awake and has minimal awareness of their surroundings, e.g. may respond with speech or gestures, may speak some understandable words or phrases; may respond to people, things, other events by crying, smiling or laughing, making sounds, reaching for objects, trying to hold onto objects, keeping their eyes focused on people or objects for a sustained time.

##### **Vegetative state**

- Definition – the individual is awake but does not have awareness of their surroundings.
- Sleep-wake cycle with periods of eyes open and eyes closed.
- Moaning and making other sounds, especially when tight muscles are stretched.
- Crying, smiling or making other facial expressions without apparent cause.
- Briefly moves towards a person or an object.
- Reacts to loud sound with a startle.
- Unable to follow instructions.
- No speech or other forms of communication.
- No purposeful movement.

##### **Primary carers/relationships**

- Spouse/partner.
- Child.
- Parent.
- Sibling.
- Friend.

##### **Theories of loss and grief**

- Elisabeth Kübler-Ross, five stages of grief:
  - denial
  - anger
  - bargaining
  - depression
  - acceptance.

## What needs to be learned

- William Worden, four tasks of mourning:
  - accepting the reality of the loss
  - processing the pain of grief
  - adjusting to the world without the individual as they were
  - finding an enduring connection with the individual.

### **Impact on families and friends**

- Fatigue due to delivery of physical care.
- Depression and loss of hope.
- Loss of social contact.
- Increased risk of illness.
- Physical injury due to having to move/lift individual.
- Anger.
- Frustration.
- Sense of bereavement and loss.

### **Required long-term adjustments**

- Moving house to accommodate the care of the individual.
- Adaptations to current home.
- No longer able to take holidays with the individual.
- Managing more areas of domestic life, e.g. financial aspects.
- Changes to domestic routines to accommodate the individual.

## **Learning outcome 2: Understand the long-term effects of acquired brain injury on family**

### **Emotional aspects**

- Depression.
- Loss of intimacy with partner.
- Loneliness due to loss of companionship.
- Stress from increased responsibilities.
- Feelings of helplessness.

### **Caring for individuals with mild to moderate acquired brain injury**

- Encourage the individual to rest.
- Observe for further symptoms.
- Contact medical help if symptoms worsen.
- Provide a quiet environment.
- Ensure that the individual is not alone for at least 48 hours.
- Do not administer pain relief without medical advice.

### **Caring for individuals with severe acquired brain injury**

- Personal care, including feeding, toileting, dressing.
- Administering medication.
- Assisting with mobility.
- Reduction/cessation of carer's career.
- Loss of intimacy between partners.

## What needs to be learned

- Restricted social life.
- Restricted opportunities for leisure activities.
- Financial restrictions/reliance on state help.

### **Socio-economic effects**

- Loss of work/reduced working hours leading to:
  - moving to cheaper accommodation
  - loss of holidays
  - reduction of leisure activities
  - less opportunities for children in the family.

### **Personality changes**

- Changes, e.g. irritability, disinhibited behaviour, frustration, loss of social skills, lack of self-awareness.

### **Impact of personality changes on family**

- Social isolation.
- Embarrassment.
- Fear due to threat of physical violence.
- Loss of friendships due to offence caused by the individual.
- Children unwilling to bring friends home/experiencing bullying.
- Stress due to unpredictability of individual.

### **Changes in relationships**

- Adults:
  - loss of intimacy between partners
  - loss of companionship
  - moving from partner to carer.
- Children:
  - loss of role model
  - loss of emotional support
  - loss of advisor
  - changes from child to carer.

## What needs to be learned

### Learning outcome 3: Understand legislation that is relevant to carers of an individual affected by acquired brain injury

#### Legislation and policy

- Mental Capacity Act 2005.
- Deprivation of Liberty Safeguards (DoLS).
- Carers (Equal Opportunities) Act 2004.
- Care Act 2014 and statutory guidance published in 2016.

#### Key principles

- Rights of carers to be assessed separately to the individual.
- Carers as partners with professionals and the individual.
- Advocacy.
- Respect.
- Dignity.
- Consideration of cultural and religious factors.

#### Obligations on social care organisations

- Duty to meet the needs of carers.
- Duty to meet the needs of the individual.
- Duty to produce a care and support plan.
- Assessment of the individual's needs.
- Assessment of carers' needs.

## What needs to be learned

### Learning outcome 4: Be able to assess the support required by families who hold the primary caring role

#### Assessment of carers' support needs

- Help with personal care of the individual.
- Financial support.
- Adaptations to home.
- Respite care.
- Carer's own needs due to:
  - medical conditions
  - dealing with additional stress
  - financial issues.

#### Plan of support

- Effects of caring role on life and wellbeing.
- Health, physical, mental and emotional issues.
- Feelings and choices about caring.
- Work, study, training, leisure.
- Relationships, social activities and goals.
- Housing.
- Planning for emergencies, e.g. the Carer Emergency Scheme.

#### Support that can best be provided by others

- Nursing care.
- Respite care.
- Some types of medication delivery, e.g. intramuscular injections.
- Advocacy.

### Learning outcome 5: Be able to work in partnership with other professionals and agencies

#### Other professionals

- May include, carers' organisations, social workers, general practitioners, supervisors, advocates, carers/family members, colleagues.

#### Roles of partnerships and agencies

- Contributing to care and support plans.
- Risk assessment.
- Risk management.
- Holistic, person-centred care.
- Monitoring and supervision of the individual.

#### Aims of partnership care and support

- Involvement of individuals and families in all aspects of planning care and support.
- Promotion of health and wellbeing of individuals and families.
- Integrated care packages with relevant skills mix.
- Risk management.
- Prompt dealing with emergencies through monitoring and supervision.
- Trust.
- Positive relationships.

## Information for tutors

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### Suggested resources

#### Book

Powell T – *The Brain Injury Workbook: Exercises for Cognitive Rehabilitation (Speechmark Practical Therapy Manual)* (Routledge, 2017) ISBN 9780863889783

#### Websites

<a href="http://www.acquiredbraininjury.com/abi_manual/consequences-for-the-family">www.acquiredbraininjury.com/abi_manual/consequences-for-the-family</a>	Support for families living with an individual with acquired brain injury.
<a href="http://www.communitycare.co.uk/2012/07/26/how-social-care-staff-can-improve-their-communication/">www.communitycare.co.uk/2012/07/26/how-social-care-staff-can-improve-their-communication/</a>	Community Care website article on improving communication within care.
<a href="http://www.legislation.gov.uk">www.legislation.gov.uk</a>	Website for current government legislation.

## **Assessment**

This guidance should be read in conjunction with the associated qualification specification for this unit.

This unit is internally assessed. To pass this unit, the evidence that the learner presents for assessment must demonstrate that they have met the required standard specified in the learning outcomes and assessment criteria, and the requirements of the assessment strategy.

To ensure that the assessment tasks and activities enable learners to produce valid, sufficient, authentic and appropriate evidence that meets the assessment criteria, centres should follow the guidance given in *Section 8 Assessment* of the associated qualification specification and meet the requirements from the assessment strategy given below.

Wherever possible, centres should adopt an holistic approach to assessing the units in the qualification. This gives the assessment process greater rigour and minimises repetition, time and the burden of assessment on all parties involved in the process.

### **Unit assessment requirements**

This unit must be assessed in accordance with the assessment strategy (principles) in *Annexe A* of the associated qualification specification.

Assessment decisions for learning outcomes 4 and 5 (competence) must be made based on evidence generated during the learner's normal work activity. Any knowledge evidence integral to these learning outcomes may be generated outside of the work environment, but the final assessment decision must be within the real work environment. Simulation cannot be used as an assessment method for learning outcomes 4 and 5.

Assessment of learning outcomes 1, 2 and 3 (knowledge) may take place in or outside of a real work environment.