Supporting families and managing expectations

Dr. Ben Papps.
Consultant Clinical Neuropsychologist

Regional Hyperacute Rehabilitation Unit
Northwick Park Hospital
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RCP Prolonged Disorders of Consciousness National Clinical Guidelines - 2103

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Family members often experience very severe distress when a relative is in a prolonged vegetative or minimally conscious state (RCP 2013)

Some authors suggest that one-third of the primary caregivers of people with a severe traumatic brain injury:

- Have clinically significant symptoms of mood disorders (e.g. Schonberger et al 2010, Cruzado et al 2013) and
- Can sometimes be described as suffering prolonged grief or a ‘prolonged grief disorder’ (e.g. Elvira de la Morena 2013)
“The academic psychological and medical literature has documented the type of feelings families discuss here. The literature describes such feelings as ‘prolonged grief disorder’ as if it is a psychological problem within the individual. The overlapping accounts family members give here, however, suggest their responses should perhaps not be seen as a ‘disorder’, but as an entirely normal reaction to a very abnormal situation”.

Healthtalk web resource introduced by Professors Celia and Jenny Kitzinger who acknowledge in their publications on the topic that they “are sisters of a patient who was previously in a prolonged disorder of consciousness” (See also Kitzinger & Kitzinger, 2014., Latchem et al 2016)
The emotional challenge for families and others

People who remain unresponsive present a great emotional and social challenge to others, especially to family members.

- They may seem alive (e.g. sleep/wake cycle, movements, noises, react to stimuli)
- But they do not initiate communication or social interaction and may appear unreactive to anything meaningful
- They may also appear to be in pain or distress
The source of the emotional challenge

- Challenges our understanding of people and behaviour
- The family cannot grieve their loss fully and yet they cannot expect a ‘good’ outcome
- They sometimes receive differing explanations and prognosis from various clinical / medical teams involved
- For some, the state of existence for a loved one may be in contradiction to that person’s prior expressed views
Formation of expectations

- Families/loved ones may be informed during the acute phase that the patient is unlikely to survive.
- The patient may then survive ‘against all odds’.
- Supporting a belief that miracles are not only possible but likely.
- The loved one may be seen as a ‘fighter’ with a determination to recover that can overcome physiological obstacles.
- May lead to high expectations and inclination to disbelieve a less optimistic prognosis.
- Often also **genuine uncertainty** about condition and prognosis.
So what practical help can we offer?

Requirement for good communication

Support
- Information
- Practical support
- Inclusion in the care program
- Emotional support
The requirement for good communication

- Free exchange of information and evaluation of progress
  - Joint assessments where appropriate
  - Recording of evidence

- Support and information, close involvement in decisions made in the patient’s best interests
Support: Information

- Explanation of the clinical state
- The prognosis, available treatments, necessary investigations
- Proposed management plan

Identified team members for questions and a recognised route to access them
Support: Practical

Practical support (which involves signposting)

- Assistance with managing finances
- Housing
- Medico-legal issues
- Signposting

- Carers UK (0808 808 7777), Advice Line
- Citizens Advice Bureau
- ‘Turn To Us’ (www.turn2us.org.uk)
Support: Inclusion

- Support families to engage in the care program if they wish:
  - Gentle massage
  - A stretching program
  - Involvement in care tasks as appropriate
  - Aspects of the stimulation program as appropriate
  - Respite aspects: Permission and confidence to leave
Support: Emotional support

1. Communication training when supporting families
   e.g. Active listening (all staff)

2. Psychological support

3. Peer support
1. Communication training for staff working to support families (RHRU ‘Shapes’ model)

[Diagram showing the SHAPES model]

- **Setting**
  - Physical & structure

- **Hold your agenda**

- **Assemble/gather**
  - OFQ > Active Listening > summarising > final check

- **Provide information**
  - Invitation > ‘warning shot’ > small chunks > check understanding

- **Ending (Summary and plan)**

- **CUES & E**

- **EMPATHY**
2. Psychological support

- Offered counselling and support at a stage when they are ready to receive this.
- May not be ready in the early stages.
- The offer should be repeated.
- Should be provided by professionals with understanding of PDOC.
  - Reactions to diagnosis.
  - Nature of diagnosis.
  - Certainties and uncertainties re prognosis.
2. Psychological support for ambiguous loss

- Help the family appreciate the normal consequences of brain injury and recovery
- Help the family appreciate the patient’s injury, consequences and prognosis
- Work hard to identify positive aspects of the situation but maintain a realistic appreciation of the context
- Preserve hope for improvement (hope for the best, prepare for the worst)
2. Psychological support for families

‘Coming to terms’ versus ‘keeping pace with changes’

Tasks for the journey? (Boss 2011)

- Find meaning
- Balance need to control with acceptance
- Broaden identity
- Manage mixed emotions
- Imagine new & realistic hopes and dreams
- Time for self (respite aspects)
3. Peer support

- Facilitated family support
  - Facilitated by staff or experienced family members
  - Create informal opportunities to build contacts
    (facilitated coffee mornings etc)

- Access to peer support, ‘normalisation’
  - Online resources (e.g. HealthTalk internet clips)
<table>
<thead>
<tr>
<th>Definitions (e.g. MCS, VS etc)</th>
<th>Impact on family and friends (e.g. hope grief, mourning and being ‘in limbo’, exhaustion and frustration, impact of visiting, family unity, impact on children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical care (e.g. the injury, Taking in information and imagining outcomes, Treatment decisions in the Intensive Care Unit etc)</td>
<td>Ongoing decisions (e.g. resuscitation and DNR, family experiences of applying to court for treatment withdrawal)</td>
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<tr>
<td>Longer term care (Rehabilitation centres and care homes, caring at home, hospital readmissions etc)</td>
<td>Death and dying (e.g. repeated life-threatening incidents Death and dying Bereavement after severe brain injury)</td>
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</tbody>
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Summary

- Family distress can be significant and there are caveats in terms of the diagnosis of ‘abnormal’ reactions in what is a highly abnormal set of circumstances.

- The challenge is that people in PDOC are alive but unable to communicate or socially interact and may seem in pain or distress.

- Unrealistic expectations can be formed along the rehab pathway.

- Support requirements include good communication, provision of information, practical support for financial aspects, possible inclusion in the program and emotional support (active listening, psychological and peer support).
Resources for families

Healhtalk web resource for families
http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/topics

The Brain Injury Group www.braininjurygroup.co.uk

Compassion in dying
http://www.compassionindying.org.uk/
Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing information and support around their rights and choices. The also provide free Advance Decisions or ‘Advance Directives’. 
References

- Cruzado JA and de la Elvira de la Morena MJ. Coping and distress in caregivers of patients with disorders of consciousness. Brain Injury 2013; 27(7-8): 793–798