

SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY

Organisation: Royal Rehabilitation Centre Sydney
Name: Ms Diane Turner, Social Work Professional Leader
Glenda McAlister, Senior Social Worker
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ROYAL**REHABILITATION CENTRE SYDNEY**

Patron: Her Excellency Professor Marie Bashir AC Governor of NSW

ABN 34 006 025 794

59 Charles Street, Ryde NSW 2112
PO Box 6, Ryde NSW 1680 Australia
Tel 02 9807 1144 Fax 02 9809 6071
www.royalrehab.com.au

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The Director
Standing Committee on Law and Justice
Parliament House
Macquarie Street
Sydney NSW 2000

Dear Sir/Madam,

Subject: Submission to Second Review of Lifetime Care and Support Authority

Thank you for the opportunity to comment on the Lifetime Care and Support Scheme introduced for adults in October 2007. Social Workers at Royal Rehabilitation Centre Sydney work with catastrophically injured individuals and their families, helping them together to adjust to the changes to life roles and relationships secondary to the catastrophic injury.

Supportive and specialist counselling

LTCS appropriately recognises that catastrophic injuries such as traumatic brain and/or spinal injury affect the whole family, not just the person who sustained the injury, by including a resettlement rehabilitation code LTCS403 Counselling/Behaviour Management.

This code allows therapy to proceed related to an individual's capacity to return to pre-injury participation in life, which can be significantly altered, as an example following traumatic brain injury resulting in cognitive deficits and changes. The brain injured individual may display loss of impulse control, challenging behaviours, memory loss, and confusion which changes their functioning in life roles and their previous relationships. While the individual needs to adjust to new parameters, the family members grieve the loss of the person they once knew as the person who remains can be vastly different to the one they were pre-injury.

The following quotes from a letter by a mother of a client with a traumatic brain injury illustrate her experiences. Stresses include the challenge of dealing with her son's personality changes, identity and role changes within the family, carer stress. This mother is also experiencing chronic sorrow, missing the son who was, and unlike paid carers she cannot go home at the end of the shift.

"How could such a tragedy happen to us too? When I recall it now, it was such a dark period! ... I am at a total loss as to what to do ... After the accident my son changed a lot in many ways. The accident has brought him huge physical and psychological injuries. – speech difficulties;

sense of smell and taste; sees things in double images; his appearance, there is an obvious scar on his head; he gets frustrated and angry with me; he became reckless when spending money; he has become short tempered and indifferent to his family. He opposes me on everything. In my mind he has become a stranger and cannot be reasoned with ... The accident basically destroyed his human nature. He is no longer the son I used to have. The things he does have made me despair. The endless sufferings will accompany us for the rest of our lives." ... I hope the time goes fast so that I can leave my son who no longer has human nature ... he brings me nothing but sorrow and pain everyday. In fact, as a mother, I cannot just abandon him."

LTCS interventions (LTCS code 403) are available to assist individuals, their families and significant others work through grief experienced due to changes secondary to catastrophic injury. Such interventions include one to one counselling, relationship and sexuality counselling, support groups for the person with the injury, siblings, spouses, carers. Clients with the support of family and friends/significant others who love them and provide encouragement and acceptance have access to round the clock support. Where family and support networks have broken down the individual can become isolated requiring additional input from paid carers.

Our experience has indicated that support of family and significant others is priceless. This freely given support can assist individuals to remain motivated, to persist in therapy, to try new things, including participation in vocational training and return to work. Such support can therefore maximise a person's capacity to make the transition from being an in-patient following catastrophic injury to accessing and participating in community life. It is therefore important that LTCS Case Co-ordinators interpret 'family and significant others' broadly to include those identified as significant others in LTCS 104 Psychosocial Assessment and give agreement that emotional adjustment therapy may proceed.

Regrettably family breakdown is known to occur more frequently for people post injury and it includes loss of children from the family. Breakdown of any relationship is both costly to the individuals concerned and to the whole community, in financial, emotional and sometimes physical terms. For those who have had catastrophic injuries the effects can have a compounded negative impact. Some people subsequently withdraw and become depressed, requiring professional assistance to return to former life roles and activities, which leads to a greater cost to the individual, LTCS and the community as a whole.

Recommendations:

- **Expand the phrase 'or other approved interventions' to include peer support, carer, spouse and sibling support.'**
- **Train LTCS Case Co-ordinators on impact of traumatic injury on a client's family as a system, and what constitutes sufficient evidence from health professionals to demonstrate 'reasonable and necessary' interventions for family and significant others under the existing LTCS 403 code.**

The above interventions are quite distinct from behaviour management interventions. Social Workers are ideally placed to undertake such counselling interventions due to their holistic approach which takes into account a person's emotional wellbeing and connections with family and friends – their place in society, which all impact on a person's response to injury, and coping /adjustment post injury.

Recommendation:**Break LTCS 403 into 2 codes:**

- 1) Supportive and specialist counselling interventions for participants and their families and significant others where related to injury**
- 2) Behaviour management – devising and implementing programs to manage a participant's behaviour at home and in the community.**

Once again thank you for the opportunity to make a submission to the LTCS review.
Yours faithfully



Diane Turner BSW, MHA, MAASW (Acc) JP
Social Work Professional Leader
Royal Rehabilitation Centre Sydney



Glenda McAlister Dip Soc Wk, MAppSc (Crit Psych), MAASW (Acc)
Senior Social Worker
Brain Injury Community Rehabilitation Team