Executive Summary

Experiences of providing care to people with long term conditions

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The Department of Health commissioned a brief scoping study to amass evidence concerning people with long- term conditions of working age (18-65). The people is the study experienced the following impairments: epilepsy, Multiple Sclerosis (MS), Motor Neurone Disease (MND), Parkinson's disease, brain injury, spinal cord injury, polio and cerebral palsy (the 'target groups'). The study covered in this executive summary aimed to identify literature that contained evidence on carer's experiences of providing care to people within the target groups. The study aimed to provide an overview of the types of evidence that exist on carer's experience of caring for a person with a target long-term condition and negotiating with health and social care services as part of this role. Studies marked * were highly rated.

Findings from the 'sudden onset' group (A) Carers of people with Brain Injury and Spinal Cord Injury

- *In the UK social services for patients are patchy and for carers patchier still. Services for carers are aspirational rather than actual. This may be because they are not seen as a priority area.

- *Carers experience distress about behavioural and social problems and adverse effects on families. Adverse effects on the family after TBI are the sole predictor of carer depression due to the impact on the carer of viewing the effects on other family members. Effective support moderates between adverse effects and depression.

- *The long-term nature of the recovery has implications for the support of carers. Both parties need some control over the situation and some privacy.

- *Neurologists must make use of carer's assessments in compiling their evaluations of treatment.

- *Carer support programmes are beneficial.

- *Carers report grief for the loss of patient's potential and personality and feel that services should provide increased aftercare, meaningful employment opportunities, avoid over-medication and establish systematised patient care.

- *The most important threats to successful family adaptation are the lack of suitable services for the injured person and the person's behavioural and emotional problems. Strengths that contribute to adaptation are within the family, or through friendship or peer support.

- *Partners of mothers with SCI express more life stress than partners of non-disabled mothers and the stress is due to situational circumstances beyond their control (that is, the impairment).
- *Carers with higher negative orientation towards problem-solving may show greater distress and depression and negative orientation in the carers impairs cognitive problem-solving performance
- *Carers who have more cognitive-behavioural resources exhibit fewer emotional difficulties adjusting to the carer role
- *Carer problem-solving abilities predict emotional and physical health of the carer and recipient
- *Caring spouses reported significantly high stress, burnout, anger and resentment and poor well-being
- *Outside help in care-giving will ease the burden only if it is care-giving and not the severity of the injury that causes problems to the carer
- *Anxiety is the best predictor of the variability in the initial levels of physical symptoms reported by carers
- *Younger carers experience more anxiety and low positive affect initially. Depressive behaviour is associated with lower positive affect and this may be due to restricted social contact. The emergence of expressive support is the best predictor of change in depressive anxiety among carers
- *Spouses with limited coping strategies and limited social support have higher depression and care-giving burden, whereas spouses with adequate coping strategies and social support score low on these items
- *Spouses and people with SCI experience the same processes of stress and adjustment. Rehabilitation professionals need to attend to both patient and spouse needs to ensure best therapeutic results

Findings from Group B, 'intermittent/unpredictable' conditions: Carers of people with Epilepsy

- *The patients' aims for epilepsy surgery are to be working; to drive a car; independence/ freedom/ socialisation; relief from medication'; change in behaviour (desired by carers on behalf of patients) and improvements in personal safety

- *Patients report a great need for social relationships and this also holds true for carers (parents in most cases).

- *Carers report a need for more respite services

- *Addressing epilepsy means having interdisciplinary systems between health policy, social policy and social theory

Findings from Group C, ‘progressive’ conditions: Carers of people with Cerebral Palsy, Motor Neurone Disease, Multiple Sclerosis and Parkinson’s Disease

- Carers of people with CP frequently have negative experience of service provision and often feel they are not listened to or valued.

- Bureaucracy and lack of funding may contribute to service users with CP and their families not obtaining full or adequate information

- Fathers and siblings of people with CP may be most affected by having a disabled adolescent in the family.

- *The health status of the patient with MND has a dramatic effect on the health status of the carer.

- *Services and MND charities need to take into account the impact of MND on the carer as well as the patient

- *Services/support provided at the time of diagnosis are important to carers who want more information on what MND is and what benefits and services are available. Carers feel they have to fight for services with the result that many individuals feel they received too little too late

- *Carer anxiety and depression is partly linked to functional incapacity of the patient. Patients and carers differ in how they perceive their own needs, in how they view, judge and evaluate the disease and how they cope with its progress

- *Carers of people with MND want more information about the disease. They feel insecure and feel a great need to talk about the burden of care. Some carers tend not to want to think about the future

- *Carers tend to employ a systematic planning approach in caring for people with MS but some can become overwhelmed and need to withdraw temporarily

- *Nurses need to explore how dependency needs are met and their impact on the family to enable effective information and counselling of the family.

- *There is a strong correlation between the severity of the patient's disability and carer depression anxiety and psychosomatic conditions.

- *Changes in the person with MS (from their former self) cause carers stress. There is a need to change personal plans and deal with financial strain. Difficulties flowing from problems with memory and independence in activities of daily living are predictive of carer strain.

- *Carers of people with PD have raised levels of distress and/or psychological disturbance although there is no link between distress and social support. Services to support the effective treatment of depression in people with PD would have a beneficial effect on carers.

- *In addition to daily living activities, carers often participate in professional/therapeutic activities. However, some carers reported that for practical or emotional reasons they did not want to be involved in these aspects of caring, furthermore some people with PD did not want carer involvement in this area.

- *Stress in carers appears to be connected to aspects of caring related to intrapersonal factors such as anxiety. Professionals need to be aware of the stress factors for carers and plan services accordingly. Assessing stress and well-being of carers should be a priority for health care providers to identify and provide services for people at risk.

- *Carers' well-being tends to be higher that that of people with PD, carer burden is linked with the severity of PD and perceived patient control over symptoms is associated with carer well-being and less carer burden. Therefore, helping the patient and family in managing symptoms will enhance perceived control and is an important aspect of quality of care which may enhance carer and patient well-being.

- *The identification and treatment of mental disturbances is of major importance for the patient with PD and carer and may enable people to be cared for in their own homes longer.

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