CASE STORY - Social Work

The following case story by Sue Sinclair, social worker, demonstrates a community Social Work perspective for MND patients. This case study was drawn from a compilation of several clients to ensure confidentiality.

In 2014 the Chronic Disease Brisbane South Team in collaboration with the Princess Alexandra Hospital (PAH) Respiratory and Neurology Services developed a Model of Care to provide community-based services for clients diagnosed with Motor Neurone Disease (MND). The service aims to offer clients continuity of care across acute and community settings and a timely response to changes in their condition and needs.

The health professionals involved in delivering the MND Model of Care include an occupational therapist, psychologist, dietician, physiotherapist, social worker and respiratory specialist nurses (Clinical Nurse Consultant and Clinical Nurse).

This multidisciplinary team meets monthly, conducts formal and informal case conferences and maintains a high level of communication, innovation and professionalism. This team works closely with the MND Association of Queensland (MNDAQ) and Mater at Home and the speech pathologist from Mater at Home (home visiting service associated with Mater Hospital). Specific roles have been developed with nursing team members acting as case managers and all disciplines having specific roles within the model of care.

*This case story does not represent any real person/s but identifies many issues that have arisen in my social work practice with clients with MND.*

Alex, aged 48 years, was diagnosed with MND - bulbar onset Amyotrophic Lateral Sclerosis (ALS). For some months prior to diagnosis, he had experienced symptoms including muscle weakness, falls and co-ordination difficulties, slurred speech, and unexplained weight loss. His diagnosis was made at the PAH Neurology Clinic and the case manager referred to the occupational therapist, dietician and social worker (SW); the latter being for assistance with application for the Disability Support Pension (DSP) and carer support issues.

Margaret, Alex’s wife, was engaged in home duties. They had a 22 year old daughter and a 19 year old son both living independently. Four months prior to referral Alex had ceased work as a self-employed delivery driver and they were living on their savings which were dwindling fast. The initial SW intervention included supporting Alex in seeking the DSP and Margaret with a Carer Benefit and Allowance. These applications were not straight forward as Alex had not lodged a taxation return for some years.
Alex and Margaret were appreciative of the services provided by the team members but expressed a lack of understanding about the roles of each professional. Clients often report difficulty in retaining the large amount of information associated with the condition, services, equipment, providers and advance care planning. [1]

Alex was fitted with a gastrostomy tube to address swallowing difficulties and weight loss. The dietitian recommended a range of enteral feeds. Due to the high cost of enteral feeding and subsequent impacts on already strained finances, SW provided a financial hardship assessment and advocacy to their local health service who agreed to a subsidised price.

Family and friends began to visit regularly when advised of Alex’s condition. This social support was welcomed but contributed additional costs as visitors often stayed for meals adding to carer worry and financial strain. [2] SW provided information on local Emergency Relief (ER) agencies where food was available free or at subsidised rates. Advocacy for ER financial support was also made for utility costs and for later funeral costs. Gardiner [2] noted considerable costs to family caregivers involved in end of life care.

Awareness of limited finances and endeavours to ensure ‘some control and normality within the home’, [1] resulted in Margaret and Alex declining services until near the end of Alex’s life, when they agreed to some personal care.

Clients usually need services initially for daily functioning and carers need support for emotional issues related to MND. [3] SW provided strengths-based supportive counselling with some problem solving, relaxation and mindfulness for Margaret in her carer role with grief counselling being a key component of the work. Alex was supported by MNDAQ Regional Advisor. SW facilitated a family meeting to foster their understanding of Alex’s condition and explore available assistance from the immediate family. Multiple referrals and advocacy were key elements in this work.

About 8 months following diagnosis Alex was admitted to Palliative Care where he died with family around him.

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References

