MS Case Summary: CCNE Region NSW

SW is a 37yr old woman, married with 2 children aged 5 & 12 years of age currently She is Australian born, with Italian maternal heritage and is one of 5 children, one other of whom also has MS. Her mother provides care for her maternal grandmother.

She was diagnosed in 1994 after a major exacerbation, following the birth of her first child, and recovered well after a period of being confined to a wheelchair.

Another major exacerbation followed the birth of her second child, however she did not recover and has now moved into secondary progressive MS.

SW has significant disability with no lower limb function & weakness in upper limbs and trunk thus is unable to walk or transfer, has severe widespread spasm, is incontinent of urine requiring a suprapubic catheter, experiences constipation, swallowing difficulties, vision impairment, low body weight, and has some cognitive impairment when stressed.

SW and her children were cared for by her husband. Referrals has been made to a range of services, however the carer & SW did not wish to use those offered. Financially they were totally dependent on the Disability Support Benefit and the Carer's Payment, and were waiting on suitable housing with the Department of Housing. In 2005 the relationship became dysfunctional and SW's husband and the 2 children moved out of the home.

As SW was in crisis she was provided with respite at the Studdy MS Society Accommodation Unit. Considerable support was provided by both the accommodation unit staff and the Lifestyle Services Team with assessments by Occupational Therapists, Physiotherapists, Psychologists, Neuropsychologists, Urologists and Continence Advisers.

Planning for the long term future and identifying suitable strategies for this young woman were then addressed. She did not wish to be accommodated in a nursing home, however her level of disability made any other supported accommodation option unworkable. It was decided that an attempt would be made to set her up at home, even though in her own words she was "terrified" of living alone, both because of her disability level & because she had never previously done so.

As SW's ability to manage alone was still in question, a trial setup was developed. The fall back position was admission to hospital by the local GP. The services and equipment have been refined over the past 12 months, and happily the outcome has been very positive, with SW very settled in her new lifestyle.

There were 4 major barriers to overcome initially. For SW to return home, services & equipment needed to be organised. Case management was required, however no service was prepared to assess for case management until SW was relocated back in her home and 2 services were already in place. Secondly a large amount of equipment was required to provide safe care and was not quickly available through the government funded services, thirdly the extensive amount of care provision was not readily available and finally SW has to go be in bed from 7pm to 7am, is unable to move independently and has no one else in the house.

There were, however, a couple of major strengths that made the plan seem achievable. SW is a brave and determined young woman with a strong Christian faith, and she was extremely well supported emotionally and practically by her local church congregation

Area of need	**Initial Provider**	**Current provider if different**
Affordable housing	Private rental (not affordable)	DOH financial assistance Waiting on modified house
Home modifications & initial set up	Volunteers Congregation MSS	
Heating	MSS Branch funding Heaters & electricity	Attendant care funding for air conditioner
Lighting (accessible)	MSS Branch funding	
Safety door lock	MSS Branch funding	
Emergency alarm	MSS Branch funding Congregation available for emergency assistance	Self funded
Accessible Telephone	MSS	Telstra
Meals	Meals on Wheels	Family, friends
Transport	Southlakes Carers Disabled Taxi	Congregation Disabled Taxi
Emotional & Spiritual	Congregation Family	
Access to children (child care)	Congregation	
Banking	Family	
Health care	GP Neurologist Pharmacy deliver CHC Pathology deliver	
Shopping	Southlakes Carers	Dolleina Pty Ltd
Respite	Studdy MS Centre	
Service provision: Personal care Housework Meals / fluids Medications Exercise Bladder / bowel	7am 1pm 6pm Funded by Life Activities as a trial for 12 weeks while waiting on possible Attendant Care or Home Care approval, service by Dolleina Pty Ltd	7am 1pm 6pm Now funded by Attendant Care Program with service by Dolleina Pty Ltd

Area of need	Initial Provider	Current provider if different
Equipment		
Electric bed	MSS	
Pressure mattress	Hunter NE Health	
Electric hoist	MSS	
Electric wheelchair	MSS	waiting on PADP
Manual wheelchair	Hunter NE Health	
Shower chair	Hunter NE Health	
Pressure cushion	Hunter NE Health	
Camel pack for fluids	MS Branch	
Heaters	MS Branch	
Lights	MS Branch	
Delivery	MS Branch	

Summary

A very successful example of team work including the person with MS, the MS Society and much more broadly community services, volunteers and personal support networks.

In terms of how this situation could be better managed, there needs to be easy access to immediate case management, equipment and personal care services with the flexibility to work within the parameters of the client need rather than service rules. While there have been significant improvement in service provision over the past few years, there remain significant constraints in actually meeting the real needs of people with disabilities.

My comments:

A large amount of resources appear to have been spent developing a myriad of services each with their own management teams, processes and administrative equipment. This system appears to enable each organisation to identify what they will and will not do with little regard to who will do what is needed. Funds have also been expended to develop a universal assessment process which doesn't suit any organisation, and a centralised service that will never be able to keep up with the changes in so many services in local areas. A new approach to the structure and coordination of community and health services seems long overdue.

Ros Chapman
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