

## **Continuing Care Health Services & Accommodation Standards Summer 2005**

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### **Introduction:**

The MS Society of Canada is committed to supporting individuals who are in the continuing care health services spectrum. The Outreach Coordinator is responsible for visiting clients who live in supported living including long-term care facilities and personal care homes. The MS Society provides a friendly visiting program, education, advocacy and support counseling to persons affected by MS including the client and their support system. It is through this contact that we have come to understand the complex needs of clients and residents.

In Alberta, MS affects about one of every 350 people. This is one of the highest rates in the world and nearly twice the rate of MS in central Canada. The Calgary MS Clinic has nearly 5,000 registered patients, one of the largest single-center clinics in the world. A similar number of people are patients in Edmonton through a fragmented service delivery system. MS is a disease of the central nervous system, which includes the brain and spinal cord. In MS the disease attacks the protective myelin covering causing inflammation and often destroying the myelin in patches. When this happens, the natural flow of nerve impulses along nerve fibres is interrupted or distorted. The result is a wide variety of symptoms including vision disturbance, severe fatigue, balance and coordination problems, spasticity, weakness, altered sensations, heat sensitivity, difficulties with speech and swallowing, bladder and bowel problems, sexual dysfunction, short term memory loss and cognitive problems and paralysis. MS is diagnosed between the ages 15 and 40 with the average age being 28. Because MS is diagnosed when individuals are in the prime of their life, they can experience many losses including loss of income. Since this is a young person's disease many individuals have not had the opportunity to develop retirement or savings plans, which leaves these individuals economically vulnerable. Additionally many individuals have not had the opportunity to start a family and develop a support system.

In Calgary for example, there are more than 120 individuals living in long-term care facilities and more than 20 living in personal care homes. The number of individuals living in institutional settings throughout the rest of Alberta is unknown. The majority of these individuals are between the ages of 18-64 yet they live with seniors who in some case are more than 40 years their senior. Because MS is an unpredictable progressive disease the needs of individuals are complex and can change over a short period of time. It is vital that these individuals receive therapeutic services such as physiotherapy, occupational therapy, recreation therapy and social work.

The MS Society is committed to working with the Government, the staff at the facilities and the Regional Health Authorities to ensure that identified unmet care needs can be addressed. We respectfully submit this document on behalf of the Alberta Division and Chapters throughout the Province as our response to the draft standards. Please do not hesitate to call with any questions or concerns.

## **Part One: Draft Standards for Continuing Care Health Services**

### **1. Albertans have timely access to continuing care health services based on assessed unmet needs.**

The MS Society supports province wide implementation of a single point of entry into the continuing care system however that is only one measure that will promote access to continuing care health services based on unmet needs.

#### Home Care Access:

- There is a lack of transparency with Home Care and how “appropriate settings for delivery of health services” is determined. What are the guidelines for determining when a community setting is not appropriate for health service delivery? How is it determined that the provision of services in these environments be denied? The MS Society receives many reports from clients who have been told by Home Care that their needs are exceeding what Home Care can provide. The ONLY alternative that is ever explored is personal care homes or long term care facilities. What choice do individuals have when Home Care will not provide necessary care in the community but to leave the family home and move into facilities that are institutional and mainly comprised of seniors?
- There are a lot of inconsistencies throughout the Health Regions with how much home care individuals are able to receive. It appears that there are Home Care coordinators who advocate on behalf of their clients and others who are quick to advise families that the individual must move into a personal care home or long term care facilities. It is critical that Home Care communicate the services that individuals qualify for and be able to provide documentation that outlines what the Home Care is responsible for. It is equally critical that Home Care provides clear explanations when they are no longer able to provide care in the community as well as a report of the options that were explored 1.2 (b).
- Individuals with MS often find themselves living in long-term care facilities because Home Care is unable to address their care needs in the community. The needs of a young chronically and progressively disabled population are not being addressed in the current system. The MS Society encourages the government to review the maximum dollar allotment (the amount has not been reviewed since 1991) provided to each individual receiving continuing care health services, specifically home care in the community. If care dollars were unbundled from Home Care, individuals would truly be allowed to choose their preferred setting

which for many would be to stay at home with their family. The cost to the system is in fact less if individuals remain in the community compared to moving in to personal care homes and long term care facilities.

#### Wait lists 1.1 (e):

- Individuals who are waiting to be placed in continuing care require a thorough explanation of the process. Currently there are individuals who are on waitlists for personal care homes and long term care facilities that do not have any clue as to what is happening. Many have been told that there is a first bed policy, which requires the individual to accept the first placement that becomes available. This means that individuals have no choice in choosing their preferred setting (Standard 1.2). The MS Society has received numerous reports from persons with MS who feel they have faced negative consequences when they have turned down the first bed that was available. The consequences have ranged from being told that are going to be taken off of the list for placement or that they are being dropped to the bottom of a long list. In reviewing some of the cases it was completely understandable why some individuals did not want to take the first placement as the home or facility was completely inappropriate. It should be noted that individuals have taken the first placement with the belief that it is short-term, only to be encouraged by Transition Services to reconsider because of the long wait list. The current system is punitive and provides limited if any choice for individuals who are already facing so many losses.
- The MS Society recommends education and sensitivity training for staff involved in the continuing care spectrum to better understand the disease and broaden the range of quality of life options. To provide satisfactory continuing care services the system needs to be more sensitive and empathetic to individuals who are facing significant losses which may include declining health, family break up, financial stress and loss of independence.

#### Long Term Care Facilities

- Residents and family members must receive consistent and factual information about their care and supported living options, and this must happen prior to admission into a facility. Recently two individuals moved into a facility that was providing physiotherapy but within months of moving in the service was cut and no longer available. The decision for these two individuals to choose that particular facility was based on the fact that physiotherapy was offered on site. A different decision would have been made if all of the facts had been shared with them upfront. Some residents with MS may not be able to access physiotherapy in the community due to such reasons as limited financial resources, personal care needs that can not be met in the community without assistance from an attendant and a lack of reliable transportation.

## **2. Albertans requiring continuing care health services should receive services based on their individual needs, with opportunities to participate in their care.**

The MS Society supports the concept of developing care plans to ensure that the services are responsive to individual needs. We support that the care plan include goals, expected results and time lines. The MS Society however is concerned that the staff who will be developing the care plans will be working within a senior's framework, which is inappropriate for young adults with progressive disability.

- It is critical that the care planner, client and family member have all the necessary information to make informed decisions. There are agencies in the community including the MS Society who would be more than willing to provide assistance with education opportunities.

For example: The majority of individuals diagnosed with MS experience heat intolerance, which can cause the disease to mimic an acute attack. If the care planner does not have this knowledge they will not understand the need for individuals to have access to air conditioning. We have had to advocate on behalf of several clients whose health was compromised because they were living in a facility that was too warm.

- It is also imperative that other factors be considered including the age of the person receiving the service, the type of disability (chronic, progressive, stable, episodic,) the anticipated length of time that they will be using the service and their quality of life opportunities. All of these factors must be integrated into the care plan to respect individual needs.

For example: Individuals with MS experience significant fatigue, in fact it can be the most disabling symptom and it is also the most misunderstood. In personal care homes and long term care facilities individuals have to wait to have a nap based on a schedule that is not reflective of their specific needs. The MS Society was visiting a woman who lived in a long-term care facility and she begged us to assist her with getting into bed so that she could rest. The nursing staff was notified of this woman's request and we were told "she knows better, she does not get a nap on Wednesdays, only Tuesdays and Thursdays". Thankfully the client's husband arrived and he lifted her into bed so that she could rest. The MS Society advocated on behalf of the client in an attempt to change the "nap schedule" but had limited success, as individual needs are not a priority in large care centres.

- Another concern that we have is that necessary services will be omitted from the care plan due to funding restrictions. The concern is that vital services such as physiotherapy, occupational therapy, recreation therapy and social work will not be included in the care plan of young people who desperately require rehabilitative services. An individual can achieve all of the goals outlined in a care plan but if the plan did not include the fundamental services needed to enhance the individual's quality of life the result will be a false positive. One

fundamental service that is almost always overlooked because of funding constraints is the opportunity to provide environmental control systems, which can offer so much more independence. By way of case illustration, a resident outside of Edmonton can't answer the phone on his own, use his home computer or change the channel on his television without assistance which wouldn't be necessary if he had an environmental control system that he could operate. Without it, this gentleman remains lonely, depressed and dependent.

- One of the biggest barriers to achieving a flexible responsive continuing care health service is funding. Additionally the red tape and the attitude of "we have always done it this way", only contributes to the belief that one-size fits all. Without proper funding the facilities are working with bare minimum staff, that are burned out and feeling overwhelmed.

### **3. Albertans with complex, multiple chronic health conditions, require integrated and interdisciplinary health care services.**

The MS Society supports the concept of integrated and interdisciplinary health services but feels that the system needs to be evaluated and properly funded to address unmet needs. There have been so many cuts to essential services that there will need to be an injection of money to bring the system back to the appropriate level of service. The MS Society had been told that facilities receive funding based on providing service to medically stable but fragile seniors, which does not allow for the diverse needs of young adults with progressive conditions such as MS.

- Standard 1.17 advises that the purpose of the therapeutic service is to assist residents or clients in achieving a maximum level of independence. The MS Society strongly agrees with this statement and supports the implementation of this section of the standards.
- Standard 1.17 (b) identifies optional therapeutic services, which include respiratory therapy, speech language pathology, audiology, kinesiology, volunteer coordination and counseling. The MS Society recommends that counseling services not be an optional service as it is critical that individuals have access to psychosocial support particularly at this time in their life.
- There are many facilities that have eliminated physiotherapy and recreation therapy services despite protests from residents, family members and community advocates. Residents have identified that they don't feel heard by the administration and feel threatened when they make too much of a commotion about the cuts. Recreation and social opportunities are essential services that can have a positive impact on an individual's physical and mental health. It is important to note that the activities must be age appropriate, meaningful and socially-valued so that it enriches their life rather than just providing an activity to kill time.

Example: There is a facility in Calgary that has eliminated all of the recreation therapy positions and replaced them with activity coordinators who are responsible for 150-200 residents. The coordinator attempts to address the social and recreational needs of a huge diverse population by providing group options.

The MS Society has been approached to provide social and recreation programming in care facilities, which is not possible with our limited resources.

- The MS Society receives calls from staff at facilities that are looking for information as to how they can reduce the time spent on care. The most recent example being a facility phoning to inquire if a resident should be switched to a liquid diet because feeding her was taking the nursing staff too long. A liquid diet should be considered when the individual has a medical need for the change, not because someone does not feel that they have time to sit a feed a person! In this particular case a liquid diet would be extremely inappropriate. Following the call we decided to visit the individual and found that she was still in bed at 11:30 am and had not been fed breakfast and was very hungry. Again, if the facilities do not have adequate funding it will be challenging to meet the goals of the care plan.

#### **4. Albertans requiring continuing care health services receive quality services from highly skilled professional and non-regulated care providers.**

The MS Society stresses that appropriate health care professionals must be available to individuals accessing continuing care services. Currently the staffing levels are inadequate at most facilities and in the community, and the standards are not being evenly upheld by the Regional Health Authorities across the Province. Without appropriate funding and regulations the issue of inadequate care will continue to challenge the system and present difficulties in achieving the outcomes identified in the standards.

#### **Part Two: Creating a Culture for System Quality Improvement and Quality Assurance Standards of Practice**

**Albertans are assured that continuing care services are of the highest quality and that opportunities are taken to continually improve the quality of service provided and the quality of life of the resident.**

The draft standards are a start to supporting quality health services. The MS Society of Canada requests that the government review services to identify gaps in service for young adults (18-64) who rely on the continuing care services spectrum. As previously mentioned the needs of a young population with progressive disability can look quite different from that of a medically stable but fragile senior.

The MS Society encourages the government to think creatively about how services can be delivered to a young population. For example: Expand funding for community Home Care, which will enable families to remain together. With the appropriate supports an individual with a disability could self direct how they receive care, allowing them the opportunity to remain an active participant in their life and in the community regardless of where they live in Alberta?

**Albertans are assured that the quality of health services are being monitored and changed, as necessary.**

The MS Society supports the draft processes for improving the monitoring and reporting on quality indicators as long as it does not take time away from the service providing client care.

**Other issues that are not adequately addressed by the new draft standards.**

The MS Society is concerned with the current abuse protocols. The current system does little to protect the individual when they are in the process of filing the complaint. It has been our experience that individuals are terrified to “rock the boat” and are willing to put up with abuse for fear of retribution. It is important to note that the individuals who are using continuing care health services are society’s most vulnerable population and are typically not in a position to advocate on their own behalf. The MS Society would recommend that the Alberta Government look to other leaders in this area for advice on how to ensure that there is a framework in place that protects the victims. We recommend reviewing framework of the Disabled Persons Protection Commission. (<http://www.mass.gov/dppc/>)

**Part Three: Proposed Accommodation Standards**

**Accommodations standards will promote the safety, security and quality of life for Albertans in supportive living and long-term care facilities.**

Please see attached information.