

PARKINSON SOCIETY OF SOUTHERN ALBERTA  
HEALTH PARTNERSHIP  
CLIENT CONSULTATIONS  
SUMMARY REPORT

In 2008, Parkinson Society of Southern Alberta was the recipient of a grant to create a seamless service delivery model which would see our organization work closely with health care providers, neurological disease specialists, and Alberta Health Services.

We applied for this grant as a result of our members sharing with us various concerns they were having with accessing services, acquiring information and getting support in the broader community. We also felt that PSSA could play a pivotal role in creating change for our members.

The first step we needed to accomplish was to determine what gaps existed for our members. We had informal statements of the challenges but in order to move forward we needed to have a comprehensive account of what it was like to live with PD in the communities of Central and Southern Alberta.

We had our first meeting in Calgary in October 2008. It was a rich and productive meeting which validated what we had guessed were some of the issues. We followed this meeting with another in Lethbridge on March 6<sup>th</sup>, 2009, Red Deer became our third consultation on March 18<sup>th</sup> and our last in Medicine Hat on March 24<sup>th</sup>. In total 222 people who are directly affected by Parkinson's were present to share what living with Parkinson's in their communities is like.

We began our conversations with a look at the positives. What was working well in terms of managing PD? We were able to gather that there were some good resources available. This portion of the day had an unintended positive effect in that people left the discussions with the names of resources they had never heard about before.

Our second conversation looked at the gaps and barriers. The participants were able to clearly identify ways in which they had struggled. It was interesting to note that certain resources that were identified in the working well portion had gaps that could be improved upon. This was a candid, constructive dialogue that will prove to be invaluable to everyone as we are all interested in filling those gaps and creating a seamless delivery of service that meets the needs of our members.

The third step consisted of three conversations designed to arrive at recommendations for action. A list of 49 recommendations was created. Those recommendations will be incorporated into PSSA's strategic plan which will formalize the process of getting them accomplished and ensure that our stakeholders determine what should be our focus.

#### Building on Success – What is Working Well?

It became apparent that family systems play an extremely important part in the successful management of PD. This message came out very strong which leads us to acknowledge that supporting the family unit also supports people living with PD.

Another key point from these discussions emphasized that listening, empathy, respect, humour and care were important for things to go well.

Up to date knowledge and information with quick response times were also key features of successful programs and services.

Clearly the role of the neurologists and nurses at the Movement Disorders Program is the primary source of expertise and guidance for people and family members. Unfortunately, it is a heavily taxed system which requires support from other resources like PSSA in order to meet the needs of people.

Allied health professionals including speech, occupational and physical therapy is a highly regarded area that for the most part remains a hidden resource for people. For many reasons this highly underutilized expertise is not readily available by the person living with PD. Lack of health funds is the primary reason this service is not available to people with chronic conditions.

Another highly valued resource is pharmacists for their guidance and expertise to assist individuals with medication questions and side affects.

Information and resources including social support is an area that requires further development and exploration. The outcome needs address issues relating to home support, long term care, therapeutic and community support with an emphasis on up to date information/resources on dealing with the different stages of PD. Assisting people through these stages of living well with PD requires an approach that links medical, allied health and support organizations like PSSA to collaborate to better utilize human resources in an efficient and affective manner. The care industry should be well connected so that people can access information and resources accordingly.

Individuals reflected on the need to better define other resources that should be connected with PD including quality of life issues through education and support. It is an important part of developing a plan to live well with PD knowing that support systems are in place that are fair and equitable.

Below is information on the themes compiled from central and southern Alberta. These items will be the starting point of defining the need to integrate a systemic model for people to have access to services regardless of where they live in our province. Working with experts at the movement disorders programs in Edmonton and Calgary we can build the foundation to work together to share resources and services that will assist a person to live well with PD.

Theme	Feed back
The Movement Disorder Program	Respectful staff, willing to help, give enough time Access to neurologists (wait times) Distance from rural communities
Home Care	Home assessments and the availability of care is valued

Theme	Feed Back
Health Care	<p>Few Family Doctors who are knowledgeable about Parkinson's</p> <p>Pharmacists who are knowledgeable about Parkinson's.</p> <p>Need more emphasis and personnel for speech, physio, exercise</p> <p>Lack of knowledge of doctors and care providers</p> <p>Case manager</p> <p>Multi disciplinary PD Clinic</p> <p>Preventative medicine</p> <p>Educate doctors in issues specific to PD</p>
PSSA	<p>Support Groups</p> <p>Supportive Counselling</p> <p>A focus on young onset employment issues (advocacy)</p> <p>PD Helpline</p>
Lifestyle	<p>Across all regions the role played by family and caregivers was recognized.</p> <p>Cultivating a positive attitude with humour</p> <p>Exercise was also promoted in every region.</p>
Community Supports	<p>Alberta Aids to Daily Living</p> <p>Access to resources</p> <p>Government support (tax deductions)</p> <p>Accessibility for transportation</p> <p>Patient advocate – have someone to go to the doctor with you</p> <p>PSSA as a central point of contact for all resources and services</p> <p>Quality of homecare workers</p> <p>Funding for trips, meds, programs, ADL, alternative treatments</p> <p>Not enough access to special programs</p>
Resources	<p>Internet</p> <p>Assistance programs</p>
Medication	<p>Medications working effectively</p> <p>Improved drug coordination and analysis</p> <p>Drug Interactions</p> <p>Not enough information regarding meds</p>
Research	<p>Learning of the results</p> <p>Find a cure of research</p>
Awareness	<p>Limited awareness of the general public</p> <p>Improved awareness to government, medical professionals and public in general</p>
Long Term Care	<p>Getting help on time in care centres</p>

	Separation of spouses when PWP moves into a facility
Caregivers	Not enough support for caregivers The need for more respite or home support (nights) Respite
Information	Not enough education on PD, care, medications Not enough clear direction at beginning of diagnosis throughout the advance of the disease Motivational videos of role models
Exercise	Exercise programs for fellow sufferers Research what exercises help most with PD What can technology do, specific to PD eg. Wii Organized exercise programs for PLWP
Funding	Lack of funding for medical services related to PD (physio, massages, medicines not covered) Money for programs and services Money for research

### Summary of Progress

Home care – The importance of home care was stressed during the working well phase and in the Gaps. It was identified that the quality of homecare workers be improved upon. Neera Garga, physiotherapist for PSSA will be providing an inservice to Home Care in order to improve the visibility of PSSA as a resource and also open the door for more training of their care staff.

Helpline – As of June 2009 PSSA and the Movement Disorders Program launched the Helpline which is a toll free, free, confidential and simple way for individuals and families to get the help they need to manage Parkinson’s and Parkinson’s Plus. The aim of the Helpline is to position PSSA as a central point of contact for all resources and services which will simplify the navigation of health care for people living with these conditions.

The Director of Fund Development at PSSA is working on the Champion’s program in the hopes of securing funds to support our caregivers.

In 2009, PSSA Lethbridge partnered with the YWCA and the MS Society in order to provide exercise classes that are better suited to individuals with chronic conditions.

PSSA and the Movement Disorders Program are also working with the Calgary region’s Living Well program to deliver three education classes for People Living with Parkinson’s in the fall. The three classes are Parkinson’s Medications, Parkinson’s Balance and Mobility and Parkinson’s Social Interaction, Memory and

Concentration. These are all designed for people living with Parkinson's. Neera Garga will be providing an orientation to Parkinson's for all Living Well staff.

Neera Garga has provided training to fitness providers at the University of Calgary and the City of Calgary as well as the YWCA in Lethbridge.

A Health Partnership Advisory Committee has been formed with the intent of monitoring the progress of these initiatives and the strategies put into place to address the gaps, building on what is working and fulfil the initiatives requested in the important points.