

Abstract

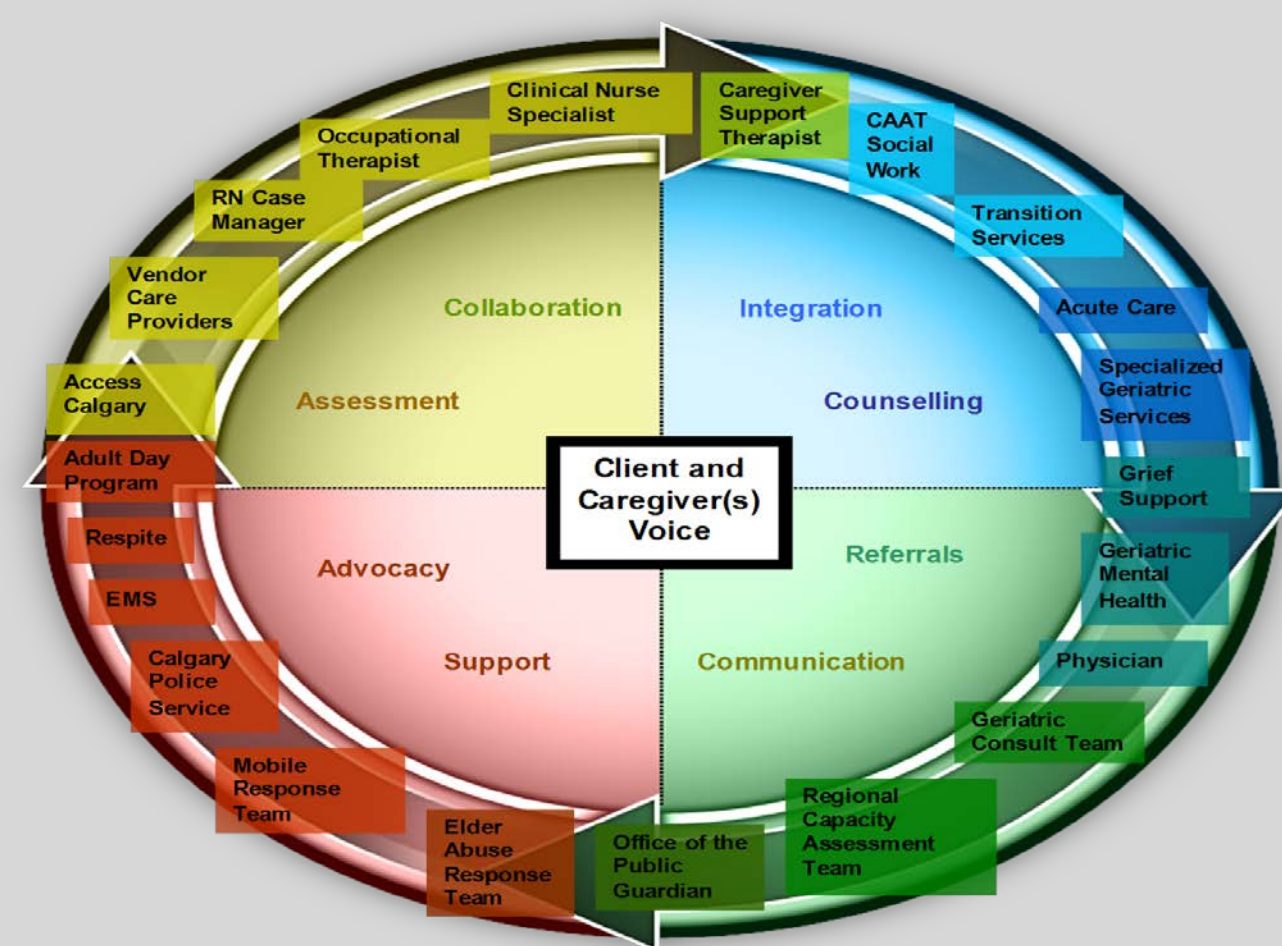
As part of the evolution of the Calgary Zone Home Care Dementia Care Team three Caregiver Support Therapists were hired and the development of a brand new program within the Calgary Zone Home Care Program began. One of the primary goals of the Dementia Care Team is to support clients living with dementia at home to enable them to remain living in their homes safely. We acknowledge that in many cases this would not be possible without the client's families and/or their informal caregivers who play a key role in supporting these clients. Recognizing that the families and/or informal caregivers often suffer their own negative consequences that impact their ability to continue in this caregiving role, these three Caregiver Support Therapists were hired to support them through structured, in-home counselling sessions. This team has received a lot of positive feedback and is already showing positive results in reducing visits to emergency departments due to caregiver burden. This presentation or poster presentation will take the form of presenting various case studies: through storytelling we will outline our challenges and our wins as our journey of supporting these caregivers who are supporting their loved ones has unfolded.

Why a Caregiver Support Therapy team ? By Lesley Sutton

As the population ages; life expectancy increases; the anticipated dementia tsunami arrives; and rapid hospital discharges continue family caregivers are increasingly required to perform complex care duties for extended periods of time. The development of the Caregiver Support Therapy Team was loosely modeled on the work of Dr. Mary Mittelman who designed a counselling support intervention model to determine the effectiveness of supporting primary caregivers who are caring for family members with dementia (Mittelman, Haley, Clay, and Roth, 2006). The Caregiver Support Team's main objective was to reduce unnecessary hospitalization of the client living with dementia by supporting the caregiver through counselling interventions. In developing this team we deviated from the model but did recognize that relatively little attention had been paid to the informal caregiver within the Calgary Zone Home Care Program. We believed that caregivers should be considered 'clients' in their own right: not only because of confidentiality issues that may arise, but also we found it necessary to perform a comprehensive assessment of the caregiver's physical and mental health. Our 'caregiver/clients' are the primary caregiver for the client living with dementia. We began by developing an assessment tool adapted from the California Resource Centers Uniform Assessment (2003). We selected five key parameters: safety of the caregiver and client, social support, health, self-care, and emotional wellbeing. We were interested in a multifaceted assessment tool that would provide a fundamental baseline of the caregiver's wellbeing. We also explored the idea of having the caregivers attend sessions together but found that there would be many social barriers to this concept such as, age of the caregiver, transportation, inability to leave the client alone, and work. Consequently, the counselling has been provided to the caregiver at their convenience either in the home, or in a nearby coffee shop.

The purpose of the team was to provide an intervention for the dementia caregiver by attempting to influence the stress process through enhancement of social support, teaching skills for caregiver tasks, or helping the caregivers to manage negative emotions. Teri (1994) demonstrated that the care of an older relative with both dementia and depression is associated with high levels of burden caused by the relative's emotional, cognitive and behavioural problems. He stated that 10% of the caregivers met the criteria for a major depressive disorder and 62 % met the criteria for minor depression (in Schulz and Martire, 2004, p.242). Essentially the clinical issues we have been presented with are: suicide and homicide assessments; abuse/safety concerns including physical, emotional, financial and sexual; and addiction issues often impacting the care situation. We have also been involved in significant work around grief, loss and transition. We have intervened when there are poor relationships between the caregiver and client with dementia which negatively affects the care outcome. The caregiver's personal health was also a significant factor in the caregiver's ability to cope, and as Schulz and Martire (2004) and Mittelman et al. (2006) have suggested, often resulted in earlier placement of the client. Finally, another factor that needs to be considered is Calgary, like many cities, has seen a significant demographic shift in the past fifteen years resulting in a culturally diverse population. Connell, Janevic, and Gallant, (2001) observed that there needs to be cultural appropriate caregiver supports for traditionally underserved groups. Some of challenges that we have observed serving this group have been that the primary caregivers are not always the decision makers. We have been faced with multigenerational households with differing opinions about the care and also found that the stigma and embarrassment about this disease has often resulted in family's reluctance to even admit there is problem. As a dynamic team we continue to learn and adapt this program. Our experience clearly replicates and confirms what many researchers have observed.

Dementia Care Team background



The goal of the Calgary Zone Home Care Program, Dementia Care Team is to provide focused and comprehensive support that will allow clients with dementia and/or cognitive impairment to safely remain in their own home as long as possible without negative consequences to the informal caregiver and/or the health system.

Principles/Assumptions:

- There are opportunities to support individuals with dementia and their caregivers in the community to maximize their capability and allow them to safely remain in their own home and community for as long as possible.
- Delaying the need for institutionalization results in cost savings for the health system and can be achieved without negatively impacting the individual with dementia and/or their caregiver.
- Capacity building across the Home Care program is required to increase the ability of the Case Managers and vendor services to successfully meet the needs of individuals with dementia and their caregivers

THE STORIES

To tell our story we asked three caregivers to tell their story. Obtaining their consent we engaged these caregivers to share their experiences of caring for clients with dementia living at home. Finally we asked an RN Case Manager to give her perspective of how this team works to meet the needs of both the client and the caregiver.

Marasco's story

"It was Linda the nurse who told me about you, a Caregiver Support Therapist but I thought that I would answer all your questions and then you would see that I am fine and go away. But that didn't happen. You helped me to understand you knew what was going to happen; you led me along the road. Sometimes I got mad at you because you made me think. I had hoped and planned for Vic to die here. I would do whatever. You made me realize that I needed to take time off to take care of myself to take care of him. Now I'm realizing that the caregiver meetings were helpful. You and Linda helped me the most, if it wasn't for you guys I wouldn't be sane and would not be able to accept what was going to happen next and because you were here so much you helped and supported me along the journey. You gave me information about the brain and the disease and helped me understand. The printed information reinforced what you had said. I realized that you weren't lying to me about Vic's disease. I think the Dementia Team is a must, it helped me so much, there's going to be more people coming up with this disease and if there wasn't a Dementia team how are people going to get help. You and Linda were always patient with me, allowed me to speak and always listened and gave me good advice and were always available. I did everything you both recommended and the system worked perfectly. You knew what was coming ahead" (personal communication, Marasco, 2014 September).

Christine's story

"My name is Christine. I am a Caregiver to my husband John who is 85 years old. Before coming to the Dementia Care Team I felt like I was at a loss. I did not realise that my husband has the disease of the brain. I do not have any family in town that can provide me with the support that I need. I have little or no knowledge of how this dementia disease will unfold. This has been a very difficult journey for us. My husband and I used to do everything together. We discussed with each other about everything and anything, and now I don't get any response from him. Most of the time, I feel like he is not interested in what I have to say or how I am feeling. What would be considered a normal conversation is not possible anymore. Daily care becomes increasingly demanding, and time consuming. Our calendar is all about him, and nothing about me. One can read all the articles, try out suggestions, and attend the educational sessions about the disease and how to care for someone with Dementia; but at the end of the day I am still alone. I find myself asking how about me the "Caregiver", who will support and care about me? I feel isolated. I feel stressed and burnt out from providing care giving. At one point I even thought of giving up on everything. Today I would like to share with you my Caregiver Support Therapist, Kim. She was sent to me by the Dementia Care Team over a year ago. She has given me hope, strength and a new light to continue my life's journey. It was like God had answered my prayer. She is caring, patient, understanding and very supportive to me. She and I have had many discussions at the local coffee shop on various strategies, coping, and the importance of self care when providing care giving. She gave me permission to take a break. To me she is a confidence booster, and knowing that she is there for me when I am in crisis is very comforting for me. I called her numerous times, and she would work with me, ground me, and at the end of our conversation I am able to see the situation from a different light. I cannot have done it without the Caregiver Support Therapist.

Thank you for your interest in my experience. My hope is for other caregivers to have the opportunity to get support from a Caregiver Support Therapist while providing care giving to their loved ones at home " (personal communication, Christine Sander, 2014 Oct 6)



Jeanette's story

"I am writing this in regards to the caregiver help I have been given over the past year and a half from the Dementia Care Team. I don't know how I would have been able to cope without their help. Having said that, I would like to focus on the Caregiver worker that was assigned to me. Leslie has been there for me in whatever capacity needed. She took my calls whenever I was having a bad day coping with my mother's behavior and had regular meetings with me at a coffee shop close to my home so that I didn't have to leave my mother unattended for a long period of time. She helped me understand the nature of my mother's disease and gave me suggestions as to how to keep myself calm and my mother comfortable. She also supplied me with information in regards to what to expect as her illness progresses. She helped move things along when I felt my back was up against the wall and helped me in planning my next steps. She allowed me to vent without having to apologize for how I was feeling at the time. I have five siblings and have been given no emotional support. Whenever I asked for help it wasn't there. I am 61 years old and with the help of my husband who just turned 80, have been caregiver to my mom in my home for three years. My husband is having health and memory issues as well but does not have dementia as far as I know. The stress at times has become overwhelming and Leslie has given me the tools to help cope. I can't thank this whole team enough. The care my mother and I have received has been compassionate and a much needed push in making sure my mother husband and myself have quality care.

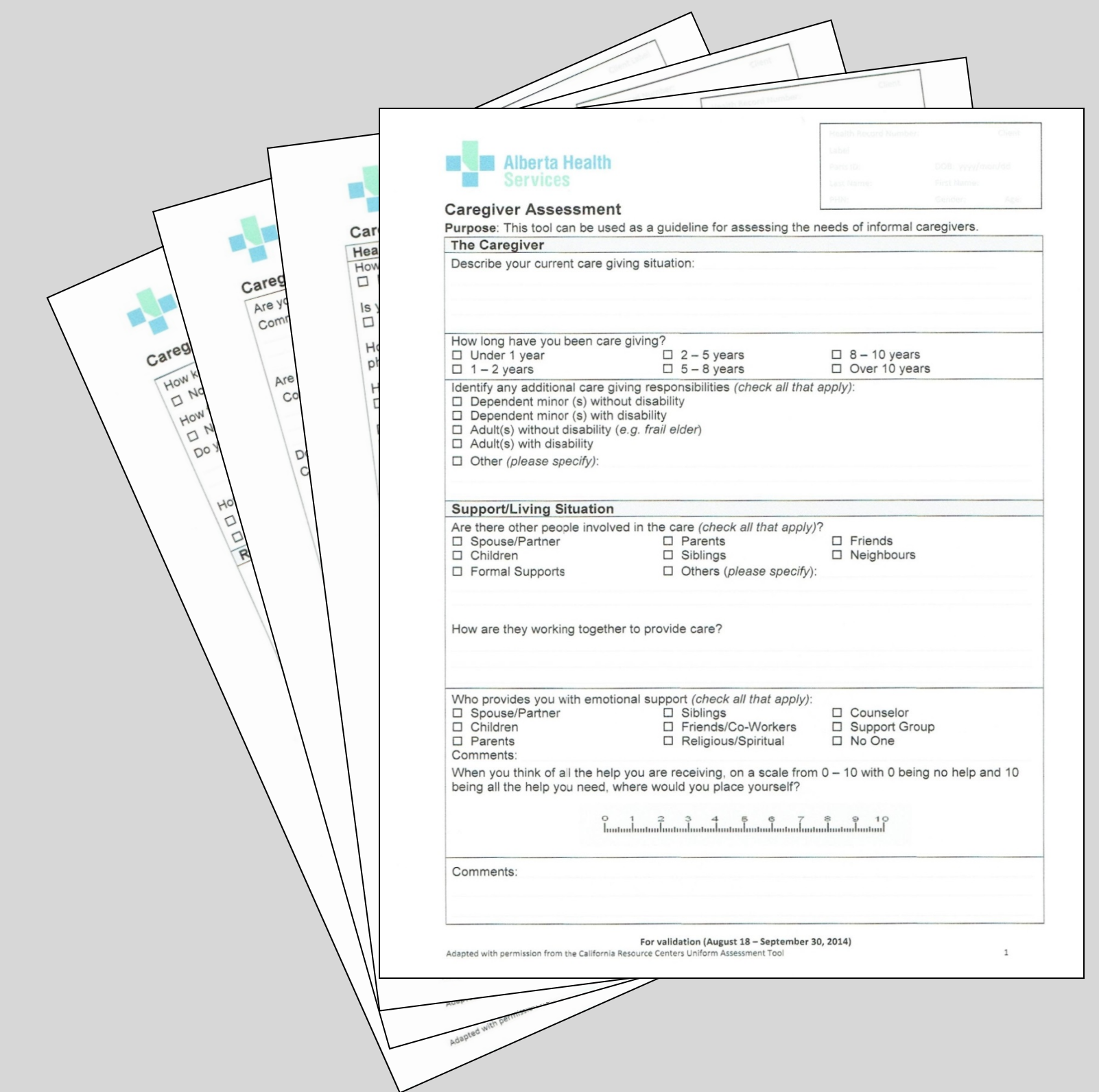
Thank you so much for the help that has been provided and I know that so many others in my situation have also been provided with much needed support. This disease of dementia is so insidious and not only takes away the essence of a loved one it also takes away from the whole family and community. I can only see that with the baby boomer generation being the ones who will next be suffering from dementia there will be such a great need for more support in years to come for the future caregivers. Until a cure is found the need will be great. Thank you for allowing me to speak on my experience. My caregiver worker has been a godsend for me and also for my family without them knowing it" (personal communication, Jeanette Nicholson, 2014 September).

An RN Case Manager's perspective by Tara LaBerge

The Dementia Care Team RN Case Managers have specialized dementia education, and concentrate in managing the challenges of cognitive impairment. Our ongoing surveillance and holistic assessment includes monitoring caregiver burden. We recognize the client and caregiver as a symbiotic unit and that brittle support systems can leave clients at high risk to fail at home. All caregivers are enduring some burden. That burden can quickly evolve into burnout and crisis, most often when client behaviours or external stressors escalate. When caregiver stress or family dynamics impact the care and wellbeing of the client, RN Case Managers are grateful to have the Caregiver Support Therapists get involved and apply their professional knowledge and skills to very difficult situations. Caregiver Support Therapists are afforded the opportunity to see another side of the caregiver, where their true emotions, feelings and thoughts are revealed in the absence of their loved ones. They dig deep down into the caregiver's personal and family history to uncover strengths, challenges and barriers. They counsel the caregivers to find solutions within themselves, their family and their community to support their journey and decision making. They have the knowledge base to select and employ therapeutic strategies as well as promote caregiver advocacy and mediation in family meetings. RN Case Managers can feel confident that an at-risk caregiver is receiving a comprehensive risk assessment, professional guidance, follow up and necessary referrals when in the hands of the therapists. In turn, RN Case Managers are able to keep focus on their role and provide enhanced case management. RN Case Managers and the Caregiver Support Therapists share a special partnership where we regularly collaborate and integrate information to identify client/caregiver needs. We are able to optimize care planning and service delivery by having RN Case Managers and Caregiver Support Therapist working together on the same team.

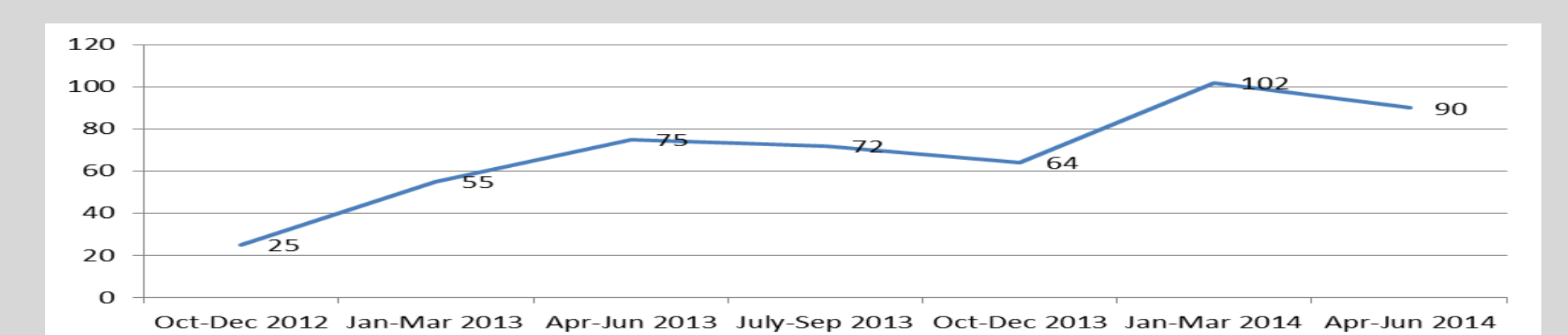
Caregiver Assessment Tool

The Caregiver Assessment is a systematic process of gathering information that describes a caregiving situation by focusing on the needs of the caregiver. It seeks to maintain the caregiver's own health and wellness, thereby increasing the caregiver's ability to continue caring for as long as possible.



Quarterly referrals to Caregiver Support Therapists (CST)

Referrals to the CST have generally increased since the inception of this team in October 2012. Provincially led evaluation has indicated that caregivers are satisfied with the services and supports stating that the support provided by these therapists has helped them cope with their caregiver responsibilities.



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