

## Supporting Caregivers of People Living with Episodic Disabilities

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### Introduction

Caregiving has become a major focus on public policy agendas due to Canada’s rapidly aging population, the increasing prevalence of chronic health conditions, and accompanying drug therapies and medical therapies that are prolonging life (Dyck, 2009; Keefe, Legare & Carriere, 2005, 2007; Shippy & Karpiak, 2005; Torjman, 2011).

Caregiving by *informal* caregivers (family and friends) accounts for approximately 80% of the hours devoted to attending to the needs of individuals with chronic health conditions and disabilities across the lifespan, with nearly 70% devoted to caring for seniors aged 65 years and older (Fast, Niehaus, Eales & Keating, 2002).

*Informal caregivers provide unpaid, ongoing care and assistance to family members and friends who need support due to physical, cognitive or mental conditions (Canadian Caregiver Coalition, 2001).*

- In 2012, over 8 million Canadians (28% of the population, aged 15 and over) provided care and support for friends and family members with serious health

conditions, according to Statistics Canada (Sinha, 2013).

- Caregivers reach out to many:
  - 48% to parents/in-laws
  - 8% to a spouse/partner
  - 5% to a child
  - 16% to a grandparent
  - 16% to a friend/neighbour
 (Sinha, 2013; Turcotte, 2013).
- Caregiving is most often provided due to aging related needs (28%). Cancer is the priority for caregiving among spouses (17%), and mental health issues is the most common condition when care is provided by a parent to a child (23%) (Sinha, 2013).
- In 2008 the estimated value of this unpaid care was considerable: \$25 billion dollars for eldercare alone (Hollander, Liu & Chappell, 2009).
- While the majority of caregivers experience rewards from providing care and support to their loved ones, caregivers do experience a variety of costs associated with caring. Especially when care is provided for many hours per week and/or when there are few resources available, caring can compromise caregivers' physical and mental health, challenge their capacity to combine paid work and care, put pressure on their financial resources, and result in less time available for carers to spend with other family members and for their own needs and interests (Keating et al., 2011; Lero et al., 2007; Turcotte, 2013).

To date, much of the research literature on caregiving has focused

on two groups – parents of children with disabilities (Brehault et al., 2009) and those who provide care to seniors, particularly seniors with chronic conditions related to aging and those suffering from dementia (Cranswick & Dosman, 2008; Duxbury, Higgins & Schroder, 2009). A smaller set of studies addresses the concerns of caregivers of adult family members with a disability or impairment as a result of illness or injury (Battams, 2013; Ivanova et al., 2009; Lightman, Vick, Herd & Mitchell, 2009).

**One group that has remained largely invisible is those individuals who have an *episodic disability* and the common, as well as unique challenges that their caregivers face.**

The 2006 Participation and Activity Limitations Survey (PALS) identified that 1.1 million Canadians, 46% of Canadians with an identified disability, have an *episodic health condition* (Furrie, 2010).

### **Purpose and Scope of this Review**

This review focuses on the challenges experienced by family/friend caregivers for individuals with an episodic disability and their often-unmet needs for support.

First, we outline some of the distinctive features of episodic disabilities and the implications for care needs and support.

Next, we outline those areas of concern that are common to most caregivers, based on the existing literature, which draws heavily on the experiences of family members caring

for an aging parent or for a child with a disability. We then identify those aspects that are particularly *relevant* and *unique* to episodic disability caregiving.

Finally, we consider various ways to support caregivers, particularly caregivers of people living with an episodic disability

## What is an episodic disability?

*The term episodic disability currently encompasses 27 different chronic illness conditions<sup>2</sup> such as HIV/AIDS, severe Migraines, Multiple Sclerosis, Lupus, Rheumatoid Arthritis, Parkinson's Disease, and certain mental health conditions. The significant variation in symptoms and illness progression that may occur means that these illnesses have unique disease-dependent trajectories that can be classified into three categories:*

1. **Episodic Stable:** *Illnesses in this category typically involve periods of relative wellness interspersed with unpredictable and fluctuating periods of acute illness. Most individuals with a stable episodic disability will have a normal life expectancy (e.g., HIV/AIDS, severe Migraines, some mental health conditions)(Smart, 2011, p. 180);*
2. **Episodic Degenerating:** *These illnesses are characterized by periods of fluctuating degeneration*

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<sup>2</sup> The term "episodic disability" currently includes 27 different types of illnesses identified in the literature and research (see Furrie, 2010). A complete list is found in Appendix A.

*coupled with periods of remission that gradually lead to physical decline and often "total" disability (e.g., MS, Parkinson's, Rheumatoid Arthritis) or premature death (e.g. Amyotrophic Lateral Sclerosis – ALS -- 80% will die 2 to 4 years after the onset of symptoms) (Smart, 2011, p. 180).*

3. **Episodic Remissive:** *Some medical conditions, such as certain types of mental health conditions (e.g., depression, bi-polar disorder) can present as "episodic stable" over many years and end in a state of remission or recovery (Green, Perrin, Leo, Janoff, Yarborough & Paulson, 2013).*

## Characteristics of Episodic Disabilities

Some of the distinguishing features of episodic disabilities are:<sup>3</sup>

**Early onset:** Episodic disabilities can present at any time in the life-course, but many of the illnesses classified as episodic disabilities tend to be diagnosed when individuals are in early adulthood or mid-life (e.g., MS -- 30-40 years; Lupus -- 30 years; early on-set Parkinson's -- 21-40 years; Rheumatoid Arthritis -- 20s to middle-age). The onset of illness most typically occurs when individuals are fully engaged in working, raising a family, and pursuing hobbies and leisure activities. Most individuals will live decades with the illness and many will have an average life expectancy. Many individuals with an episodic disability will grow old *with* a

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<sup>3</sup> CWGHR; Hurt, 2007; Proctor, 2002

disability rather than age *into* a disability.

**Traumatic:** Unlike the gradual aging process, the diagnosis of an episodic disability often marks a sharp and sudden demarcation in the life-course – before and after diagnosis. This is often unsettling as the individual and close family members come to terms with the nature of the illness and struggle with the implications for their futures (Rolland, 1999; Smart, 2011).

**Fluctuating periods of acute illness/flare-ups:** The trajectory of the illness is punctuated with times of flare-ups that may involve acute medical care and periods of recuperation or remission until eventually settling into a ‘new normal’ or plateau until the next flare-up. Caregiving may be more acute during these times and require that the caregiver take unplanned time away from work (Vick & Lightman, 2010).

**Unpredictable trajectory – Uncertain future:** For *episodic degenerating conditons*, the trajectory of worsening decline varies from person to person, depending on the nature of the illness. Uncertainty about the overall trajectory and the unpredictability of periodic declines or health crises that may inhibit work, parenting, or the ability to participate in favourite leisure activities, in turn, impact the caregiver. The challenge is to ‘plan’ for an uncertain future.

**Invisible and ambiguous disability:** Many episodic conditions may persist for years with few overt symptoms or “evidence” of disability. Smart (2011) has noted that there is more prejudice

and discrimination associated with episodic disabilities than with disabilities that are more overtly visible and persistent. The management of an episodic disability is often unseen; the individual’s efforts to adhere to a drug regime or implement lifestyle adaptations to “maintain” and manage their condition are not overtly seen by others. Employers, friends and family may be unaware of the illness or may be unsympathetic to reports of fatigue or other ‘vague’ ailments associated with the illness (Lightman et al., 2009; Moss, 2000; Smart, 2011).

**Off-time caregiving:** Having a partner or parent with an episodic disability results in caregiving that is not part of the normal expected life course pattern, such as an adult child caring for an aging parent or a partner caring for their aging spouse. Due to the typically early onset of an episodic disability, caregiving of a parent is more likely to be done by a *Young Carer* (under 18 years of age) or by a partner during the throes of adulthood when one is still also working, paying a mortgage, planning for retirement and/or raising children and contemplating their child’s post-secondary educational needs.

**Ongoing adaptations:** The nature of episodic disability means that the individual, the caregiver and other close members of the family system will have to continually adapt, often over many years, to the physical, emotional, cognitive and financial changes that the illness generates. Family members will repeatedly have to adjust to the psychological discrepancy between times of crisis and non-crisis -- periods of normalcy

interspersed with periods of flare-ups (Rolland, 1999).

**Caregiving Demands:** The extent of caregiving needs is closely tied to the type of illness and its characteristics and trajectory.

People living with *stable* episodic disabilities will have varying caregiving needs depending upon the intensity of symptoms, the impact on daily life, and the frequency and severity of flare-ups. Individuals who suffer from migraines, for instance, may only require minimal support for a day or two. People living with mental health conditions may require sustained care and assistance until the illness enters a phase of remission.<sup>4</sup> People with *degenerating* episodic disabilities will require increasing levels of caregiving assistance as the disease progresses. Some episodic degenerating illnesses may only require acute caregiving during times of flare-ups in the early phases of the illness with gradually increasing needs for greater assistance with activities of daily living as the illness brings about diminished physical capacity. Later phases are associated with the greatest adjustments for both the individual with the episodic disability and their caregiver(s) (Smart, 2011, p. 183).

The combination of the *nature* and the *trajectory* of the illness impacts on caregiving needs. As caregiving needs intensify, the demands impact the

caregiver across many domains including employment, out-of-pocket expenses and caregiving labour (Keating, Lero, Fast & Lucas, 2011; Lero, Keating, Fast, Joseph & Cook, 2007; Lero, Spinks, Fast & Tremblay, 2013).

## The Stages of Care for Episodic Disabilities

Care needs and caregiving supports for people with episodic disabilities are highly variable, reflecting the nature of the diverse conditions that comprise episodic disabilities. The need for care and assistance from family members, friends, and health professionals varies, dependent on the individual, their condition, and the timing, duration, and severity of periods of illness or decline (Smart, 2011).

The following figure (See Figure 1 below) outlines possible trajectories for people living with an episodic disability, including the suggested impact on the extent of caregiving needs. The arrow is double-tipped – this highlights the fact that symptoms can fluctuate from better to worse and back to better, depending on the nature of the illness. Those illnesses that are characterized as *episodic stable* are likely to show little degeneration beyond the initial stages of diagnosis and flare-up. Illnesses that are *episodic degenerating* in nature are more likely to progress through many more stages; the timing ultimately depending on the nature of the illness. And some illnesses, such as some mental health conditions, can be classified as *stable remissive*,

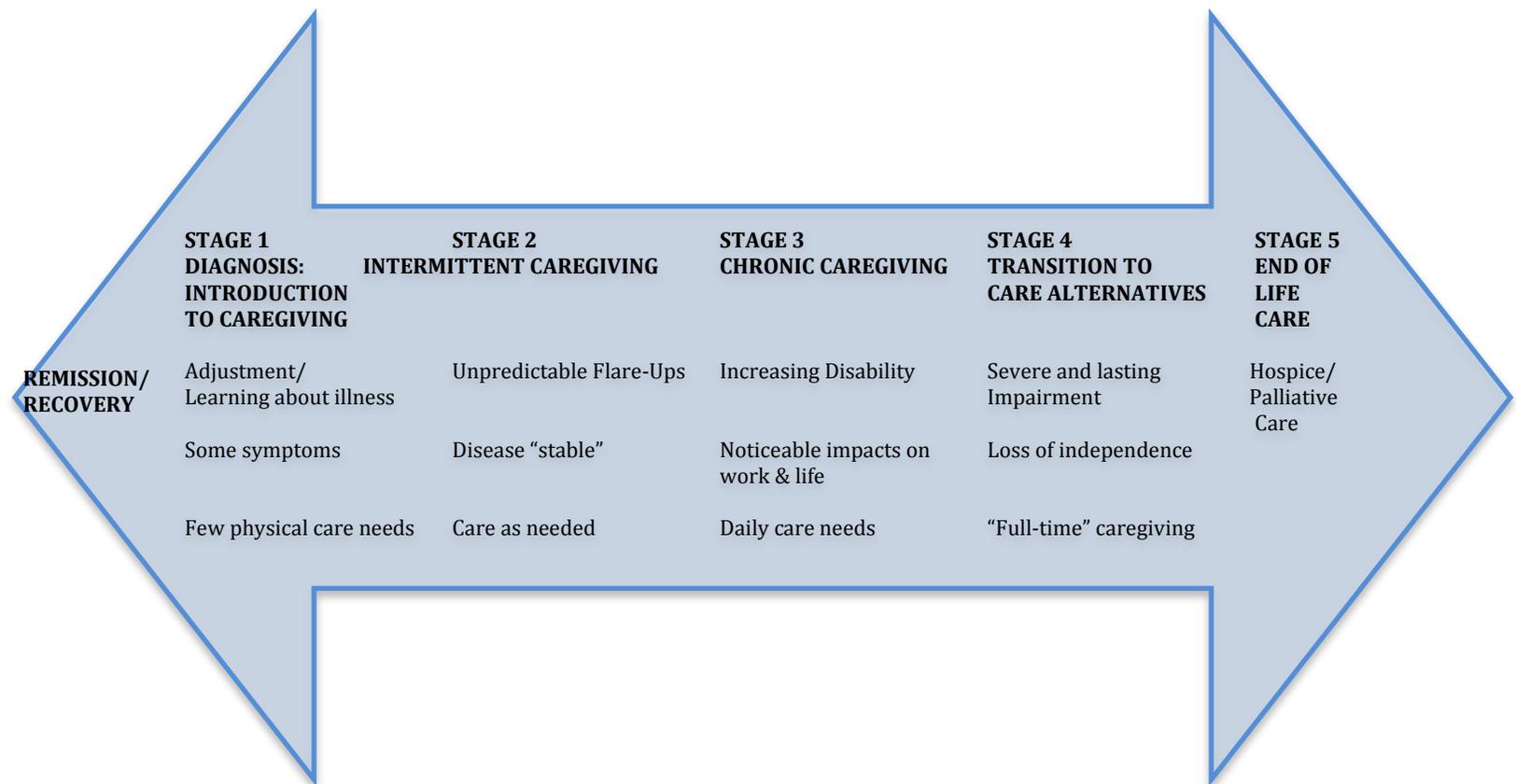
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<sup>4</sup> Canadian Mental Health Association (2012). *Being there: When mental illness strikes someone near you*. Available at <http://www.beingthereguide.com/beingthereguide.pdf#zoom=100>

presenting as fluctuating over the years, potentially resulting in long-term remission or full recovery.

Ultimately, each disease and person has a unique path with some diseases segueing through the stages faster or slower than others. One aspect of caregiving that extends across the trajectory is providing *emotional support* to the person living with an episodic disability.

**FIGURE 1: Stages of Care for Episodic Disabilities<sup>5</sup>**



<sup>5</sup> Adapted from “The 6 Stages of Caring for a Person with Alzheimer’s”  
<http://www.fullcirclecare.org/alzheimers/carestages.html>

The reality of living with an episodic disability in **Stage 1 (Diagnosis: Introduction to Caregiving)**, will usually involve the initial diagnosis, learning to understand and accept the disease, adapting to medical and drug regimes, and learning to cope with an “uncertain future.” At this stage day-to-day “caregiving” needs may be few if the illness can be managed by drug therapies and lifestyle changes. This will not be true for all diagnoses. In some instances the diagnosis results from acute medical interventions due to the presentation of critical need, such as some mental health conditions that present urgently and with intense needs for medical care and caregiver supports. In such instances, caregiving needs are acute and pass quickly to a later stage of care, such as **Stage 3 (Chronic Caregiving)**.

**Remission/Recovery:** Some episodic conditions may present as episodic-stable for many years, ultimately entering recovery or full remission, such as some types of mental health conditions, including more serious conditions such as schizophrenia or bi-polar disorder (Green, Perrin, Leo, Janoff, Yarborough & Paulson, 2013). Mental health conditions present the possibility of necessitating more acute care soon after diagnosis, but unlike many episodic degenerating conditions, also have the potential to enter a stage of remission or recovery not associated with many other types of episodic illnesses.

In **Stage 2 (Intermittent Caregiving)** the disease is “stable,” but the person living with the episodic disability likely experiences periodic and unpredictable flare-ups. Given the

current state of care provision in most Canadian provinces, it is unlikely that publicly funded supports will be provided unless the disease presents an acute flare-up requiring hospitalization and potentially time limited home care/nursing. In response, home care services and access to rehabilitative services are likely available through Ontario’s Community Care Access referrals and coverage through government health care. The focus at this stage is likely on the ill care recipient with minimal attention given to the role of the caregiver as care needs are most likely viewed as time limited.

In reality, reliance on others for caregiving, particularly during these acute flare-ups, may present new challenges to caregivers who may find that they have increased demands on their time, including a need for workplace accommodations, even if for a limited period. At this stage, there may be some disease “remission” that segues back to some of kind of “normal” although repeated flare-ups may potentially bring worsening physical and emotional changes over the years and as the individual ages.

Degenerative episodic disabilities (such as Multiple Sclerosis, Parkinson’s Disease and Rheumatoid Arthritis) that progress to **Stage 3 (Chronic Caregiving)** and into **Stage 4 (Transitions to Care Alternatives)** are likely to bring the need for more intensive care supports. At these stages the disease will have impacts that meet the definition of being a “severe and lasting impairment” that most often fits within definitions associated with

access to paid caregiving, income tax credits and access to government disability income (e.g., CPP-D, Ontario Disability Support Plan (ODSP)). At these stages, attention to supporting the caregiver is also likely to arise. The person living with the episodic disability most likely requires more intensive assistance with daily living tasks such as physical care needs, meal preparation, transportation etc. During these later stages, the care recipient may be more likely to face the challenges associated with *aging with a disability*.

**Stage 5 (End of Life Care)** represents total care needs as the ill individual navigates end of life care and requires access to hospice/palliative care. Many people living with an episodic disability will not reach this stage until decades after their diagnosis, and are likely to be facing care needs as a result of their age as well as co-morbidity associated with their illness. Episodic disabilities, such as Amyotrophic Lateral Sclerosis (ALS) are likely to reach this end stage within five years of diagnosis (Smart, 2011). Caregivers may be eligible for up to 8 weeks of federal *Compassionate Care Benefits* (via Employment Insurance) if they need to take time away from work as their loved one reaches the final stages of their illness.

## Understanding the Role of Family/Friend Caregivers of People Living with an Episodic Disability

Caregivers have been identified as a critically important resource in helping individuals cope with chronic illness and aging, as well as persons dealing with episodic disabilities like HIV/AIDS (Solomon, O'Brien, Wilkins, Gervais, 2014), Parkinson's (Casey, 2013), mental health conditions (Caqueo-Urizar et al., 2009) and Multiple Sclerosis (Nauen, 2012).

Caregivers provide a broad range of tasks such as assistance with:

- Housekeeping
- Care management
- Personal care
- Administering medical treatments
- Emotional support
- Home maintenance/Outdoor work
- Transportation/ Shopping/Banking
- Maintaining social interactions/connections
- Organizing medical appointments and services
- Advocacy for health care, supports and services

The health care system has increasingly assumed that there are family caregivers available to help. The policy shift of reducing hospital stays and avoiding or delaying the use of long-term care facilities necessarily means a greater reliance on family/friend caregivers. While viewed as cost-effective for the health

care system, these practices largely assume that there are caregivers who are able and willing to take on responsibilities for patients who are being moved home “sicker and quicker” (Keefe et al., 2007, p. S74).

### **The “threshold” effect of caregiving**

The ability of caregivers to manage the demands that caregiving may entail depends upon the personal resources caregivers have at their disposal: financial, physical health, emotional well-being, and formal and informal supports (Fast, Dosman, Lero & Lucas, 2013).

The demands of caregiving are also influenced by the personal characteristics of the care receiver, including the severity of the symptoms of the disability, living arrangements and personal attributes (O’Brien, Davis, Strike, Young & Bayoumi, 2009).

Canadian caregivers are most likely to reduce their hours in the work force as their hours of caregiving meet or exceed 15 hours a week (Sinha, 2013). Other research has identified a “threshold effect” wherein the employment consequences of caregiving (absenteeism, reducing hours of paid work, or leaving the labour force) are most likely to occur when women are providing 20 hours per week of caregiving; for men the threshold is lower – 10 hours per week (Fast, Dosman, Lero & Lucas, 2013). As Fast et al. (2013) summarize, a critical threshold of intensity or level of demands on the caregiver is likely to be reached when the caregiver lives with the care recipient, provides personal care, is

the primary caregiver, and the length of time caregiving is required.

When caregiving demands exceed the resources available, both the caregiver and care recipient are at risk -- financially, mentally and physically (Lero et al., 2007; Turcotte, 2013).

### **The Costs of Care: The Challenges for Caregivers**

The financial and emotional costs of caregiving have received ample attention over the last decade, particularly in anticipation of a rapidly aging population. Similar concerns pertain to people living with an episodic disability and their family and friends. There is increasing concern about the risk factors that can negatively impact the financial resources and health and well-being of those who are called on to care (Duxbury et al., 2009; Lero et al., 2007; MS Society; Turcotte, 2013).

#### ***Employment and Financial Strain***

It is well documented that many caregivers acutely feel the financial strain associated with caregiving (Duncan, Shooshtari, Roger & Fast, 2013; Duxbury et al., 2009; Turcotte, 2013) as a result of:

- Reduced household income and access to employer-provided benefits when the individual with an episodic disability must reduce their hours of paid work or leave the work force (Morrow et al., 2010; Vick, 2013). The 2006 PALS survey revealed that 50% of people

with an episodic disability will “often” or “sometimes” find that they are limited in the workplace by their condition (Furrie, 2010). For some individuals (20%), their episodic condition is associated with intermittent periods of unemployment (Furrie, 2010). On average, people with a disability have lower earnings than a person without a disability and this earning gap continues to widen as the number of years with a disability increases (Galarneau & Radulescu, 2009). In instances where the caregiver lives with the care recipient, this can lead to increased financial burden due to loss of an income and/or elimination of health and drug benefits.

- Compromised earnings due to the caregiver’s reduction of time in the paid work force, including reduced income and pension, loss of benefits, and increased family-work conflict that can result in reduced productivity.
- Increased out-of-pocket expenses for prescription drugs and over the counter medications, groceries, home modifications, transportation, household expenses, paid caregiving assistance, and fees to access other services such as Occupational or Physical Therapy when publicly funded services and/or private insurance is insufficient (Duncan et al., 2013).

### ***Emotional Strain: Stress and Depression***

Most caregivers want to provide care, and consider it to be a “labour of love” (Duxbury et al., 2009) and simply “what families do” (Qualls, 2013). Yet, the ongoing physical demands and time strain can, over time, contribute to caregivers feeling stressed and depressed, sometimes resulting in physical health issues of their own (Lero et al., 2007; Pinguart & Sorensen, 2003).

Caregiving can interfere with sleep patterns and social and leisure activities – further contributing to stress that is associated with poor health outcomes and chronic health conditions (Caqueo-Urizar et al., 2009; Pyper, 2006; Turcotte, 2013).

Caregivers assisting individuals with dementia and other cognitive challenges have *higher* rates of depression than other caregivers (Covinsky et al., 2003; Pinguart & Sorensen, 2003). Certain episodic illnesses such as MS or Parkinson’s Disease may include the gradual onset of dementia.

Caregiving can also be associated with feelings of guilt over the lack of time available to spend at work or with other family members (Pyper, 2006), and with feelings of anxiety, grief, social isolation and feelings of being overwhelmed (CRNCC, 2011).

## The Impact of Episodic Disabilities on Different Care Relationships

Caregiving, in the context of coping with episodic disabilities, generates different issues for different types of relationships. There is a hierarchy of care provision – typically starting with the spouse or life partner, followed by children, other relatives and friends (Qualls, 2013).

This section considers the implications for four different types of caregivers and the unique aspects they may experience:

- 1) Spouse/partner
- 2) Men and masculinity
- 3) Young carers (children and young adults) and
- 4) Friends/Extended family

### 1. Spouse/Partner as Caregiver

Having a spouse or partner who is diagnosed with an episodic illness during young adulthood or mid-life has been identified as '*off-time*' caregiving (Rolland, 1999, p. 252). Unlike elder care, which is 'expected' in the normal life-course, off-time caregiving is not the norm nor socially expected. A spouse caring for their partner is associated with greater caregiving intensity, which in turn is associated with more stress, depression and decreased self-efficacy and well-being (Pinquart & Sorensen, 2003).

A chronic illness diagnosis can be *traumatic*, usually given after many attempts at finding a diagnosis

(McLaughlin et al., 2011). Family members must learn to adjust and readjust their emotional, practical and financial resources to adapt to the different phases of the illness (Steinglass & Horan, 1987).

The challenges associated with caregiving are related to the type of episodic disability.

### *The impact of degenerating episodic disabilities on caregiving*

Degenerating episodic disabilities are usually associated with a slow and intermittent progression of the disease/illness (Smart, 2011). Degenerating episodic disabilities pose the greatest challenge for caregivers. In the first stages of the illness, caregiving may be minimal. The caregiver may not even formally acknowledge their efforts as "caregiving", but rather simply as part of the helping role that individuals assume within a family or for a friend. For instance, in the early stages, the caregiver may be concerned with whether the person with an episodic disability is getting enough rest, or assume more household chores without consciously acknowledging such efforts as caregiving.

Gradually, over time, there may be a further re-allocation of responsibilities around household chores, transportation, cooking, and/or childcare and personal care (bathing, dressing, toileting). Eventually, as the disease progresses there may be discussions and decisions about paid work with the focus on whether the person with the episodic disability should move to part-time work or leave the work

force altogether. This, in turn, may place increased demands on the other partner/caregiver who may need to increase their paid work in order to compensate for loss of earnings by the person living with the episodic disability.

### ***Impact on family resources***

The illness diagnosis, trajectory and subsequent adaptations are experienced within the family's social, emotional, and economic resources, or lack thereof. Therefore, a family's ability to cope with a diagnosis and the subsequent alterations and adaptations to work, finances, leisure and relationships is highly contingent on the resources that the family can bring to bear. Adequate financial resources make adaptations easier. Problem-solving abilities – adaptability and cohesiveness – are also associated with enhanced family resilience to weather the challenges of various crises, such as a medical diagnosis (Rolland, 1999; Walsh, 1982). Furthermore, there is evidence that an extended social network of family, friends and community also adds to a family's resilience (Walsh, 1982).

### ***Loss of parenting***

The challenges associated with raising minor children when a parent develops a chronic illness can severely tax the financial and social-emotional resources of the family. This takes two forms: 1) the ill adult's needs may compete with children's needs for financial and caregiving resources, and 2) the illness and its effects can lead to '*parental loss*' wherein the ill parent is no longer able to sustain the same level or types of parental

interaction as they could prior to the onset or a certain level of severity of the disease (Nauen, 2012). This places greater burdens on the well parent, who is typically also the caregiver, to provide for the needs of the children. Ultimately, family stress and reduced parenting capability can compromise children's development and well-being when neither the ill parent nor the well parent has the financial or emotional resources to fully attend to their needs (Miller, 2012).

### ***Burden on the 'well' spouse and risk of mental health issues***

The well spouse typically assumes additional responsibilities with respect to childrearing, paid work, and housekeeping, as well as assuming caregiving tasks for the ill spouse. The burdens of caregiving impact on family members as they navigate work, daily living, leisure, relationships, role negotiation and childrearing. While the person with the episodic disability is usually the focus of care, the reality of a serious and/or chronic illness is that other family members are also at risk for developing depression and anxiety (Kouzoupis, Paparrigopoulos, Soldatos & Papadimitriou, 2010).

A Danish study found that only 33% of MS patients remained in the same relationship after 24 years as compared to 53% of the non-ill control group, suggesting that many couples do separate under the pressures associated with chronic illness (Pfleger, Flachs & Koch-Henriksen, 2010).

## 2. Men and Masculinity: The Impact of Caregiving

Men's gendered roles and expectations have been considered with respect to two distinct experiences around care: being a caregiver and being a care recipient.

### ***Men as Caregivers***

Being a male caregiver, whether as a partner, adult child of an aging parent, or friend, generates issues that are different from those experienced by most female caregivers. Men may be called on to provide personal care (assistance with dressing, bathing, and housekeeping) with little to no experience or comfort in that role and limited support from others for doing so (Singleton, 2013).

In an attempt to maintain an appearance of stoicism and self-reliance in the face of high caregiving responsibilities, men may assume an attitude of "guarded vulnerability" (Wenger, 2013a). This persona often prevents men from asking for and accessing the help and social-emotional resources they need (Wenger & Oliffe, 2013).

One fallout may be domestic violence. This can occur when the male caregiver is stressed and burdened and the woman is socially isolated due to her disability and potentially greater inability to access Intimate Partner Violence resources.<sup>6</sup> The

other potential fallout is separation or abandonment of the relationship.

### ***Higher rates of separation/divorce for ill female partners***

There is evidence to suggest that the assumption of the caregiver role may be disproportionately *more difficult* for men and result in higher rates of separation/divorce among ill female patients (Pfleger et al., 2010). Female cancer survivors are 80% more likely to be divorced than women without cancer, while the divorce rate for male cancer survivors was not statistically different from their counterparts without cancer. This gender imbalance was also identified by Glantz and colleagues (2009) who found that the rates of separation and divorce were essentially the same for patients with a serious medical illness (11.6%) as compared to the general population (5-17%), but that when there was a separation *90% of the separations occurred where the patient was female*. This suggests that men may have unique struggles when it comes to caregiving.

Yet, other research has suggested that men may be disadvantaged when they are the ones who experience a work-related health limitation. Teachman (2010) found that husbands whose work was compromised due to health limitations were at an increased risk of divorce as compared to wives. It was not the loss of economic means that resulted in marital disruption, but rather the loss of noneconomic factors that are associated with marital functioning. Teachman suggests that "poor health can operate as a shock to the economic, social and emotional

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<sup>6</sup> See Disabled Women's Network Canada (DAWN): Women with disabilities and violence: Factsheet. Available at [http://www.dawncanada.net/?attachment\\_id=375](http://www.dawncanada.net/?attachment_id=375)

balance that couples negotiate” (2010:930).

### ***The male experience of being “cared for”***

A second issue in the literature addresses the experiences of men when they are the care recipients. Being “cared for” as a result of illness can be a challenging position for men to accept, which can impact their loved ones and friends who step up to serve in the caregiver role. Many men struggle with masculinity ideals and the impact that illness has on their ability to be strong and independent.

Wenger’s (2013a) research on men with cancer noted their response to losing their independence as a result of the diagnosis and accompanying treatment:

*As capacities were reduced, the men described watching others step forward to accommodate their physical and cognitive restrictions, caring for their weakened body, driving them to appointments, taking on additional tasks in the home, carrying more of the financial load... many noted discomfort and limited experience with relying on others for physical supports (p. 5).*

Research on men’s health and illness experiences has revealed a masculinity of experience wherein men can be reluctant to discuss personal matters (Oliffe & Mroz, 2005). This also extends to a reluctance to access psycho-social supports, both lay and professional, during times of illness (Wenger, 2013a) or to accept help from non-family members for fear of becoming too much of a burden (Wenger,

2013b). Ironically, the fear of accepting help from an array of professionals and other family members/friends can actually mean that a much heavier burden falls to the immediate family member, typically their caregiver spouse.

### ***Supports for men***

Oliffe & Mroz (2005) state that professionals and helping services must be willing to meet men within their frame of comfort, but also recognize that men do want to share and express their emotions. Since men often are challenged to find or utilize resources that may be beneficial in the face of their own illness, it is likely that some men also may fail to seek help and use supports when they are in the role of a caregiver to someone else, particularly a partner/spouse. One potential source of male-oriented support is the on-line resource, *Male Caregiver Community*, a U.S. based resource that provides a forum and articles specifically geared to men and their caregiving experiences.<sup>7</sup>

### **3. Young Carers**

In Canada, it is estimated that 1 in 10 children and youth under the age of 18 years provide active care to an adult family member (Charles, Marshall & Stainton, 2010; Miller, 2012).

***Young Carers: Children under the age of 18 who are providing care to someone who is their usual “natural” caregiver, but is unable to because of illness or incapacitation (Miller, 2012, p. 8).***

<sup>7</sup><http://www.malecaregivercommunity.com/Home.aspx>

The atypical timing of an episodic disability occurring in early adulthood or midlife may require that children step into the role of a carer within their family taking on a level of responsibility that is above and beyond the norm (Charles, Stainton & Marshall, 2012). Young carers may have considerable responsibility for the daily care and support of a parent, a grandparent, or a sibling.

### ***Invisibility of young carers***

Young carers have been an invisible, often unacknowledged, and hence undercounted population among caregivers (Baago, 2005; Butler & Astbury, 2005; Charles et al., 2012). An analysis of data from the Canadian General Social Survey (2007) revealed that 8.3% of men and 11.6% of women in the survey had become a caregiver in adolescence or as a young adult (under the age of 25) (Fast, Dosman, Lero & Lucas, 2013).

### ***Consequences for young carers***

- **Hinders normal development:** Caregiving can interfere with normal development when children or adolescents must compromise their own time for school, friends, and extra-curricular and leisure activities as a result of caregiving responsibilities (Butler & Astbury, 2005; Chalmers & Synes-Taraba, 2007). Furthermore, the transition to adulthood can be compromised when young carers face challenges successfully completing school and making the transition to work when their caregiving role has interfered with their ability to have the time and energy to complete

these necessary milestones (Charles et al., 2012).

*The difficulty most community agencies have is that the primary mandate of Canadian health and social services is to provide support either for the care recipient solely, or for the care recipient/primary caregiver dyad, but not to other members of the family in a holistic sense...The needs of young carers, whose own lives may be seriously impacted by the unique circumstances facing their family, are not assessed or even taken into account in the current system.*  
(Baago, 2005, p. 5)

- **Stigma of Caring:** There can be stigma and embarrassment associated with being a young carer and concern that friends and teachers won't understand the burdens and stressors they face (Miller, 2012), especially in cases when a parent is struggling with substance abuse, mental health issues, or a personality disorder (UK Department of Health, 2010).
- **Mental Health:** Children's mental health can be affected when they face the typical stressors associated with adolescence coupled with the additional pressures of caregiving and the economic and social vulnerabilities that come with having an ill family member. This can result in suicidal thoughts and self-harm (Cree, 2003).
- **Positive Benefits:** Caregiving can generate social and emotional growth, greater maturity, new

skills and competencies and a closer relationship with the ill parent/family member (Chalmers & Synes-Taraba, 2007; Miller, 2012).

### ***Educational and other supports for young carers***

There is growing awareness that the social-emotional needs of young carers must be identified and addressed.<sup>8</sup> The UK legally recognizes Young Carers as being entitled to regular assessments to determine their ability to provide care and the impact that caregiving has on their life (Charles et al., 2012). This legitimizes the vital role that young carers play, while also keeping watch over them as vulnerable members of the care system (Miller, 2012).

Critically important is recognizing the supports young carers need to succeed in school. Family Action UK<sup>9</sup> has specifically researched this area of concern and has identified the invisibility of young carers in schools and amongst teachers. Furthermore, the lack of supports, policies and procedures to address their need for different expectations around attendance, behaviour, anxiety, fatigue, concentration and homework completion are not always well addressed, even within the UK that has made young carers a priority.

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<sup>8</sup> Canadian programs are identified in the Environmental Scan & Inventory

<sup>9</sup> Family Action. (2012). *Be bothered! Making education count for young carers*. United Kingdom. <http://www.family-action.org.uk/uploads/documents/Be%20Bothered!%20Make%20Education%20Count%20for%20Young%20Carers.pdf>

The 2013 Young Carers Action Canada Task Force has also identified the need for educational supports for Young Carers including<sup>10</sup>:

- Creation of training workshops and educational packages for teachers and other educational professionals to better understand and address the needs of Young Carers in school
- Allocating a designated support person in every Canadian school
- Support programs to help teenagers transition from high school to post-secondary programs

### **4. Friends and Extended Relatives as Caregivers**

Friends and extended family members also play a critical role in providing care. In 2012, 16% of Canadian caregivers identified the person for whom they provided care and assistance as a friend, neighbour or colleague (Sinha, 2013). In some cases, friends supplement the care provided by family members, but in other cases friends may play a more significant role when family members are unavailable or geographically dispersed.

There is no distinct data on caring for individuals with episodic disabilities, but many of the issues associated with family care apply. As our population ages with families having fewer children than in previous generations, a number of factors promote the

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<sup>10</sup> *Who cares about young carers: Raising awareness for an invisible population*. <http://www.scribd.com/doc/124089317/Who-Cares-About-Young-Carers-Raising-Awareness-for-an-Invisible-Population>

importance of friends who step up to provide care:

- More individuals are **single** because of higher rates of divorce and dissolution of common-law relationships (Statistics Canada, 2012)
- **Fewer children** or no children – it is projected that by 2031 one in four elderly women will have no surviving children to aid in their care (Keefe et al., 2007)
- Similarly, there are **fewer siblings** to provide care to each other or to share the caregiver burden for a mutual family member (Keefe et al., 2007)
- **Mobility** has increased such that people are less likely to live near family due to immigration and migration (Statistics Canada, 2012)
- Individuals with **HIV** are less likely to have a partner or children, and are more likely to live alone (Shippy & Karpik, 2005). Many are unable to reach out to family due to the stigma associated with being HIV-positive and many others have lost their partner or network of friends to the disease (Solomon, O'Brien, Wilkins & Gervais, 2014).
- Greater diversity in sexual preferences and sexual orientation may result in more individuals who have close ties, but who are not recognized as related by blood or marriage. Recognition and respect for caregivers among the

LGBT community has been identified as an important issue as it relates to medical consultations and medical directives.<sup>11</sup>

### ***Instrumental versus Intensive Caregiving***

Friends, siblings and neighbours are more likely to provide *instrumental* care such as assistance with transportation or grocery shopping than personal care. They are also less likely to live in the same home as the person with the episodic disability and therefore face fewer care demands. Close family members, such as spouses and children, tend to live with the ill individual and provide more *intensive* and intimate forms of daily living care (e.g., personal care, emotional support) (Keefe et al., 2007). Therefore, while friends, neighbours and siblings provide care and invest time, in most cases, the burden is less likely to be as time intensive, financially costly or as emotionally straining.

### ***Caregivers to those living with HIV***

Individuals living with HIV face unique challenges accessing informal care.

- Care networks are often smaller
- Many individuals will have lost a partner to the disease
- Most do not have children
- Many lack support from extended family and relatives because of the stigma associated with HIV

Amongst HIV-positive seniors the social network is often smaller and

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<sup>11</sup> A guide to LGBT caregiving. See [http://issuu.com/lgbtagingcenter/docs/lgbt\\_guide/1?e=0](http://issuu.com/lgbtagingcenter/docs/lgbt_guide/1?e=0)

more fragile, with 57% of participants in one study reporting that they had inadequate emotional support from their informal care networks (Shippy & Karpiak, 2005). In contrast, research with younger populations of gay and lesbian individuals are revealing that the wider LGBTQ community can provide an effective support network in times of need (Brotman et al., 2007).

***Stigma of caring for HIV-positive individuals.*** There can be stigma associated with caregiving for someone who is HIV-positive or LGBTQ, regardless of the caregiver's sexual orientation or disease status. Some caregivers face the added burden of exposure to discrimination by "coming out to care" (Brotman et al., 2007, p. 491) or by having to openly acknowledging their gay partnership in order to be given access and be recognized as the caregiver. As a consequence, caregivers to those who are HIV-positive or living with AIDS can face issues similar to those living with the illness – isolation, rejection by family and society, reduced support and invisibility in their role as a caregiver (Brotman et al., 2007).

***Dual-role caregiving.*** Some caregivers to those living with HIV can find themselves in a unique role - the ***dual roles*** of both HIV-positive patient and caregiver (Hackl, Somlai, Kelly & Kalichman, 1996). Caregivers who are also HIV-positive report more burdens compared to HIV-negative caregivers, because the disease exacts its toll on their own physical and emotional resources (Folkman,

Chesney, Cooke, Boccellari & Collette, 1994).

***Consequences.*** There are consequences for the care receiver and caregiver due to smaller networks and societal stigma. Individuals lacking a network of caregivers must place greater reliance on long-term care facilities and utilize those services earlier in their illness than those with community supports (Shippy & Karpiak, 2005). The concern for caregivers is that a greater burden falls on the few who are willing, compromising their own mental and emotional well-being.

Caregiving is even more challenging in the face of covert and overt discrimination and greater difficulty accessing appropriate services for their ill friend/relative and for themselves. Individuals have reported that some home care service providers will refuse to provide care if the care receiver is lesbian or gay and/or HIV-positive (Brotman et al., 2007).

This discrimination becomes particularly noticeable when institutional policies such as hospital visiting rules permit "family members" enhanced access, but do not include the broader network of friends and "*chosen kin*" that are more likely to make up the network of persons with HIV (Brotman et al., 2007; Shippy & Karpiak, 2005).

## Addressing the Needs of Caregivers: 'Planning' for an Uncertain Future

The presence of an episodic disability means that the person living with the episodic disability and their family and support network must 'plan' for an *uncertain future*. An episodic disability will challenge the psychological, financial, legal and practical aspects of their lives. Many of these challenges are similar to those experienced by caregivers generally, but episodic disabilities can create unique challenges and concerns.

Supporting caregivers requires policies, programs and services in four key areas:

1. Education/Information Supports
  - a. Counseling
  - b. Access to information
2. Caregiver Wellbeing: Physical and Psychosocial Supports
  - a. Assess the needs of the caregiver
  - b. Respite: The need for personal time
  - c. The need for peer supports
  - d. Health agency supports: The need to serve the caregiver
  - e. Networks of friends and family: The need to share the caring
3. Employment Supports - The need for flexible workplace practices and caregiving leaves
4. Financial and Legal Supports – addressing the loss of current and future earnings; and the increased

care costs not covered by the public system

- a. Greater losses; more expenditures: The need for income supports and access to extended health and drug benefits
- b. Tax credits: The need for tax advice
- c. Compromised retirement: The need to plan for the future while living with an episodic disability in the present
- d. Legal services: The need to access cost-appropriate resources

### 1. Education/Information Supports

#### a. Counseling

*"When one is sick...two need help."*  
~The Well Spouse Association~

Episodic disabilities carry a great deal of uncertainty as to their future course and the trajectory of the illness. This has an enormous impact on the care receiver, their primary caregiver, and their network of informal caregiving support.

Chronic illness impacts the very relationships that one hopes will be there to support an individual in their time of need. The physical and mental/emotional changes of the care recipient create stressors and considerable burdens for caregivers. The patient-caregiver roles add a dynamic to the couple relationship that requires a particular approach to communication that allows both partners to fully embrace feelings associated with loss, caregiver burden, daily hassles, and the loss of a future

that the illness has interrupted (Rolland, 1999, p. 255).

An episodic disability may add anxiety and stress because the illness is unpredictable. This often makes it impossible to anticipate what additional supports the person may require (and when), as they may be quite well one week and quite unwell the following (Proctor, 2002). The unpredictability also contributes to stress for the caregiver who may find that they have to alter work demands and childrearing responsibilities on very short notice in order to accommodate unexpected caregiving duties.

***What is needed?***

Evidence of higher rates of separation and divorce suggests that the nature and trajectories of chronic illness and the stressors that accompany them are a serious problem. Ideally, the goal should be to provide up-front support, early after the diagnosis to help couples adjust rather than waiting for the couple to demonstrate distress, or until a partner simply abandons the relationship due to financial demands, emotional burdens and the shift in couple intimacy.

Couples facing the challenges of episodic disabilities need access to counseling that is different from traditional couples therapy (Baucom, Porter, Kirby and Hudepohl, 2012). The focus is the medical disorder and its effect on *both* the ill individual and the partner/caregiver. Furthermore, there needs to be access to on-going counseling so that the couple can address changes in their relationship as the disease progresses.

Counseling may address the following areas of potential concern depending upon the type and trajectory of the episodic disability:

- 1) Psycho-education about the disorder
- 2) Sharing thoughts and feelings regarding the disorder
- 3) Making decisions focal to the medical disorder
- 4) Implementing relationship changes that are nonmedical, but that result from the disorder
- 5) Addressing relationship functioning unrelated to the disorder

Tompkins and colleagues (2013) have created a specific relationship enrichment program for couples where one partner has MS. The program, “*Relationship Matters*” (RM), offers 8 hours of programming via in-person workshops or teleconferences. Outcome analysis showed improved relationship quality as compared to control couples who did not receive the RM programming (Tompkins et al., 2013).

***b. Access to Information***

One of the critical roles caregivers often assume is gathering information about the illness and about medical and rehabilitative resources that may be available. Whether gathering information has a positive effect on caregivers is not entirely clear from the research to date:

*Carers that actively seek information have higher levels of anxiety compared with carers who actively reject information, with carers requiring both biomedical information provision and emotional support when faced with caregiving-related distress... findings suggest support for the positive influence of knowledge on carers' resilience [emphasis added] (Cherry et al., 2013, p. 254).*

One challenge to information gathering is that many organizations focus on specific conditions or episodic disabilities (e.g., MS Society, Arthritis Society, Mental Health Association) - an effect known as 'siloining' (Proctor, 2002). These organizational services tend to start with the assumption that the patient and family can only be understood in the specific context of their particular illness (Steinglass & Horan, 1987). However, particularly as people age or conditions progress, many patients experience co-morbidity (more than one disease or problem area). Issues related to long-term care or alternate housing, for example, apply to many groups. The disease-specific information and supports specific societies provide play an important role; however, there is also a need to address the cross-cutting and shared challenges that are present across different illnesses/ disabilities. The divisions between organizations may also duplicate efforts to serve the wider community. Siloining may also require caregivers to look across many organizations to locate the supports and services that they personally need to support the person they are caring for. Information

therefore should be both specific and more general.

Information should:

- Be easy to access through multiple channels, current and credible (CRCNN, 2011; Pyper, 2006).
- Result in coordinated care plans and linked services, facilitated by someone who is responsible for care management (e.g., a social worker or system navigator) who can act as an important support to carers who are helping to manage complex illnesses, such as Parkinson's (McLaughlin et al., 2011).
- Include the caregiver as an integral part of the patient's care team and decision-making team as advocated by The Institute for Patient- and Family Centered Care.<sup>12</sup>

## 2. Caregiver Wellbeing: Physical and Psychosocial Supports

### a. *Assessing the needs of the caregivers*

Care plans for the person living with the episodic disability must consider the needs of both the care receiver **and** key caregivers. The emphasis on the plurality of caregivers recognizes that in many instances, particularly where the needs of the care recipient are high and ongoing, caregiving is often shared amongst family members and friends (Kemp, Ball & Perkins, 2013). Evaluations of need can be accomplished by requiring that an

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<sup>12</sup> See <http://www.ipfcc.org/faq.html>

assessment of relevant caregivers be completed as part of home-care assessments (Keefe et al., 2007). Measures have been developed such as:

1. *The Caregiving Distress Scale* (CDS): Initially developed to assess relationship distress, emotional burden, care-receiver demands, social impact and the personal costs associated with caregiving to individuals with Parkinson's disease (Cousins, Davies, Turnbull & Playfer, 2002).
2. *The Caregiver Strain Index*: Assesses the caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and care recipient (Deeken, Taylor, Mangan, Yabroff & Ingham, 2003).
3. *Resident Assessment Instrument-Home Care* (RAI-HC): This comprehensive assessment is used worldwide, including Canada, to address issues related to home care. The RAI-HC is also used to identify caregiver distress, which the RAI-HC defines as "the overall impact of physical, psychological, social and financial demands of caregiving." The RAI-HC identifies caregiver distress if one or both conditions exist:
  - i) A caregiver is unable to continue in caring activities, for example due to decline in the caregiver's health; and/or
  - ii) The primary caregiver expresses feelings of distress, anger or depression.

***b. Respite: The need for personal time***

*"Respite refers to caregivers' physical, emotional, psychological, social and/or spiritual relief or renewal which results from anything intended to help them maintain their own health and achieve greater balance in their lives."*<sup>13</sup> (p. 8)

The need for respite depends upon two aspects: 1) the type of illness and degree of dependence that the person with the episodic disability has on the caregiver; and 2) the extent of the burden experienced by the caregiver with respect to the physical, psychological, emotional, social and financial impact (Cherry et al., 2013).

Respite is usually assumed to be "time away" from the care recipient when someone else steps in to care or the person with the illness is housed elsewhere for a period of time to allow the caregiver the opportunity to rest or take a vacation. In the context of caring for someone with an episodic disability the topic of "respite" requires more nuance. The nature of many episodic disabilities may mean that the person requires some supports, but that the supports do not require constant vigilance/supervision or required assistance with the tasks of daily living. This is not to say that caregivers do not feel the stress and weight of being available, worrying about the ill individual or carrying out

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<sup>13</sup> Building Respite Knowledge: A Knowledge Series on the Milestones of the Care Renewal Projects. Available at <http://www.von.ca/carer renewal/eng/pdfs/CareRenewalBuildingRespiteKnowledge.pdf>

household tasks that may be beyond their strength or fatigue level. Simply stated, individuals with episodic disabilities may require accommodations, but the care needs are not such that respite in the form of “time away” is necessary because the caregiver is unable to have undisturbed sleep, recreational time on their own or pursue work and leisure activities. Rather, focusing on **respite of choice**, as defined by the caregiver’s needs, whether that is theatre tickets, a gym membership or dinner out with a friend, has been identified as an important distinction.

For those with degenerating episodic disabilities, “time away” respite may be a fundamental support for caregivers who are providing long-term, daily care for an individual with a chronic illness, particularly when the patient is not mobile or suffering from dementia or other cognitive challenges and can’t be left alone. Time off from caring may be provided by other family members, friends or neighbours, a private caregiver, a respite service or through government arranged home care (Pyper, 2006).

### ***c. The need for peer supports<sup>14</sup>***

Caregivers must have the ability to access personal emotional support for their needs that allows the caregiver to give voice to their experiences – both positive and negative. These supports include:

- Individual counselling
- Peer support groups offered through community agencies

- Telephone support
- Internet chat groups
- Booklets and other written resources

Support groups and services should also be tailored to support the specific social-emotional needs of various groups such as Young Carers, caregivers of those with mental health illness, men, LGBTQ carers, and couples groups. It is also important to ensure that support is available in a variety of languages with sensitivity to the needs and values of different cultural groups.

### ***d. Health care providers: The need to serve the caregiver***

The health care system provides a variety of primary care, acute medical, rehabilitative, and home care services that can be central to the care and well-being of the individual with an episodic disability. Services in the form of medical assistance, housekeeping, transportation, and opportunities for social interactions, such as day programs, can also assist the caregiver.

In making assessments of care needs one must also examine the effect of such services on the caregiver. It is most often assumed that if the patient is well-served, so too is the rest of the family/caregiver (Walsh, 1988). In many instances this is usually true. As Walsh warns, however, one must be careful as there can be times when “doing right” by the patient, in fact, may add to the caregiver’s/family’s burden (e.g., providing for at-home medical procedures that a family member is uncomfortable

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<sup>14</sup> This is canvassed in detail in the Environmental scan

administering). Likewise, home support services may lessen the load with respect to housekeeping or direct patient care, but may add stress to the household as support workers come and go and disrupt other family and household routines.

***e. Networks of friends and family: The need to share the care***

Discussions about caregiving often presume that there is a single caregiver for the care recipient. This focus on a single dyad overlooks the fact that care is often negotiated and shared among spouses, children, parents, friends and neighbours, as well as with health and human service professionals (Lero et al., 2007).

“Caring convoys” reflect the reality that caregiving is often shared among a larger network of friends and family (Kemp et al., 2013). When there are others to share the care, they also support the caregiver. The internet provides a tangible way to share care among many caregivers via personalized websites that allow caregivers/care receivers to register with family and friends for the kinds of services they need such as child care, transportation, meals etc. (e.g., Caring Bridge<sup>15</sup>). Web-based sharing of information among friends and family can also be integrated with confidential information sharing of health information with agencies or professionals through a medium such as Tyze.<sup>16</sup>

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<sup>15</sup> <http://www.caringbridge.org/>

<sup>16</sup> See [www.Tyze.com](http://www.Tyze.com)

### 3. Employment Supports

***a. The employed caregiver: The need for flexible workplace practices and more flexible leave options***

In 2012 approximately 60 percent of caregivers age 15-64 were employed. Not surprisingly, many employed caregivers (roughly 6 in 10) cope with competing work and caregiving demands by arriving late or leaving work early, taking time off when needed (part or full days), or reducing their work hours. Time pressures are particularly acute for the 28% of caregivers who are also managing childrearing (Sinha, 2013).

Recent research suggests that many Canadian employers do not yet see the needs of caregivers as an important business issue, with few providing flexible work options, financial assistance or information and resources specific to caregiving (Lero, Spinks, Fast & Tremblay, 2013). Yet, the costs to employers of not addressing the needs of employees with caregiving responsibilities can be considerable, and is only expected to increase as the number of employees who are caregivers increases.<sup>17</sup>

There are significant benefits to employers when they have an organizational culture and policies that support caregiving:

- Increased work performance
- Employee retention
- Stress reduction
- Healthcare cost prevention

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<sup>17</sup> Keating, Fast, Lero, Lucas & Eales (in press)

➤ Reduced absenteeism<sup>1819</sup>

The fluctuating capacity of workers with an episodic disability presents real challenges for the employee and the employer (Sweetland, Howse & Playford, 2012). This also filters to the caregiver. During periods of relative “wellness”, employees with an episodic disability may often manage the demands of the workplace fairly well; caregivers can also manage. An unexpected relapse or flare-up, however, can mean the employee, even if just temporarily, may be unable to meet the demands of their work role – often with little or no notice to the employer.

Increasing efforts are being made to sensitize employers to the importance of accommodating employees with caregiving responsibilities, both from a business perspective and to prevent discrimination due to family status amongst those who are caregivers (Canada Human Rights Act<sup>20</sup>, Ontario Human Rights Code, 1982).

One important policy issue for caregiving employees is access to compassionate care leave. Currently, most provinces, including Ontario, provide for Family Care (or

Compassionate Care) Leave – typically up to 8 weeks of unpaid leave to provide care or support to a gravely ill family member or close friend who is at risk of dying within six months.<sup>21</sup> Partial income replacement is available through federal Employment Insurance Compassionate Care Benefits to those who qualify with a doctor’s certificate attesting to the seriousness of the patient’s condition. To date, many employees have not formally applied for compassionate care leave or benefits, but instead use paid sick days or vacation days or unpaid leave. One concern is the requirement that the family member must be terminally ill. As a consequence, many circumstances that may require a caregiver to take a leave of absence to provide care and support during a period of crisis that is not life threatening will be unable to use these provisions. Employees with low or modest incomes and those whose employers or managers are not particularly sympathetic may find these situations particularly challenging.

The province of Ontario recently gave royal assent to a new bill which amends the *Employment Standards Act* and implements new leaves for family members who need to provide care: 8 weeks of job protected unpaid family caregiver leave and 37 weeks to care for a critically ill child<sup>22</sup>. These

<sup>18</sup> <http://www.fcns-caregiving.org/wp-content/uploads/2013/11/Employer-Toolkit-Digital-Version-FINAL.pdf>

<sup>19</sup> A win-win proposition: The business case for actively recruiting and retaining people with episodic disabilities.  
[http://www.hivandrehab.ca/EN/episodic\\_disabilities/documents/The-Business-Case-for-Actively-Recruiting-and-Retaining-People\\_with\\_Episodic\\_Disabiliti.pdf](http://www.hivandrehab.ca/EN/episodic_disabilities/documents/The-Business-Case-for-Actively-Recruiting-and-Retaining-People_with_Episodic_Disabiliti.pdf)

<sup>20</sup> Canada Human Rights Act (R.S.C., 1985, c.H-6)

<sup>21</sup> See

<http://www.labour.gov.on.ca/english/es/faqs/fml.php>

<sup>22</sup> Bill 21: Ontario Family Caregivers Bill (Employment Standards Amendment Act -- Leaves to Help Families) (Royal Assent April 30, 2014)

leaves have the benefit of not being strictly reserved for a dying family member, but can be used to address broader caregiving needs associated with caring for an elderly individual or someone with a chronic or episodic health condition.

There are no statistics specifically related to employment-related consequences for employees who are caregivers for people living with an episodic disability. The timing of episodic disability in the life course would suggest that most caregivers are likely to be employed and may experience repeated instances when meeting work and caregiving demands will be challenging (see for example Fast, Dosman, Lero & Lucas, 2013 who considered the life course demands of caregiving).

Advocacy of the rights and needs of caregivers is increasingly finding a foothold as our population continues to age and as the need for caregivers continues to grow. The Canadian Caregiver Coalition (CCC)<sup>23</sup> has advocated that provincial and federal governments recognize the “integral role of family caregivers” by creating flexible workplace environments that respect caregiving obligations. The UK’s “right to request” legislation<sup>24</sup> mandates employers to seriously consider an employee’s request for time off to care. This provision also protects the worker from being

dismissed because they asked for accommodations.

Accommodating caregiving needs can be accomplished through workplace strategies including:

- Paid personal leave days
- Use of vacation time
- Flextime
- Working from home
- Job sharing
- Part-time and reduced load options
- Phased retirement
- Leaves of absence (paid/non-paid)

#### 4. Financial and Legal Supports

##### a. *Greater losses; more expenditures: The need for income supports and access to extended health and drug benefits*

Caregivers of individuals with episodic disabilities may face income loss on two fronts: the loss of income by the ill spouse/partner and the challenges the caregiver may face maintaining his or her own income/workplace attachment in the face of caregiving demands.

It has been acknowledged that episodic disability often rests in a grey zone of disability income replacement policies due to the complicated nature of illness progression, often yielding inadequate coverage for the individual with the episodic disability (Lightman & Vick, 2009).

One of the ongoing challenges for people with episodic disabilities, particularly in the decades in which the illness is not all encompassing, is

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<sup>23</sup> See CCC press release at <http://www.ccc-ccan.ca/media.php?mid=380>

<sup>24</sup> <https://www.gov.uk/flexible-working/overview>

that most income replacement programs (e.g., CPP-D, work accessed short-term disability leave benefits, etc.) are not designed for individuals who are still attached to the workforce, even if only part-time. In other words, many income replacement models are not designed to accommodate individuals who may need periods of part-time work or intermittent leaves of absence to cope with the consequences of an episodic disability. Hurt identifies this as “residual work capacity” (2007, p.3). Typically, federal income replacement models, such as Canada Pension Plan Disability (CPP-D) or sickness benefits through Canada’s federal Employment Insurance require that you are either “in” (able to sustain some attachment to the workforce and thus ineligible for benefits) or you are “out” (unable to maintain ANY attachment to the workforce and thus eligible for income replacement). There is very little leeway to navigate the spaces in-between (Lightman et al., 2009; Hurt, 2007; Moss, 2000).

It is our contention that this situation, in turn, has often left the needs of caregivers similarly under-addressed. Reduction or retreat from the work force for *both* the care receiver and caregiver not only affects income, but also can affect access to important employment benefits such as extended medical coverage for drug and dental care, and other health related medical services such as occupational and physio-therapists, nursing services and assistive devices.

In addition to compromised incomes, the family may also face increased monetary outlays for medications,

paid caregiving, household help, therapies, mobility aids and home modifications (Duncan, et al., 2013; Stadnyk, Fletcher, Eales, Fast & Keating, 2009). The “catch-22” here is that as income levels decrease, or are in greater jeopardy, the family is faced with increased expenses associated with the episodic disability.

Approximately one in five caregivers (this applies to ALL types of caregiving) receive some type of financial support. According to data from the 2012 General Social Survey the most likely source comes from family and friends (12%). Only a small minority of caregivers receive financial assistance from government sources: only 7% of caregivers received help from a government program. Caregivers in receipt of income support were more likely to be caring for a child (49%) or a spouse (28%).<sup>25</sup> Not surprisingly, the greater the number of care hours provided, the more likely the caregiver was in receipt of financial assistance.

For a person living with an episodic disability, continued attachment to the workforce may give access to other important income supplementation including short-term disability and/or long-term disability benefits as well as extended health and medical insurance coverage. This is important not only for the individual with the episodic disability, but also can add immeasurably to

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<sup>25</sup> As Sinha notes, eligibility requirements for these types of government supports are often linked to these types of family relationships.

allowing a couple or family to deal with the financial implications of the illness. It can also lower the financial burden on the caregiver who serves as the main income earner.

The lack of an adequate income safety net for those with moderate or cyclical disabilities has been identified as a serious issue (Prince, 2008; Stapleton, 2013). Currently, federal Employment Insurance provides 15 weeks coverage in the event of a short-term documented illness for those deemed to still be employable. For those who are disabled and no longer able to work, coverage is provided under the Canada Pension Plan (CPP-D).<sup>26</sup> Many episodic disabilities fall between the cracks of coverage, meaning that individuals with an identified episodic disability often lack adequate income replacement, potentially increasing the burden for a working caregiver or other family members (Prince, 2008). According to Prince (2008) a substantial proportion of adults with disabilities do not have access to, or qualify for, federal, provincial or private income supports. As a result, 27% of disabled non-seniors are low income (Spector & Kapsalis, 2005 in Prince 2008). Furthermore, as the prevalence of precarious employment and contract work increases, access to both employer-provided income supports such as long-term disability and sickness benefits through Employment Insurance are becoming available to a smaller percentage of the workforce that must turn instead

to social assistance (welfare) and a life of poverty (Stapleton, 2013).

### ***c. Tax Credits: The need for tax advice***

If the illness progresses to substantial disability, the supporting caregiver may be eligible for tax credits through both federal and provincial initiatives. According to the 2012 GSS, only 5% of caregivers received Federal tax credits such as the *Caregiver Tax Credit*, *Infirm Dependant Tax Credit*, or *Medical Expense Tax Credit* (Sinha, 2013). While an acknowledgement of some of the expenses associated with caregiving, non-refundable tax credits are not the same as receiving money to off-set expenses and tend to be of greater financial benefit to those with higher incomes, and less, or not at all beneficial to low and modest income households, which often include individuals with a disability or chronic illness. One exception is the province of Nova Scotia that provides a caregiver benefit of \$400/month available to caregivers of low-income adults who have a high level of disability or impairment.<sup>27</sup>

Supports for families dealing with episodic disability should consider that there may be a need for tax advice around eligibility for tax credits and assistance with the preparation of annual tax returns in order to properly claim and document any entitlements.

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<sup>26</sup> CPP-D covers all provinces and territories except for Quebec, which administers its own program

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<sup>27</sup> <http://novascotia.ca/dhw/ccs/FactSheets/Caregiver-Benefit.pdf>

***d. Compromised retirement: The need to plan for the future while living with episodic disability in the present***

Retirement is shaped by many forces, but sufficient financial resources is a primary one. Unlike those facing illness in old age after a life time spent planning and saving for this event, individuals with episodic disabilities tend to find themselves being diagnosed and having to make necessary financial adaptations to cope with the illness during their critical earning years. The ability to continue earning – for the caregiver and for the individual with an episodic disability – has long-term implications for retirement.

A caregiver’s ability to save for retirement can be compromised on two fronts – the inability of the care receiver to adequately save for retirement and access benefits as well as the caregiver’s own compromised ability. Caregivers are more likely to retire early, particularly women. The higher the care burden, the earlier one is likely to retire (Fast et al., 2013).

Reducing time in paid work or leaving the workforce due to illness or caregiving impacts many facets of retirement income including:

- Failure to maximize contributions to the Canada Pension Plan, thus lowering benefits payable
- Compromised ability to contribute to a Registered Retirement Savings Plan (RRSP)
- Inability to fully contribute to a company/employer-based pension plan

- Difficulty paying off a home mortgage by the age of retirement

The acquisition of adequate life insurance or disability insurance is often a part of ‘future’ planning, but individuals with episodic disabilities will likely find themselves ineligible to acquire such income replacement alternatives once they have a “pre-existing condition.”

Individuals with episodic disabilities who are being cared for by a partner/spouse or children have their financial lives closely intertwined. These caregivers are in need of information and support to help them understand their current and future needs and direct them to all possible supports to allow them to take full advantage of those resources that can help with the present and their future (e.g., Registered Educational Savings Plan, Canada Child Tax Benefits, GST/HST rebates).

Not all individuals with an episodic disability are necessarily low income; other income earners in the household may buffer the economic resources (Galarneau & Radulescu, 2009). Whether an individual or couple will be able to afford to contribute to a Retirement Savings Plan or savings account (e.g., Tax Free Savings Account – TFSA) will perhaps require the services of a bank or financial management firm for guidance. Many banks now offer on-line retirement calculators that may be beneficial.

At the very least, there is a need for individuals to learn about what possible retirement income will be

available to them including through government options such as the:

- Canada Pension Plan (CPP) - tied to years of work and income earned
- Old Age Security (OAS) - available to all, but clawed back for higher income earners
- Guaranteed Income Supplement (GIS) - available to those in receipt of OAS who may need to have their income boosted due to lack of contributions to CPP, perhaps due to illness or compromised attachment to the workforce.

**e. Legal services: The need to access cost-appropriate resources**

Though seldom mentioned, access to legal services and supports can be vital to individuals and their families who are facing the realities and repercussions of episodic disability. As a recent report by the Canadian Bar Association<sup>28</sup> has made clear, access to legal justice is quite abysmal in Canada. This report takes note that individuals should have access so that “essential” legal needs are met.

*Essential legal needs are those that arise from legal problems or situations that put into jeopardy a person or a person’s family’s security – including liberty, personal safety and security, health, employment, housing or ability to meet the basic necessities of life. (p. 25)*

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<sup>28</sup> Canadian Bar Association. (2013, August). Reaching equal justice: An invitation to envision and act. Available at [http://www.cba.org/CBA/equaljustice/secure\\_pdf/Equal-Justice-Summary-Report-eng.pdf](http://www.cba.org/CBA/equaljustice/secure_pdf/Equal-Justice-Summary-Report-eng.pdf)

Living with an episodic disability can result in a wide range of “essential” legal needs including wills and estate planning, protection of rights for employment, housing, and access to disability benefits, and family law matters (Kerzner, 2008). These legal needs are discussed below.

*Wills and Estates.* Diagnosis of an episodic disability will necessitate that individuals realize the need to plan for the future to deal with potential incapacity (Power of Attorney), death (Will and Estate Planning) and Guardianship of minor children, when applicable. Ensuring that someone has the proper and legal authority to make critical medical decisions and to oversee financial resources is an aspect of “personal safety and security”.

*Protection of Rights.* Individuals with episodic disabilities and their caregivers may also find that they need legal advice if dealing with discrimination with regards to employment or housing or collecting compensation from insurance, government, employers or other sources – all of which fall under the various headings associated with essential need.

*Family law.* As discussed earlier, it is not unusual for a breakdown in one’s marital or common-law relationship to occur as a result of the stresses associated with coping with an illness. Legal representation is needed to ensure that rights and obligations are protected. Family law has been particularly vulnerable to a lack of access to legal representation. It is currently estimated that 50% of

family law litigants are self-representing, thereby potentially exposing themselves to being unable to fully have their financial and personal interests protected (Birnbaum, Bala and Bertrand, 2013).

Access to justice is already an issue for most Canadians (CBA, 2013) and this is most pronounced for those of limited financial means. Legal Aid has been woefully inadequate for addressing the types of concerns identified above and individuals with incomes of \$208/week or more are ineligible based on the income-needs test; a qualification level so inadequate that it is unable to address citizens' most basic legal needs.

## Conclusions

The onset of episodic disabilities in young adulthood or midlife and the long-term, unpredictable and fluctuating nature of these illnesses yields challenges for caregivers that are both similar and different to those experienced by those who care for a person with a long-term disability or aging-related conditions. Caregivers can face distinct challenges in being called on to care by virtue of their age (young carers), gender (male), other caregiving responsibilities (usually women with children) and the difficulties of balancing paid work or school with caring. Caregiving may be very different for episodic stable conditions, with care needs that are fluctuating and unpredictable, but possibly lasting for decades. For those managing a degenerating episodic disability, the overall trajectory of decline may eventually lead to high

care needs and associated higher caregiver burdens.

An episodic disability may add stress to family relationships, interfere with paid employment, compromise the parenting of children, or inhibit the ability to plan for the future, including saving for retirement. The closer the relationship the caregiver has with the individual with an episodic disability, the greater the potential for financial and relationship repercussions.

Often the needs of the care recipient and caregiver are closely intertwined. Policies, programs and services that serve the care recipient, such as workplace accommodations, may benefit the caregiver by helping to maintain the household income for a longer period of time. Similarly, home care, rehabilitative services, and respite from others can reduce caregiving demands and caregiver burden.

The research on what caregivers need in the earlier stages of episodic disability, before the illness is severe and needs are acute (for which there are many identified services and programs), has not been adequately investigated to date. The importance of caregivers as a resource to the people they care about and for our health care system is clear. To date, the needs of caregivers to individuals with episodic disabilities have been overlooked. It is important that caregivers of people living with episodic disabilities have access to information, emotional support and practical resources in their communities in order to sustain their

capacities and maintain the quality of family/friend care.

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**Appendix A**  
**List of 27 Episodic Disabilities**  
**(Furrie, 2010)**

ALS (Amyotrophic Lateral Sclerosis)
Arthritis
Asthma
Cancer
Chronic bronchitis
Chronic fatigue syndrome
Diabetes
Emphysema
Epilepsy
Fibromyalgia
Guillain-Barre Syndrome
Hepatitis B
Hepatitis C
HIV/AIDS
Long-term pain
Lupus
Major depression
Menieres disease
Mood disorders
Multiple sclerosis
Muscular dystrophy
Parkinsons
Personality disorders
Repetitive strain injury
Schizophrenia
Severe migraines
Tuberculosis