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"Care that honours seniors is person centered. It focuses on providing individualized care tailored to meet the needs of the person and their family. Care for the caregivers is an important aspect of person centered care as well."

- Respondent to Covenant Health’s "Shape Seniors Care" campaign
Who are Caregivers?

There are many definitions for caregivers (also called family or informal caregivers). Two of note are:

- The Canadian Caregiver Coalition (2001) defines them as individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental conditions.
- The World Health Organization (2012) defines caregivers as those who provide informal unpaid care.

In addition, the act of family caregiving can also be defined in different ways:

- Messecar (2012) defines caregiving as a wide range of unpaid care provided in response to illness or functional impairment to a chronically ill or functionally impaired older family member, partner, friend, or neighbour that exceeds the support usually provided in family relationships.
- Schumacher, Beck, & Marren, (2006) define caregiving as care that is provided in response to illness or functional impairment that exceeds the normal care or help provided within families.

What Impact do Caregivers have on our Health System?

Caregivers are the backbone and increasingly overburdened part of the health care system (Bookman & Harrington 2007). In fact, 70% of all care to seniors in the community is provided by caregivers (Carstairs & Koen 2009). They are an essential component of our health and social care delivery systems and need to be provided with the care and supports that they require to continue in these roles.

Over the past few years the importance of caregivers has been highlighted, along with the import of meeting their needs and recognizing their rights, such as having their needs assessed, having good physical and mental health, being able to continue working and having time away from their caregiving responsibilities. This has resulted in an increase in the amount and quality of services and supports available. Although significant, this increase has not been sufficient to meet the needs of all caregivers.

There is increasing evidence that caregiving is being provided at significant physical, emotional and financial costs to the caregiver (Dumont et al., 2009). A large number of caregivers are stretched beyond their capacity and report high levels of distress (Health Council of Canada, 2012).
Why was this Document Created?

Access to information can be a barrier to receiving the support and information required to enhance day-to-day life for caregivers and care recipients, and can increase the burden felt by caregivers.

This document was developed to provide inventories of resources, services and support organizations that will help support caregivers in Alberta, increasing accessibility.

Please note: The information in this document may not be entirely comprehensive or complete.

References:

Inventory of Current Support Organizations for Caregivers in Alberta

“Care that honours seniors is built on the principles of respect and compassion. Seniors and their loved ones become actively engaged in every aspect of care through direct participation and avenues of reciprocal communication.”

- Respondent to Covenant Health’s "Shape Seniors Care" campaign
Background

The following information includes a list of the organizations that offer caregiver supports to Albertans, along with a description of the organization, and the types of services they offer.

The majority of this list was last updated on October 17, 2014 by Alberta Health. Additional details about some organizations were gathered on September 22, 2015 and some additional organizations were added January 11, 2016 by CH NESHW.

Please note: The information in this section may not be entirely comprehensive or complete.

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General Caregiver Support Organizations

**Alberta Association for Community Living (AACL)**
- AACL is a family based, non-profit that advocates on behalf of children and adults with developmental disabilities, and their families
- It is accessible in Edmonton and Calgary and online
  - [http://www.aacl.org](http://www.aacl.org)
  - 1-800-252-7556
- Types of services offered:
  - Advocacy
  - Resource library
**Alberta Caregiver College (AHS)**
- The Alberta Caregiver College is a virtual college dedicated to providing courses to enhance the knowledge and skills of caregivers to provide for their family member.
- It is accessible to all Albertans online
  - [http://www.caregivercollege.ca/](http://www.caregivercollege.ca/)
  - 780-735-8283
- Types of services offered:
  - Tools and tips for caregivers
  - Online courses

**Alberta Meals-on-Wheels Programmes**
- Meals-on-Wheels provides home-delivered meal and food services.
- It is available at multiple locations across Alberta in person and online
  - [http://www.mealcall.org/canada/alberta/](http://www.mealcall.org/canada/alberta/)
- Types of services offered:
  - Provide home delivered meals
  - Some community locations have freezers

**Canadian Caregiver Coalition (CCC)**
- The CCC is a virtual alliance of diverse partner organizations that work collectively to identify and respond to the needs of caregivers.
- It is accessible online
- Types of services offered:
  - Tools & tips for caregiving
  - Advocacy
  - Links to other resources

**Canadian Nanny**
- Canadian Nanny is a resource and online services for finding a nanny, babysitter, adult caregiver and more.
- It is accessible in Calgary and online
  - [http://www.canadiannanny.ca/](http://www.canadiannanny.ca/)
  - 1-866-221-7918
- Types of services offered:
  - Other education or information resources
  - Online resource for finding a formal caregiver
**Canadian Employers for Caregivers Plan**

- The Government of Canada launched the Canadian Employers for Caregivers Plan (CECP) in June 2014. As part of Economic Action Plan 2014, the federal government committed to working with employers to find cost-effective workplace practices to help informal caregivers participate as fully as possible in the labour market. The plan includes:
  - The establishment of the Employer Panel for Caregivers
  - The development of business cases analyzing the cost-benefit of existing workplace supports
  - The exploration of mechanisms for sustained employer engagement in this area
- It is available online:

**Caregivers Alberta**

- Caregivers Alberta is an organization of caregivers for caregivers offering information, supporting, networking and advocacy.
- It can be accessed in Edmonton and online
  - [http://www.albertacaregivers.org](http://www.albertacaregivers.org)
  - 1-877-453-5088
- Types of services offered:
  - Online and in person support group or network
  - Counselling or therapy (short term)
  - Home visits (on request)
  - Tools and tips for caregiving
  - In person courses
Caregiver College

- Alberta Caregiver College® is a virtual college dedicated to providing courses to enhance the knowledge and skills of caregivers to provide for their family member.
  - The educational programs were developed by the Glenrose Rehabilitation Hospital, Alberta Health Services, with contributions from other partnering organizations in Alberta.
  - The individuals who developed the programs are educators and professionals in rehabilitation and geriatrics and include dietitians, nurses, occupational therapists, physical therapists, physicians, psychologists, social workers, and speech language pathologists.
- It can be accessed online:
  - http://www.caregivercollege.ca/
- Types of services offered:
  - Online courses

Caregiver Connect

- Caregiver Connect is an online collection of information to help and support caregivers.
- It is accessible online
- Types of services offered:
  - Information on specific illnesses or conditions
  - Tools & tips for caregiving
  - General resources about caregiving and self-care

Caregiver Omnimedia Inc.

- The Caregiver Omnimedia works to understand the ever changing caregiver population, connect with them as individuals and consumers, and educate the country to both face the realities of this burgeoning market and effectively promote a new and vital dialogue with them.
- It is accessible online
  - http://www.caregiveromnimedia.com/
- Also see:
  - The Family Caregiver
Care-ring Voice Network

- Care-ring Voice is a free, bilingual and confidential program that connects caregivers and families to information and support through tele-learning.
- It is accessible online and telephone
  - 1-866-396-2433
- Types of services offered:
  - Online Courses
  - Other education or information resources

Centre for Public Legal Education Alberta (CLEA)

- The CPLEA, formerly known as the Legal Resource Centre contributes to, advances and promotes the legal knowledge and education of people.
- It is accessible in Edmonton and online
  - [http://pub.cplea.ca/seniors](http://pub.cplea.ca/seniors)
  - 780-451-8764
- Types of services offered:
  - Other education or information resources
  - General information on legal resources for seniors

Family Caregiver Centre

- The Family Caregiver Centre offers support to caregivers who are not paid including connections to healthcare and community services, education programs and more.
- It is accessible in Calgary and online:
  - [http://www.albertahealthservices.ca/services.asp?pid=service&rid=1604](http://www.albertahealthservices.ca/services.asp?pid=service&rid=1604)
  - 403-955-1674
- Types of services offered
  - In person support group or network
  - Counselling or therapy
  - Other education or information resources
  - Resource library
**Health Link Alberta**
- Health Link is a health information portal (telephone and online) for Albertans.
- It is accessible online and by telephone
  - https://myhealth.alberta.ca/Pages/default.aspx
  - Call: 811 (811# on cell phones)
- Types of services offered:
  - Tools & tips for caregiving

**Inform Alberta**
- Inform Alberta is a provincial online directory of not-for-profit community, health, social and government organizations and services.
- It is accessible online
  - http://www.familyberta.ca/
- Types of services offered:
  - Access to advisors or knowledge experts
  - Searchable database of programs, services and organizations

**Jewish Family Services**
- Jewish Family Services provide counselling, support, education, referral and other services to promote the well-being of residents in the greater Edmonton community.
- It is accessible in Edmonton
  - http://www.jfse.org/
  - 780-454-1194
- Types of services offered:
  - In person support group or network
  - Counselling or Therapy
**Medically At-Risk Driver Centre**

- The MARD Centre is committed to enhance the safety and mobility of medically at-risk drivers and all road users. The MARD Centre also is committed to reducing the social and health impacts, as well as the economic costs, associated with medically impaired driving.

- The Mobility Guides developed for the Edmonton and Calgary areas provide valuable information to help promote health and independence and include information on organizations and businesses that provide in-home services and transportation. A majority of the organizations listed have a focus on seniors and/or offer seniors a discount toward the services they offer.

- It is accessible online:
  - Main page: [http://mard.ualberta.ca/](http://mard.ualberta.ca/)

- Types of services offered:
  - Education or information resources
  - Transportation options

**Red Deer Museum and Art Gallery**

- The Red Deer Museum and Art Gallery is piloting social activities for caregivers and recipients.

- It is accessible in Red Deer

- Types of services offered:
  - In person support group or network (monthly)
  - Piloting social activity for caregivers and care recipients including a snack, activity and looking at art
Saint Elizabeth

- Saint Elizabeth provides a full range of integrated care solutions that respond to client, community and health system needs.
- It is accessible in Edmonton and online
  - [http://www.saintelizabeth.com/family](http://www.saintelizabeth.com/family)
  - 1-877-625-5567
- Types of services offered:
  - Tools and tips for caregiving
  - Access to advisors or knowledge experts
  - Helpline
  - Respite funds for distressed caregivers

The Family Caregiver

- The Family Caregiver is a Canadian home care and family caregiving resource website.
- It is accessible online
  - 1-800-209-4810
- Types of services offered:
  - Online support group or network
  - Information on specific diseases or conditions
  - Other education or information resources
Home Care Caregiver Support Organizations

Alberta Health Services (AHS) Home Care

- AHS is the provincial health authority responsible for planning and delivering health supports and services to Albertans.
- It is accessible at multiple locations across the province and online
  - Continuing care - Home Care: [http://www.albertahealthservices.ca/cc/Page13336.aspx](http://www.albertahealthservices.ca/cc/Page13336.aspx)
  - Home Care in My Zone: [http://www.albertahealthservices.ca/cc/Page4482.aspx](http://www.albertahealthservices.ca/cc/Page4482.aspx)
  - Phone numbers:
    - North Zone, Central Zone: 1-855-371-4122 (toll free)
    - Edmonton Zone: 780-496-1300
    - Calgary Zone: 403-943-1920 or 1-855-955-6665 (toll free)
    - South Zone: 403-388-6380 or 1-866-388-6380 (toll free)
- Types of services offered:
  - Online support group or network
  - Counselling or therapy
  - Day programs or respite
  - Information on specific illness or conditions
  - Access to Advisors or Knowledge Experts

Alberta Health Services (AHS): Adult Day Programs (part of Home Care program)

- Adult day programs play a key role in supporting individuals to remain living in their community for as long as possible, by optimizing their physical, spiritual, social, cognitive and emotional functioning, while simultaneously providing support, respite and education to their caregivers. Adult day programs operate during the day on weekdays with clients attending on a routine basis, usually 1-2 days per week.
  - There are two types of adult day programs: basic and comprehensive.
    - Basic adult day programs target stable community-living individuals and focus primarily on the socialization needs of the client and the provision of caregiver respite.
    - Comprehensive adult day programs target medically complex individuals, and in addition to socialization needs, provide a professional health service component including rehabilitation, social work, health monitoring and on-site access to physician services.
- It is accessible online
  - [http://www.albertahealthservices.ca/services.asp?pid=service&rid=1026103](http://www.albertahealthservices.ca/services.asp?pid=service&rid=1026103)
- Types of services offered:
  - Day programs or respite
Alberta Health Services (AHS): Respite Care (part of Home Care program)

- Respite care is part of Alberta Health Services Home Care program. It provides caregivers with a short period of rest or relief from their responsibilities. This can be provided in the home or as short-term facility based care. AHS provides Home Care Services based on assessed health-care needs. This assessment could indicate the consideration of respite services.

- The Home Care in My Zone brochures contain information for home care services as well as contact information:

- It is accessible online:
  - [http://www.albertahealthservices.ca/cc/Page4482.aspx](http://www.albertahealthservices.ca/cc/Page4482.aspx) (Home Care in my Zone)

- Types of services offered:
  - Day programs or respite

Alberta Health Services (AHS): Self-Managed Care Program (part of Home Care program)

- Self-managed care is a program in which eligible home care clients, and/or their legal representative, enter into a contractual agreement with Alberta Health Services. This agreement allows a home care client to receive funding to directly pay for and manage assessed personal care and home support services provided within the province of Alberta. Based on the home care assessment, personal care, home support services and respite care can be purchased with self-managed care funds.

- It is accessible online:

- Types of services offered:
  - Funding Support
Canadian Home Care Association (CHCA)
- The CHCA advances excellence in home care through leadership, awareness, advocacy and knowledge.
- It is accessible online
  - http://www.cdnhomecare.ca/
  - 289-290-4389
- Types of services offered:
  - Advocacy

Palliative Care and Hospice Caregiver Support Organizations

Alberta Hospice Palliative Care Association (AHPCA)
- The AHPCA is a provincial non-profit that builds awareness, and engages the community and government in the provision of hospice palliative care.
- It is accessible in Calgary and online
  - http://ahpca.ca/
  - 403-206-9938
- Types of services offered:
  - In person support group or network
  - Information on specific illness or conditions
  - Directory of services listing

Canadian Hospice Palliative Care Association (CHPCA)
- The CHPCA advances and advocates for quality end-of-life/hospice palliative care in Canada including work in public policy, education and awareness.
- It is accessible online
  - http://www.chpca.net/
  - 1-800-668-2785
- Types of services offered:
  - Information on specific illnesses or conditions
  - Other education or information resources
  - Directory of services listing
**Canadian Virtual Hospice**
- Canadian Virtual Hospice is an online information and support resource on palliative and end-of-life care, loss and grief.
- It is accessible online
  - [http://www.virtualhospice.ca/](http://www.virtualhospice.ca/)
- Types of services offered:
  - Online support group or network
  - Other education or information resources
  - Access to advisors or knowledge experts
  - Caregivers can submit questions for personalized responses from professionals

**Hospice Calgary**
- Hospice Calgary supports children, teens and adults coping with life-threatening illness, sudden or expected death. They have two centres of care: Sage Centre and Rosedale Hospice.
- It is accessible in Calgary
  - 403-263-4525 or 403-284-5195
- Types of services offered:
  - In person support group or network
  - Counselling or Therapy

**Pilgrims Hospice**
- Pilgrims Hospice is a voluntary hospice providing family centered end-of-life care, caregiver support and bereavement services for children, teens, families and adults.
- It is accessible in Edmonton
  - [http://pilgrimshospice.com](http://pilgrimshospice.com)
  - 780-413-9801
- Types of services offered:
  - Counselling or Therapy
  - Day programs or respite
Seniors Caregiver Support Organizations

**ElderCare Edmonton**
- ElderCare Edmonton is a non-profit that assists seniors to remain independent and active in their communities by providing seniors with supportive and structured day programs.
- It is accessible in Edmonton
  - [http://www.eldercareedmonton.ca](http://www.eldercareedmonton.ca)
  - 780-434-4747
- Types of services offered:
  - In person support group or network
  - Day programs or respite
  - Home visits
  - Access to advisors or knowledge experts

**Golden Circle Senior Resource Centre**
- The Golden Circle is a vibrant hub for seniors' to meet, build community and enjoy the company and support of their peers.
- It is accessible in Red Deer
  - [http://www.goldencircle.ca/](http://www.goldencircle.ca/)
  - 403-343-6074
- Types of services offered:
  - Other education or information resources
  - Access to advisors or knowledge experts
  - Outreach coordinators connect caregivers with community resources

**Kerby Centre**
- The Kerby Centre is a not-for-profit organization committed to enhancing the lives of older adults.
- It is accessible in Calgary
  - [http://kerbycentre.com/](http://kerbycentre.com/)
  - 403-265-0661
- Types of services offered:
  - Day programs or respite
Seniors Association of Greater Edmonton (SAGE)
- SAGE works to enhance the quality of life of older person and their families.
- It is accessible in Edmonton
  - [www.mysage.ca](http://www.mysage.ca)
  - 780-423-5510
- Types of services offered:
  - Access to advisors or knowledge experts
  - Provide programs for finances and referrals for housekeeping and other supports

Immigrant Caregiver Support Organizations

ASSIST Community Services Centre
- ASSIST provides diversified services to Canadian immigrants and their offspring, helping them integrate into and contribute to mainstream society.
- It is accessible in Edmonton and online
  - 780-429-3111
- Types of services offered
  - Counselling and therapy
  - Language Services: general orientation to health and care for newcomers

Multicultural Women and Seniors Services Association (MWSSA)
- The MWSSA is a non-profit organization helping immigrants and people newly arrived to integrate into Canadian society by providing education, counselling and other support services.
- It is accessible in Edmonton
  - [http://www.mwssa.org/](http://www.mwssa.org/)
  - 780-465-2992
- Types of services offered:
  - Home visits
  - Assistance with shopping and meals
  - Translation services
ALS (Amyotrophic Lateral Sclerosis) Caregiver Support Organizations

**ALS Society of Alberta**
- The ALS Society of Alberta supports people living with and affected by ALS across Alberta.
- It is accessible in Edmonton and Calgary and online
  - [http://www.alsab.ca/](http://www.alsab.ca/)
  - 1-888-309-1111
- Types of services offered:
  - In person support group or network
  - Home visits
  - Information on specific illnesses or conditions
  - Advocacy
  - Equipment loans

**Autism Caregiver Support Organizations**

**Autism Calgary**
- Autism Calgary provides a voice and supports individuals with autism spectrum disorder and their families.
- It is accessible in Calgary
  - 403-250-5033
- Types of services offered:
  - In person support group or network
  - Information on specific illnesses or conditions
  - Resource library

**Autism Society Alberta (ASA)**
- ASA is a network and collaboration amongst autism groups in Alberta providing support and creating awareness of individuals with autism spectrum disorder and their families.
- It is accessible in Calgary and online
  - [http://www.autismsocietyalberta.org/](http://www.autismsocietyalberta.org/)
  - 1-877-777-7192
- Types of services offered:
  - Information on specific illnesses or conditions
  - Advocacy
**Autism Society of Edmonton Area (ASEA)**

- ASEA helps families and communities embrace and support people on the autism spectrum by providing information, programs and supports.
- It is accessible in Edmonton
  - [http://www.autismedmonton.org/](http://www.autismedmonton.org/)
  - 780-453-3971
- Types of services offered:
  - In person support group or network
  - Information on specific illnesses or conditions
  - Advocacy

**Centre for Autism Services Alberta**

- The Centre for Autism Services Alberta offers programs, services and supports to individuals diagnose with autism as well as to family members.
- It is accessible in Edmonton and online
  - [http://www.centreforautism.ab.ca/](http://www.centreforautism.ab.ca/)
  - 780-488-6600
- Types of services offered:
  - Day programs or respite
  - In person courses
  - Resource library

**Cancer Caregiver Support Organizations**

**Canadian Cancer Society (Alberta Region)**

- The Canadian Cancer Society is a community based organization whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer.
- It is accessible in Edmonton and Calgary and online
  - [http://www.cancer.ca/en/?region=ab](http://www.cancer.ca/en/?region=ab)
  - 403-205-3966
- Types of services offered:
  - Online support group or network
  - Information on Specific illnesses or conditions
  - Other funding available: transportation for those accessing treatments from a rural location
Mesothelioma Prognosis Network

- The Mesothelioma Prognosis Network is accessible online:
  - [http://www.mesotheliomaprognosis.com/mesothelioma](http://www.mesotheliomaprognosis.com/mesothelioma)
- Types of services offered:
  - Connecting caregivers to treatment and support groups
  - Information on specific illnesses or conditions
  - Advocacy

Cerebral Palsy Caregiver Support Organizations

Calgary Cerebral Palsy Association

- The Calgary Cerebral Palsy Association provides support, resources, programs and opportunities to Calgary area individuals and families affected by cerebral palsy.
- It is accessible in Calgary:
  - [http://www.calgarycp.org/](http://www.calgarycp.org/)
  - 403-205-4935
- Types of services offered:
  - Information on specific illnesses or conditions
  - Funding request program for recreational programs, daily living aids, summer camp subsidy, etc.

Cerebral Palsy Association in Alberta (CPAA)

- The CPAA is a non-profit organization that supports people affected by cerebral palsy and other disabilities in Alberta.
- It is accessible in Edmonton and Calgary and online:
  - [http://www.cpalberta.com/](http://www.cpalberta.com/)
  - 1-800-363-2807 or 1-888-477-8030
- Types of services offered:
  - Counselling or therapy
  - Home visits
  - Information on specific illnesses or conditions
  - Funding request program
**Edmonton Cerebral Palsy Association**

- The Edmonton Cerebral Palsy Association provides assistance to those affected by cerebral palsy.
- It is accessible in Edmonton
  - [http://www.edmontoncp.com/](http://www.edmontoncp.com/)
  - 780-453-6950
- Types of services offered:
  - Information on specific illnesses or conditions
  - Equipment funding programs or equipment lending programs

**Dementia and Alzheimer's Disease Caregiver Support Organizations**

**Alberta Health Services (AHS) Dementia Advice Line**

- The Dementia Advice line offers 24/7 telephone nurse advice for individuals and caregivers living with Dementia and Alzheimer's
  - When needed, callers will be referred to a specialized dementia nurse for additional support.
- It is accessible by phone
  - Call: 811 (811# on cell phones)
- Types of services offered:
  - Helpline

**Alzheimer's Disease International (ADI)**

- ADI is the International federation of Alzheimer associations around the world, in official relations with the World Health Organization. Each member is the Alzheimer association in their country who support people with dementia and their families. ADI's vision is an improved quality of life for people with dementia and their families throughout the world.
- It is accessible online
  - [www.alz.co.uk](http://www.alz.co.uk)
- Types of services offered:
  - Information on specific illnesses or conditions
  - Other education or information resources
  - Education for Alzheimer's association staff and volunteers
Alzheimer Society of AB and NWT (and national)

- The Alzheimer Society of AB and NWT heightens awareness about Alzheimer's and dementia, provides support services, and supports research into the cause and a cure.
- It is accessible at multiple locations across Alberta and online
  - http://www.alzheimer.ab.ca
  - 1-866-950-5465
- Types of services offered:
  - Online and in person support group or network
  - Counselling or therapy
  - Home visits
  - Information on specific illnesses or conditions
  - Tools and tips for caregiving
  - Online courses
  - Other education or information resources
  - Access to advisors or knowledge brokers
  - Resource library
  - ASANT Café

Alzheimer Society of Calgary

- The Alzheimer Society of Calgary works to ensure that people with dementia and their families have access to education, care and support in Calgary and surrounding areas.
- It is accessible in Calgary and online
  - http://www.alzheimercalgary.ca
  - 403-290-0110
- Types of services offered:
  - In person support group or network
  - Counselling or therapy
  - Day programs or respite
  - Information on specific illnesses or conditions
  - Tools and tips for caregiving
  - Online and in person courses
  - Other education or information resources
  - Access to advisors or knowledge experts
  - Helpline
  - Resource library
  - Best friends approach training for care providers and students
Golden Age Drop In Centre - Alzheimer’s Support Group

- Golden Age Drop In Centre offers a support group for Alzheimer's caregivers
- It is available in Coronation
  - 403-578-3410
- Types of services offered:
  - In person support group or network

Down Syndrome Caregiver Support Organizations

**Canadian Down Syndrome Society**

- The Canadian Down Syndrome Society is a national non-profit providing information, advocacy and education about Down syndrome.
- It is accessible in Calgary and online
  - [http://www.cdss.ca/](http://www.cdss.ca/)
  - 1-800-883-5608
- Types of services offered:
  - In person support group or network
  - Information on specific illnesses or conditions
  - Other education or information resources

**Edmonton Down Syndrome Society**

- The Edmonton Down Syndrome Society provides opportunities and experiences for people with Down syndrome to learn, grow and strive for their individual potential.
- It is accessible in Edmonton
  - [http://www.edss.ca/](http://www.edss.ca/)
  - 780-944-4224
- Types of services offered:
  - In person support group or network
  - Information on specific illnesses or conditions
  - In person courses
Ups and Downs Calgary Down Syndrome Association

- Ups and Downs provides education and support for parents and social activities for children and adults with Down Syndrome in Calgary and the surrounding area.
- It is accessible in Calgary
  - [http://www.upsdowns.org/](http://www.upsdowns.org/)
  - 403-289-4394
- Types of services offered:
  - In person support group or network

Epilepsy Caregiver Support Organizations

**Edmonton Epilepsy Association (Northern Alberta)**

- The Edmonton Epilepsy Association promotes an improved quality of life for persons with epilepsy by providing assistance and support to persons with epilepsy and their families.
- It is accessible in Edmonton
  - [http://www.edmontonepilepsy.org/](http://www.edmontonepilepsy.org/)
  - 780-488-9600
- Types of services offered
  - In person support group or network
  - Information on specific illnesses or conditions
  - Access to advisors or knowledge experts
  - Resource library

**Epilepsy Association of Calgary**

- The Epilepsy Association of Calgary is a charitable social service agency that addresses community, individual and family needs related to epilepsy.
- It is accessible in Calgary
  - [http://www.epilepsycalgary.com](http://www.epilepsycalgary.com)
  - 403-230-2764
- Types of services offered:
  - In person support group or network
  - Information on specific illnesses or conditions
  - Other education or information resources
Epilepsy Canada

- Epilepsy Canada is a non-profit whose mission is to enhance the quality of life for persons affected by epilepsy and who work with partner organizations to deliver direct services to people with epilepsy and their families.
- It is accessible online or by phone
  - http://www.epilepsy.ca/
  - 1-877-734-0873
- Types of services offered:
  - Information on specific illnesses or conditions

Heart Disease Caregiver Support Organizations

Heart and Stroke Foundation of Alberta

- The Heart and Stroke Foundation is a volunteer-based health charity focused on the advancement of research and its applications, the promotion of healthy living and advocacy.
- It is accessible in multiple locations across Alberta and online
  - http://www.heartandstroke.ab.ca
  - 1-888-473-4636
- Types of services offered:
  - Information on specific illnesses or conditions
  - Other education or information resources
  - Advocacy
Huntington Disease Caregiver Support Organizations

Huntington Society of Canada (Alberta Centres)

- The Huntington Society of Canada is a not-for-profit charitable organization which raises funds to deliver individual and group counselling service to support individuals and families living with Huntington disease (HD) and to fund medical research to delay or stop the progression of the disease.

- It is accessible at Alberta Chapters across the province and online on the national webpage
  - [http://www.huntingtonsociety.ca/](http://www.huntingtonsociety.ca/) (national site)
  - [http://www.huntingtonsociety.ca/chapters-near-you/](http://www.huntingtonsociety.ca/chapters-near-you/) (list of Chapters)

- Types of services offered:
  - Counselling or Therapy
  - Information on specific diseases or conditions
  - Provides community referral and community service provider education

Liver Disease Caregiver Support Organizations

Canadian Liver Foundation (CLF)

- The CLF provides support for research and education into the causes, diagnoses, prevention and treatment of all liver diseases.

- It is accessible in Calgary and online
  - [http://www.liver.ca/](http://www.liver.ca/)
  - 403-276-3390

- Types of services offered:
  - Information on specific illnesses and conditions
Mental Health Caregiver Support Organizations

211 Alberta - Edmonton and Area

- 211 is a 24-hour information and referral line that is operated by the Canadian Mental Health Association – Edmonton Region. 211 provides information/referral services and connects people to a full range of essential social, health, and government services in the community.

- It is accessible in the Edmonton area and has online resources
  - Call: 211 (Edmonton, Leduc, Parkland County)
  - 780-482-4636 (other areas)
  - www.ab.211.ca (self-service site)
  - http://edmonton.cmha.ca/programs_services/211-alberta-edmonton-and-area/#.Vp58CLYrLct (information)

- Types of services offered:
  - Tools and tips for caregivers
  - Information and referrals

Alberta Mental Health Help Line

- The Alberta Mental Health Help Line provides a confidential, anonymous services including information about mental health programs and services, and crisis intervention.

- It is accessible by phone
  - http://www.albertahealthservices.ca/services.asp?pid=service&rid=6810
  - 1-877-303-2642

- Types of services offered:
  - Helpline

Canadian Mental Health Association (CMHA) (including regional chapter)

- The CMHA promotes mental health of all and supports people experiencing mental illness.

- It is accessible in Edmonton and online
  - http://alberta.cmha.ca/
  - 780-482-6576

- Types of services offered:
  - In person support group or network
  - Information on specific illnesses or conditions
  - Tools & tips for caregiving
**Schizophrenia Society of Alberta**

- The Schizophrenia Society of Alberta works towards improving the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy and research.
- It is accessible in multiple locations across Alberta
  - [http://www.schizophrenia.ab.ca/](http://www.schizophrenia.ab.ca/)
  - 403-986-9440
- Types of services offered:
  - In person support group or network
  - Information on specific diseases or conditions
  - In person courses
  - Respite survey and study

**Multiple Sclerosis Caregiver Support Organizations**

**MS Society of Canada (AB & NWT Division)**

- The MS Society provides services to people with multiple sclerosis and their families, and funds research to find the cause and cure for the disease.
- It is accessible in multiple locations across Alberta and online
  - [http://mssociety.ca/alberta/](http://mssociety.ca/alberta/)
  - 1-800-268-7582
- Types of services offered:
  - In person support group or network
  - Counselling or Therapy
  - Home visits
  - Information on specific diseases or conditions
  - Other education or information resources
  - Resource Library
  - Equipment purchase funding, equipment loans, special assistance funding
Muscular Dystrophy Caregiver Support Organizations

Muscular Dystrophy Canada

- Muscular Dystrophy Canada is a non-profit organization providing support and resources to clients impacted by neuromuscular disorders.
- It is accessible online
  - [http://muscle.ca/](http://muscle.ca/)
  - 1-800-366-8166
- Types of services offered:
  - Online and in person support group or network
  - Information on specific diseases or conditions
  - Other education or information resources
  - Financial assistance for equipment
  - Funds for respite services

Parkinson's Disease Caregiver Support Organizations

Parkinson Society of Canada

- Parkinson Society Canada provides education, support and advocacy on behalf of Canadians living with Parkinson's.
- It is accessible online
  - [http://www.parkinson.ca](http://www.parkinson.ca)
  - 1-800-565-3000
- Types of services offered:
  - Counselling or Therapy (available over the phone)
  - Information on specific diseases or conditions
  - Tools and tips for caregiving
Parkinson Alberta

- Parkinson Alberta provides support to Albertans affected by Parkinson's disease, including patients, family, friends, caregivers and healthcare professionals.
- It is accessible in multiple locations across Alberta and online
  - [http://www.parkinsonalberta.ca/](http://www.parkinsonalberta.ca/)
  - 1-800-561-1911
- Types of services offered:
  - In person support group or network
  - Counselling or Therapy
  - Information on specific diseases or conditions
  - Other education or information resources
  - Helpline
  - Advocacy
"Care that honours our seniors means including them in the care planning as much as possible. Being transparent, ethical, respectful and patient with each senior and their family members/caregivers.

Reminding yourself that you are working with someone that still has lots to offer and that has experienced many things in their lifetime. Taking the time to hear their story to better understand where that senior is coming from."

- Respondent to Covenant Health's "Shape Seniors Care" campaign
Background

Many of the documents listed below were identified by the Covenant Health and University of Alberta's Discovery Toolkit Project Team and included on page 39 of the toolkit. Other documents were identified by the Alberta Dementia Strategy and Action Plan’s Caregiver Supports Working Group and the Enhancing Caregiver Education and Supports Project team.

Please note: The information in this section may not be entirely comprehensive or complete.

General Caregiver Resource Documents

- Discovery Toolkit for Supporting Caregivers of Seniors: Improving Care and Caregiver Outcomes:
  - [http://www.shapeseniorscare.ca/providing-a-gateway-to-information/documents/2730/download](http://www.shapeseniorscare.ca/providing-a-gateway-to-information/documents/2730/download)


- Caregiver Consultation 2010: Towards a Provincial Caregiver Strategy (Alberta Caregivers Association, 2010)

- Family caregiving: What are the consequences? (Statistics Canada, 2013)

- Health Care in Canada, 2011: A focus on Seniors and Aging (Canadian Institute for Health Information, 2011)

- Portrait of caregivers, 2012 (Sinha M, Statistics Canada, 2012)
  - [www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm](http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm)

- Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada (Health Council of Canada, 2012)

- Study: Caregivers in Canada, 2012 (Statistics Canada)
  - [www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.htm](http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.htm)

- Supporting people who care for older family members (Parmar J, et al., Canadian Medical Association Journal, 2015)
  - [http://www.cmaj.ca/content/186/7/487?citedby=yes&legid=cmaj;186/7/487](http://www.cmaj.ca/content/186/7/487?citedby=yes&legid=cmaj;186/7/487)
• Supporting informal caregivers – the heart of home care (Canadian Institute for Health Information, 2010)
  ○ https://secure.cihi.ca/free_products/Caregiver_Distress_AIB_2010_EN.pdf

• Who cares and how much. The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the Elderly. (Hollander M, Liu G, Chappell N, Healthcare Quarterly, 2009)

• Yours Mine & Ours, Final Report on Alberta Caregivers Strategy Consultations, 2010 (Alberta Caregivers Association)

• Living Longer, Living Well: Seniors Care Strategy Report, 2012 (Government of Ontario, Ministry of Health and Long-Term Care)

• Supporting Informal Caregivers - the Heart of Homecare (Canadian Institute for Health Information, 2010)
  ○ https://secure.cihi.ca/free_products/Caregiver_Distress_AIB_2010_EN.pdf

  ○ http://www.alzheimer.ca/durham/~/media/Files/on/Media%20Releases/2012/April%202012/HCC_HomeCare_2d.pdf

• Carers at the heart of 21st century families and communities, Social Care/ Partnership Working Policy, 2008 (United Kingdom, Her Majesty’s Government)


• Caregiving for Older Adults with Disabilities. Janet Fast, IRPP Study #58, December 2015
Dementia Caregiver Resource Documents

- Dementia – A Public Health Priority (World Health Organization, 2012)
  - http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1
- The Provincial Dementia Action Plan for British Columbia (Ministry of Health, 2012)
- A Strategy for Alzheimer Disease and Related Dementias in Saskatchewan (Government of Saskatchewan, 2005)
- Manitoba’s Framework for Alzheimer’s Disease and Other Dementias (Government of Manitoba, 2014)
- Ontario’s Strategy for Alzheimer Disease and Related Dementias, 1999 (Summary)
- Evaluation of Ontario’s Strategy for Alzheimer Disease and Related Dementias, 2005
- Alzheimer’s Disease and Other Dementias Care Course (Nova Scotia)
- The Provincial Strategy for Alzheimer’s Disease and Other Dementias (Government of Newfoundland and Labrador)
- National Dementia Research and Prevention Plan (Government of Canada, 2014)
- National Plan to Address Alzheimer’s Disease, 2015 Update (United States Government, Department of Health and Human Services)
- Living Well With Dementia: A National Dementia Strategy (United Kingdom, Department of Health, 2009)
• Helping Australians with dementia and their Carers – Making Dementia a national Health Priority (Parliament of Australia, House of Representatives Committees)

• National Plan for "Alzheimer and Related Diseases" 2008-2012 (Government of France)

• Addressing Dementia - the OECD Response. OECD Health Policy Series, March 2013
"Seniors care needs to include family and close friends to the full extent it is legally possible, and communication between caregivers, seniors, family, social factors and friends need to improve vastly. A way has to be found that invites all factors to work together."

- Respondent to Covenant Health’s "Shape Seniors Care" campaign
Background
The resources in this section were compiled by Covenant Health’s Palliative Institute and includes the links and resources that are useful for caregivers of individuals requiring palliative care at the end of life.

Please note: The information in this section may not be entirely comprehensive or complete.

Caregiver Resources for the End of Life

MyHealth Alberta

- Contact information:
  - Website (Palliative Care): https://myhealth.alberta.ca/palliative-care
  - Phone (Health Link): 811 or 811# on cell phones (24 hours a day, 7 days a week)

- Available palliative and end of life care resources, supports and services throughout Alberta

- Provides information on symptom management, what to expect in the last few days of life, videos, public education, grief and bereavement and links to the following organizations:
  - Palliative Coverage (financial aid for medications and ambulance)
    - Phone: Alberta Blue Cross 1-800-661-6995
    - A Physician or Nurse Practitioner will need to complete the application form
  - Saying Farewell
    - A free guide to planning funerals and legal and money issues in Alberta
    - Phone: 1-877-644-9992
  - Compassionate Care Leave (financial aid)
    - Phone: 1-877-427-3731
  - Office of the Public Guardian and Trustee
    - Information related to Personal Directives, Wills, and Enduring Power of Attorney
    - Phone: 1-877-427-4525
    - http://www.humanservices.alberta.ca/guardianship-trusteeship/personal-directives-how-it-works.html
○ Conversations Matter
  ▪ To assist with Advance Care Planning and Goals of Care discussions
  ▪ [http://www.albertahealthservices.ca/info/page12585.aspx](http://www.albertahealthservices.ca/info/page12585.aspx)

○ Canadian Virtual Hospice
  ▪ An excellent web based resource including videos on how to provide care; links to other resources; and ability to email questions to professionals
  ▪ [www.virtualhospice.ca](http://www.virtualhospice.ca)

○ Alberta Palliative Care Hospice Association
  ▪ Phone: 403-206-9938
  ▪ [http://ahpca.ca/](http://ahpca.ca/)

○ Alberta Organ and Tissue Donation Registry
  ▪ [https://myhealth.alberta.ca/Pages/OTDRHome.aspx?selected=overview](https://myhealth.alberta.ca/Pages/OTDRHome.aspx?selected=overview)

○ You may also ask your physician

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- Addresses when a terminal illness is first diagnosed, caring for yourself, support networks, adapting your home, giving physical care, care of physical problems, complications that might happen, dying at home, last days of life, arrangements after death, grief and other books and resources that may be helpful

- Available in many languages

- How to access the book:
  - Home Care may have free copies for Home Care Clients
  - Multiple books can be purchased through: [http://market-marche.chpca.net/a-caregivers-guide](http://market-marche.chpca.net/a-caregivers-guide)
Service Canada

- General Enquiry Phone Number: 1-800-622-623
  - A helpful guide of what to do following a death including first steps, how to obtain a death certificate, benefits survivors may be eligible to receive, and managing personal finances

- Canadian Benefits When Dealing with Death
  - A list of web links and phone numbers including: Allowance for the Survivor; Funeral, Burial and Gravemarking Assistance; CPP Survivor’s Pension; CPP Children’s’ (<25 years old) Benefits; CPP Death Benefit; Decedent’s Estates Program; War Veteran’s Allowance
  - Homepage:
  - Tax Information What to Do When Someone Dies
  - Employment Insurance Compassionate Care Benefits
    - Phone: 1-800-206-7218

Alberta Funeral Service Association

- Web based resources addressing: physical signs of approaching death; Organ & Tissue Donation; How do I know (when death occurs)?; Who to call first?; Writing an Obituary; and Funeral Etiquette

- Contact information:
  - Phone: (403)342-2460 (Red Deer)
Financial Supports Available for Caregivers in Alberta

"Many seniors can care for themselves without too much intervention. Expenses for rent and food go up, but not pensions. If there was a "living wage" for everyone and less taxes for those who need it, people can live in their own homes with little help."

- Respondent to Covenant Health's "Shape Seniors Care" campaign
Background
This section provides an overview of government supports available for caregivers in Alberta. This list was last updated on April 14, 2015.

The supports are separated into four categories:

- employment leaves
- tax credits and other financial benefits
- legislation, policies and strategies
- other programs, initiatives and services.

Within each category, supports are separated by provincial and federal jurisdiction.

Please note: The information in this section may not be entirely comprehensive or complete.

Employment Leaves

Alberta

Compassionate Care Leave

Up to 8 weeks of unpaid leave to care or support a gravely ill family member with a significant risk of death within 26 weeks.

Federal

Employment Insurance: Compassionate Care Benefits

Employees who have to be away from work to provide for a family member who is gravely ill may also be eligible for up to six months of paid employment insurance benefits.

Tax Credits and Other Financial Benefits

Federal

Child disability benefit
http://www.cra-arc.gc.ca/bnfts/dsblty-eng.html

Families who care for a child under 18 with a severe and prolonged impairment in physical and mental functions may be eligible for a tax-free benefit. The child must be eligible for the disability amount (also known as the disability tax credit) in order for the family to be eligible for the child disability benefit.
Family Caregiver Amount Tax Credits
http://www.cra-arc.gc.ca/familycaregiver/

An individual may be able to claim multiple tax credits if they maintained a dwelling where he or she and one or more dependents lived. The possible tax credits in this category include:

- Spouse or common-law partner amount
- Caregiver amount
- Amount for an eligible dependent

More information on each of these in their section

Spouse or common-law partner amount Tax Credit (Line 303)

You can claim this amount if at any time in the year you supported your spouse or common-law partner and his or her net income was less than a certain amount.

Caregiver Amount Tax Credit (Line 315)

An individual may be able to claim a caregiver amount if the individual maintained a dwelling where he or she and one or more dependents lived. Each dependent must be at least 18 years of age, have income less than a specified amount, and be dependent on the individual due to an impairment in physical or mental functions.

Amount for an eligible dependent Tax Credit (Line 305)
http://www.cra-arc.gc.ca/E/pub/tg/5000-g/5000-g-04-15e.html#P1111_145996

An individual may be able to claim an eligible dependent amount if the individual did not have a spouse/common-law partner (is not living with or being supported by them), if the individual supported a dependent, and if the individual lived with the dependent. The dependent must meet specific relationship criteria.

Disability amount transferred from a dependent Tax Credit (Line 318)
http://www.cra-arc.gc.ca/E/pub/tg/5000-g/5000-g-04-15e.html#P1256_167648

An individual may be able to claim all or part of a dependent’s disability amount if the dependent was a resident in Canada and was dependent on the individual for all or some necessities of life (food, shelter or clothing).
**Amount for infirm dependents age 18 or older Tax Credit (Line 306)**

http://www.cra-arc.gc.ca/E/pub/tg/5000-g/5000-g-04-15e.html#P1138_149243

An individual may claim an amount for infirm dependents age 18 or older. The infirm dependents must be a certain relationship, have an impairment in physical or mental functions, be dependent on the individual for support, and be a resident of Canada.

**Allowable amount of medical expenses for other dependents (Line 331)**

http://www.cra-arc.gc.ca/E/pub/tg/5000-g/5000-g-04-15e.html#P1400_191323

An individual may be able to claim an amount for medical expenses the individual paid for his or her dependents. The dependent must meet specific relationship criteria.

**National**

**Muscular Dystrophy Canada**

http://muscle.ca/; 1-800-366-8166

Muscular Dystrophy Canada is a non-profit organization providing support and resources to clients impacted by neuromuscular disorders. It provides financial assistance for equipment for individuals with these disorders and their caregivers.

**Private Benefits**

Employer benefits plan may provide some financial supports for caregivers.