THIS DOCUMENT OFFERS A BRIEF INTRODUCTION TO DEMENTIA FOLLOWED BY AN INTRODUCTION TO DEMENTIA CONNECTIONS AND GUIDELINES TO HELP WRITERS GENERATE EFFECTIVE AND POWERFUL EDITORIAL CONTENT THAT ALIGNS WITH DEMENTIA CONNECTIONS’ VOICE, STYLE AND BRAND.

THE DEMENTIA CONNECTIONS EDITORIAL GUIDE WILL CONTINUE TO EVOLVE AND BE ADAPTED TO COMMUNICATE WITH AND SERVE PEOPLE IMPACTED BY DEMENTIA.
WHAT IS DEMENTIA?

More than half a million Canadians live with dementia today, and this number is expected to double by 2030. One in five Canadians have experience caring for someone living with dementia, and the cost to care for those living with dementia is over $12 billion dollars annually.

Dementia is not a disease in itself; it’s a set of symptoms that form a condition or syndrome that results in a progressive decline in functioning that is not a normal part of aging. The symptoms of dementia include 1) memory loss, both short-term and long-term, 2) difficulties with thinking, problem-solving or language that are severe enough to reduce a person’s ability to perform everyday activities, and 3) changes in mood or behaviour.

The four major neurodegenerative diseases that cause dementia are: Alzheimer’s disease, Lewy Body disease, Frontotemporal dementia, Vascular dementia. There are many dozens of other diseases that will cause dementia. Disease processes can occur singularly and in combination. Most diseases that cause dementia are associated with advanced ageing. Alzheimer’s disease is the root cause of dementia in 60-80% of cases, but dementia and Alzheimer’s disease are not synonymous.

Dementia has a profound impact on individuals, families and communities, posing significant challenges to quality of life. While most people living with dementia are over the age of 65, a small number of people in their 40s and 50s can and do develop young onset dementia. Fear and stigma surrounding dementia are the biggest barriers for people living with dementia to live fully with dignity and respect. 56% of Canadians are concerned about being affected by dementia, and 46% admit they would feel ashamed or embarrassed if they had dementia. People living with dementia have the same human rights as any other person, although these rights are not always respected by those responsible for planning and providing care and support to live well with dementia.

Increasing numbers of people living with dementia are the result of an aging global population. Dementia is a global issue; more than 50 million people have dementia world-wide, and there are nearly 10 million new cases each year. The World Health Organization has recognized dementia as a public health priority since 2017.

ROLE OF DEMENTIA CONNECTIONS

Dementia Connections empowers people impacted by dementia to live a good life by connecting them with a community of allies and curated information resources.

People living with dementia and family care partners experience multiple disabling factors that threaten their independence and quality of life due to a lack of collaboration, coordination and innovation at individual, organizational and systems levels.

Dementia Connections enables access to expert knowledge through connection to allies and curated information resources through our print/digital magazine, website and app, acting as

1. an information intermediary enabling access to information and tools from multiple sources about dementia, dementia care and innovative approaches a good life to live with dementia,

2. a knowledge translator helping people living with dementia and family care partners to make sense of and apply relevant information to improve daily life,

3. a knowledge broker fostering coproduction of knowledge to improve decision making and amplify the voices and stories of people living with dementia,

4. an innovation broker building bridges that enable knowledge exchange across boundaries and accelerate the transformation of the stigma that surrounds dementia into understanding, empathy, and positive action.

Our mission is to build a Canada-wide community where collaboration empowers people impacted by dementia to live well with freedom from stigma.

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1 Some content sourced from: Alzheimer Society of Canada, World Health Organization, Dementia Alliance International
AUDIENCE

Dementia Connections is for Canadians impacted by dementia. While primarily designed for people living with dementia and their care partners, Dementia Connections will also be of interest to their families, friends and support networks, and to healthcare providers who work with them. In addition, Dementia Connections will be of interest to policy and decision makers, politicians and others interested in deepening their understanding of the lived experience of dementia.

It is important to keep in mind that the Dementia Connections audience is as diverse as Canadians; they are multicultural, speak many languages and embrace varied values. Primary readers may face multiple barriers to accessing support they need to live well with dementia due to their gender or gender orientation, ethnicity, race, religion, sexual orientation or socioeconomic status. Dementia Connections readers live in urban and rural environments across Canada, where access to information, technology, skills training and resources are disparate.

VOICE AND STYLE GUIDELINES

Dementia Connections is

Inspiring | Evidence-based | Friendly
Helpful | Positive | Informative | Reliable
Respective of diversity

Dementia Connections is first and foremost a lifestyle brand, focused on living well with dementia. Editorial content contains inspiring, positive, factual, useful and relevant information about the condition and the people who live with it.

Dementia Connections employs a varied ‘Readers Digest’ approach where topics in each issue can range from the latest research to the accomplishments and life stories of people with dementia, with a strong “news you can use” component. The goal of all content within Dementia Connections is to support people with dementia, and all readers, understand that a person can live well with dementia and that a diagnosis of dementia doesn’t define a person. Dementia Connections also strives to raise public awareness of the impacts of dementia, to reduce stigma surrounding dementia, and to help people understand how to reduce their risk of dementia.

The tone the Dementia Connections brand employs is personal and emotional, never clinical or overly technical. It is a lifestyle publication, not an academic or medical journal. The writing must avoid jargon, and use clear, concise language. Quotations and examples can help put information into context. The information presented must be evidence-based and accurate, while written so that the average adult without any specialized knowledge will understand it easily and, importantly, enjoy reading it.

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2 Some content sourced from Dementia Australia Dementia Language Guidelines
DOS AND DON’TS

**Do** refer to the Dementia Connections language guide below for preferred terms. Appropriate language must be accurate, respectful, inclusive, empowering and nonstigmatizing.

**Do** write in journalistic but friendly, lifestyle-oriented magazine prose — conversational and lively, with authority and style.

**Do** base everything you write on plenty of rock-solid facts. Along with personality, facts are the bedrock of any story. Be mindful of not reinforcing stereotypes or myths about dementia.

**Do** use your journalistic instincts to find the story. Dementia Connections is a magazine dedicated to its readers and driven by the editorial standards of excellent storytelling.

**Don’t** refer to people with dementia as patients, sufferers or victims. Instead, use “people living with dementia.” They are people, with complex lives and stories, who happen to have been diagnosed with dementia. Respect them as human beings first and don’t be afraid to ask each individual about how they use or avoid terms relating to dementia.

**Don’t** drain authentic emotion out of a story. There are genuine and heartfelt emotions involved with this subject matter, and readers need to feel them. At the same time, never try to evoke pity or sorrow.

The Canadian Press (CP) guide is our go-to for any other style questions, except all doctors, regardless of whether they are MDs are referred to as “Dr.” on first reference. CP-style is followed in all other cases in regard to names and titles. This means job titles and positions are lower case when they follow a person’s name. E.g. Bob Smith, manager of client relations, Fun Factory.

**Health care** is two words as per CP-style. The word takes a hyphen when used as an adjective. E.g. Health-care worker, health-care aide, health-care cost etc. Similarly, **long-term care** is hyphenated.

**COVID-19/COVID** is capitalized.

**OTHER DEMENTIA CONNECTIONS STORY SELECTION CRITERIA AND VALUES:**

- Accurate, evidence-based information
- A photo of person living with dementia on the front cover
- Involvement of people living with dementia as much as possible
- High quality photography
- Positioning people living with dementia as experts
- A focus on living as well as possible with dementia
- Objectivity and respect for a variety of perspectives and personal beliefs.
- Include a variety of support images – too many hands!
ACCESSIBILITY CONSIDERATIONS

Every effort should be made to ensure Dementia Connections print and digital editorial content is accessible for people with dementia and older persons who may experience visual, spatial or cognitive barriers to reading.

Low literacy in Canada is a personal, family, community, and societal problem, and people age 65+ have higher rates of low literacy than other age groups. Content for Dementia Connections should reflect a readability level equivalent to 7th/8th grade, as this level is actively used as a benchmark for written guidelines in the medical industry.

- Be direct and specific
- Put key points up front
- Use positive statements
- Use active voice
- Support information with real examples and relatable stories
- Focus on action steps
- Reinforce main points with questions
- Use every-day language, avoid jargon

MINIMUM DESIGN CONSIDERATIONS INCLUDE:
- Use easy to read font, 12 point minimum
- Create contrast
- Allow for white space, build breaks for the eyes
- Keep the layout simple
- Avoid blue and green print especially with yellow background

DEMENTIA CONNECTIONS LANGUAGE GUIDE

Words matter and can impact how people living with dementia are viewed and treated. Dementia Connections must consistently use of appropriate, inclusive and non-stigmatising language when talking or writing about dementia and people living with dementia.

The language that we use when talking about dementia should reflect the following human rights principles:
- Respect for dignity, autonomy, freedom to make choices and independence,
- Non-discrimination,
- Full participation and inclusion in society,
- Respect for difference; acceptance of disability as part of human diversity,
- Equality of opportunity,
- Accessibility and
- Equality among race, national or ethnic origin, colour, religion, gender, sex, age and mental or physical disability.

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3 Some content sourced from the Dementia Engagement & Empowerment Project Writing Guide, Tips from the National Institute on Aging, Centre for Plain Language
4 Some content sourced from Alzheimer Society Person Centred Language, Dementia Engagement & Empowerment Project Writing Guide, Dementia Engagement & Empowerment Project Writing Guide
Appropriate language is accurate, respectful, inclusive, empowering, non-stigmatizing and culturally aware. Generally, do not use abbreviated terms to describe people with dementia, for example a person with dementia is not expressed as PwD. Don’t overgeneralize by using blanket phrases like ‘behavioural and psychological symptoms of dementia’. Describe the symptom itself e.g. memory loss, change in mood, word finding problems, and the impact it is having e.g. difficulty communicating.

**PREFERRED TERMS**

- Dementia
- Alzheimer’s’ disease and other forms of dementia
- A form of dementia
- Symptoms of dementia
- A person/people with dementia
- A person/people living with dementia
- A person/people with a diagnosis of dementia
- Younger onset dementia
- Living with the impact of dementia
- Care partner
- Family care partner
- Person supporting someone living with dementia
- Effects of providing care
- Meaningful caregiver experience
- Child, parent, friend, spouse of a person with dementia
- Disabling
- Challenging
- Life-changing
- Stressful
- Expression of needs

**TERMS/PHRASES THAT SHOULD NOT BE USED**

- Dementing illness
- Demented person
- Affliction
- Senile dementia
- Senility
- Going on a journey
- Demented person
- Afflicted
- Sufferer
- ‘they’ talking about all people with dementia rather than the individual
- Patient
- Victim
- Pre-senile dementia
- Loved one
- Informal caregiver
- Hopeless
- Unbearable, Impossible
- Tragic, Devastating
- Burden
- Epidemic

Avoid the term “facility/facilities.” Instead use “home(s)” whenever appropriate. For example, long-term care home.

Avoid infantilizing language and choose respectful language instead. For example, an “adult diaper” is “incontinence protection.”

Avoid overuse of the word “therapy” when appropriate. For example, “music therapy” is simply music, “art therapy” is art or art classes etc.

Avoid terms like acting out, aggressive behaviour, challenging behaviours, violent, wandering and use words that describe the behaviour as specifically as possible.