

A horizontal teal-colored band featuring a close-up, abstract pattern of overlapping leaf shapes and veins, creating a textured, organic appearance.

Initial Insights Brochure

December 2016

**AGING
BY
DESIGN**



A TASTE OF WHAT WE'VE HEARD

Empathy is at the heart of human-centered design—allowing us to learn about the world through the experiences of others. With the help of enthusiastic organizations across the state, Aging By Design has already collected hundreds of glimpses into the lives of older adults and caregivers throughout Western and Central New York.

So far, data has been collected in the format of empathy maps and postcards. Through the analysis of 141 postcards and 91 empathy maps, over 600 unique needs statements have been generated—short and often simple sentences describing what the end-user of a service has identified as a requirement. Need statements are expressed explicitly and implicitly, and can range from very tactical (e.g. I need help getting up and down stairs) to complex, emotional needs (e.g. I need to feel less alone).

As we analyse the data, similar needs from separate sources begin to group together and form themes. Each theme points towards an issue that caregivers and vulnerable older adults are facing. At present, these themes are very preliminary—many will still shift and evolve as we add data from other sources. Some very obvious and extremely prevalent needs are mentioned often (e.g. concerns about financial matters, challenges getting around, desire to connect more with family) while other needs have only a few mentions, and may or may not continue to grow. This document is a quick capture of the themes that have emerged from our initial analysis.

Aging By Design engagement work has only just begun—empathy maps and postcards continue to pour in, with supplementary engagement activities scheduled for early 2017 that include journaling, street teams, stakeholder labs and ethnographic research. As we continue to learn directly from older adults and caregivers through these different methods, we will build on the needs uncovered so far and gain an entirely new level of insight into their experience.

The following pages present a few need statements for each of the themes that have formed to-date. As you read through, think about which needs resonate with you, which surprise you, and which you're interested to learn more about.

I need a safe place

- I need a peaceful environment where I can feel safe
- I need help dealing with today's world
- I need support in a hostile political environment

I need faith

- I need help maintaining my faith
- I need to keep going to my church
- I need to be an active member of my church

I need to keep smiling and have a sense of humour

- I need to maintain my sense of humour
- I need to continue to laugh and smile
- I need to use humour and sarcasm in uncomfortable situations

I need support in the winter

- I need support during the winter months
- I need help getting around in winter

I need inclusive and accessible transportation

- I need someone who can drive me
- I need a self-driving car
- I need to maintain my ability to get around
- I need transportation at night
- I need more transportation options
- I need help getting around now that I no longer have a car
- I need everyone to have rides when we host an event or get together

I need independence

- I need to feel a sense of independence
- I need to maintain my independence as much as possible
- I need to not be lonely and maintain my independence
- I need people to support me to go back home (including professionals and family)
- I need to continue living at home (I'm 103!)
- I need homecare for older adults who want to stay in their homes that's matched to what they need, not just what they ask for

I need motivation to be active and things to do

- I need opportunities to get in shape
- I need activities for humans and pets to do together
- I need help finding things to do
- I need encouragement to participate in social activities
- I need to play games
- I need to continue playing cards with others
- I need more to keep me busy
- I need things to do that don't require my right hand (I can't use it)
- I need quality time at the senior's centre
- I need to push myself to exercise
- I need a positive attitude about exercise

I need opportunities, programs and supports that help me be active

- I need to take part in programs and activities to keep me active and fit
- I need my workout classes
- I need exercise classes like "Great Strong Bones" and "Silver Sneakers"
- I need trips to the pool to exercise and strengthen my body
- I need support so I have a chance to regularly walk
- I need more opportunities to exercise
- I need accessible exercise equipment
- I need help to be active

I need help with my memory

- I need help with my short-term memory
- I need help remembering things
- I need to be able to remember names
- I need a brain capable of thinking
- I need ways of managing my forgetfulness

I need to not feel alone

- I need social interaction to avoid feeling alone
- I need loved ones to join my husband and I at doctors' appointments for support
- I need company
- I need to feel less lonely
- I need company even though I live with my sister
- I need to not feel isolated
- I need ways to encourage seniors to participate in social activities
- I need to be social
- I need to have friendships in spite of my health challenges
- I need normal conversation

I need to cope with stress

- I need for my health issues to not cause this degree of stress
- I need to cope with chronic anxiety
- I need help dealing with everything I've been through
- I need less stress
- I need to know where to turn
- I need help moving forward

I need to manage my pain

- I need a way to share that I am in pain
- I need to feel well more often so I can go places in the van
- I need help with pain management
- I need to minimize the pain I feel

I need positivity

- I need to feel full of love
- I need to be around friendly people
- I need to be surrounded by positive, happy people
- I need dining hall staff to be gentler, less overbearing, less scary so it's not triggering
- I need those around me to be happy
- I need to feel a sense of self-satisfaction

I need to eat healthy

- I need to keep motivated to eat healthy
- I need to not let junk food tempt me
- I need to ensure my mom doesn't have rotten food in the house
- I need it to be easy to eat healthy
- I need to be able to eat healthy

I need to lose weight

- I need to lose weight
- I need help losing weight
- I need to attend Taking Off Pounds Sensibly (TOPS) meetings
- I need to eat less

I need to stay healthy

- I need to keep myself as healthy as possible
- I need to keep feeling great
- I need to maintain my great health despite my arthritis
- I need to stay healthy, mentally and physically
- I need to live an active, healthy lifestyle

I need to have fun!

- I need to have fun
- I need to share my adventurous side with others

I need to partake in sports

- I need to ride my new four-wheeler
- I need to do my outdoor sports
- I need to do extreme sports

I need a creative outlet

- I need to sing in my choir
- I need to have a creative outlet
- I need to do crafts
- I need to remain musically active
- I need to continue to enjoy writing and typing

I need to read

- I need to be able to read
- I need respite so I have time for my hobbies
- I need to go to my library book club

I need ways to meet people

- I need to get out of my shell and meet people
- I need to be open to people
- I need to find people to be social with
- I need people to connect with so that I feel less lonely
- I need to make friends
- I need to continue attending community events
- I need programs with small groups
- I need to be around people
- I need a place to meet people my own age
- I need to continue organizing and participating in social events in spite of chronic back pain and difficulty breathing

I need to overcome pain and mobility challenges to be active

- I need to continue walking in spite of my arthritis
- I need to feel active despite having rheumatoid arthritis
- I need to keep dancing regardless of my arthritis problems
- I need to keep active despite my considerable mobility issues
- I need to continue my exercise routine
- I need to do yoga
- I need to be able to do things that keep me healthy, in spite of the pain I feel

I need to get out and about

- I need reasons to get out of my apartment
- I need to go on leisurely drives
- I need to continue to make day trips
- I need to continue taking road trips with my husband
- I need to get out of the house
- I need to travel
- I need to visit my local Amish community
- I need to keep driving during the day
- I need to walk around town
- I need to move despite my medical issues
- I need help maneuvering around the packed grocery store

I need to cope with aging

- I need to be able to keep up with my own expectations
- I need my mom to understand that she can't take care of her house like she used to
- I need my elderly neighbour to seek the appropriate level of care for her injury
- I need to realize that my body will never be the way it used to be
- I need to not feel like my life is over
- I need my body to feel as young as my brain and heart do
- I need to know that getting older doesn't mean giving up
- I need to understand that not everyone ages the same
- I need to admit I need help
- I need to realize when I need a break
- I need to admit and not ignore my considerable mobility issues
- I need to better understand and accept aging
- I need help realizing my stamina is continuously reduced as I age
- I need help dealing with aging
- I need to feel young again

I need my mobility issues to not affect my life

- I need to feel a sense of mobility
- I need ways to improve or deal with my limited mobility
- I need to mitigate the impact of mobility and balance issues on my life
- I need walking to be less of an obstacle
- I need to be able to be mobile
- I need to keep up with my grandkids
- I need limited mobility (walking with a cane) not to get in the way of going out and meeting people
- I need help with stairs
- I need to find a way to enjoy golf even if I have a hard time standing

I need better balance and stability

- I need better ways to manage stairs (my balance isn't great)
- I need to use a trekking pole for my vertigo
- I need help with my balance
- I need to not fall
- I need help standing
- I need to improve my balance

I need better stamina and range of motion

- I need to be able to move with ease
- I need stamina to make it to multiple appointments
- I need to be able to bend down and stand back up
- I need better knee movement

I need help walking and moving

- I need help with my mobility
- I need to be able to walk
- I need help walking
- I need help moving

I need to spend time in nature

- I need to feel the sunshine
- I need to get out of the house and enjoy nature with my aging mother
- I need more time being outside with other people
- I need to get outdoors, even in the fall and winter
- I need lots of opportunities to continue to get outside and enjoy nature
- I need to commune with nature in a meaningful way
- I need to take long walks with my dog despite the weather
- I need to be able to go for a walk outside
- I need to stay connected to the outdoors

I need to feel connected to my loved ones

- I need to tell my family I would like to see them more
- I need to tell my family how much I miss them
- I need my loved ones to know how much they mean to me

I need pets/animals in my life

- I need to be in contact with cats
- I need my dog
- I need my pets
- I need a pet or companion
- I need to continue to care for my horses
- I need to walk my dog
- I need to take care of my dog

I need to see my family

- I need to be able to spend time with my great-grandchildren
- I need to be able to see my family
- I need to see my friends more
- I need to see my kids more often, spend more time with them
- I need my granddaughter and great-granddaughter to visit more often
- I need to spend more time with my family, especially my children who live far away
- I need my family to make time to see me
- I need to take vacations to visit family
- I need the money and mobility to visit my children

I need to remain youthful

- I need to keep my youthful attitude
- I need to be young at heart
- I need to not be called a senior

I need others to not make assumptions about me because of my age

- I need people to not assume things about me
- I need people to not judge my health based on my appearance
- I need to not be judged by my appearance
- I need to challenge cultural assumptions of aging

I need financial security

- I need to feel stable and secure enough to retire
- I need to not worry about bills
- I need financial help
- I need help with medical costs
- I need to feel financially secure
- I need to be able to work until I can retire
- I need to make money but I can't work
- I need to know I won't run out of money before I die
- I need to not live in fear of financial crisis

I need better financial skills

- I need help budgeting my finances
- I need to save money to buy my family dinner
- I need help managing my money
- I need to understand how to pay my bills
- I need to not have financial stress
- I need help getting my finances in order

I need to share my story

- I need for my personal history to be understood and respected
- I need to remain mobile so that I can keep telling my interesting stories
- I need to reminisce about my hometown
- I need to tell people how my life was during WWII

I need help dealing with situations that are difficult and scary

- I need people to understand when I am uncomfortable or find a situation difficult
- I need help dealing with loneliness
- I need to not die alone
- I need to feel less afraid
- I need you to know I am depressed

I need to feel supported

- I need support
- I need help getting through the day
- I need the kind of caregiving I gave my mother

I need to enjoy life

- I need to live life to the fullest
- I need to be happy
- I need to be the best person I can be
- I don't need anything—I'm enjoying life
- I need to feel alive
- I need to continue to challenge myself
- I need to celebrate kicking cancer's butt!
- I need things to keep my spirits up

I need to learn and stay mentally active

- I need to continue to learn so that I don't forget
- I need to be mentally active

I need time for myself and the things I care about

- I need to find time for everything I want to do
- I need retirement
- I need more time for myself and doing things I want to do
- I need personal time every single day
- I need time
- I need things to be done at my pace
- I need the world to slow down
- I need to be more patient

I need to plan for my future

- I need to plan for my future
- I need help decide whether to move south or not
- I need help understanding when to transition to a long-term care home

I need to take care of myself so that I can take care of others

- I need to maintain my physical and mental health so that I can help others
- I need to make time for my mental health so that I can better help others
- I need to limit the impact that caring for my neighbour has on my own wellbeing

I need to be a “good” caregiver

- I need help being a good support system for my ill husband
- I need to cook a wholesome meal for my family
- I need to make sure my mom takes her medication
- I need to make sure my mom has food to eat

I need the healthcare I need to be accessible

- I need flexibility when arranging doctors’ appointments
- I need the system to understand how my health complications affect my ability to go to the hospital
- I need community resources to be close to me
- I need local healthcare options
- I need community resources that come to me
- I need help getting to distant appointments

I need to sleep and rest

- I need time to myself to relax, sleep and enjoy the peace and quiet
- I need to get enough sleep to function
- I need to sleep through the night
- I need to feel less tired
- I need ways to improve the quality/length of my sleep

I need to understand my/my loved one’s medical issues

- I need my husband’s doctor to explain his condition in language we understand
- I need to know about how my disease is going to unfold and what might happen
- I need to be better equipped to understand my loved one’s declining health
- I need to better understand my husband’s medications and their side effects

- I need to understand how my health complication affects my ability to go to the hospital
- I need to know what's happening next and when things will happen as I am treated in the ER
- I need help understanding my concurrent health issues
- I need for a diagnosis of dementia to be confirmed (or not) for my husband

I need help/support/treatment for my medical issues

- I need my feet fixed
- I need a cure for Parkinson's Disease
- I need to keep my seizures under control
- I need help with my arthritis
- I need support in continuing to recover from my alcoholism
- I need to not struggle with my health as much as I do
- I need help with my chronic health issues
- I need help with my depression
- I need medical help coping with my disordered spine

I need to be organized and keep to a routine

- I need programs that work for my schedule
- I need to plan my time more effectively
- I need day-to-day consistency
- I need to be more organized
- I need everything to go according to plan, as much as possible

I need help caring for my loved ones

- I need to know that my disabled son will be cared for when I am gone
- I need to ensure my teenaged daughter with disabilities is looked after when I no longer am able to
- I need support taking care of myself and my partner
- I need someone to occupy my mom so that I can complete her household chores
- I need to provide appropriate care for my husband
- I need to be able to feel confident in taking care of my aging husband as I age
- I need to be patient with caregiving
- I need to continue providing the caregiving that I love

I need help taking care of myself/my body

- I need help physically taking care of myself
- I need my hearing aids to work
- I need help shaving
- I need to know how or if I can do better to prevent bladder infections
- I need to understand how what I eat affects my body

I need hope

- I need something to look forward to, to get out of bed in the morning
- I need hope
- I need motivation to keep going
- I need help remaining positive and upbeat on a daily basis
- I need to stay positive in the face of adversity
- I need to believe in myself
- I need confidence in myself
- I need encouragement
- I need to remain optimistic
- I need someone to believe in me

I need help with big chores

- I need the strength, stamina and mobility to prepare my gardens for the winter
- I need to clean my garage
- I need to organize my cellar
- I need to organize my garage
- I need help doing big jobs around the house

I need help with daily chores

- I need help getting through all my chores each day
- I need someone to do my grocery shopping for me
- I need to do laundry and shower
- I need help with the new responsibilities I have since my husband passed away
- I need to keep up with my daily responsibilities
- I need help to take care of my house
- I need help cleaning
- I need to eat healthy meals without having to cook them all
- I need help with yard work

I need help navigating healthcare bureaucracy

- I need help finding a long-term care home
- I need choosing health insurance to be a simpler, clearer, easier and less confusing process
- I need someone to help me with the health insurance process
- I need help figuring out the local support system
- I need help with my medical insurance
- I need help understanding Medicare changes
- I need to understand the bureaucracy of the healthcare industry
- I need help understanding the legalities around my husband's healthcare
- I need to know what questions to ask
- I need to know where to start asking for support

I need to feel connected to others

- I need intimacy
- I need to build family beyond the nuclear model
- I need deep emotional connections with others
- I need someone to sit in the hot tub with me at the end of the day
- I need to continue to listen to audiobooks and bond with my husband
- I need a connection to the younger generations

I need help keeping up with technology

- I need help to keep up with technology
- I need someone to teach me how to use an iPad and other new technology
- I need classes on how to use new technology

I need to be able to hear

- I need to learn how to use my hearing aid
- I need to be able to hear what others are saying
- I need help getting my hearing aid to function properly
- I need my poor hearing to be less of a limitation when I catch up with friends

I need to be able to see well

- I need to be able to read
- I need materials provided with fonts I can read
- I need help with my sight
- I need enough light to be able to see my surroundings
- I need to be able to see better what I am doing

I need to give back/help others

- I need to find opportunities to make a positive impact in society
- I need to show people how personable and caring I am
- I need to feel able to help others
- I need to make time for my physical health so that I can better help others
- I need to spread the message of peace over war
- I need to continue volunteering and not always caregiving
- I need to help spread empathy
- I need to help others with similar challenges to me

I need to continue to see friends

- I need to be able to go out and meet with old friends
- I need to maintain my active social life
- I need to be more mobile so that I can be social
- I need senior centres for both exercise and a social life
- I need to take part in programs to keep me active and social

Currently Unsorted

- I need my house to be arranged so that I can complete daily tasks easily
- I need medical care appropriate for transgender individuals
- I need to understand complex life challenges
- As a concerned (and impacted) neighbour, I need some ability to influence/set up at-home help for the elderly
- I need a new water well so that I can wash clothes at home
- I need good water at home
- I need to block incoming sales calls and avoid talking to sales people
- I need to prepare for when my bladder fails during a bladder infection
- I need to feel that my efforts to be healthy are making a difference, preventing incidents
- I need others to not tell me their horror stories
- I need doctors to watch the things they discuss in front of patients
- I need help getting up in the morning

SAMPLE STORIES

If you really knew me...

Importance of creating family outside traditional/genetic models.

Helping individuals, especially older people, improve both physical and emotional health and the relationship between both aspects of health.

Seeking and giving support in the new, somewhat hostile, political environment.

PLEASE DO NOT INCLUDE NAME, ADDRESS, OR OTHER IDENTIFYING INFORMATION.

If you really knew me...



PLEASE DO NOT INCLUDE NAME, ADDRESS, OR OTHER IDENTIFYING INFORMATION.

AGING
BY
DESIGN

Age: 59

Gender: M

I am (check all that apply):

- An older adult
- A caregiver for an older adult
- A service provider for older adults

I consider my biggest challenge to be...

Caring for my husband, more of a privilege than a challenge.

AGING
BY
DESIGN

Age: 61

Gender: Female

I am (check all that apply):

- An older adult
- A caregiver for an older adult
- A service provider for older adults

I consider my biggest challenge to be...

Losing weight and trying to stay Active

SAMPLE STORIES

If you really knew me ...

As an Aging Activist -
I challenge our "Ageist"
etc. culture - We all need
more empathy for one another
and trust/understanding/respect
for one another - for our
planet/environments, et-al.
We all can do more - Lots
to hear! I'm personally
optimistic!

PLEASE DO NOT INCLUDE NAME, ADDRESS, OR OTHER IDENTIFYING INFORMATION. THANKS!

If you really knew me ...

You would know that
I am under a lot of
stress and feel that
doctors can't help me
take care of my husband
because of legalities.

PLEASE DO NOT INCLUDE NAME, ADDRESS, OR OTHER IDENTIFYING INFORMATION. THANKS!

AGING
BY
DESIGN

Age: 73

Gender: Male

I am (check all that apply):

- An older adult
- A caregiver for an older adult
- A service provider for older adults

I consider my biggest challenges to be ...

Financial stress
Disordered "my
space" - etc.
Chronic health
issues.

AGING
BY
DESIGN

Age: 70

Gender: Female

I am (check all that apply):

- An older adult
- A caregiver for an older adult
- A service provider for older adults

I consider my biggest challenge to be ...

caring for
my husband who
may have dementia