

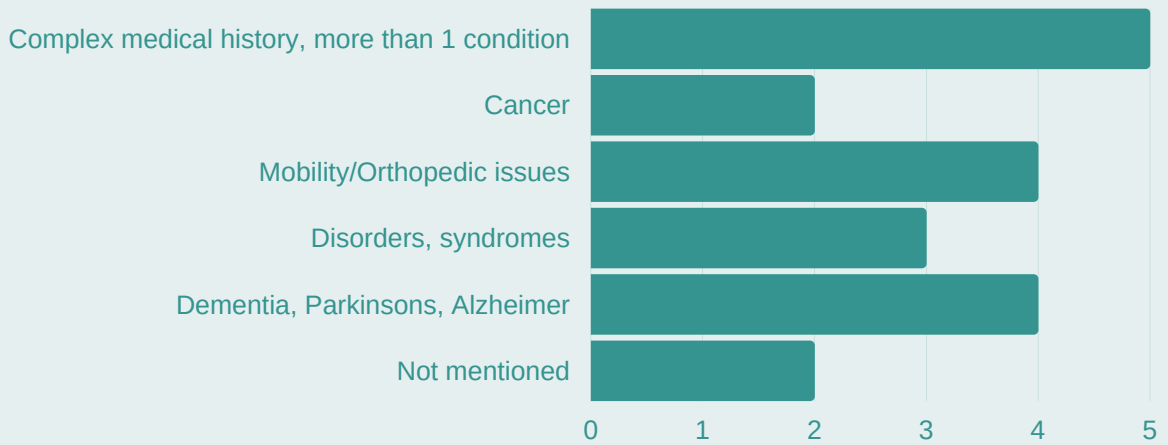
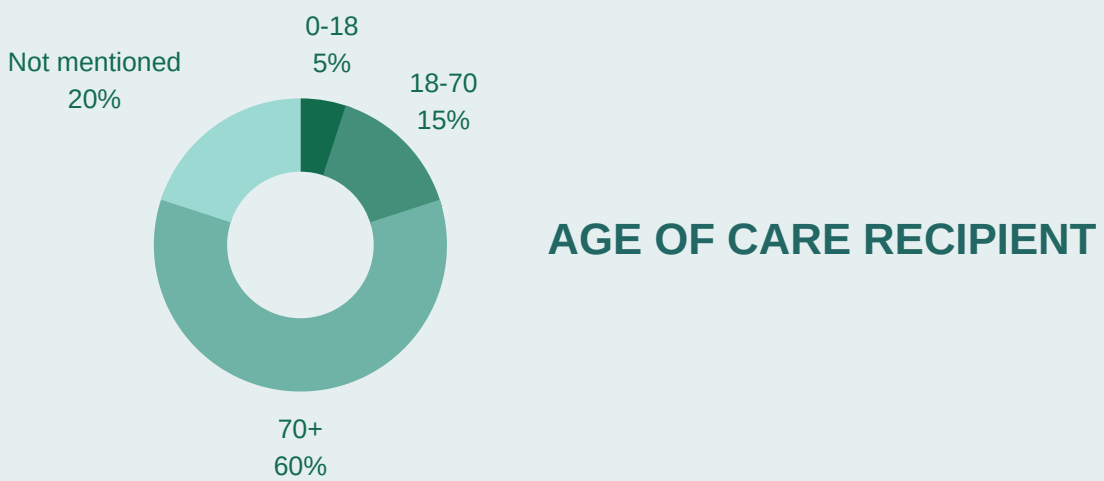
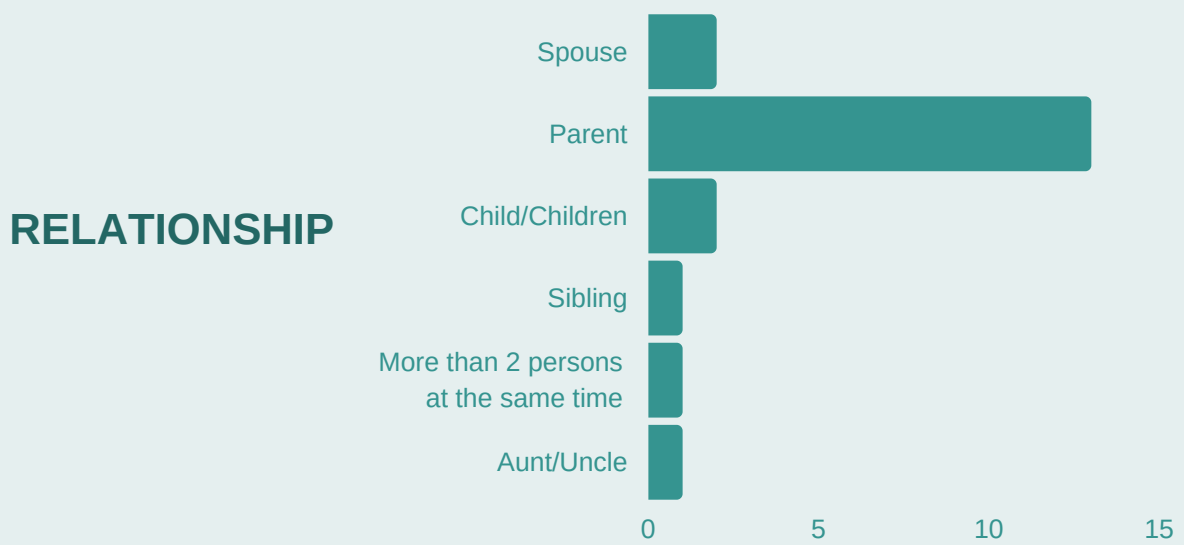
# Caregiver Research Study & Results

## INTERVIEW SURVEY RESULTS

**20** Caregivers  
Interviewed



## WHO IS IT THAT YOU CARE FOR AND SUPPORT?



# HOW HAS BEING A CAREGIVER IMPACTED YOUR LIFE?



## POSITIVE FEEDBACK

### IMPROVE FAMILY CONDITION

- LEARNING MORE ABOUT THE LIFE OF THE FAMILY MEMBER
- DEVELOPING DEEPER CLOSENESS
- FAMILY COHESIVENESS
- THE PHYSICAL PROXIMITY OF THE FAMILY MEMBER IS MORE CONVENIENT, ESPECIALLY DURING THE PANDEMIC

### PERSONAL EMOTIONAL GAIN

- FEELING OF SATISFACTION AND TIME SPENT WITH FAMILY MEMBERS
- RECEIVING APPRECIATION FROM THE FAMILY MEMBER PROVIDING CARE TO
- HONORING THE FAMILY BY PROVIDING CARE
- EXPERIENCING A MOTHERING ROLE FOR SOMEONE WHO DOES NOT HAVE CHILDREN

### SELF IMPROVEMENTS

- LEARNING A LOT ABOUT NAVIGATING THE SYSTEM

## NEGATIVE FEEDBACK

### MENTAL AND EMOTIONAL STRESS

- FEELING DRAINED AND HAVING NOTHING LEFT TO GIVE
- CONSTANT WORRY
- FRUSTRATION
- A “ROLLER COASTER”
- ANXIETY
- OVERWHELMING GUILT
- SLEEPING ISSUES

### FAMILY DYNAMICS CHANGES

- LACK OF PRIVACY IN OWN HOME
- MODIFIED HOME TO FIT CAREGIVING NEEDS
- IMPACT OF RELATIONSHIP WITH THE SPOUSE
- YOUNG ADULT CHILDREN HAVE MOVED OUT OF THE FAMILY HOME SOONER DUE TO THE LIVE-IN SITUATION
- CAREGIVING BECAME THE CORE OF THE RELATIONSHIP WITH CO-CAREGIVER (FAMILY MEMBER)

### PERSONAL SACRIFICES

- INABILITY TO ORGANIZE OWN TIME TO TAKE A BREAK
- THE SACRIFICE OF OWN FREEDOM
- ADJUSTED CAREER PLANS
- CHANGED RETIREMENT PLANS

# ARE THERE THINGS THAT MAKE IT DIFFICULT FOR YOU TO GIVE THE CARE YOU WOULD LIKE?

CARE IS DEPENDENT ON A SINGLE CAREGIVER

RESISTANCE TO ADDITIONAL/OUTSIDE CARE BY THE PERSON CARE IS PROVIDED TO

LACK OF KNOWLEDGE OF SUPPORT GROUPS AND EQUIPMENT

UNCERTAINTY OF THE HEALTH FUTURE OF THE PERSON RECEIVING CARE

LACK OF SOCIAL OPPORTUNITIES FOR THE PERSON RECEIVING CARE

PERSONAL SUPPORT WORKERS SHORTAGE IMPACTS HOW MUCH RELIEF THE CAREGIVER CAN HAVE

INCONSISTENCY OF PERSONAL SUPPORT WORKERS

LACK OF IN-HOME SUPPORT

NAVIGATING THE SYSTEM AND THE PAPERWORK IS TIME CONSUMING, CONFUSING AND DIFFICULT

INCONVENIENT HOUSE SETUP

LACK OF FAMILY SUPPORT AND UNDERSTANDING

THE PERSON THE CARE IS PROVIDED TO NOT EXPRESSING APPRECIATION

INCONVENIENCE OF HAVING TO DRIVE LONG HOURS TO SEE SPECIALISTS

STRUGGLE OF BEING A "SANDWICH GENERATION" CAREGIVER

INABILITY TO FIND CONSENSUS WITH SIBLINGS/OTHER FAMILY MEMBERS

DETERIORATING HEALTH OF THE PERSON CARE IS PROVIDED TO

LACK OF ADEQUATELY SUBSIDIZED RELIEF CARE

FINANCIAL BURDEN TO FULFILL BASIC CARE NEEDS

# WHAT EFFECTS HAS CAREGIVING HAD ON YOUR OWN HEALTH?



ACQUIRED SOFT SKILLS, ART OF NEGOTIATION



KEEPING POSITIVE AND ACTIVE

BECAME MORE GRATEFUL



**MENTAL HEALTH ISSUES-STRESS, FEAR, WORRY, ANXIETY AND GUILT**

## RELATED ISSUES:

- Sleeping issues
- Fatigue
- Weight gain
- Aching muscles
- Headaches
- Weight loss
- Hair turned grey and started falling out
- Increase of osteoarthritis pain

# If there has been an effect on your health, what might help it?

**Easy access to supports and resources in the community**



**Access to counselling services**

- Virtual counseling



**Access to information on Caregiver support groups.**



**Relief by fulfillment of home care hours**



**Respite care**



**More Effective Communication**

More effective communication between government departments a Caregiver deals with would reduce stress



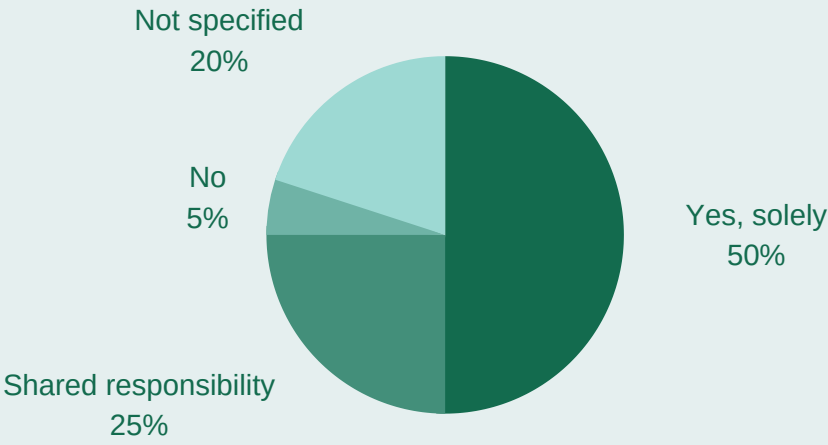
**More understanding and empathy from employer**



**More help and understanding from family members and friends**



# As a caregiver, do you help organize medical appointments or arrange other healthcare services for your person?



## Experiences accessing healthcare services in the community

### Having community services was very helpful

Things such as:

- Foot care
- Attentive Geriatrician, Healthy Aging Clinic
- Pharmacists
- Family doctor home visits
- Veteran’s affairs
- Supports from the Extra-Mural Program

## Experiences accessing healthcare services after a hospital admission.

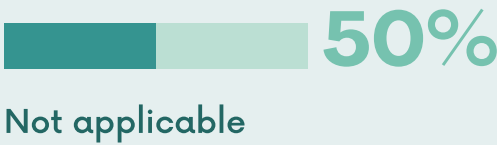
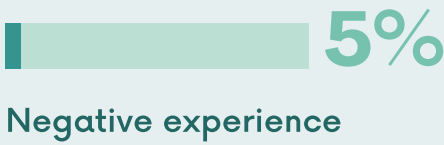
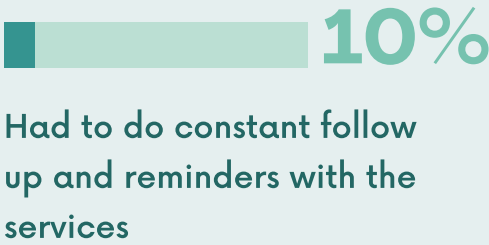
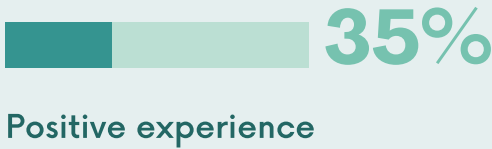
- Extra-Mural was set up before discharge and it is amazing.
- Things went smoothly after enrolling in Social Development
- Private Health navigator assisted in facilitating the discharge planning
- Radiation staff and specialists at hospital are patient and understanding

**Additional comments:**

- **Confusion over hiring private or a company**
- **It is easier to communicate when one is a community based person, i.e. knows the involved individuals and the process**

- **Lack of organization and coordination at discharge (equipment, medications and home care workers were not set up)**
- **Delayed referrals post hospitalization due to communication breakdown**
- **Interactions with Social Development cause stress**
- **Impatient hospital doctor**
- **Discharge from hospital happens quickly and did not feel prepared when Extra-Mural came in on the day of discharge**
- **At times, especially during Covid, caregivers were not allowed to accompany their loved ones during ER visit/hospital admission/hospital stay which led to miscommunication and overall negative experiences**

## Healthcare services experience follow up:



# Has there been times in your caregiving when the advice of a healthcare professional would have helped with a difficult decision or situation?

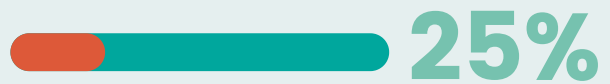
**YES**  
healthcare professional's advice is valued by caregivers and persons receiving care as well



**YES**  
but do not want to bother healthcare professional

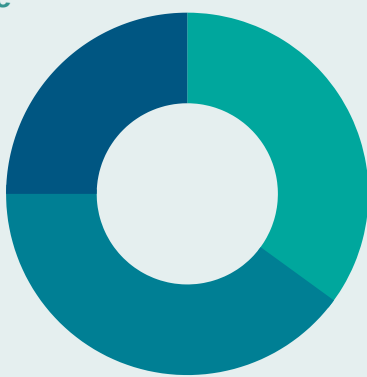


**Not applicable**



## Was there any difficulty getting in touch with someone to talk to?

Not applicable  
25%



Yes  
35%

No, access to advice from healthcare professionals has been good  
40%

## What tasks do you struggle with the most, or are the most challenging? (personal, physical, emotional)

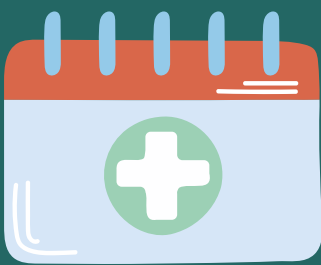
### Emotional, such as:

- Lack of informal support
- Lack of understanding from other family members/friends
- Helping the person the care is provided to understand own limitations (safety risk)
- Relinquishing control
- Trying to educate others on disease progression
- Understanding Dementia behaviours and how to respond.



### Personal care, such as:

- Keeping track of medication schedule and equipment
- Toileting/personal hygiene
- Nursing care
- Managing behaviour
- Constant monitoring
- Feeding
- Help with incontinence



### Supportive/coordinating tasks, such as:

- Appointments and transportation to appointments
- Coordination of care and assisting as a helper
- Unpredictability of the health situation
- Person requiring care refuse to accept help around the house



### Other: Administrative/Financial

- Lack of information (ex. Care hours, equipment, Social Development) and difficult system to navigate
- Overwhelming and redundant paperwork
- Financial burden to provide care as needed



## What are the things that would make your life as a Caregiver easier to do the work you need to do?

SAFE PLACES/ENVIRONMENTS WHERE PEOPLE WHO THE CARE IS PROVIDED TO CAN GO/RELOCATE AND THE CAREGIVER CAN HAVE A PIECE OF MIND

“LIAISON” BETWEEN AVAILABLE RESOURCES AND CAREGIVERS, A GUIDE THROUGH ALL THE QUESTIONS

PERSON WHO CAN PROVIDE MORE HOURS OF RELIEF

CONSISTENCY OF WELL-MATCHED IN-HOME SUPPORT WORKERS: BETTER EDUCATION, TRAINING, BIGGER SALARIES AND THE ROLE BEING APPRECIATED

KNOWING THE ANSWERS OF HOW THE HEALTH SITUATION WOULD DEVELOP

MORE ALLOCATED FUNDS THROUGH SOCIAL DEVELOPMENT FOR SERVICES AND EQUIPMENT

MORE FAMILY SUPPORT TO SHARE THE LOAD WITH

MORE PERSON- CENTERED SUPPORTIVE CARE HOMES (LIKE IN EUROPEAN COUNTRIES) INSTEAD OF BUSINESS-ORIENTED SUPPORTIVE CARE HOMES

COUNSELING  
◦ READILY AVAILABLE ON-LINE COUNSELING

HEALTHCARE NAVIGATION

EASIER ACCESS FOR THE DISABLED IN RURAL COMMUNITIES (EX. RAMPS)

MORE PRIVACY IN OWN HOME

LONGER APPOINTMENTS WITH SPECIALISTS - TAKING THE TIME TO EXPLAIN THE PROCESS TO PATIENTS (NOT ONLY TO CAREGIVERS)

HOME MEDICAL VISITS

REQUESTING SPECIFIC SUPPLIES THAT SHOULD BE READILY AVAILABLE SHOULD BE MADE SIMPLER (EX. UPLOADING A PHOTO OF WHAT IS NEEDED) - TECHNOLOGY SHOULD BE USED MORE

MORE PROGRAMS FOR SENIORS PROVIDED BY THE GOVERNMENT THAT ARE REALISTIC TO PEOPLE'S CIRCUMSTANCES

UNDERSTANDING OF THE FINANCIAL BURDEN CAREGIVERS BEAR - FINANCIAL ASSISTANCE FROM OTHER FAMILY MEMBERS OF THE LOVED ONE

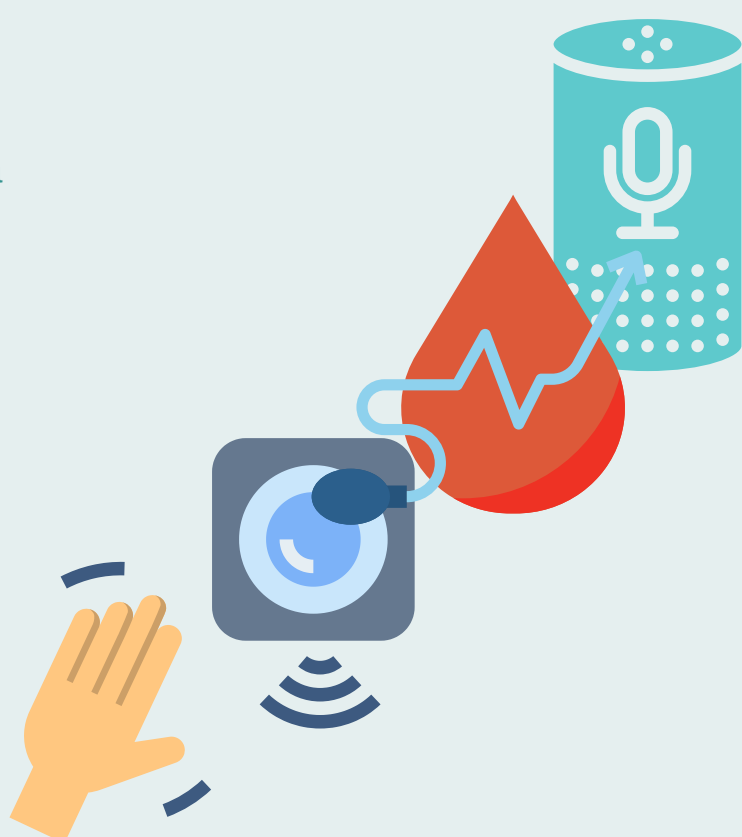
MORE AVAILABILITY AND OPTIONS FOR DAY PROGRAMS AND RESPITE CARE



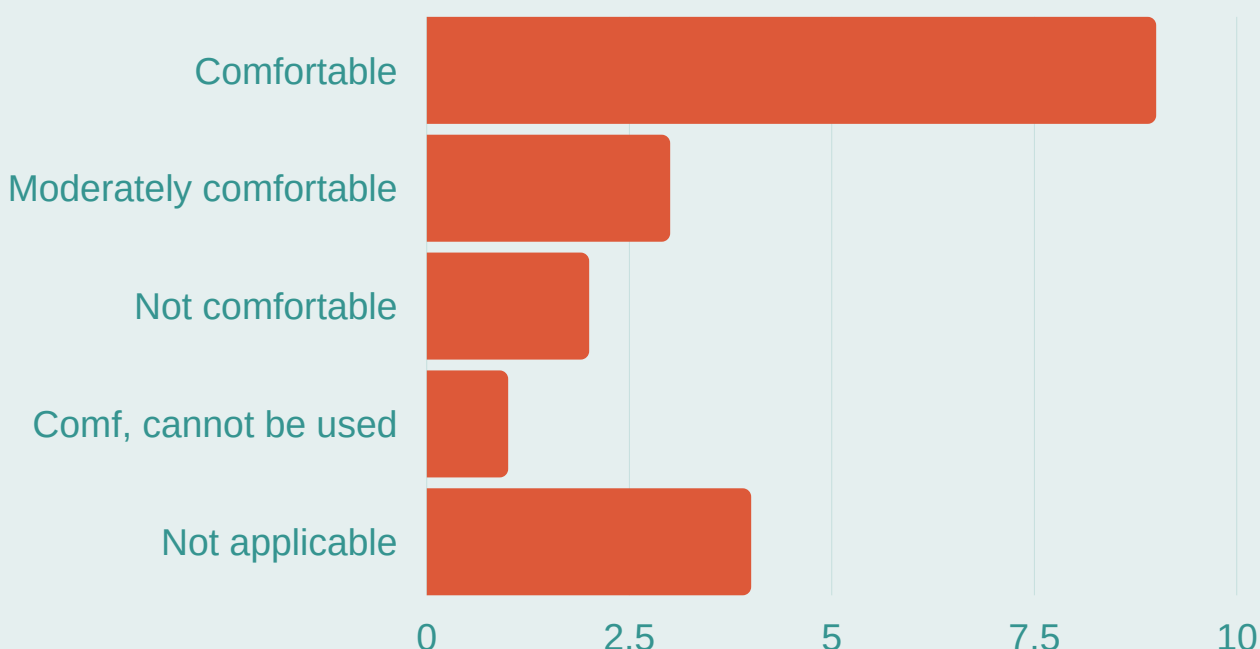
## DO YOU AND THE PERSON YOU CARE FOR CURRENTLY USE ANY TYPES OF TECHNOLOGY?

- Falls alert
- Motion sensor on the door bell
- Lifeline
- Webcam in bedroom and main area
- Baby monitor
- Freestyle libre

- Glucometer
- Blood pressure cuff
- Alexa
- Dementia clock/talking clock
- Geeni App
- O2 sat monitor
- Lift chair



## WHAT IS YOUR COMFORT WITH HELPING OTHERS USE THE TECHNOLOGY?



## ARE THERE ANY BARRIERS TO TECHNOLOGY USE THAT YOU CAN IDENTIFY?

Reception and internet coverage/speed is not consistent, especially in rural areas on limited phone plans

Resistance to technology/no interest/lack of understanding/inability to use from the person care is provided to

Eyesight or other medical condition that makes use of technology difficult

Information is overwhelming  
(ex. So many different platforms, logins, difficulty to navigate)

Financial costs

Privacy concerns when not using technology right, especially with medical information

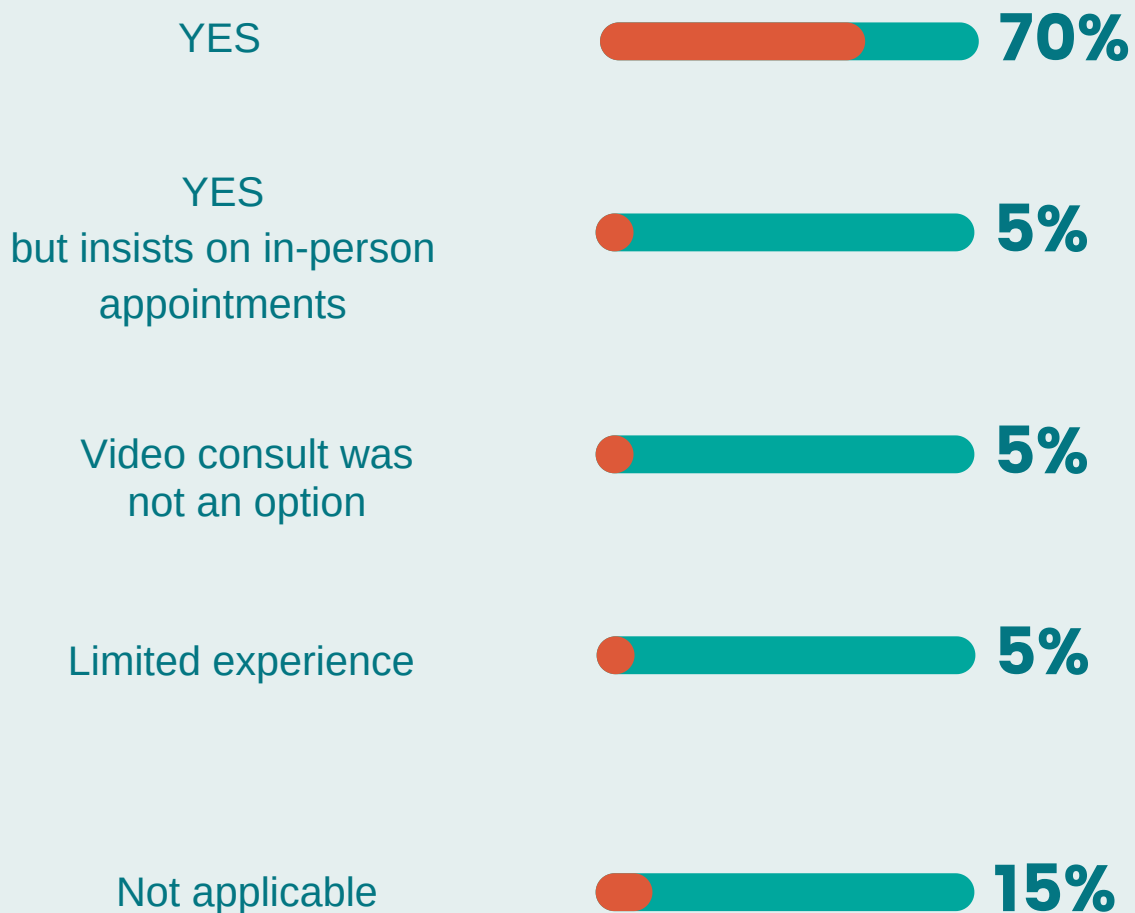
## DO YOU HAVE ANY SUGGESTIONS ON IMPROVING TECHNOLOGY THAT WOULD ENCOURAGE YOU TO USE IT?

- Training on using technology
- Available technical support
- User friendly and easy - ease of sign in, ease of navigation etc.
- Interactive, visual, not confusing, information provided right to the point
- A comprehensive list of available technology and where to obtain it

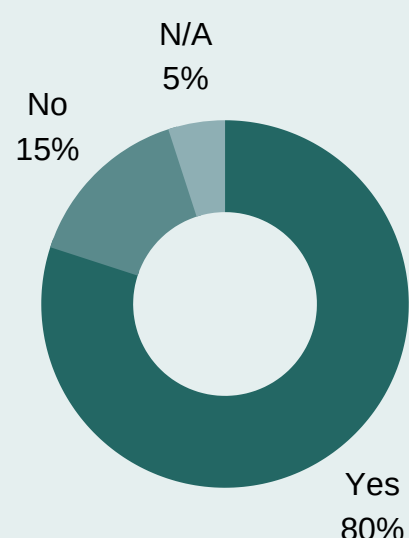
## IS THERE ANY TECHNOLOGY WHICH COULD HELP SUPPORT YOU WITH THE MORE DIFFICULT ASPECTS OF CAREGIVING?

- A central source to locate technology options available
- Door alarms
- Doorbell cameras
- GPS tracker
- Tile app and device
- Falls alert
- Virtual support groups
- Care Navigator services
- Medication dispenser/monitor
- Blood pressure monitoring system
- Video demonstration on how to provide care
- An iPad or computer that is senior-friendly
- Virtual communication with healthcare practitioners, such as
  - email, phone, text, video calls (zoom, facetime)

## HAVE YOU HAD ANY EXPERIENCES WITH VIRTUAL HEALTHCARE? IF YES, WHAT TYPE.



## DO YOU CURRENTLY USE SOCIAL MEDIA (VIRTUAL) PLATFORMS, SUCH AS FACEBOOK, INSTAGRAM, TWITTER, YOUTUBE, ZOOM?



## DO YOU USE SOCIAL MEDIA (VIRTUAL PLATFORMS) TO COMMUNICATE WITH YOUR FAMILY/FRIENDS AND IN WHAT METHODS?



## DO YOU HAVE ANY POSITIVE OR NEGATIVE FEELINGS/EXPERIENCES ABOUT USING SOCIAL MEDIA?

- Convenient and helpful
- Valuable experience during the pandemic
- (Virtual) support groups are very helpful (such as the I-Care community)
- Occasional frustration with technology
- Privacy and security concerns with technology
  - Privacy concerns with medical discussions via zoom requires user awareness
- Other comments:
  - Caution is needed with what is seen on social media, especially with children
  - Feels like many people live on social media, not being able to be themselves and convincing others to see things their way (political statements)



**Do you think that if you had access to one internet site which contained all healthcare-related information such as medications, medical history, and health monitoring items you would be interested in using it?**

We envision a site that is designed like a social media site, such as Facebook, where you could interact with your doctor/NP, your support person, pharmacist, and specialists as required. Also, there would be access to education to help support you in your role, and a forum where you could communicate with people going through similar experiences.

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Fabulous idea

All under one roof  
would be good

Good idea!

Interesting and  
blows my mind!

Would love to test  
it and know more  
about it

Amazing!

it would have made  
an astronomical  
difference

Convenient to have specialist  
from outside the area having  
access to her files in NB

A portal to care

---

**Reservations:**

- Scepticism whether doctors would have enough time - already overwhelmed with basic things
- Sounds interesting but privacy/security is a concern

Do you believe that this type of internet site could improve your sense of community and support in your caregiver roles?

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Gift to caregivers and could lift the burden

Amazing idea as it takes a village to care for somebody

A big benefit

Sounds like a dream and very helpful

Amazing!

Access is key

---

Reservations:

- It would be difficult for the elderly to embrace such systems
- It should provide information/training for caregivers on how to provide care and access resources they need/are eligible for - a guide book
- Important to make it simple and visual, provide training on using it

# IS THERE ANYTHING ELSE YOU WOULD LIKE TO SHARE THAT HAS NOT BEEN BROUGHT UP?

## THE CAREGIVER NEEDS CARE

- INCREASED MENTAL SERVICES
- HANDBOOK FOR CAREGIVERS IS NEEDED
- KNOWLEDGE AND SHARED EXPERIENCES ARE OF IMMENSE HELP

**NB SHOULD ADOPT BEST PRACTICES TO ASSIST PEOPLE TO REMAIN IN THEIR HOMES**

**ASSISTANCE TO NAVIGATE THE HEALTHCARE SYSTEMS WOULD BE HELPFUL**

**PERSONAL CARE WORKERS FROM AGENCIES NEED MORE EDUCATION AND QUALIFICATIONS**

## HOLISTIC HEALTHCARE IS IMPORTANT

- MORE MOBILE HEALTHCARE (INCLUDING NURSE PRACTITIONERS) IS NEEDED

**THE SOCIAL ASPECT IS CRUCIAL FOR SENIORS' EMOTIONAL WELLNESS**

- CHURCHES PROVIDE A GOOD SENSE OF COMMUNITY AND ARE ENJOYED BY SENIORS

# IN CLOSING

The information contained within this document is a summary of relevant data collected during interviews with 20 New Brunswick family caregivers. We thank them for their time and sharing with us their deeply personal experiences.



# ACKNOWLEDGEMENTS

Special thanks to the members of the **Steering Committee** for their guidance and invaluable contributions to this Caregiver Research Study.

- **Amy McLeod**, BN, RN, MHS, ENCC, GNC; **Project Lead**
- **Karen Lake**, BN, RN Caregiving Consultant and Care Navigator; **Research Assistant**
- **Jamie Rose**, MA Counselling Psychology; **Research Assistant**
- **Shirley Renouf**; **Caregiver Representative**
- **Jenna Roddick**, APPTA Manager of Research and Knowledge Translation; **Project Advisor**
- **Heather Higgins**, APPTA Coordinator of Policy and Knowledge Exchange; **Project Advisor**
- **Dr. Hanif Chatur**, ERP, Co-founder eVisitNB; **Project Advisor**





# CONTRIBUTORS

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