



Being a caregiver

A challenging but meaningful experience



SPECIAL EDITION

In collaboration with :

Appui
proches aidants

Who are the caregivers?

This heartfelt testimonial helps us look beyond definitions and statistics.

Finding balance

Are you a caregiver? These strategies may help you make space for your own needs.

Science news

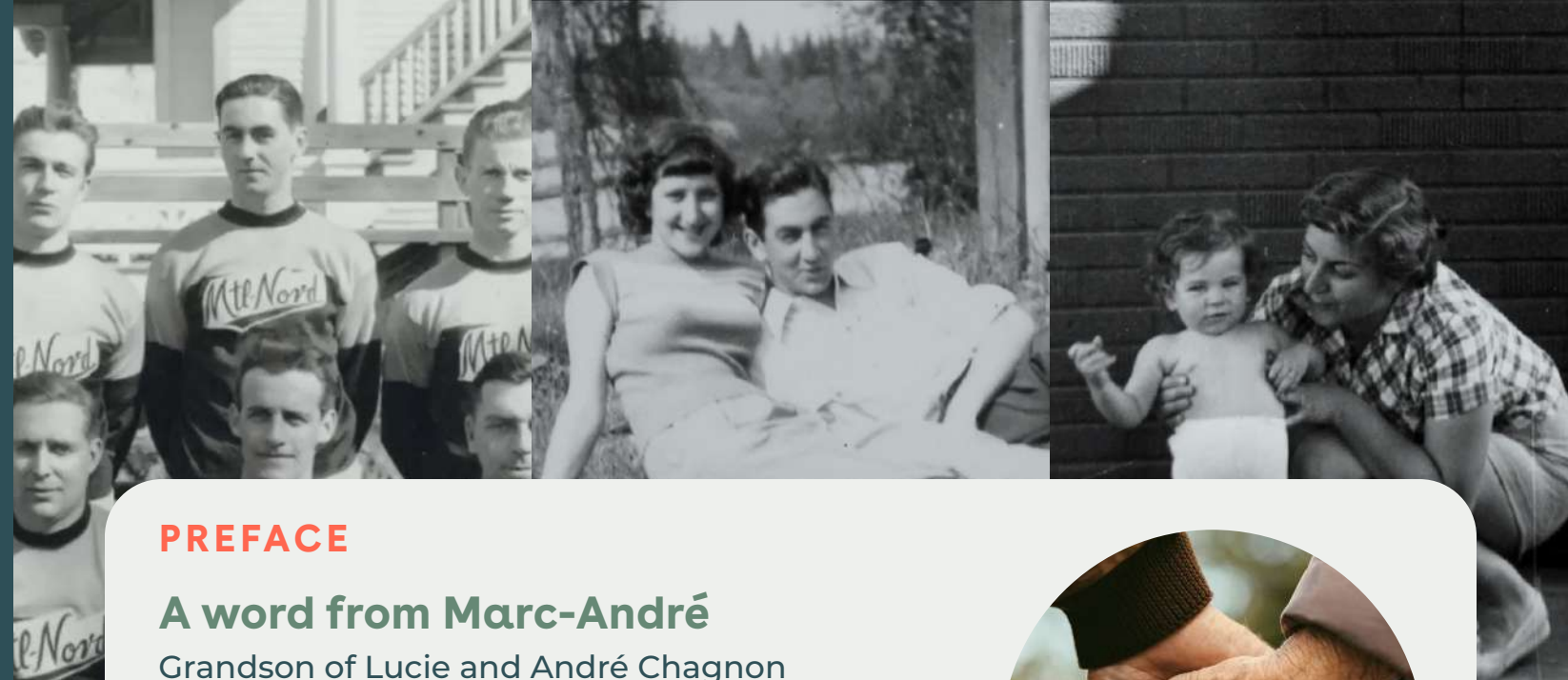
View the results of Lucilab's latest study and find out whether participants managed to improve their lifestyle habits.

About the Luci ebook

The Luci ebook is a digital publication that you can browse, download, and share. It was designed by the Lucilab team to help you lead a healthy, active, and stimulating life.

For more information, visit lucilab.ca

POUR
LIRE LE
BULLETIN EN
FRANÇAIS,
CLIQUEZ
ICI



PREFACE

A word from Marc-André

Grandson of Lucie and André Chagnon
and president of Lucilab



The talents behind this ebook

Among the Lucilab team

- Cindy Laplante, RD, writer-editor specialized in health
- Sophie Geoffrion, MBA, PMP, marketing manager
- Maria Alcaraz, M.Sc., UX/UI designer

Our valued collaborators

- Nicolas Gendron, project manager, transfer knowledge and communications, at L'Appui
- Lucie B., caregiver for her mother
- Ariane Savard, graphic designer

Thank you for your contribution!

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Subscribe



The touching story of my grandparents

My grandparents' love story started on a baseball field in the 1940s. André pitched for the Montréal-Nord team and Lucie was the coach's daughter. For 65 years, they were a formidable team, in life and in business. Together, they raised five children while building successful companies and supporting many social causes.

But their lives took a difficult turn when Lucie was diagnosed with Alzheimer's disease. My grandfather was a real hero. He took care of her at home for as long as he could, until she had to be placed in a residence to receive the care she needed.

Despite his busy schedule, my grandfather visited Lucie every day. They'd share a meal, go for a walk, or play cards. In his eyes, she remained the same

outgoing and playful woman he'd always known, even though the disease was affecting her memory. Lucie's eyes would lighten up as soon as André was in sight.

It was this challenging yet beautiful experience that inspired my grandfather to found L'Appui pour les proches aidants, a support organization for caregivers, followed by Lucilab a few years later. On behalf of these two organizations, I encourage you to read this ebook to better understand the role that caregivers play. You'll also find a heartwarming testimonial and advice on finding balance.

Happy reading!

In this edition

05. What's new at Luci?

There are some new faces on our team!

SPECIAL EDITION: BEING A CAREGIVER

06. Who are the caregivers?

Understanding the tasks and challenges that accompany this gratifying role.

10. Testimonial

Lucie B. opens up about her experience as a caregiver.

14. Practical advice

Finding a balance between your own needs and those of the person you're caring for.

18. The LuciLAB

A look at the results of our latest scientific study.

20. Playful page

Can your eyes spot the differences between the two images?



What's new at Luci?

There are some new faces on our team

With no less than 7 new members since the start of the year, the Lucilab team is now over 30 strong!



From left to right : Stéphanie, Christéva, Leila, Justine et Geneviève.

Important projects in the works

In the coming months, our new recruits will assist the rest of the team in a few key areas:

- Producing multimedia content
- Developing new features on the web platform
- Rolling out a series of pilot projects to make the Luci program accessible to a diverse clientele

To learn more about Lucilab's multidisciplinary team, visit [our web site](#).

BACK TO TABLE OF CONTENTS

Meet the 6 new Lucilabers!



CHRISTÉVA
Research project coordinator



LEILA
Marketing coordinator



STÉPHANIE
Business analyst



GENEVIÈVE
HR business partner




JUSTINE
Healthy lifestyle advisor



SANDRINE
Healthy lifestyle advisor

Who are the caregivers?

Caregivers are individuals who care for a loved one, either temporarily or over a long period of time. Their role changes continuously depending on the recipient's condition, the caregiver's previous relationship with the recipient, and their socioeconomic circumstances. Being a caregiver can be as rewarding as it is demanding. That's why making time for self-care, however difficult that may seem, is paramount.

 **Reading time** : 2 min

The caregivers support spouses, parents, grandparents, siblings, in-laws, friends, neighbours, and others who have temporary or permanent disabilities, regardless of age or living situation, by providing unpaid occasional or ongoing care and support.

26



The average number of hours of informal care provided each week to seniors with dementia in Canada.

Source: Canadian Institute for Health Information. [Unpaid caregiver challenges and supports](#) [report]. Accessed February 3, 2023.

Frequent tasks

- Providing transportation and help with errands
- Giving emotional support
- Arranging outside care and services and attending appointments
- Helping with household chores
- Maintaining the home and property
- Managing finances
- Handling administrative procedures (e.g., legal and juridical matters)
- Administering medication or providing care

Caregivers also have needs

- Information and education about the recipient's illness
- Individual and group psychosocial support
- Flexibility at work and school
- Respite services
- Financial and material support
- Support with domestic and day-to-day activities
- Social time to break isolation, e.g., talking with people outside the situation
- Personal hobbies and activities
- Exercise and fresh air
- Feeling of being valued in their caregiving role

A rewarding and valuable role

In addition to playing a valuable role in society, informal caregiving can be very fulfilling on a personal level. It can deepen your relationship with the recipient, lead to better self-knowledge, help you discover hidden strengths, and more.

However, it can be difficult to acknowledge your role as an informal caregiver and gain confidence in your abilities. It's not uncommon to feel useful and yet experience stress, fatigue, and even social or financial impoverishment at the same time. This may cause you to feel irritable or angry, both perfectly normal reactions that should be met with compassion.

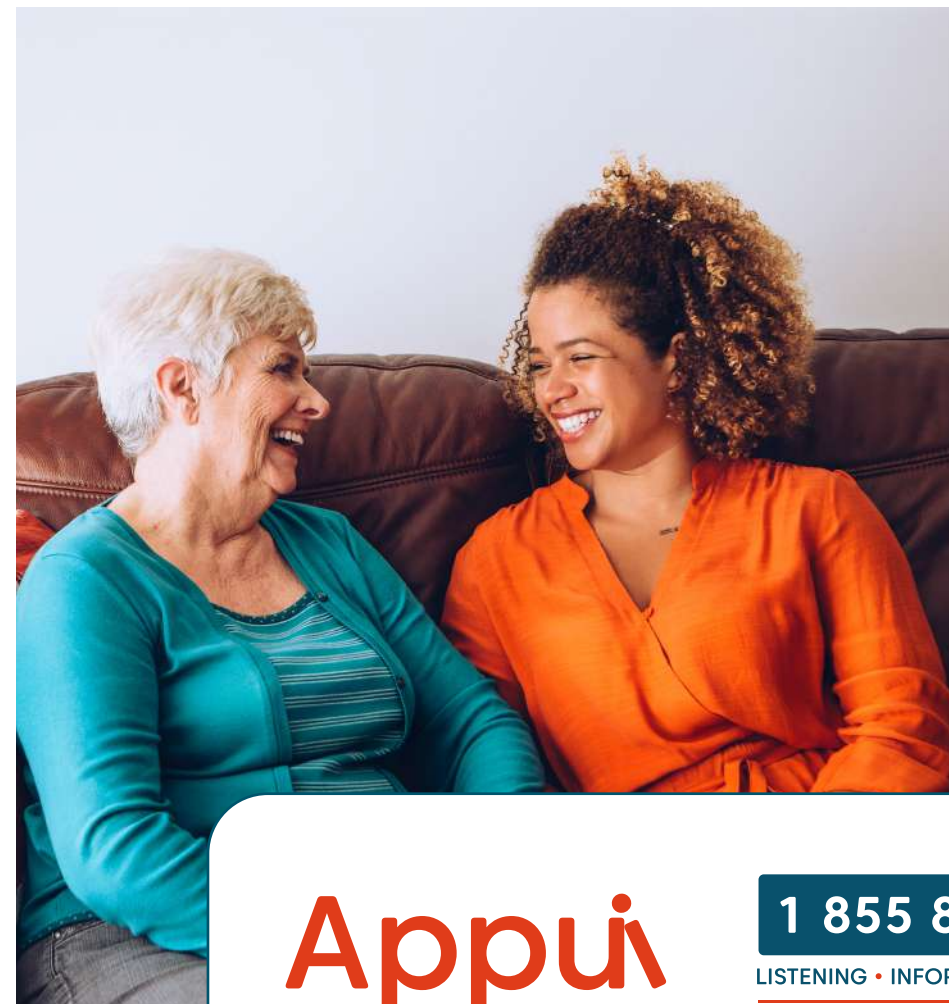
If you're an informal caregiver, asking for and accepting help may not come naturally. Feeling recognized and supported by those around you can make a big difference and allow you to better care for yourself.

Thanks to our partner L'Appui for writing this article.



YOU SUPPORT A LOVED ONE

We are here for you



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Testimonial

Mrs Lucie B. takes a frank and moving account of her caregiving experience

Being a caregiver is a serious commitment. The experience can be challenging at times, but it's also filled with tenderness, humanity, and strength. In the following poignant testimonial, we hear from a woman who devotes time and energy to caring for her mother with Alzheimer's disease.

This is the story of Lucie B., an inspiring woman, a loving daughter ... and a [Luci program](#) participant.

🕒 Reading time : 3 min



Lucie B. and her mother

“In 2008, I learned that my mother was being monitored by a neurologist because she was worried about some minor memory lapses. My father, then at the end of his life, confided in me and asked me to take over her care. Mom was 74 at the time. She was healthy and seemed to be in full control of her life.

However, in the following years, she gradually developed mild cognitive impairment. She went through a very difficult time—grief, selling the family home, moving into a retirement home—that no doubt contributed to the decline.

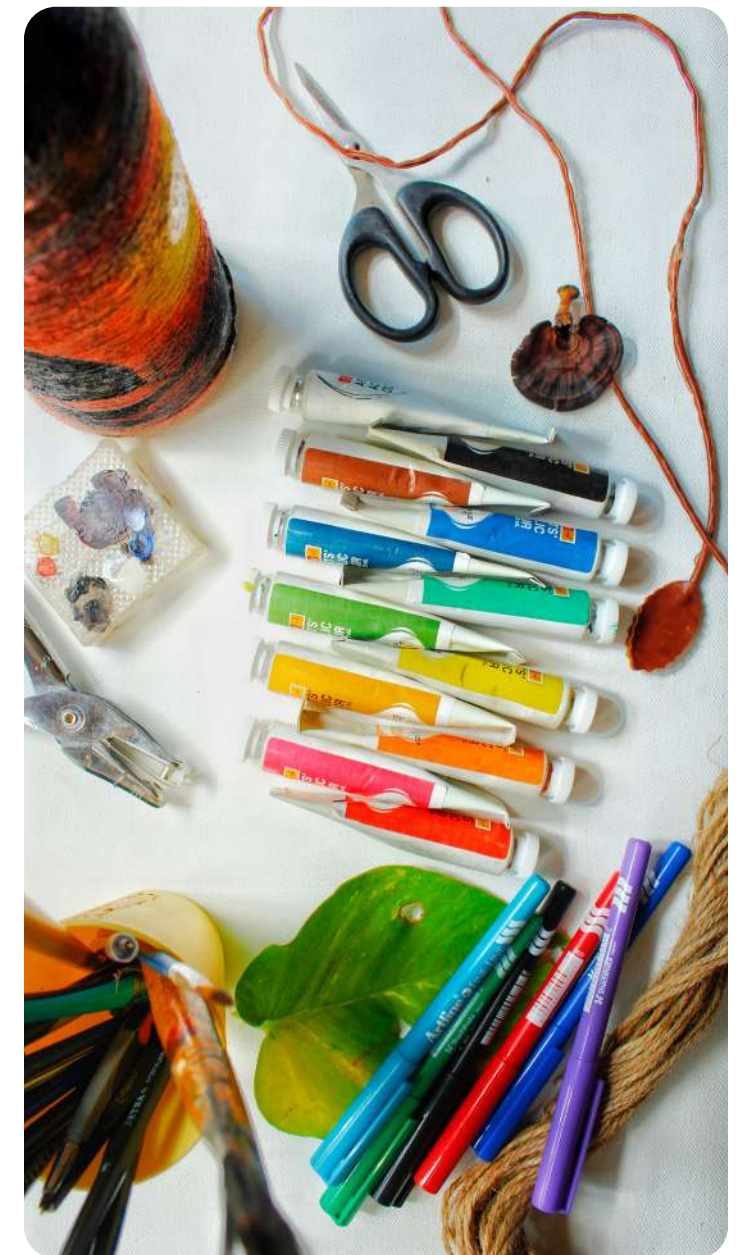
There were the typical episodes of memory loss. She started repeating herself, forgetting appointments, missing medication doses, struggling to manage her finances, etc.

Then, she began to show signs of more serious functional decline. Routine tasks like driving, cooking, and washing herself became challenging. She was becoming anxious and isolated. All her mental faculties were slowing down; nothing was spared. Her judgment declined.

She was diagnosed with Alzheimer's disease in 2017.

“ ”

I'm very invested in my role as a caregiver. [...] I'm able to do a lot for my mom, [but] I also do something for myself every day.



Today, Mom is in a CHSLD. She's 89 years old. She still recognizes her family. She can still have simple conversations. She still feeds herself. Her motor skills are impaired, she uses a wheelchair, she wears diapers, and she suffers from [sundown syndrome](#). She has good days and bad days.

Almost every day, she has one or more episodes of brain fog. They make her cry and can trigger an anxiety attack.

Every loss was painful for my mother and for the people who love her, because Mom is a fighter. She struggles and is in constant denial. To this day, Mom still refuses to let go.

I visit her almost every day, and we talk on the phone or by video call several times a day.

The mother-daughter role has long since been reversed for us. We're close. Very close. I love her. I can still see the generous, gentle, and loving woman she always was. It's hard to witness so much vulnerability and distress. I'm very invested in my role as a caregiver. I help her through her days. I lend her my voice. I'm able to do a lot for my mom. I'm happy and even grateful to be able to give her my support and my time.

Of course, there are times when I struggle to cope, too. Sometimes I get discouraged. But we always find solutions! It passes. And life goes on. I have help. A companion helps me cover some critical hours of the day. She's a gem. I take care of myself, too, so I can show up fully. I do something for myself every day.

It could be a nature walk or something physical or artistic. It's my own way of balancing the beauty and the darker side of my days."



A word from Marianne

Healthy lifestyle advisor at Lucilab

I was delighted to meet Lucie through the Luci Program. She's an inspiring, joyful, passionate, athletic, and creative woman.

In addition to caring for her mother for many years, she's an active member of her motorcycle, walking, and dragon boat clubs. She also enjoys a wide variety of other activities: writing, watercolour painting, photography, downhill skiing, cross-country skiing, skating, etc. Nothing can stop her!

She is living proof that you can both take care of yourself and be a dedicated caregiver.

On behalf of the Lucilab and L'Appui teams, thank you so much for sharing your story!

Need an energy boost?

Try a snack! Whether sweet or savoury, healthy and satisfying snacks can be prepped in advance to keep you fueled on busy days. Browse our articles on this topic for information and inspiration.

CLICK ON AN ARTICLE TO READ IT IN THE APP!



Inspiration

40 delicious, healthy snack ideas

 4 min



Information

Healthy snack or mindless munching?

 5 min

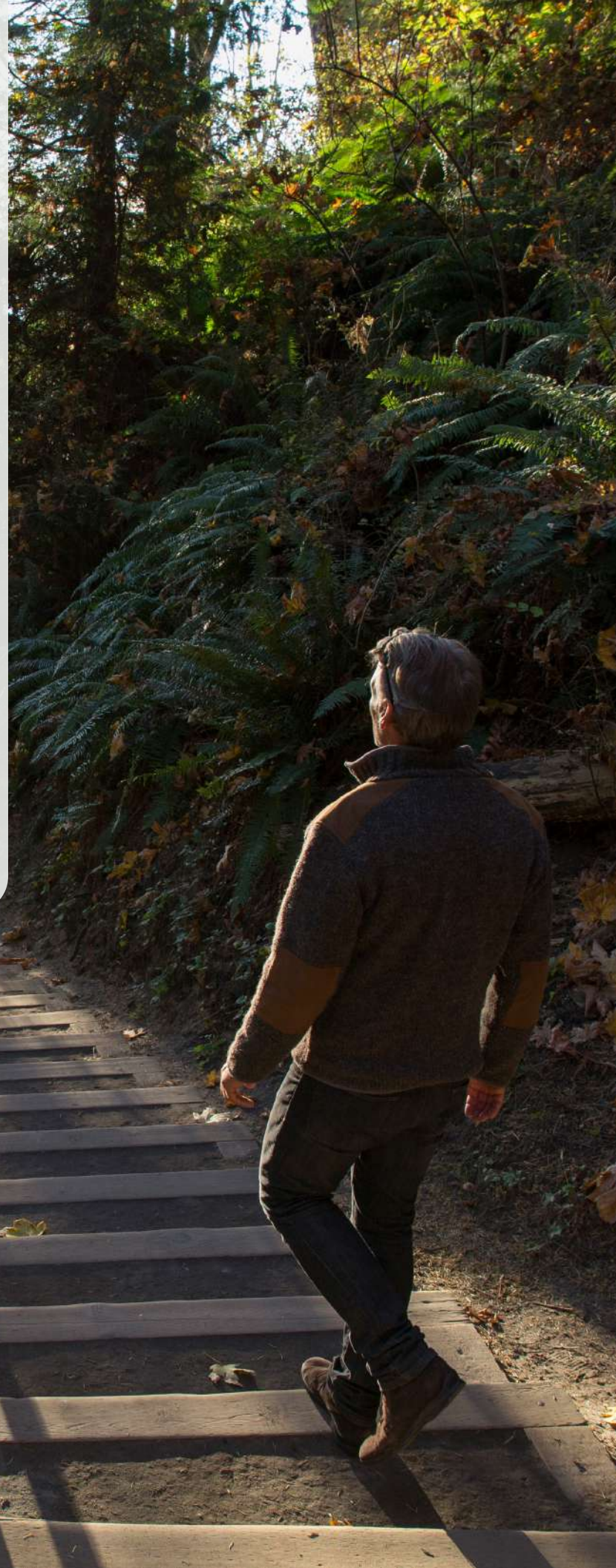


FOR MORE ARTICLES, VISIT LUCIAPP.CA

Practical tips to help you find balance

It's not easy to juggle family, work, and a social life while supporting a loved one. By prioritizing another person's care, you may neglect your own needs and burn out. Getting help and making time for yourself can help you strike a balance.

🕒 Reading time : 2 min



RECOGNIZE YOUR NEEDS

- You have limitations.
- You have the right to say no, to express your feelings, and to make your opinions heard.
- This is a demanding role, but it's important to take care of yourself, too.
- You're allowed to have moments of sadness or grief; it's perfectly normal.



GET HELP

- Attend workshops, conferences, or training to better understand your role and find tools and resources.
- Join a [support group](#).
- Meet with a counsellor for psychosocial support.
- Join the [L'Appui pour les proches aidants Facebook page](#) (French only), a welcoming



STRIKE A BALANCE

- Reach out to your [support network](#) or that of your loved one to delegate certain tasks.
- Consider [requesting outside help](#), such as Meals on Wheels, friendly visits, or help with errands.
- Take breaks from your role and recharge your batteries (e.g., play sports, make art, read, walk outside).
- Try to find situations where you can let go of your responsibilities.
- Remember all the good deeds you've done for your loved one.
- Exercise self-compassion and give yourself permission to make mistakes.



DO THINGS FOR YOURSELF

- [Eat well to provide better care](#).
- [Exercise](#).
- Accept help.
- Practise self-compassion and self-sufficiency.
- Consult a physician.
- Find resources to meet your health or [psychosocial](#) needs.

Luci

Be the hero of your journey!

Luci is a platform that makes it fun to build a healthy, brain-protective lifestyle.

CLICK ON THE CARDS TO OPEN THE APP



Review my current habits



Learn about brain health and healthy lifestyle habits



Set my personalized goals



Get support from an advisor



Ready to play?

Take me to Luci >



Feasibility study

The results are in!

The feasibility study is the second step in a three-phase scientific validation process. As the name implies, this study aimed to assess the feasibility of the Luci program by answering the following questions:

- Are we able to recruit participants quickly?
- Do participants complete the study?
- Do participants follow the program consistently?

We were also interested in whether participants with immediate access to the Luci program managed to improve their lifestyle habits and what they thought of their experience.

Results

Feasibility measures: **We met our targets!**

RECRUITEMENT

All participants were recruited within **1 week**.

RETENTION

92% of participants who started the study filled out the end-of-study questionnaires.

ENGAGEMENT

In the Luci group, **85%** of participants attended at least 12 of the 18 scheduled meetings.



ISABELLE LUSSIER, PH.D.
Research director at Lucilab



SYLVIE BELLEVILLE, PH.D.
President of Lucilab's scientific committee

An overview of the method

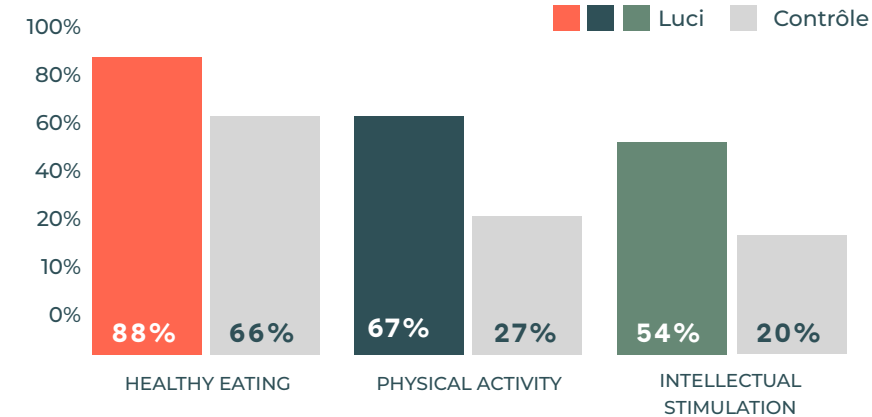
DURATION: 24 weeks (6 months)

POPULATION : A total of 123 adults aged 50 to 70, randomly split into two groups

LUCI GROUP	CONTROL GROUP
83 people ... who had immediate access to the Luci program.	40 people ... who had access to the Luci program after 6 months.

Did participants in the Luci group manage to improve their lifestyle habits over the course of the study? **YES**

Proportion of participants who made a lifestyle change over the course of the study, for each domain.



Over a 6-month span, more participants improved their lifestyle habits in the group that had immediate access to the program (the Luci group) than in the group that didn't (the control group).

That's encouraging news!

What did participants think about the Luci program?

% of participants who indicated that they "somewhat agree" or "strongly agree" with the following statements

98 %

"The Luci program has helped me realize the importance of improving my lifestyle habits to keep my brain healthy."

98 %

"The Luci program has helped me learn more about behaviours that contribute to brain health."

100 %

"The Luci program has increased my motivation and desire to improve my lifestyle habits."

90 %

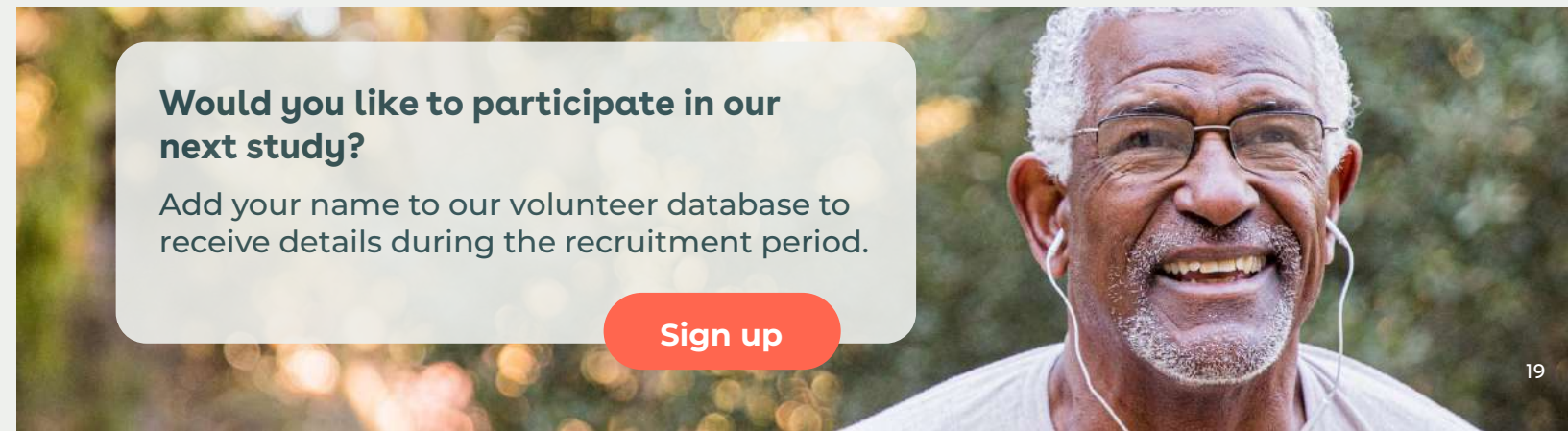
"I feel more capable of improving my lifestyle habits than I did before I started the Luci program."

These results allow us to move on to the last step: the efficacy study.

Would you like to participate in our next study?

Add your name to our volunteer database to receive details during the recruitment period.

[Sign up](#)





Luci

To read (or re-read!) our previous edition is here.

Ebook vol.03
Spring 2022

**CONSULT
IT IN ONE
CLICK!**



Notice

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