



# **BUILDING A BETTER ONTARIO FOR CAREGIVERS**

**by Listening to the Voices of Caregivers**

**The 2024 Ontario Caregiver Coalition Survey of Caregivers:  
Policy Brief #1 - An Overview of Caregiver Experiences & Needs**

**“Caregiving needs to be valued by our society. It needs  
to be a collaborative effort by everyone involved.”**

**June 2024**



## ABOUT THE ONTARIO CAREGIVER COALITION

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Our members include both caregivers from across Ontario and organizations that support them. For more information about the OCC and our work, please see our website at [www.ontariocaregivercoalition.ca](http://www.ontariocaregivercoalition.ca), or follow us on social media.



### BUILDING A BETTER ONTARIO FOR CAREGIVERS: POLICY BRIEF SERIES

This Policy Brief, developed by the Ontario Caregiver Coalition (OCC) and informed by OCC's 2024 Ontario Caregiver Survey, is the first of a series of six Policy Briefs that will be presented to the Ontario Government in 2024 and 2025.

The OCC's 2024 Ontario Caregiver Survey sought to explore policy priorities among Ontario caregivers. The Survey was in the field from January 31, 2024, until March 12, 2024, and received 612 responses from Ontario caregivers. The policy recommendations presented in each Policy Brief are based on the views expressed in the Survey by caregivers.

The Ontario Caregiver Coalition would like to extend our thanks to all of the many members and friends who worked to design, distribute and complete our 2024 Ontario Caregiver Survey. Your passion for supporting unpaid caregivers and your commitment to change are inspiring, and make the impossible possible!

In particular, we would like to thank the following members of the Research and Advocacy Committee who devoted their time and skills to the development of this Policy Brief.

*Lauren Bates*

*Rebecca Cheff*

*Dr. Mary Chiu*

*Dr. Sharon Gabison*

*Rose-Marie Fraser*

*Dr. Matthias Hoben*

*Jessica Hogle*

## LISTENING TO CAREGIVERS: BUILDING MEANINGFUL POLICY CHANGE

“Listen to what families need before you put programs in place. I feel many government programs/funding have already been decided on before they consult with parents/or other caregivers.”

There is growing awareness of the important role of unpaid caregivers in our health and social systems. Family, friends and neighbours provide vital emotional, physical, navigational and advocacy supports to persons living with acute or chronic illness, disability or frailty. **In Canada, an estimated 75% of care is provided by unpaid caregivers, equating to approximately \$26–\$72 billion per year in unpaid work.**<sup>1,2</sup> Our health, long-term care, and social services sectors are profoundly reliant on unpaid caregivers, and indeed could not function without them. Demographic shifts mean that there is a growing population of older persons. At the same time, family sizes are declining, and families are becoming more geographically dispersed. With these changes, caregivers will become more essential, but also fewer in numbers.<sup>3</sup>

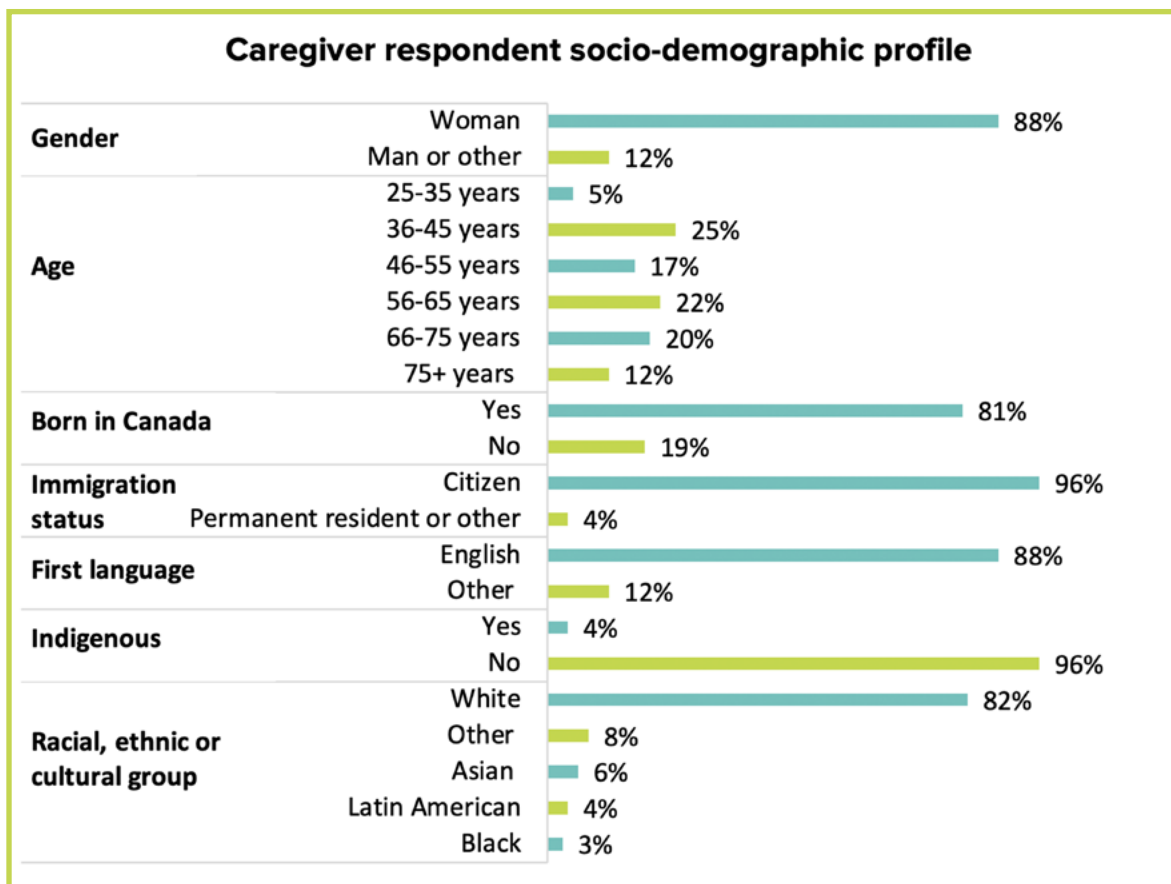
Yet, little policy attention has been paid to sustaining caregivers in their vital role. Few supports target caregivers directly. The supports that exist often differ from region to region, target only very specific needs or types of caregiving, or are institution-specific. This leaves caregivers navigating a patchwork of programs and services. Existing provincial supports are often designed in ways that make them inaccessible or ineffective for those they are intended to help. Caregivers know that they are essential, but at the same time feel invisible. In our Survey, caregivers spoke of feeling overwhelmed by their responsibilities, and abandoned.

To build effective and meaningful systems of support for unpaid Ontario caregivers, we need to understand what will work for them. While research into caregiver needs is increasing, there has been limited work on developing effective policy options. For example, caregivers have been very clear about the need for more and better financial supports to address the out-of-pocket costs of caregiving, and the loss of income associated with reduced employment. However, there has been limited research to understand how financial support is best delivered to caregivers, what levels of support would meaningfully reduce caregiver-related financial distress, and how needs for financial support differ among caregivers.<sup>4</sup> This may explain why the predominant vehicle for direct financial supports for Ontario caregivers, **the Canada Caregiver Credit, is estimated to reach fewer than 8% of caregivers across Canada.**<sup>5</sup>

To address this evidence gap for policy design, the Ontario Caregiver Coalition (OCC) launched a Caregiver Survey that aimed to understand, in concrete terms, what supports caregivers most need and how supports could be best designed to assist them. The survey was developed in collaboration with caregivers, persons supporting caregivers,

and researchers. Between January 31, 2024, and March 12, 2024, the link to the online survey was disseminated broadly via social media, mailing lists, and websites of OCC membership organizations and supporters.

**Our survey was completed by 612 Ontario caregivers. These are individuals who provide unpaid support for a family member, friend or loved one. Figure 1 provides a more comprehensive description of who completed this survey.**



## WHY DOES CAREGIVING POLICY MATTER?

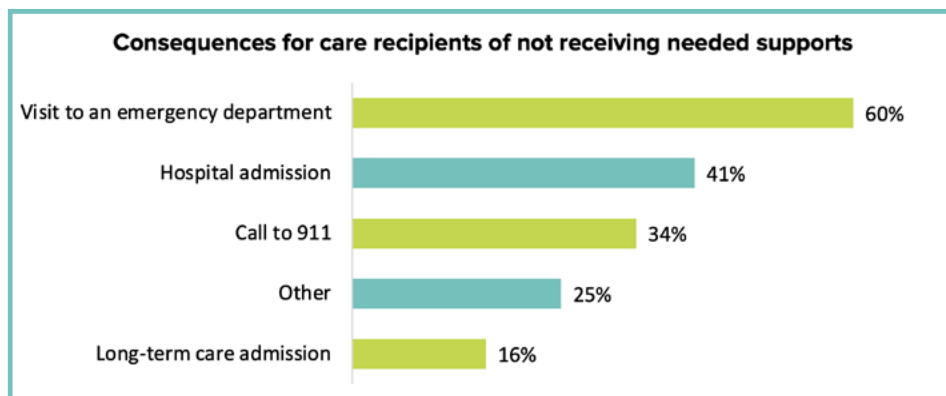
“Physically I can’t do it all. Emotionally I can’t do it all. It’s my partner who has Alzheimer’s and I have to do it all, his meds, keep track of appointments, advocate for better care for him, for different medications, for more services. Then do the cleaning, the laundry, the shopping, the supporting, etc. Sometimes I don’t eat all day, I forget to take my medications, I feel exhausted and don’t realize it. And I do all this without my best friend and confidant, making major decisions alone.”

Caregiving can be incredibly taxing, physically, mentally, emotionally, financially and socially. Survey respondents emphasized that while they find their role important and meaningful, it is also often difficult, isolating and saddening. It affects their employment, their finances, their relationships and their own physical and mental health. Research indicates that **caregivers experience high levels of stress, depression and physical health decline due to the intense demands of caregiving**.<sup>6</sup> Caregivers bear substantial out-of-pocket expenses, averaging several thousands of dollars annually, for medical supplies, home modifications, and additional care services.<sup>7,8</sup> This is not sustainable.

While the costs to caregivers of their role have been well outlined in the academic literature, the broader social and economic costs of failing to support caregivers have been less explored.

“If there had been more supports available in the home my father would not have been admitted to long-term care. Neither he nor my mom wanted that, but my aging mom couldn’t care for my dad in the home any longer. It’s a very broken system.”

Currently, health system policy is of central concern for both Ontarians and their government. A recent Leger poll found that fewer than one-third of Ontarians considered our health system “good”, with a similar number rating it as “poor” or “very poor”.<sup>9</sup> The majority of Ontarians (72%) are worried that they or their family will not be able to receive the health care that they need when they need it. **Health and long-term care systems rely heavily on unpaid caregivers, while providing little support for caregivers in return.** When care in the community fails under the strain, the impact on the health system can be significant. When Survey respondents were asked about the impact of failure to provide necessary supports, they pointed to a range of costly health system interventions for care recipients, including visits to emergency rooms, hospital admissions, 911 calls, and admission to long-term care facilities.



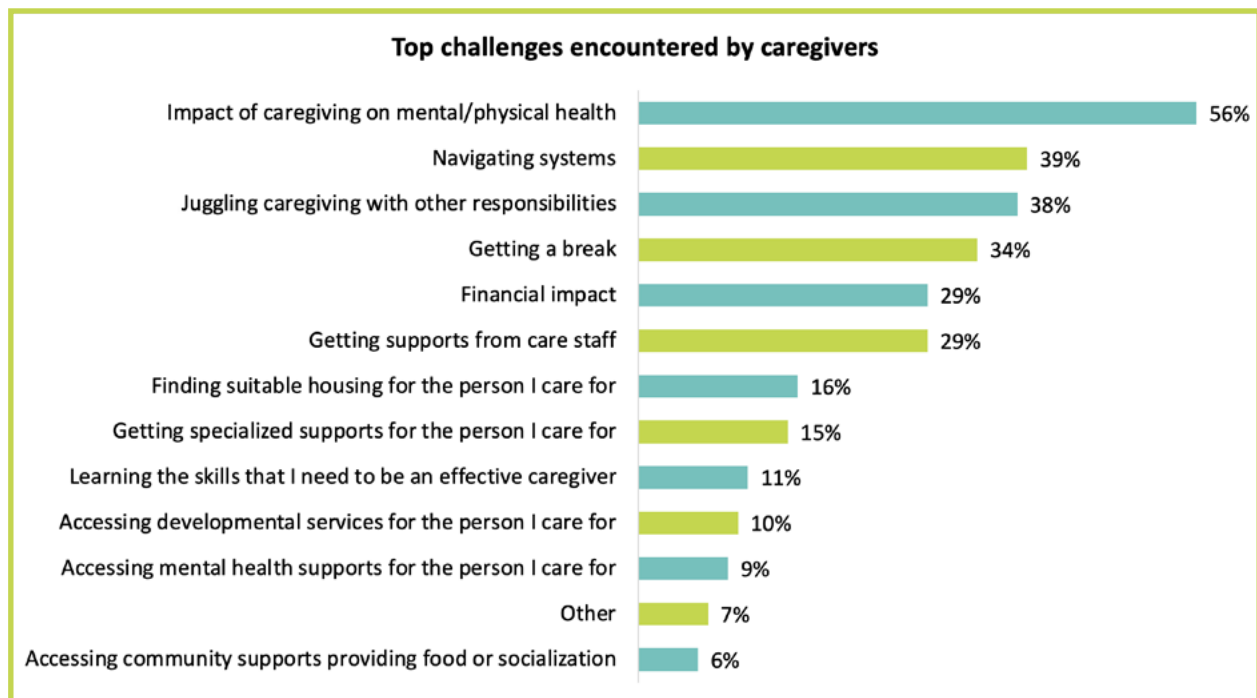
The lack of supports also affects the ability of caregivers to juggle their caregiving responsibilities with their employment commitments. Survey respondents told us that they were passing up opportunities for advancement in their careers, giving up learning opportunities, downshifting to part-time, casual or freelance work, scaling back their small businesses, or leaving the workforce altogether.

“I ended up leaving the workforce for part-time freelance work, at the height of my career and skills, because my intensive caregiving responsibilities could not be balanced with work. This happens to a lot of women, and it’s a loss for them, for employers and for society. This will only get worse as demographic trends intensify, if employers and government don’t take another look at how to support caregivers in the labour force.”

These constrained choices have long-term consequences for families and Ontario. Survey respondents highlighted their lack of retirement savings and Canada Pension Plan contributions due to their caregiving responsibilities, and the likelihood that they face an old age where they themselves would be living in low-income and dependent on government supports for basic necessities. At the same time, employers lose workers and their potential contributions to society.

## WHAT ARE CAREGIVER PRIORITIES FOR POLICY REFORM?

“It’s not enough to try to ‘increase resilience’ for caregivers or help them to ‘navigate’ to supports that don’t actually exist. Caregivers need concrete, practical systems of support – good homecare, financial backstops, proper housing options. This cannot be dealt with as an individual problem. It’s a systems problem.”



While some Survey respondents indicated that they had received the supports they needed for caregiving, or lauded specific programs or services, the overwhelming message was that caregivers are struggling to access needed programs or supports for themselves and their loved ones. Caregivers spoke of “**navigating to nowhere**”, as they were repeatedly referred to multiple organizations or services, only to ultimately find that the service they needed was not available in their region, was not available to families in their particular circumstances, was so inflexible in its rules that it was not meaningful for them, or had such a lengthy waitlist that they could not rely on receiving supports within any reasonably foreseeable future. Caregivers living in rural, remote or Northern settings emphasized the additional difficulties they face in accessing supports. It is telling that when asked to select their top three challenges, 39% of Survey respondents selected finding supports (navigation) as one of their primary difficulties.

**Beyond navigating to locate supports, the most common policy priorities identified by Survey respondents were:**

1. **Addressing the impact of caregiving on their mental and physical health.** Caregiving is intrinsically difficult. Facing the illness, disability or oncoming death of a loved one is a profound life challenge, and the responsibilities associated with supporting the care recipient to live the most dignified and meaningful life possible are heavy ones. The shortfalls of our systems of support greatly exacerbate these challenges, and the impact on caregiver health can be significant. However, few Survey respondents had access to any significant supports for their own mental and physical health.
2. **Juggling caregiving with employment.** Two-thirds of Survey respondents were working-age adults. Some had found their caregiving responsibilities too extensive to continue in the workforce. Others were working more intensively than ever to address the financial burdens of care. Many were struggling to manage both work and care, with very limited assistance either in the form of employer supports or of services that would provide reliable care for care recipients during working hours.
3. **Getting a break (respite).** For many caregivers, their role is a 24/7 responsibility. Some live with the person they care for and provide care all through the day and also at night. Others find that whether or not they are present with the person they are caring for, they are always on call. Getting a break is a top priority for almost 40% of Survey respondents. What a break might look like will differ among caregivers. It might be an adult day program to allow them to work, overnight respite to permit a night of uninterrupted sleep, or simply reliable provision of home care so that they can run errands or take a walk. Whatever their vision of a break might be, one-third of Survey respondents found that the supports that would enable that break are elusive.

4. **Alleviating financial hardship.** Caregiving entails significant out-of-pocket costs, and at the same time it often limits the ability to maintain paid employment. Barely any financial supports are available for caregivers themselves. Financial hardship was a recurrent theme among Survey respondents.
5. **Finding care in the community.** Survey respondents care for those living in a range of settings, including their own homes, retirement homes, long-term care homes. However, for many families, avoiding institutional settings is a primary goal. The supports needed to achieve this are often difficult to find. Survey respondents find that publicly funded home and community care services are overstretched, often providing limited and minimal support, while private services are often beyond their financial reach. Developmental services entail long wait lists and complicated processes. Long-term planning seems impossible, as families and systems must constantly respond to crises.

While these are distinct areas of public policy, they are tightly connected in caregivers' lived experiences. For example, the lack of supports for care in the community affects the ability of caregivers to maintain paid employment, which in turn increases financial hardship. These barriers intertwine and accumulate to overwhelm and negatively impact caregivers' physical and mental health. That is, these policy challenges are dependent on each other. What caregivers need is not one single magical fix, but a coherent system of supports.

In subsequent Policy Briefs, the OCC will examine each of the above five policy areas, looking closely at Survey responses to identify provincial policy interventions that will make a real difference in the lives of unpaid caregivers in Ontario.

## **HOW CAN WE DESIGN PROGRAMS AND POLICIES THAT WORK FOR CAREGIVERS?**

“The ‘system’ is broken. Totally shattered. Refer yourself, they say, and then refuse to take your call because...we don’t know why. Don’t tell me that there is a system in place, because there is not... If you work in one of these ‘systems’, get out of your office and visit the people who need you and learn from them and help implement the ‘supports’ that you feel exist.”

It is clear from the responses to the Survey that many of the existing programs and services are not designed to be effective for caregivers. Respondents describe a bewildering and frustrating maze of outdated information, multiple fruitless referrals, narrow eligibility requirements, burdensome processes and lengthy waitlists, all to be traversed in order to access services and supports that may be unreliable, provide limited supports, or are too rigid to meet the actual need. **It is not enough to create additional programs and services for**



**caregivers: these must be designed to meet the actual needs of caregivers.** To be effective in supporting caregivers, in addition to being adequately funded, programs and services must be:

**Easy to find:** Caregivers described spending endless, fruitless hours trying to locate available services. Survey respondents called for “one-stop shopping”, whether through true case management systems, a centralized and easy to navigate information hub, or proactive and timely offers of service and referrals. For example, one Survey respondent indicated that she did not learn about the availability of respite care until she had been caring full-time for her mother for more than four years.

**Coordinated:** Information is often not shared between programs and service providers, meaning that caregivers must provide the same information over and over again to different providers, as well as taking responsibility for managing test results, referrals and reports. As one caregiver said, “The current system appears to be ad hoc and tossed together by multiple organizations. At present, there is practically zero coordination amongst the organizations.”

**Simple to access:** Whether seeking to access funding, housing, developmental services, self-directed services or other supports, caregivers are confronted with complex, repetitive and time-consuming paperwork, and thickets of technical rules and processes. One caregiver described her experience as one of “absolute mind-boggling rules and regulations to follow, paperwork that is time consuming, usually requires me to take online training sessions to figure out how to get funds reimbursed.” Another respondent pointed out that while everyone knows that her son’s autism is a permanent condition, she must nonetheless recomplete all of his eligibility paperwork for his services on a regular basis. Another caregiver stated that managing the “business” of supporting her daughter essentially required her to be a full-time administrator.

## **BUILDING A BETTER ONTARIO FOR CAREGIVERS**

“We have mostly given up. I do what I can for my husband, but there are no resources that will help and no agency, or government entity that can or will help. The most they say is ‘you will have to try a little harder’.”

**Currently, approximately one in four Ontarians is providing care for a family member or friend.**<sup>10</sup> The reality is that almost all of us will be either caregivers or care recipients at some point in our lives, and many of us will have multiple experiences of caregiving. Caregiving is not a niche issue, but a common condition of our lives. None of us can – or should – walk these difficult paths feeling alone. We owe it to ourselves and to our loved ones to ensure that unpaid caregivers are valued and supported. Building a better Ontario for caregivers is possible. In future policy briefs, we will set out a pathway to that better Ontario.

## REFERENCES

1. Barylak, L., & Guberman, N. (2016). Beyond Recognition—Caregiving & Human Rights in Canada: A Policy Brief. Available from: [https://www.carerscanada.ca/wp-content/uploads/2021/03/CCC\\_Policy\\_brief\\_Human\\_rights\\_EN.pdf](https://www.carerscanada.ca/wp-content/uploads/2021/03/CCC_Policy_brief_Human_rights_EN.pdf)
2. The Change Foundation. (2019). 2nd Annual Spotlight on Ontario’s Caregivers: 2019. Available from: [https://www.niagaraknowledgeexchange.com/wp-content/uploads/sites/2/2020/01/Spotlight-on-ontario-caregivers-2019\\_final.pdf](https://www.niagaraknowledgeexchange.com/wp-content/uploads/sites/2/2020/01/Spotlight-on-ontario-caregivers-2019_final.pdf)
3. MacDonald, B., Wolfson, M., & Hirdes, J.P. (2019). The Future Cost of Long-Term Care in Canada. National Institute on Ageing. Available from: <https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5dbadf6ce6598c340ee6978f/1572527988847/The+Future+Cost+of+Long+Term+Care+in+Canada.pdf>
4. Bates, L. (2023). Addressing the Costs of Caregiving: Policy Solutions for Caregiver Financial Distress in Ontario. Ontario Caregiver Coalition. Available from: [https://www.ontariocaregivercoalition.ca/\\_files/ugd/675ebda9a28eff67624eee8732c87454e88047.pdf](https://www.ontariocaregivercoalition.ca/_files/ugd/675ebda9a28eff67624eee8732c87454e88047.pdf)
5. Statistics Canada, Insights on Canadian Society. (2020). Support received by caregivers in Canada. (Catalogue no. 75-006-X). Government of Canada. Available from: <https://www150.statcan.gc.ca/n1/en/pub/75-006-x/2020001/article/00001-eng.pdf?st=ic7VbkpV>
6. Chiao, C.Y., Wu, H.S., & Hsiao, C.Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *Int Nurs Rev.* 62(3):340-50. doi: 10.1111/inr.12194.
7. Hollander, M.J., Liu, G., & Chappell, N.L. (2019). 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. *Healthc Q.* 12(2):42-9. doi: 10.12927/hcq.2009.20660.
8. Bates, L. Hoben, M., Gabison, S., & Chiu, M. (2024). Who Cares for our Caregivers? Building the Evidence for Change. *Journal of Recovery in Mental Health* 7(2):8-13. <https://doi.org/10.33137/jrmh.v7i2.43069>
9. Leger. (2024). Health Care in Canada. Available from: [https://leger360.com/wp-content/uploads/2024/04/Leger-X-CP\\_Health\\_In\\_Canada-1.pdf](https://leger360.com/wp-content/uploads/2024/04/Leger-X-CP_Health_In_Canada-1.pdf)
10. Statistics Canada, Economic and Social Reports. (2023). What can be learned about caregivers in Canada from the analysis of families claiming the Canada caregiver credit? (Catalogue no. 36-28-0001). Government of Canada. Available from: <https://www150.statcan.gc.ca/n1/en/pub/36-28-0001/2023007/article/00002-eng.pdf?st=uXJ3PphS>