

**EMERGING IDEA**

for health care executives worldwide

# Informal Caregiver Flexible Working Arrangement

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How a workforce support tool is redefining the employer-employee relationship

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# Overview

## The idea

An informal caregiver flexible working arrangement is an agreement between an employer and a staff member who has other unpaid caregiving responsibilities outside of work. These arrangements are reshaping the employer-employee relationship and have the potential to be adopted globally.

## The promise

Historically, health care staff who double as informal caregivers have rarely been offered dedicated support by their employers. As a result, these employees rarely share details about non-work-related challenges due to stigma or shame, even if these challenges contribute to fatigue and burnout. Flexible working arrangements allow informal caregivers to fulfill both working and caregiver responsibilities, and can be used to increase engagement, decrease turnover, and even reduce unnecessary care utilization.

## Why now

As the population ages, an increasing number of people require at-home support to manage chronic illness, frailty, disability, mental health issues, and addiction. Many full-time health care professionals are among those who provide such care for their loved ones. Doing both jobs is hard, though, and can lead to burnout. Employers need to support these informal caregivers to address labor shortages and keep staff engaged.

## Reality check

Informal caregiver flexible working arrangements are a novel trend, and limited data exists on their full potential. If implemented, arrangements require a robust, executive-led communication plan to ensure system-wide adoption.

# What is it?

Informal caregivers are those who care, in any capacity, for a loved one, family member, or friend outside of their paid job. People who need longitudinal care often rely on this type of assistance. A significant portion of full-time health care workers, both clinical and non-clinical, are also informal caregivers.

## **Flexible work arrangements help informal caregivers fulfill external responsibilities**

Informal caregiving has historically been stigmatized in the workplace. Because of this, many informal caregivers feel embarrassed to raise the issue of external responsibilities for fear of being judged or penalized. As a result, managers don't know about employees' external responsibilities and tend to not provide support or flexibility. The stress of trying to fulfill both external and work-related responsibilities places informal caregivers at a heightened risk of burnout.

Flexible working arrangements benefit both employers and employees. Employers can create resources to help managers lead difficult conversations and more easily craft working arrangements. By reshaping the employer-employee relationship to focus on transparency and trust, such arrangements can destigmatize informal caregiving.

Details of specific working arrangements should be documented. As employees move within the organization, new managers will then be aware of the employee's situation. This alleviates the need to renegotiate work arrangements repeatedly.

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**WHAT IS IT?****How a flexible working arrangement for informal caregivers helps improve retention**

Day-to-day job responsibilities in health care can be extremely taxing. With informal caregiving duties on top of that burden, many employees are at risk of burnout.

Pulled in two directions by their jobs and caregiving responsibilities, these employees are often late to work or may miss shifts altogether—and they have little time to care for themselves. Over time, they may be forced to leave their jobs, to the detriment of both the health system and the employee.

Flexible work arrangements can alleviate that stress. And this helps the organization retain staff with valuable knowledge and skill, and it reduces the cost of turnover.

**How flexible working arrangements for informal caregivers can improve ‘system citizenship’**

Normalizing and codifying flexible working arrangements for informal caregivers signals that the organization cares about their employees' responsibilities outside of work—and their overall well-being.

This can lead to increased employee engagement, which is critical to a health system's mission. Engaged employees are more successful at meeting their goals and contributing to the system as a whole. They are more likely to support the organization and get on board with change initiatives—which helps staff, the organization, and (most importantly) patient care.

# Why now?

## More patients require more care, health systems feel the strain

As the global population ages and the incidence of chronic conditions and comorbidities rises, the number of informal caregivers continues to increase globally.

- In the United States, an estimated **32 million** informal caregivers are forced to forgo **\$67 billion** in wages per year due to shortened working arrangements.
- Around **35%** of employed Canadians, or **6.1 million** people, are balancing working and informal caregiving.
- Between 2018-2020, there was a **5.5%** increase in the number of informal caregivers in Australia. There are now **2.8 million** in the country, around **11%** of the entire population.
- There are **250,000** informal caregivers working in the United Kingdom's National Health Service (NHS), equaling about **25%** of the entire NHS workforce. The care provided by informal caregivers in the UK saves the country **£132 billion** a year in reduced care costs.

Even though informal caregivers are everywhere, there are often few policies or resources in place to support them. To care for loved ones, many people have to leave their jobs. And their own health may suffer—in one study, 87% of caregivers said their responsibilities had a negative effect on their mental health, and 39% said they had to put off their own medical treatment to focus on their loved ones. Only one in five informal caregivers in Ontario, Canada felt they were coping well with their responsibilities.

24%

Of informal caregivers in the UK consider quitting their job

80%

Of informal caregivers don't tell their manager about their caring responsibilities

Source: "Why Canada Needs to Better Care for Its Working Caregivers," National Institute on Ageing, 2018; "The value of informal care in 2020," Deloitte, 2020; "Supporting our working carers," NHS, 2021; "Caregiving in the US," National Alliance for Caregiving, 2020; "Quarter of working carers have considered quitting their job, study finds," People Management, 2020; "In Sickness and in Health," Carers UK; "Unpaid carers save the UK £132 billion a year—the cost of a second NHS," Carers UK, 2015; Carer Passport, 2021; "Work-Related Opportunity Costs Of Providing Unpaid Family Care In 2013 And 2050," Health Affairs, 2019; "Spotlight on Ontario's Caregivers," The Change Foundation, 2019

WHY NOW?

## The Covid-19 pandemic increased the health system’s reliance on informal caregivers



PRE-PANDEMIC

Gradual increase in **life expectancy**, the number of **long-term conditions**, and **multi-morbidity** requires an increasing number of informal caregivers.



NOW

**Widespread closure or relocation of services** has forced more people to undertake informal caregiving.

The emergence of **long covid** as a chronic health condition means more people require long-term rehabilitation care and chronic disease management.

The Covid-19 pandemic further increased both the number of informal caregivers and the average number of responsibilities each caregiver has:

- Up to **39.7%** of informal caregivers in Germany reported that their caring situation had worsened in the pandemic.
- **70%** of caregivers in Norway said their caring responsibilities had increased during lockdown.
- **55%** of unpaid caregivers in the United Kingdom were concerned that they were going to burn out during the pandemic, and the average caregiver provided an average of **10** additional hours of care per week.

## Workforce shortages add urgency to retention of informal caregivers

Shortages of health care workers require organizations to do all they can to retain staff, including informal caregivers. Although the number of young people acting as informal caregivers is increasing, most informal caregivers are between 45 and 64 years old—often the most experienced and skilled staff. If they are forced to leave their jobs to focus on caring for their loved ones, organizations would lose a tremendous amount of expertise and institutional knowledge. This has significant financial implications for health care organizations, since finding new staff is costly. And perhaps more importantly, informal caregivers provide significant financial savings to society by providing care for free that the health care system would otherwise have to provide.

Source: "Informal caregivers during the COVID-19 pandemic perceive additional burden: findings from an ad-hoc survey in Germany," BMC, 2021; "Covid-19 and care in Norway," Euro Carers, 2020; "Caring behind closed doors," Carers UK, 2020; Nursing and midwifery, WHO, 2020; "The Global Health Care Worker Shortage: 7 Numbers to Note," Project Hope, 2020

# Early adopter

## West Yorkshire and Harrogate Health and Care Partnership

*Integrated care system in the UK that supports joined up working of health, care, and wellbeing for 2.7 million people across the area*

Developed the Working Carers Passport in 2019 to support informal caregivers across 15 organizations within the system. The passport enables flexible working arrangements for these employees. Conversation records and agreements are stored on the employee's electronic staff record.

## The Working Carers Passport

West Yorkshire and Harrogate Health and Care Partnership (WY&H) used data from the UK's National Health Service (NHS) staff survey to make the case for investing in more support for employees who are informal caregivers. WY&H realized that many informal caregivers were at risk of burning out or were leaving the system altogether. System leaders saw that this problem existed across all its programs and facilities, and thus elevated informal caregiver support within the system strategic plan.

**20%**

Of all staff at WY&H balanced work with informal caregiving before Covid-19

Developed by the leadership team in collaboration with six acute care providers, the Working Carers Passport is the principal tool within a suite of broader initiatives to engage and retain informal caregivers.

The passport is a discussion guide used by informal caregivers and their managers to plan, discuss, and agree upon mutually beneficial flexible working arrangements that enable staff to adequately fulfill both working and caring for their loved ones. The tool provides space for informal caregivers to input their responses to questions like *“What support would you like or feel would help you?”* or *“What skills have you gained from caring for your loved one?”*





EARLY ADOPTER

The Working Carers Passport is a convenient tool that helps managers and staff jump-start conversations about informal caregiving responsibilities and possible flexible working arrangements. It helps shape the employer-employee relationship by fostering openness and trust. A record of the conversation and any agreed upon flexible work arrangement is stored on the employee's electronic staff record and stays with them throughout their career in the NHS. This means a caregiver can move elsewhere in the system and future managers can discreetly access the record, so they are aware of the employee's caregiving responsibilities without the need for further difficult conversations. This tool can be used by other facilities and programs throughout the NHS.

At least **11,500** members of WY&H's staff are informal caregivers, although this figure is likely to be much higher. By fulfilling both their job responsibilities and their caregiving outside of work, they save the NHS about **£4.3 billion** each year and act as a crucial part of the system to meet patient needs and maintain staff services.

**Leaders play a critical role in widespread implementation**

Executive buy-in has been integral to the success of the Working Carers Passport at WY&H. Executives created a working carers program team to spearhead the system's engagement of informal caregivers. The CEO, executive team, and program team led a successful, multifaceted communication campaign to publicize the Working Carers Passport at 15 facilities within the system including acute care, mental health, and community health sites.

A key factor in gaining buy-in from leaders was getting the passport program to resonate with different stakeholders. For example, when promoting the program to an organization's CFO, the program team focused on ROI and cost savings. But when the team engaged with the CEO, they focused on workforce attraction and retention.

**“The passport is the last piece of the jigsaw. The biggest piece is awareness that those people exist.”**

*Fatima Khan-Shah, Program Director for Unpaid Carers, WY&H HCP*

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EARLY ADOPTER

Each organization within WY&H has an executive-level working carers champion to galvanize utilization and engagement. Other program team members with informal caregiving experience act as ambassadors of the program to staff throughout the system, from primary care physicians to mental health teams.

The working carers program team works with the local champions, organization leaders, and informal caregiver associations. The program team collects questions and feedback about the Working Carers Passport, which helps shape how the team refines and publicizes the program. The feedback is fed through one individual within the working carers program team, who coordinates with leaders at each participating organization to ensure the passport is always a priority.

Through the system’s leadership and working carers program team, WY&H plans to expand use of the passport beyond the health system to local non-health care organizations. The passport is also now available to the entire NHS as part of the 2020 national People Plan, expanding access to—at minimum—an additional **56,000** informal caregivers around the UK. Members of the program team regularly meet with other systems to share what they’ve learned and highlight success stories.

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We recognise that, if carers are willing to share information about their personal circumstances and impact of their caring responsibilities, then as an employer we are on the road to becoming a high trust organisation with a good workplace culture. It’s all about valuing your workforce.

SANDRA KNIGHT  
Human Resources Director, Bradford District Care Trust, WY&H HCP



# Should you pursue this idea?

Creating flexible working arrangements for informal caregivers is still a novel concept. As such, most organizations will want to wait and see how these arrangements develop, how they fare at other organizations, and if they recoup measurable benefits for organizations.

However, your organization might benefit from informal caregiver flexible working arrangements now if you...

- Have data you can share with leadership showing that informal caregiver retention is poor throughout your organization or demand is higher than ever for at-home support in your jurisdiction.
- Are able to gain buy-in from your staff to normalize the creation of flexible working arrangements for informal caregivers.
- Can provide a direct line of visibility from caregiver representation to your leadership team to inform strategy and provide feedback.
- Have a platform to store information about the reasons for and structure of a flexible work arrangement during an employee's career within the system.

## Pros

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- ✓ Allows caregivers ability to fulfill work responsibilities while also caring for their loved ones
- ✓ Tailored to suit each informal caregiver's needs
- ✓ Could improve retention and engagement of staff

## Cons

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- ✗ If rules aren't communicated well, staff may abuse flexibility
- ✗ Employment laws or organization's basic staffing needs may prohibit action
- ✗ Buy-in must be obtained throughout organization leadership

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# What we're keeping an eye out for

Emerging from the Covid-19 pandemic, many organizations are looking inward to identify and address staffing disparities, pain points, and issues such as burnout and lack of engagement that were exacerbated by the pandemic response. We'll be watching out for:

- 1. Advancements in policy:** New policies relating to the support or funding of informal caregivers, or policies mandating the support of informal caregivers through alternative working arrangements
- 2. New tools or models:** Additional tools, resources, or models that address retaining and engaging informal caregivers
- 3. Adoption of informal caregivers discussion guides:** Other organizations that are employing this tactic and seeing beneficial outcomes

Informal caregivers are an important part of the health care workforce today, and their numbers will likely grow in the future. Tools and programs to address the needs of this group will be increasingly vital to organizational strategy. A systematized, effective strategy to retain and engage informal caregivers may provide significant benefits to both the organization and its employees. 

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