Helsinki Declaration on Patient Safety at Home

April 2026

Informal caregiving as part of the patient safety system

Caring for others is as old as humanity itself. It is a fundamental human practice rooted in solidarity, reciprocity, and shared responsibility. Yet what was long treated as a private and largely invisible reserve of care has become a structural pillar of European welfare systems.

The discussions held in Helsinki (14 and 15 April 2026), reached a broad consensus on one central point: **informal caregiving can no longer be regarded as peripheral or residual. It is a core issue for patient safety, continuity of care, social equity, and sustainability of welfare systems**.

In line with person-centred care, caregivers and care recipients should be recognised not only as individuals in situations of vulnerability, but also as people with capabilities and resources that can be strengthened. At the same time, informal caregiving today takes place in profoundly transformed conditions. Health systems are evolving from episodic, institution-centred models towards continuous, distributed, and technology-enabled care. Patients and their informal caregivers are increasingly recognised as active participants in care processes, supported by ongoing communication, monitoring, and shared responsibility with professionals.

In this context, the home is no longer a passive setting of recovery but an active site of care delivery, increasingly equipped with medical devices, digital tools, and remote-monitoring solutions. Care is no longer bounded by institutional walls but extends into everyday environments supported by new models and the principle of continuity of care 24 hours a day, 7 days a week, 365 days a year (24/7/365). Accordingly, the Helsinki meeting participants agreed that home care must be recognised as a care setting in its own right, with its own risks, support needs, and safety requirements.

The scale of the challenge is already substantial. In the European Union, 30.8 million people needed long-term care in 2019, and this number is projected to rise to 38.1 million by 2050. Looking specifically at care at home, in 2024, 8.5% of the EU population, about 38.2 million people, lived in households where at least one member needed long-term care because of health problems. Yet only 28.3% of those situations, roughly 10.8 million people, were in households receiving professional home-care services. At the same time, around 52 million people in Europe provide informal long-term care, while paid care in private homes remains partly hidden. A Eurofound publication released in 2025, drawing on 2021 European Labour Authority estimates, reported that 2.1 million undeclared workers were active in the EU care sector. This burden is also deeply gendered: women represent 62% of informal long-term care providers in the EU, equivalent to roughly 32.2 million women if this proportion is applied to the current estimate of informal carers.

Against this background, the Helsinki meeting calls on governments, public authorities, providers, and policy leaders to act on the following principles:

1. Informal caregivers must be recognised as a structural part of the patient safety and care system.

Informal caregiving is not an accident, a temporary patch, or a marginal phenomenon. It is now an essential component of Europe's care architecture for demographic, economic, social, and institutional reasons. This role should therefore be explicitly recognised in legislation, care strategies, and patient safety frameworks.

2. Home must be recognised as a priority setting for safe care and an essential component of the care continuum.

The transformation towards care delivered across settings implies that the home is becoming a key node within an extended care system. As technologies enable advanced interventions, monitoring, and communication at a distance, the boundaries between hospital, community services, and home are increasingly blurred. Deinstitutionalisation should not result in the transfer of complex risks, tasks, and decisions to families without preparation, follow-up, or support. If more people are to remain at home for longer, policies and care strategies should explicitly include the home as part of patient safety planning, ensuring that caregivers and patients have access to appropriate guidance, coordination mechanisms, escalation routes, and support.

3. Health and social care integration across the life course is indispensable for safe care at home.

Achieving continuity of care in a 24/7/365 model requires not only integration between health and social services, but also coordination across physical and digital care environments, including telemedicine, remote monitoring, and home-based interventions.

The safety challenges of informal caregiving do not concern only older people. They also affect children, people with a disability, those living with chronic illness, cognitive decline, frailty, or other long-term care needs. Policies and services must therefore adopt a life-course perspective. Many people cared for at home do not have only medical needs. They also require social support, functional assistance, supervision, environmental adaptation, and help with daily living. Fragmented systems leave families to navigate disconnected services, unclear responsibilities, and different eligibility rules on their own. Safer home care therefore requires genuine integration between health and social care.

4. The silent transfer of responsibility from healthcare organisations to families must be made visible, and institutional accountability must begin at system design.

Families are often expected to monitor symptoms, administer medicines, assist with mobility, prevent falls, recognise deterioration, and make day-to-day care decisions without these responsibilities being explicitly acknowledged, assessed, or supported. Institutions should be accountable for safe discharge, clear information, medication reconciliation, practical preparation, accessible contact points, and follow-up, rather than for blaming non-professional caregivers when unsupported systems fail.

Care systems must be designed to provide continuous support and responsiveness, ensuring that patients and informal caregivers have access to guidance, supervision, and intervention when needed, regardless of time or location. The concept of continuity of care 24/7/365 should be recognised as a foundational principle of safe and equitable care in modern health systems.

5. Every complex home-care situation should have access to case management and practical navigation support.

In increasingly complex and technology-supported care environments, case management must also include coordination of digital tools, data flows, and communication between caregivers and professionals.

Care recipients and informal caregivers need more than information. They need a clear point of reference able to coordinate resources, guide them through the system, support safe transitions, and activate an early response when risk signals emerge. Case management should be understood as a practical continuity mechanism, not merely an administrative function. Relevant touchpoints may include primary care, home and hospice care, telemedicine services, hospital outreach teams, follow-up clinics, and social services.

6. Informal caregiver training, support, and health literacy must be treated as a basic safety intervention.

This includes the ability to safely use medical devices at home, interpret digital health information, administer and document medicines, and engage in remote communication with professionals.

Discharge information, medication reconciliation, practical training, simple checklists, named contact points, respite options, and accessible low-tech or digital tools are not optional extras. They are minimum conditions for reducing avoidable harm at home, improving quality of care, and strengthening the confidence, competence, and wellbeing of both caregivers and care recipients.

Caregivers also need training to understand the importance of self-care. If the carer is unwell from the long hours of care duties and does not benefit from respite and support, the safety of the care recipient as well as the caregiver are at risk.

7. Informal caregiver burden and burnout must be addressed as system-level safety concerns.

Exhaustion, isolation, lack of rest, and sustained emotional strain increase the likelihood of error, undermine care quality, and contribute to crises, reattendances, and disruption of care plans. Protecting the caregiver is therefore part of protecting the care recipient, and reducing caregiver overload should be an explicit objective of integrated health and social care systems. Caregivers also need support to understand warning signs, know when to seek help, and know what kinds of incidents or near misses should be reported. Most informal caregivers do not know what merits reporting, and many may hesitate to speak up if reporting is associated with blame. Europe needs a practical reporting framework for home care, one that clearly identifies reportable safety problems, encourages learning, and helps make visible recurrent but under-recognised risks such as medication errors, falls, pressure injuries, and failures in coordination.

8. The double victimisation of informal caregivers must be recognised and addressed.

When a preventable incident occurs at home, the harm may not stop with the care recipient. Informal caregivers may also experience guilt, distress, loss of confidence, and functional deterioration. This emerging phenomenon of double victimisation harms the caregiver, can negatively affect the safety and wellbeing of the person receiving care, and may weaken the response capacity of health and social protection systems through additional crises, reattendances, disrupted care plans, and avoidable demand for urgent support. Systems should therefore provide rapid, proportionate, and non-blaming responses after incidents, including clear entry points, emotional support, practical reorganisation of care, and crisis-response mechanisms.

9. Paid care in private homes requires greater formalisation, better working conditions, and stronger protection – Patient safety is a priority in all care settings.

Europe cannot build sustainable home-care systems on invisible, underqualified, or weakly protected labour. This is especially urgent in a sector marked by workforce shortages, low pay, informality[1], gender inequality, and the overrepresentation of migrant workers and overreliance on informal carers. Better regulation, recognition, employment standards, and stronger social protection and pension rights are necessary both for fairness and for patient and informal caregiver safety.

10. What is not measured cannot be protected – Unwavering commitment to patient and informal caregiver safety.

Europe needs common definitions regarding the types of carers and other relevant terminology as well as comparable indicators, including on medication and care errors at home, unsafe transitions, community-acquired infections, unmet home-care needs, caregiver burden, avoidable reattendances, and the emotional consequences of caregiving. Without visibility, common understanding of terms, monitoring, measuring, and accountability, home care will remain a blind spot in patient safety and social protection policy.

The Helsinki Declaration therefore calls for a decisive shift in policy and practice integrating informal caregiving in national and international patient safety strategies and implementation. This shift includes recognising that care is no longer confined to institutions, but delivered across a continuum that includes the home as a technologically supported and professionally connected environment. It requires embracing new models such as the hospital without walls, strengthening partnerships between formal and informal caregivers, and ensuring continuous, coordinated care.

Protecting those who care is part of protecting those who receive care. Without recognition, integration, training, measurement, and institutional responsibility, home care will not be safe, fair, or sustainable across Europe.

The meeting, supported by **BetterCare,** involved 28 health and care professionals and informal carer representatives, working in 15 European countries in Ministries, National Agencies and networks of public and private institutions providing care.

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[1] This can refer to informal carers (typically family or kin-carers) as well as informal migrant workers (who may be working under the table or 'black').