

Home support for patients with advanced diseases and their families: joint statement from international patient, carer and palliative care associations

International associations representing patients (International Alliance of Patients' Organizations - IAPO), informal carers (Eurocarers), and palliative care professionals (International Association for Hospice and Palliative Care – IAHPC, and the International Children's Palliative Care Network - ICPCN) call on governments to strengthen home support for patients with advanced diseases and families who wish to be at home and to die at home, whenever possible.

The call follows the findings from the largest study of international time trends in place of death to date and the first showing a rise of home death in COVID-19 pandemic across countries. The fact that it was generally rare for someone with COVID-19 to die at home (less than 10% across the countries included) suggests that much of the rise of home death related to patients (younger to older adults) suffering from other life-threatening conditions, most amenable to palliative care. The rise was higher for women and in cancer in most countries. The researchers call for future health policy and planning to ensure that palliative and end of life care resources are appropriately allocated to support the growing trend. The study, led by researchers from the University of Coimbra in the context of the EOLinPLACE Project, funded by the European Research Council, was published today in the Lancet's eClinicalMedicine.

The IAHPC and the ICPCN flag the role of specialist palliative care services in the provision of better home support and the need to improve coverage across countries.

The IAPO and Eurocarers support patient and informal carer representative organisations and groups in all countries to advocate locally for compassionate, humanised and patient-centred healthcare that respects the patient's dignity and individuality to make informed decisions, and for better home support in advanced disease.

The scientific paper is available in <https://doi.org/10.1016/j.eclinm.2023.102399>.

More information on the associations:

<https://www.iapo.org.uk>

<https://eurocarers.org>

<https://hospicecare.com>

<https://icpcn.org>