

INSTRUCTIONS

This toolkit contains the information you need to communicate the outcomes of the **Carers of Persons with Heart Failure – A Four Nation Study**.

The toolkit will help you share the findings with your carer community and reinforce the challenges and value of family caregiving to the health care system and to persons with heart failure.

In this Communications Toolkit you will find:

1 KEY MESSAGES »

2 WHERE CAN I ACCESS THE STUDY? »

3 SOCIAL MEDIA STRATEGIES »

4 RESOURCES AND TEMPLATES »



The study was supported by Novartis.

ABOUT THE INTERNATIONAL ALLIANCE OF CARER ORGANIZATIONS (IACO)

The International Alliance of Carer Organizations (IACO) is a global coalition of 15 member nations committed to building a global understanding and respect for the vital role of family carers. Each member country is represented by a nationally recognized carer organization. The coalition works to identify and share best practices, build awareness of global carers' issues, and advocate for family carers with international entities such as the United Nations.

Carers of Persons with Heart Failure

A Four Nation Study

Supported by Novartis

Communications Toolkit

IACO International Alliance
of Carer Organizations

www.internationalcarers.org

The International Alliance of Carer Organizations (IACO), in collaboration with carer and patient organizations in four countries, initiated a study using the Caregiver Questionnaire for Heart Failure tool to describe the effects of caregiving for a person with heart failure on the daily life and well-being of family caregivers, and to explore the factors that influence caregivers' outcomes. Data was collected from 519 caregivers who completed the online Caregiver Questionnaire for Heart Failure.

The study was conducted in Australia, Canada, United Kingdom (UK) and United States (US). The leading organizations were: Carers Australia, Carers Canada, Carers UK, National Alliance for Caregiving (US), WomenHeart: The National Coalition for Women with Heart Disease (US), Pumping Marvellous (UK), Canadian Home Care Association, The Heart and Stroke Foundation of Canada, and Heart Support-Australia Ltd.

1 KEY MESSAGES

What is the Study About?

A landmark study about the impact of caregiving on persons with heart failure in Australia, Canada, the United Kingdom and the United States. Conducted by the International Alliance of Carer Organizations (IACO) and supported by Novartis, this work advances IACO's mission to build a global understanding and recognition of the role of carers.

Who is a Carer?

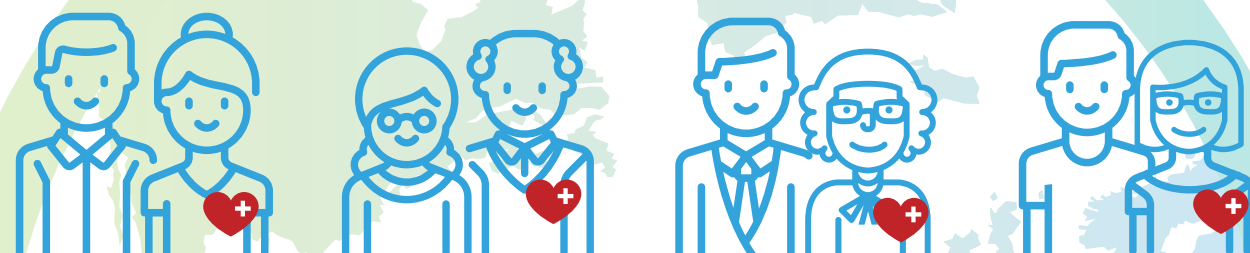
In this study the definition of a carer is an individual that provides unpaid care to support a relative or friend, 18 years or older, who is diagnosed with heart failure. This may include helping with personal needs, household chores, assisting with medical or nursing tasks, managing finances and arranging for outside services. Around the world, the term carer is used interchangeably with caregiver or family caregiver.

Why Study Caregivers of Individuals with Heart Failure?

- + Heart failure (HF) is a chronic and degenerative disease which does not allow the heart to pump enough blood to the body, causing it to have less oxygen and nutrients¹.
- + HF directly impacts the lives of 26 million people globally²—1 in 5 individuals will develop heart failure.
- + HF accounts for 1–3% of all hospital admissions in Europe and the USA.
- + HF is associated with a significant impact on the functional capacity of a person with the condition, corresponding to increased need for support with daily activities. However, caregivers in general, and heart failure caregivers in particular, are an under-recognized group. The impact of heart failure on caregivers is an under-studied area.

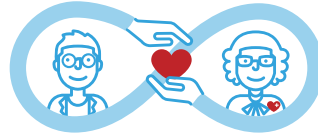
¹ (IHHUB, 2017)

² (Cowie MR et al, 2014)



What did the Study find?

Carer and patient well-being are directly linked.



- + Carers have a positive influence on the health outcomes of persons with heart failure and can contribute to a better quality of life, reduced hospitalization, and improved survival for the patient.
- + Support for caregivers leads to better outcomes for persons with heart failure regarding the increased health-related quality of life and improved survival.

Caregivers give their time and support to individuals with HF.

- + 70% of persons with heart failure depend upon a family caregiver when receiving care in the home.
- + Carers spend on average 22 hours/week looking after a person with heart failure.
- + 70% of carers helped with medical and/or nursing tasks.
- + 75% supported the health care plan through supervision, reminding and coaching.

Caring impacts the health, well-being and work-life of caregivers.

- + Caregivers stated that they had changed jobs, decreased working hours or become self-employed to manage the caregiving situation.
- + 13% of carers quit their jobs, 9% turned down a promotion, 9% lost job benefits.
- + 52% experienced a deterioration in their own health - only 3% of carers reported that caregiving had improved their health.



Carers are not prepared for, or supported to look after a person with heart failure.

- + 50% of carers felt unprepared for their caring role.
- + Only 19% received support from the healthcare professionals.
- + 50% found it difficult to help with daily caregiving tasks.
- + More carers in the US (37% and Australia (35%) felt supported than ones in Canada (27%) and the United Kingdom (21%).



What is needed to support the vital role of carers for persons with heart failure?

Caregiver engagement:

- + Recognize and include carers as partners in the health care team.
- + Assess caregiver needs as part of the care planning process and provide appropriate supports.

Implement policy measures to support caregivers:

- + Invest in research on heart failure caregiving to support evidence-based policies and programs.
- + Increase awareness and understanding of heart failure caregiving and the challenges families face.
- + Minimize the financial burden of caregiving and encourage flexible workplaces for employed carers.

Accommodating the needs of caregivers:

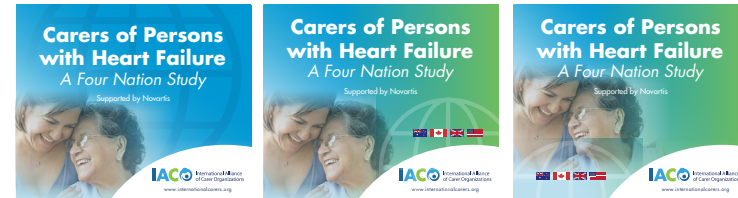
- + Provide resources to help carers navigate health and social care systems.

2 WHERE CAN I ACCESS THE STUDY?

Organization website banner:

Use the digital banner on your organization's website to direct users to the report or the IACO website.

300 x 250 px



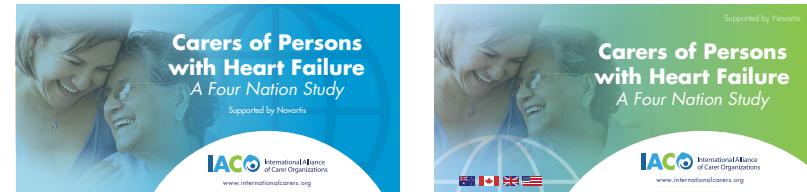
300 x 150 px



320 x 50 px



900 x 450 px



970 x 90 px



4 RESOURCES AND TEMPLATES

The full communication package can be [downloaded here](#)

KEY MESSAGES

NEWSLETTER SAMPLE

TWITTER

FACEBOOK

INFOGRAPHIC

WEBSITE BANNER

REPORT PDF



www.internationalcarers.org