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 »

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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
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 nutrients.
+ HF directly impacts the lives of 26 million people globally—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.
+ 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.
WHERE CAN I ACCESS THE STUDY?

The full study and the press release can be downloaded from the IACO website at: www.internationalcarers.org/publications

SOCIAL MEDIA STRATEGIES

This section helps you promote the Carers of Persons with Heart Failure – A Four Nation Study using online tools such as website banners, sample tweets and Facebook messaging.

Post the infographic and pre-written templates provided on your social media channels to spread the study results and build awareness about Carers of Persons with Heart Failure.

Newsletter sample:
A sample newsletter article to be shared with your communications team and distributed in your local newsletter. Post it on your website, or send it electronically to your staff/stakeholders/members. Fill in your organization’s name and run an article in the next issue of your newsletter.

Twitter:
Use the twitter pictures, and start a Twitter trend using these suggested tweets. Include #CarersHaveHeart.

Facebook:
Create your own facebook post using the digital banner. Include #CarersHaveHeart.

Infographic:
Share highlights of study findings.
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