

# HEART FAILURE CHARTER:



## A Multi-Stakeholder Call to Action to Reduce Preventable Heart Failure Hospitalizations and Improve Patient Outcomes

The Heart Failure Charter built by advocates (representing patients, caregivers, and healthcare providers) for advocates and their communities, represents their collective shared values and perspective to minimizing the number of hospitalizations and preventative readmissions by targeting key unmet needs across the continuum of care where intervention and educational efforts can have the greatest impact

Unmet needs were identified and prioritized by all Multi-stakeholder Summit<sup>1</sup> participants comprised of patient and caregiver advocacy organizations and professional societies.



**Approximately one in four patients with Heart Failure are re-hospitalized within a month of their initial hospitalization.<sup>2</sup>**

**Many of these hospitalizations are preventable and increase the burden on patients, caregivers, and the healthcare system.**

## TRANSITION OF CARE AIMS TO:

- 1 Reduce the incidence of mortality within the first 30 days after leaving the hospital<sup>2</sup> after a heart failure hospitalization
- 2 Reduce the percentage of Heart Failure patients readmitted to the hospital within 30 days of discharge<sup>3</sup>
- 3 Increase the number of patients hospitalized with Heart Failure who are prescribed guideline-directed medical therapy before hospital discharge<sup>4</sup>

To achieve these goals, patients and caregivers must feel empowered to recognize symptoms of worsening heart failure, manage their Heart Failure and comorbidities, and demand better care throughout their journey.

Given the complexity of the hospitalization and re-hospitalization journey, each stakeholder – patient, caregiver, healthcare provider, advocate – is crucial in improving hospitalizations and transitions of care.



## Path to success: Origins of the Heart Failure Charter

Advocates from patient, caregiver, and professional groups collectively identified patient and caregiver challenges to optimal transitions of care, and are committed to address unmet needs Heart Failure patients face during the journey from home, to ER, to hospital, to post-care, and to ongoing monitoring.

The multi-stakeholder group agreed on the importance of putting patients first and empowering patients and caregivers to be engaged decision-makers to improve overall care and treatment. This agreement led to The Heart Failure Charter, which enumerates all core aspects of ensuring a smooth care transition.



## A Shared Value Approach to Optimize Hospitalizations and Transitions of Care

Advocacy organizations who understand the importance of shared value commit to support The Heart Failure Charter, which emphasizes patient and caregiver unmet needs and demonstrates where interventions and educational efforts can affect patients at initial hospitalization, discharge, and post-discharge.

<sup>1</sup>The Multi-stakeholder Summit was convened by Novartis Patient Advocacy with the goal of bringing together patient and caregiver advocacy groups and professional societies to better understand the burden of HF hospitalizations and transitions of care across patient touchpoints.

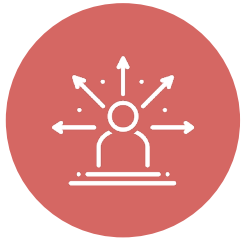
<sup>2</sup>Albert, Nancy M., et al. "Transitions of Care in Heart Failure: A Scientific Statement from the American Heart Association". Circulation: Heart Failure 8 (2015): 384-409.

<sup>3</sup>Bueno H, Ross JS, Wang Y, et al. "Trends in Length of Stay and Short-Term Outcomes among Medicare Patients Hospitalized by Heart Failure". JAMA 303(3010):2141-2147.

<sup>4</sup>Bradely EH, et al. "The Greatest Burden of Hospitalization and Re-Hospitalization Cost Occurs Within 6 Months After 1st Hospitalization." Circ Cardiovasc Qual Outcomes 6(2013):444-450.

<sup>5</sup>Allen La, et al. "Medication Initiation Burden Required to Comply with Heart Failure Guideline Recommendations And Hospital Quality Measures. Circulation 132(2015): 1347-1353.

# PRIORITIZED PATIENT-CENTERED UNMET NEEDS



## UNMET NEED: PATIENT-CENTERED DECISION-MAKING

*Focusing on patient-centered decision-making creates partnerships and alignment between patients, caregivers, and healthcare providers.*

Lack of patient-centered practices leads to misalignment between patient, caregiver, and healthcare providers. For Heart Failure patients, patient-centered discharge instructions and follow-up calls have served as promising interventions<sup>6</sup> to improve clinical and quality of life outcomes.

The Charter calls on community members to support and inform patients and caregiver decision-makers, by:

**INCREASING** patient and caregiver knowledge of their disease, risks and benefits of certain treatments.

**EVALUATE** patient and caregiver social determinants and understand patient treatment goals.

**DESIGNING** tools to help patients and caregivers implement lifestyle changes.

**PROVIDING** education and support on advance care planning and emphasizing its importance with patients and caregivers.



## UNMET NEED: EMPOWERING AND SUPPORTING CAREGIVERS

*Empowered caregivers are important in supporting patients through treatment decision-making, monitoring symptoms, and helping patients to successfully manage their Heart Failure.*

Caregivers are often left out of decision-making and lack the tools to successfully play “point of contact” with healthcare provider teams. To improve patient outcomes, caregivers must be involved in educational efforts, treatment decision-making, and self-care management.

The Charter calls on community members to empower caregivers by:

**DEFINING** the role of patient-identified caregivers as partners in decisions involving patients and patient care.

**RECOGNIZING** caregivers’ role in monitoring and conveying patient symptoms to HCPs.

**ENSURE** caregivers have the education and support needed to understand and differentiate the association of comorbidities with symptoms of HF.

**ARMING** caregivers with tools to increase their confidence in supporting patients post-discharge.

**EDUCATING** caregivers on disease and lifestyle management (i.e., diet and nutrition).

<sup>6</sup>Albert, Nancy M., et al. “Transitions of Care in Heart Failure: A Scientific Statement from the American Heart Association”. *Circulation: Heart Failure* 8 (2015): 384-409.



## UNMET NEED: PERSONALIZED EDUCATION AND SUPPORT

*Providing patients and caregivers with consistent education throughout their journey supports the development of activated patients and caregivers to control and manage their Heart Failure.*

Each patient has a unique Heart Failure journey and corresponding implications. Lack of personalized education makes it more difficult for patients to understand their disease and treatment options.

The Charter calls on community members to collaborate to ensure patients' personalized education by:

**PRIORITIZING** the education patients and caregivers receive, so patients can take an active role in managing their care.

**CUSTOMIZING** education to each patient and at key transition points, providing patients with the specific information they need during hospitalization, upon discharge, and during seven-day and 30-day follow up visits.

**REVIEWING** patient-friendly education modules and discharge planning details with patients to reduce medication errors and improve adherence to self-care and detection of worsening symptoms.



## UNMET NEED: SYMPTOM RECOGNITION AND MANAGEMENT

*Self-monitoring Heart Failure symptoms promotes confident and appropriate decisions of care.*

Patients with Heart Failure often face the scary prospect of another heart-related event. While self-monitoring is a key component in indicating worsening conditions<sup>7</sup>, many lack the tools and confidence to self-manage their symptoms and make appropriate, timely, and evidence-oriented decisions.

The Charter calls on community members to support symptom recognition and management by:

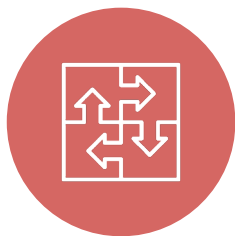
**EMPOWERING** patients and caregivers to recognize symptom changes early and promptly seek care. Having the knowledge and confidence to self-manage is key - the earlier changes in symptoms are recognized, the less likelihood of hospitalization or re-hospitalization.

**DIFFERENTIATING** symptom severity levels to inform patients and caregivers when and how to act.

**PROMOTING** two-way dialogue between patients, caregivers and healthcare providers about treatment and management, increasing patient confidence when explaining symptoms to their HCPs.

**DEVELOP** mechanisms to educate and encourage patients and caregivers to track and report changes in symptoms, allowing for increased dialogue with HCPs who can determine HF progression and support symptom differentiation.

<sup>7</sup>Yu, Doris S.F., et al, "Disease management programmes for older people with Heart Failure: crucial characteristics which improve post-discharge outcomes," in the European Heart Journal, Vol. 27, Issue 5, March 2006: 596-612.



## UNMET NEED: COORDINATION OF CARE

*Coordinating care across care settings lessens the burden from patients to manage complex treatment plans and reduces the chance of mismanagement.*

Heart Failure patients and caregivers typically seek advice from multiple healthcare providers, many of whom are not informed of patients' discharge medications, other medication changes and/or possible side effects. Additionally, lack of coordination between in-hospital and out-of-hospital settings results in an increased burden on patients and caregivers to coordinate their own care.

The Charter calls on community members to increase care coordination for Heart Failure patients by:

**CREATING** mechanisms to ensure patients, caregivers and HCPs are aligned around care decisions.

**EMPOWERING** patients to take an active role in managing their HF post-discharge in partnership with their provider.

**REFERRING** patients and caregivers to practical tools tracking all aspects of care, including managing multiple medications and treatments, preparing them to actively discuss their treatment with their healthcare provider (i.e. use of digital applications and/or other programs for continual engagement).

**INTEGRATE** technological advancements to support coordination of care when appropriate (e.g., remote monitoring, telemedicine)

## GLOSSARY



### COMMUNITY MEMBERS

Individuals that come into direct contact or have touchpoints with patients and caregivers during their journey, e.g. HCPs, community health workers, payers, community agents, etc.



### CAREGIVERS

Patient-identified individuals that represent patient touchpoints beyond traditional caregivers (friends, family, neighbors, professional caregivers, etc.) who provide direct care to an individual, or individuals, who are chronically ill.



### ADVOCACY ORGANIZATIONS

May represent any one or a combination of the following: patient groups, caregiver groups, professional societies.



### HEART FAILURE

"A complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricles to fill or eject blood."<sup>8</sup>

*Advocacy organizations who commit to supporting patient and caregiver needs:*



<sup>8</sup>Hunt SA, Abraham WT, Chin MH, et al. 2009 focused update incorporated into the ACC/AHA 2005 guidelines for the diagnosis and management of heart failure in adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines: developed in collaboration with the International Society for Heart and Lung Transplantation [published correction appears in Circulation. 2010;121(12):e258]. Circulation. 2009;119(14):e391-e479.