

**TAILORING CONSUMER RESOURCES TO ENHANCE SELF-CARE  
IN CHRONIC HEART FAILURE**

## **Abstract**

Chronic heart failure (CHF) is associated with high hospitalisation and mortality rates and debilitating symptoms. In an effort to reduce hospitalisations and improve symptoms individuals must be supported in managing their condition. Patients who can effectively self-manage their symptoms through lifestyle modification and adherence to complex medication regimens will experience less hospitalisations and other adverse events. Self-care relates to the activities that individuals engage in relation to health seeking behaviours. Supporting self-care practices through tailored and relevant information can provide patients with resources and advice on strategies to manage their condition. Evidence-based approaches to improve adherence to self-care practices in patients with heart failure are not often reported. Recently the Heart Foundation CHF consumer resource was updated based on evidence-based national clinical guidelines. The aim of this resource is to help consumers improve understanding of the disease, reduce uncertainty and anxiety about what to do when symptoms appear, encourage discussions with local doctors, and build confidence in self-care management. Adherence to self-care practices will enable early detection of changes in clinical status and appropriate decisions for self-management that can reduce hospitalisations and improve the quality of life for people with CHF.

(Current word count 191)

**Key words:** Heart failure, self-care, health literacy, patient information

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## **Background**

Self-care in chronic heart failure (CHF) and health outcomes are closely linked. Mortality and hospitalisation rates remain high, particularly in the elderly. In Australia, approximately 40,000 patients were hospitalised with newly diagnosed CHF in 2003.<sup>1</sup> Patients with CHF experience debilitating symptoms such as shortness of breath, increasing exercise intolerance and lethargy which impacts on their everyday day life. In an effort to reduce these symptoms and hospitalisations patients must learn how to manage their CHF through adhering to several self management strategies. These include: a low sodium diet, engaging in physical activity, restricting their fluid and adhering to a complex medication regimen. Patients who can effectively self manage their symptoms through lifestyle modification and adhere to complex medication regimens will experience fewer hospitalisations and improved quality of life.<sup>2</sup>

Educating and supporting patients about optimal self-care behaviours is the cornerstone of effective CHF management. Self-care refers to the decision making process of patients concerning their choice of healthy behaviour and response to worsening symptoms when they occur.<sup>3</sup> The science of self-care is rapidly growing. Both intrinsic factors, for example cognitive ability, and extrinsic factors such as access to appropriate and relevant information, impact on an individual's capacity for self-care. The purpose of this paper is to explain how providing evidence-based information, using patient education resources, can support self-care .

The Heart Foundation has recently updated its national consumer resource entitled 'Living well with chronic heart failure'<sup>4</sup>, based on the current national clinical guidelines<sup>1</sup>. The resource will be referred to in this paper to demonstrate principles of consumer engagement, mapping of evidence based guidelines, and end-user feedback, in the development of consumer resources. Similarly principles of adherence, knowledge and health literacy which underpinned the development of this product will be discussed

### **Self-care of heart failure**

Self-care involves cognitive decision making, requiring the recognition of signs and symptoms that indicate a change in condition, which is based on knowledge and prior experiences of deterioration.<sup>5</sup> It also refers to the ability to engage in constructive behaviours to monitor and maintain health<sup>5</sup>.

Recommendations for self-care activities should be based upon evidence for improved outcomes. Evidence-based self management strategies for CHF are detailed in the Heart Foundation / Cardiac Society of Australia and New Zealand guidelines and include monitoring and controlling fluid balance, maintaining a low salt diet and taking recommended medications.

Self management of CHF depends on patient adoption of healthy behaviours and management strategies. Patients living with a chronic illness often find self-care decision making overwhelming. Reasons for this include conflicting sources and complexity of information. Ageing, psychological and social issues, health literacy, physical symptoms, and previous experiences<sup>6</sup> might also pose a barrier to adopting healthy behaviours. Self-

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<sup>1</sup> Consumer resource developed in collaboration with a working group of key experts, including the National Institute of Clinical Studies (NICS)/National Health and Medical Research Council (NHMRC) and the National Prescribing Service (NPS).

care can be supported by the use of written materials that address these barriers. The Heart Foundation CHF consumer resource was developed to encourage adherence and improve knowledge of self-care strategies. This approach has resulted in consumer information that is relevant, practical, and easy to understand.

### **Adherence with self care**

Adherence with self-care is vital in chronic disease management and has been shown to reduce morbidity and mortality.<sup>7</sup> The capacity to adhere with recommended treatment strategies is often suboptimal in individuals with CHF, especially in those who are recently diagnosed. A study by Michalsen, Konig & Thimme<sup>8</sup> surveyed 179 hospitalised patients and showed that only 26% of patients knew about the importance of restricting fluid intake. While the majority of the patients (87%) had weighing scales, only 38% of patients weighed themselves regularly.<sup>8</sup> In another study by Jaarsma et al<sup>9</sup> only 23% of patients were compliant with their fluid restriction and 50% with their sodium restriction diet. In this sample, 77% of patients did not notify their doctor about weight gain.

Adhering to treatment recommendations can be improved through providing information and strategies to the patient and their family to support self-care. Furthermore adherence is encouraged if consumer information or strategies are directed at those patients who need it most. There is some evidence to show that people diagnosed with long standing CHF were more likely to report or act on their weight gain than those who are newly diagnosed.<sup>10</sup> This was supported by another study<sup>11</sup> showing that initiation of self-care strategies was higher in patients with CHF for several years, and postulated that this may be related to experience with previous hospital admissions, or past education interventions.

The evidence reflecting poor adherence with treatment recommendations and adverse health outcomes demonstrates that there is a need to improve patient understanding of CHF, particularly those who are newly diagnosed and those who have experienced deterioration in their condition.

For these target groups the Heart Foundation CHF resource provides an easy to read day-to-day reference for patients learning about symptoms, lifestyle, and medicines. Testing with consumers during the development stage ensured the resource was tailored to patient needs. The resource uses large font, pictures and simple language. Furthermore information is focused on patient information needs such as tips for recognising symptom changes, while minimising overly detailed or complex information. This approach aims to overcome some of the barriers to adherence.

### **Knowledge of self care**

Knowledge and understanding are essential elements for patient empowerment and successful self management. Information and resources used to provide this knowledge should be evidence-based to ensure safety as well as to maximise opportunities for improving patient satisfaction and health outcomes.<sup>12</sup>

. A lack of knowledge can lead to non-adherence with self-care practices such as following fluid restriction, low sodium diet and daily weighing routines.<sup>5</sup> Ni et al.<sup>13</sup> investigated 41 hospitalised heart failure patients and found that knowledge was significantly correlated with adherence with self care behaviour.

Educational interventions to provide information and support knowledge acquisition have shown promising results for CHF. Results from a meta-analysis of CHF management

programs has shown that an emphasis on self-care and patient education improved outcomes; all-cause hospitalisations were reduced by 32% (RR 0.68, 95%CI 0.54-0.87) and CHF-related hospitalisation by 40% (RR 0.60, 95%CI 0.41-0.88).<sup>14</sup> These programs included the provision of guideline-based information on disease pathology, medication and non-pharmacological treatment recommendations. Additionally, information and advice was provided on self-care practices, such as monitoring symptoms and adjusting treatments accordingly, including when to seek urgent or non-urgent medical advice.<sup>15-17</sup> Programs that achieved positive outcomes also included advice about health maintenance practices such as annual influenza vaccinations, exercise recommendations, maintaining a healthy weight, alcohol restrictions, smoking cessation and a low sodium diet.<sup>14</sup>

### **Health professional support of self-care practices**

Health care providers can influence adherence to treatment. Simpson<sup>18</sup> describes a constructive patient-provider relationship as one of trust that motivates patients to adhere to lifestyle changes and complex medication regimes. In spite of the importance of providing timely and relevant information, there is evidence to suggest that health care providers do not always use consumer resources within education opportunities. For example the results of a recent survey of 496 general practitioners concerning the use of resources for CHF patients found that 74% of general practitioners did not routinely provide written information to patients.<sup>19</sup> Of the health professionals that were aware of online resources very few used these, with 60% of them never accessing the resources.<sup>19</sup> Whether this relates to the scepticism of the benefit of these resources or time limitations is unclear.

In the hospital setting, patient and carer education opportunities can be limited by a reduced length of stay and the patient's physical and cognitive status during the acute care

episode.<sup>11</sup> This may result in patients being discharged from hospital with an inadequate level of knowledge to support self-care. In spite of the limitations associated with in-patient education, this is an ideal opportunity to provide patients and carers with a consumer resource. Ideally the clinician can emphasise important aspects of the resource. Although numerous information resources are available, providing *evidence-based* information is important, as incorrect or contradictory advice can lead to uncertainty about what should or should not occur and impede decision making processes about when to seek medical help.<sup>12</sup> In order to address some of these challenges, the Heart Foundation developed a resource to support self-care.<sup>15</sup> This resource not only provides evidence-based information but targets known limitations to accessing accurate and relevant information through considering the role of health literacy in promoting self-care. For example, information about salt intake is enhanced through definition of ‘low salt’, information on how to read food nutrition panels and tips on healthy food choices.

### **Health literacy in supporting self-care**

Health literacy refers to an individual’s ability to use and interpret information relating to health issues. Low health literacy can result in poor understanding of the information about CHF. Approximately 83% of Australians aged over 65 years have a health literacy level that is below the minimum required to meet the complex demands of everyday life.<sup>20</sup> The elderly population also has the poorest health literacy skills<sup>21</sup> and are the biggest users of the health care system. During 2003 heart failure was the most common cause of hospitalisations in people aged over 65 years.<sup>22</sup>

Previous research has shown that poor health literacy is related to adverse health outcomes.<sup>23</sup> Low health literacy has been shown to be an independent predictor of mortality<sup>24</sup> and hospitalisations. One study investigated health literacy in people



hospitalised in a public hospital. Over a 12 month period, they found that patients with a low health literacy were 69% more likely to be hospitalised compared with patients with high health literacy.<sup>25</sup> Another study by Baker et al.<sup>26</sup> also found similar results among Medicare patients. Those with a low health literacy score were 29% more likely to be hospitalised than patients with high health literacy after adjusting for age, gender, race and education status. Another study investigating the impact of health literacy on asthma outcomes showed that patients with poor health literacy were more likely to attend the Emergency Department for management of their asthma.<sup>27</sup>

Addressing low health literacy needs to be addressed to improve capacity for self-management. However it is unknown as to whether poor health literacy is a primary cause of poor health outcomes or whether it is an underlying problem of other issues such as low socioeconomic status, inadequate access to health services or a low trust in health care providers. Nevertheless, low health literacy needs to be addressed in an effort to improve knowledge and self management skills.

Health literacy can be improved through consumer resources that are easy to read, both in terms of the language and format used. Visual content is far superior to other forms of communication for memory retention<sup>28</sup>, therefore pictures and images in a resource will help to enhance patient understanding. Ensuring that consumer resources are developed with an awareness of the health literacy levels of the target audience is critical to its effective use and adoption of healthy behaviours and can improve health outcomes.<sup>29</sup>

### **‘Living well with chronic heart failure’**

‘Living well with chronic heart failure’ consumer resource has been developed as a companion to the CHF guideline and as such communicates management strategies that

are well known to optimise health outcomes<sup>15</sup>. The consumer oriented approach to resource development ensures information is tailored to patient needs. Table 1 gives examples of how the clinical content and format and layout has been adapted for consumers. The development process was staged to include needs and barrier analysis through expert clinical and consumer consultation, content development and the use of medical writers, piloting and refinement and finally establishing a channel for resource dissemination.

**Insert table 1 approximately here**

One important component of the consumer resource is the action plan (Figure 1). The action plan outlines recommended daily activities to assist the patient with managing their heart failure. It also stipulates when the patient should notify their local doctor, heart failure nurse or ambulance should their symptoms deteriorate.

The booklet can be used as a resource to improve communication between the consumer and their health care provider especially when developing an individualised action plan. A partnership based on effective communication skills will improve adherence to healthy lifestyle behaviours and self management strategies.

**Insert figure 1 approximately here**

## **Conclusion**

Patients in contemporary health care systems, together with their health care provider, need to engage in partnerships to promote self-care strategies. In order to be effective partners, patients need and want accurate, practical information and advice; *‘Living well*

*with chronic heart failure*' underpinned by a robust evidence-base on self-care, has been developed to address this need. In particular, this resource targets newly diagnosed or hospitalised people with heart failure. As a practical communication tool, it can enhance information sharing between health professional and patient. As an evidence-based resource that is easy to read it can promote health literacy and adherence to self-care practices by people with CHF and result in better day to day management and early detection of symptoms change.

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**Table 1: Adapting evidence for a consumer resource**

<b>“The evidence”</b>	<b>Adapted to: Heart Foundation consumer resource</b>
Recommendations, such as; multidisciplinary programs for high risk chronic heart failure patients prolong survival and improve quality of life.	Within a section titled ‘Key questions for your doctor’, questions complement recommendations in the CHF guideline, for example; Is there a chronic heart failure program I can attend? Questions encourage patients to be actively involved in their own healthcare
Clinical definition and aetiology of chronic heart failure	A short definition of chronic heart failure using easy to understand terms (such as a ‘weak’ or ‘tired’ heart), including the most common causes of chronic heart failure
Detailed diagnostic information. Echocardiograms are recommended as the ‘single most useful investigation’ in chronic heart failure patients	A short section titled ‘How is chronic heart failure diagnosed’ summarises the four main tests used and what the tests show, including echocardiograms
Non-pharmacological management, for example fluid restrictions, and monitoring of weight can lead to improved outcomes	Description of symptoms, usual cause and practical recommendations to relieve, avoid or take action on symptoms. Use of practical ‘tips’ (such as daily weighing and raising feet to help fluid circulate around the body) encourages self-management.
Benefits of specific pharmacological treatment of symptomatic chronic heart failure	The most common heart failure medicines by class and how they work. Includes tips for using medicines wisely and tips for managing side effects.
Management of acute exacerbations of CHF	Booklet includes a one page ‘Action Plan’ (Figure 1), summarising daily management activities, how to recognise and respond to symptoms and which symptoms require urgent medical attention. The Action Plan can be removed and put on the refrigerator for easy reference.
Format and layout to enhance communication of key messages	<ul style="list-style-type: none"> <li>• Colours and bold text to emphasise key messages</li> <li>• Limited amount of information per page and lots of white space to assist comprehension</li> <li>• Use of pictures to communicate key messages, such as a picture of measuring jug to monitor water intake and a picture of scales</li> <li>• Lift out summary sheet/ action plan for easy reference</li> <li>• Translated versions of resource into 15 community languages</li> </ul>

**Figure 1 "Living well with chronic heart failure" ACTION PLAN**

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