



The Needs of Heart Failure Patients in Ireland

Based on the Irish Heart Foundation's
Heart Failure Patient Survey



**Irish Heart
Foundation**

The National Stroke & Heart Charity

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Introduction

The Needs of Heart Failure Patients in Ireland survey was carried out by the Irish Heart Foundation in 2022, to ascertain the scale of need that existed amongst heart failure patients in our service.

The survey was conducted after a series of communications from these patients about the struggles they were experiencing post-diagnosis, with the long-term impact of this life-long condition on their lives across many areas, including, medically, psychologically, economically, socially, practically, and in relation to their family life.

The survey was completed by 182 respondents. It is from this sample that the following data has been recorded.

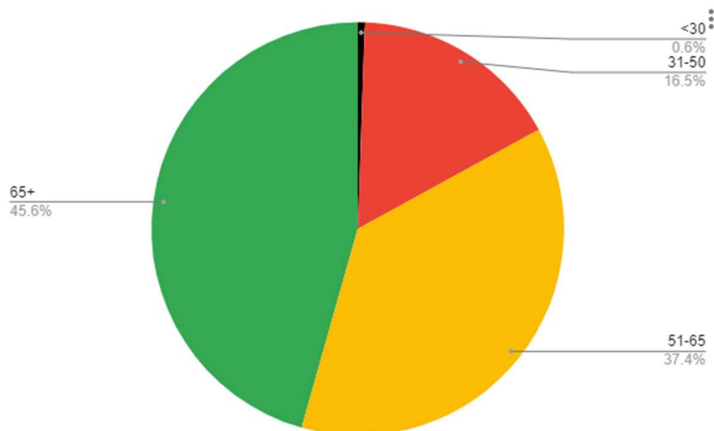
Survey Findings

1.0 AGE

Survey participants

Age	Patients	% of population
<30	1	.55%
31-50	30	16.48%
51-65	68	37.36%
65+	83	45.61%

Fig. 1. Age of heart failure patient's surveyed



2.0 MEDICAL CARE

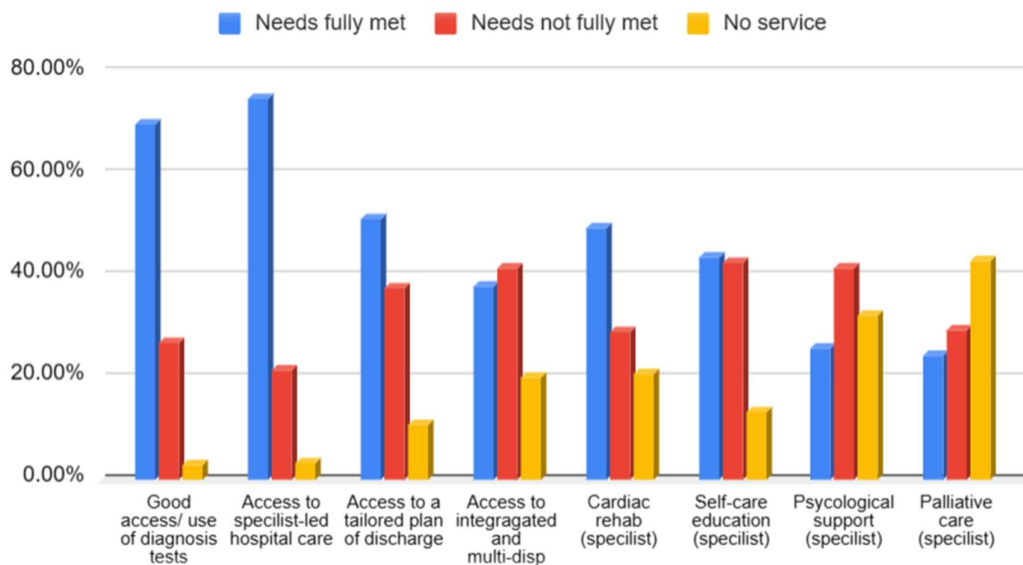
2.1. How was the service you received?

Patients were asked about their experience of hospital and community services from the onset of their condition.

They were asked to record this experience in terms of whether their needs were fully met, their needs were not fully met, or whether there was no service available to meet their needs.

The following is a recording of their responses across a number of patient service experiences;


Fig. 2.1 How was the service you received?



Service	Needs fully met	Needs not fully met	No service
Timely diagnosis	62.15%	33.9%	3.95%
Good access/use of diagnostic tests	70.11%	27.01%	2.88%
Access to specialist-led hospital care	75.0%	21.51%	3.49%
Access to a tailored plan of discharge	51.22%	37.80%	10.98%
Access to integrated and multi-disciplinary services	38.19%	41.67%	20.14%

Team of HF specialists

- Cardiac rehab	49.68%	29.30%	21.02%
- Self-care education	44%	42.67%	13.33%
- Psychological support	26.06%	41.55%	32.39%
- Palliative care	25.45%	30.41%	44.14%

 While it is evident from above that access to diagnostics and treatments in a hospital setting are more likely to meet the needs of the patients, when it comes to plans of discharge and post hospitalization, and access to heart failure specialists, the results are poorer, **with approximately half to two-thirds, of heart failure patients surveyed here reporting that their needs were either not fully met or that there was no specialist heart failure services available to them post hospital discharge.**

2.2 Life post discharge

Based on feedback that the Irish Heart Foundation had received from some heart failure patients in advance of the survey, we decided to ask survey participants to agree/disagree with a series of statements as follows;

When I go home from hospital I feel abandoned - **26.9% Yes**

I need more help to make living with heart failure at home better - **36.4% Yes**


I needed psychological services or counselling - **45.09% Yes**

I feel my relationships with my friends and family have been negatively affected - **45.76% Yes**

Specifically, when asked to assess their satisfaction levels with some heart failure supports post-discharge, heart failure patients responded as follows;

	Overall Satisfaction	Overall Dissatisfaction	Not sure
Psychological support	35.53%	43.4%	21.07%
Education and support for my family	39.16%	42.7%	18.14%
Support in planning for my future needs	45.3%	24.34%	30.36%

Support in linking me to the services I need	62.85%	18.04%	19.11%
Support in learning how to manage the effect of heart failure	61.2%	21.32%	17.48%
Practical support to enable me to live as independently as possible	59.06%	21%	19.94%

 It is clear from comments and evaluations with regards to life post-discharge that **many patients are looking for greater support post-discharge**, especially in the areas of;

- Post discharge follow up contact
- Psychological support
- Family supports
- Practical supports to living independently
- Information on living with heart failure
- Referrals to other services
- Support with planning future needs

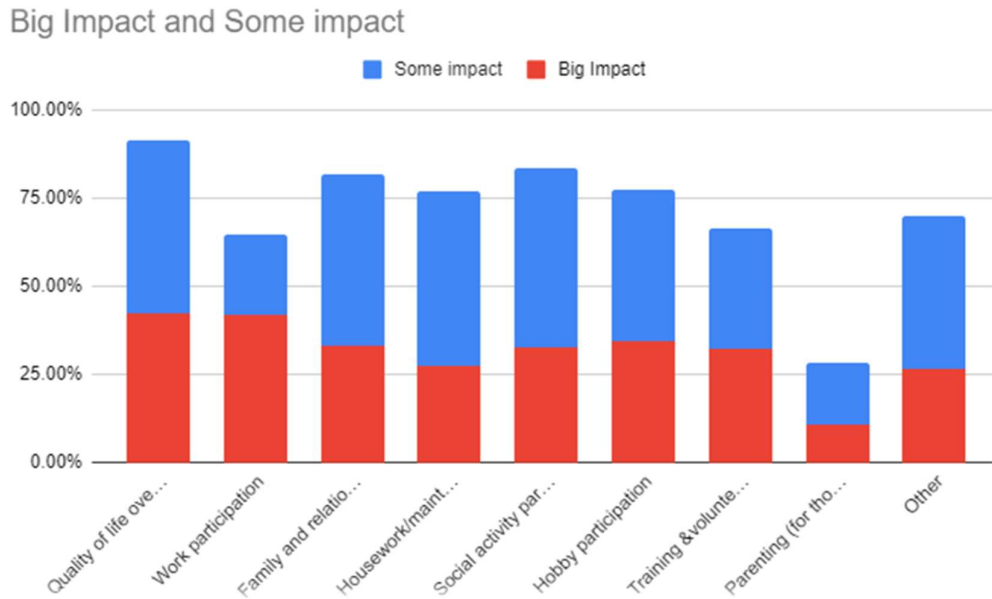
3.0 IMPACT OF HEART FAILURE

We looked at the impact of heart failure across a number of aspects of life, from overall quality of life, to ability to work, how it impacted on cost of living, how it impacted on relationships, and more. To follow is a breakdown of the results.

3.1 *Impact on life*


Patients were asked how they felt their heart failure diagnosis had impacted various areas of life and responded as follows;

Fig. 3.1. Impact of heart failure diagnosis on life



	Big Impact	Some impact	No Impact	Don't know	N/A
Family and relationships	33.3%	48.63%	14.21%	1.64%	2.22%
My overall quality of life	42.31%	48.90%	7.69%	1.10%	0%
Participating in work	42.01%	22.49%	11.83%	1.78%	21.89%
Being able to maintain house	27.68%	49.15%	18.08%	1.13%	3.96%
Impact on parenting for those with children U18	10.76%	17.72%	8.23%	.63%	62.66%
Participating in social activities	32.57%	50.86%	13.71%	1.71%	1.15%
Participating in hobbies.	34.48%	43.10%	18.97%	1.15%	2.30%


Participating In training or volunteering	32.35%	34.12%	17.65%	2.35%	13.53%
Other	26.51%	43.37%	13.25%	4.82%	12.05%


 **A heart failure diagnosis has a big or some impact on multiple facets of life including, overall quality of life, working life, family life, the need for help in the home, the ability to pursue interests, be social, or take part in activities.**

3.2 Financial impact

3.2.1 Impact on working life (for purposes of measuring ‘working’ life only, we have excluded those who said they are ‘retired’ or ‘homemakers’.)

	Y/N
Are you working?	25.9% / 54.14%
Were you working before your heart failure diagnosis?	62.29%/25.71%
Did you have to give up work after your diagnosis, or as a result of heart failure?	35.43%/46.86%
If you are still working, have you had to reduce hours?	17.28%/28.40%
Has your income fallen significantly since your heart failure diagnosis?	44.51%/29.48%
Did a family member have to reduce their work hours to help you?	15.2%/57.89%

 **35.43% of working heart failure patients had to give up work after their heart failure diagnosis.**

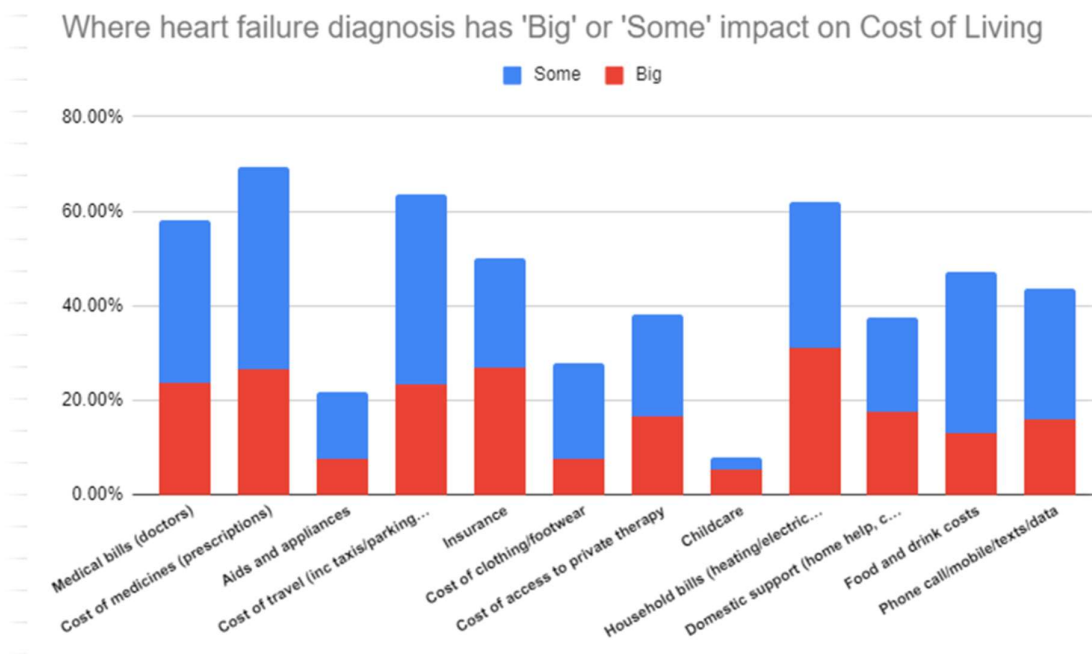
 **45% of those working up until their heart failure diagnosis suffered a significant reduction in income as a result of heart failure.**

3.2.2. Cost of living impact

Impact on cost of living due to heart failure diagnosis (including medical costs)

When asked about the financial impact of their diagnosis on their cost of living, the following information was recorded

Fig 3.2.2 Cost of living impact



	Big impact	Some impact	No impact	N/A
Medical bills (doctors)	23.73%	34.46%	24.86%	16.95%
Cost of medicines (prescriptions)	26.7%	42.61%	17.61%	13.07%
Aids and appliances	7.50%	14.37%	38.13%	40%
Cost of travel to appointments	23.3%	40.34%	23.3%	13.07%
Insurance	27.06%	22.94%	31.18%	18.82%
Cost of clothing/footwear	7.56%	20.35%	53.49%	18.6%
Cost of access to private therapy	16.77%	21.56%	24.55%	37.13%
Childcare	5.52%	2.45%	28.22%	63.80%

Household bills (heating/electricity)	31.25%	30.68%	25.57%	12.5%
Domestic support (home help, cleaner etc)	17.54%	19.88%	30.99%	31.58%
Food and drink costs	12.94%	34.12%	37.06%	15.88%
Phone call/mobile/texts/data	15.88%	27.65%	42.94%	13.53%

Medical costs

- ➔ 58.19% declared medical bills, such as paying for doctor visits as being of big, or some impact on outgoings.
- ➔ 69.31% say prescription costs are having a big or some impact on patients.
- ➔ The costs of travel to medical appointments was recorded by 63.64% of patients as also being of big or some impact.

Non-medical costs

Fuel and energy

- ➔ 61.93% report a big or some impact on their household bills, especially in relation to electricity/heating (**please note that this survey was conducted before the current energy crises and escalation in costs as a result of same*)

Insurance

- ➔ 50% report the diagnosis as having a big or some impact on their Insurance costs.
(In addition, it was also noted there are further complications, with access to **Life Assurance / Life Insurance** once a diagnosis received, of the 9.25% who tried to take out insurance 90.74% were refused entirely)

Food

- ➔ 47.06% reported a big or some impact on their food bill

Household /domestic support

➡ 37.42% recorded a big or some impact on their need for domestic support

➡ In addition to increased medical costs in relation to their condition, it appears that half to two-thirds of heart failure patients experience an impact on their non-medical costs, especially in relation to household bills like electricity and heating, food and drink, and insurance costs.

3.2.3 Economic supports and gaps

3.2.3.1 Medical card/GP visit card

While 58.19% declare medical bills, such as paying for doctor visits as being of big, or some impact on outgoings, 69.31% assess that prescription costs are of big, or some impact, and the costs of travel to medical appointments was recorded by 63.64% of patients as also being of big, or some impact, ownership of a medical card/GP visit card amongst heart failure patients is not guaranteed, such that approximately one-third of all survey respondents have neither to help them weather the cost. This figure rises to close to 40% in the case of the under 65 survey respondents.

Medical Card/GP visit cards

	All respondents	Over 65	Under 65
Medical Card	61.5%	67.47%	56.31%
GP visit card	9.09%	14.46%	4.85%
Neither	29.41%	18.07%	38.83%

Fig 3.2.3.1 (a). Medical card/GP visit card All

All heart failure respondents

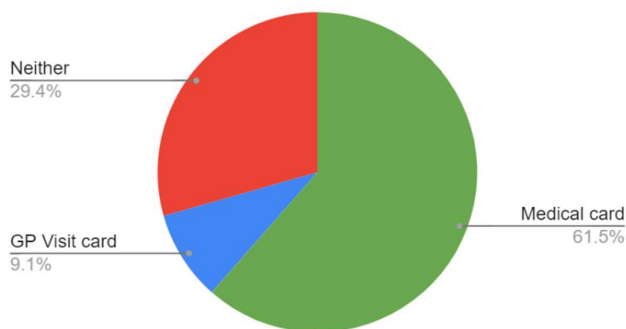
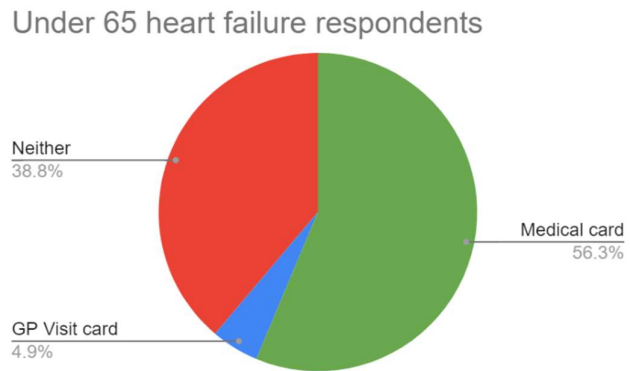


Fig 3.2.3.1 (b). Medical card/GP visit card U 65



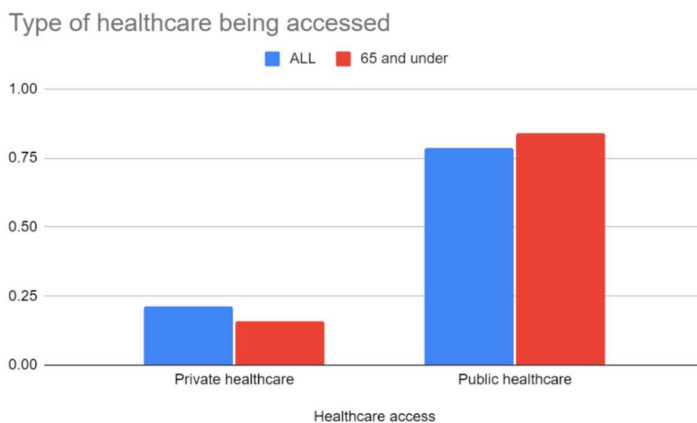
➔ Almost one-third do not have a medical card or a GP visit card, this figure rising to 40% amongst those aged 65 and under

3.2.3.2 Health care provision – priority v standard care

Private V public health care

21.3% of all patients surveyed here had private health insurance and 78.65% were being treated under the public health service. However, when broken down further it appears that amongst working age heart failure patients (65 and under), 84% are relying on the public system of healthcare.

Fig 3.2.3.2 Private V public health care



➔ The vast majority of heart failure patients are relying on the public healthcare system for medical maintenance of their condition.

3.2.3.3. Social welfare supports – provision v need

Approx. 60% of all those surveyed declared that they were on a social welfare payment. While it assumed that this refers to a state pension for those aged 66+, it is less clear what type of payment the under 65 age group received.

➔ 60% of those surveyed are on social welfare supports. However, these standard payments take no account of the increased medical and non-medical costs of having a heart failure diagnosis

3.2.3.4. What patients say they need in terms of Gov economic support

➔ Qualification for Medical card/GP visit card, by virtue of diagnosis.

➔ *In addition, the majority of heart failure patients surveyed here are asking for;*

Booklets detailing financial support and state support available	58.39%
Freephone support line	54.49%
Additional social welfare supports	56.77%

➔ Over half of the patients surveyed say they need additional social welfare supports and information on financial supports

Conclusion

This survey identifies that heart failure patients in Ireland, need a range of supports, beyond the diagnostic and therapeutic care provided in clinical settings.

These additional support requirements are not only important for the betterment of a heart failure patient's physical health, but to ensure that the patient does not suffer deterioration in their health due to the additional burdens of mental health challenges, economic stresses, or the isolation, or lack of optimum physical recovery that can come with a deficit in community service provision.

The vital additional supports required by heart failure patients include;

- Increased levels of psychological supports post-diagnosis and at community level.
- Economic reliefs to help ease the financial stress burden of the diagnosis and employment challenges associated with the condition, especially in relation to the provision of a medical card.
- Access to information, services, referrals, and follow-up care at community level to support educational and social wellness needs.
- Access to appropriate cardiac rehab services.
- A register of heart failure patients to ensure that there can be adequate planning and delivery of cardiac services, based on actual patient need.

Meeting these needs could provide heart failure patients with some of the additional tools and means through which to live well with this condition in their communities.



The Irish Heart Foundation is Ireland's national charity fighting heart disease and stroke through advocacy, research, prevention and care.

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