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www.hospicefoundation.ie

PLANNING FOR THE FUTURE

Living with advanced
heart failure



Heart failure covers a broad spectrum of disease. Some people have very few symptoms while other people may be sicker and have debilitating symptoms. This booklet is for people with more severe disease.



Treatments for heart failure have improved significantly in recent years. However when you have a serious illness such as heart failure, even with the best medical care, there may come a time when your illness reaches an advanced stage and you are no longer able to get better.

At this stage of your illness, the type of medical and nursing support you receive will focus on your quality of life, helping to make you feel as comfortable as possible, relieving your symptoms, and also providing emotional support for you and your loved ones as required.

The purpose of this booklet is to both signpost and prompt discussions you can have with your medical and healthcare team as well as your family so you can be more prepared for the future. The booklet also gives you some practical tips about arrangements you can undertake yourself.

Planning for the future with heart failure

When you become seriously ill, many different worries about your future may present themselves. Planning your future medical care, in consultation with your doctors, will help ensure that your wishes for how you want to be cared for as your illness progresses are respected and carried out. All decisions about your on-going medical care will be made in consultation with you and your doctor, taking into account your best interests.

Sorting out practical matters such as your finances, support for your family in the future and making a will can reduce your stress levels and allow you to focus on living with as good a quality of life as possible, for as long as you can.

It is ideal to make plans for your future while you are still relatively well and able to make decisions about your medical care and your finances. The public awareness initiative **Think Ahead** may help you discuss these matters with your family and medical team. More details are available from www.thinkahead.ie or by contacting the Irish Hospice Foundation. The website www.carers.ie provides guidance to your family members or loved ones as they support you.

Discussions and decisions you may want to have about your future care with your medical team include

- What are your preferences with regard to your place of care in the future? Would you like to stay in your own home or live somewhere else?
- Are there decisions you would like to make about your future medical care in the event that you become unable to make such decisions in the latter stages of your illness? This process is called advanced care planning, and decisions made as a result of this type of planning can be included in an Advance Healthcare Directive.
- Have you thought about whether or not you want to be resuscitated if your heart stops beating or you stop breathing. This is a type of advance healthcare directive known as a Do Not Attempt Resuscitation (DNAR) order.

Advance Care Planning

Normally, you would make an advance care plan in consultation with your medical team. If you wish, you can also include your loved ones in the discussion and decision making. You are the best judge of what matters to you and your treatment preferences, so it is important that your medical team and family understand, respect and agree to abide by your wishes for the care you receive towards the end of your life.

Advance care plans can be useful if the situation arises that you are no longer able to communicate your wishes or make decisions. Your advance care plan will allow your doctors to continue to care for you according to your wishes. You may wish to

continue to receive treatments designed to make you comfortable and reduce your distress. You may want to be much more specific about which treatments you want or don't want. It may be helpful and make your loved ones feel more confident about ensuring your wishes and treatment preferences are respected, if you write down the details of the type of care you want.

You have a right to refuse any medical or surgical treatment that is not in your best interest. Your doctors, nurses can help you understand how your disease may progress in the future and what treatments will be available to maximise your quality of life. If you wish they can also help you put your advance healthcare directive and a do not attempt to resuscitate (DNAR) order in place.

Do not attempt resuscitation order

This is a written instruction that you are not to be resuscitated if your heart stops beating or you stop breathing. You may feel that if you were resuscitated, there is a risk you would suffer brain or other organ damage that would significantly reduce your quality of life. Or you may want to have a peaceful and natural death, even if doctors feel that resuscitation would be successful. Regardless of your reasons, you have the right to refuse this treatment. This decision should be discussed with your medical team and recorded in your notes.

ICDs

If you have an ICD, you may want your device to stop treating you at some point. It is possible to switch off these devices and you can discuss how you would like this to be managed with your doctor or heart failure nurse. The process of switching off your ICD is simple and will not cause you to die. However, once your ICD has been disabled, you won't get shocks from your device should you develop a life-threatening heart arrhythmia.



Palliative care

As your disease progresses, the focus of your care will be to keep you well, optimising your comfort and your quality of life. This is often called a palliative approach to care.

The purpose of the palliative approach to care is to:

- Give you relief from physical symptoms such as breathing difficulties, pain and nausea.
- Give you and your loved ones emotional and psychological support to assist you adapt to the progression of your illness.
- Help you plan for the future - help you make decisions about your future medical care and making sure that your medical team and loved ones understand and respect your wishes.

Your heart failure and palliative care teams will often work together to devise the best treatment options for you.

When should I receive palliative care?

Palliative care can be provided to people with advancing disease throughout their illness. You, your doctors and healthcare team will know when the time is right.

Who provides palliative care?

Initially your cardiologist, heart failure nurse or healthcare team will adopt a palliative approach to your care. They can introduce medical treatments to improve your symptoms, help you plan for the type of care you want in the future and also make decisions on treatments you don't want when you become very ill.

As your needs for support and symptom management increase, your doctor or heart failure nurse may find it helpful to get advice from the specialist palliative care service to assist in your care, and to decide what treatments are most beneficial. This service works alongside your cardiologist, heart failure nurse and GP to provide the care and support you and your family need while in hospital, in your home or in a hospice.

Along with medical symptom relief, the specialist palliative care team may provide you with services such as counselling and spiritual support. The team can also give your family bereavement support.

If you are able to stay at home in the final stages of your illness, there are homecare hospice teams throughout Ireland, providing palliative care services in your own home. The Irish Hospice Foundation Nurses for Night Care services may also be accessed. In occasional circumstances some people with heart failure may require admission to one of the inpatient hospices for management of complex symptoms.

Getting the care you need to stay at home

Where possible, most people would prefer to be cared for in their own homes. The HSE, along with some voluntary organisations, provides a range of supports, grants and payments available to you and your carers to create a suitable living environment and to allow you to be cared for at home. Some are means tested, others not. They are available to people with long term illness and disabilities as well as to people in the final stages of serious illness.

HSE home care services include:

- Home care package scheme
- Respite care
- Home help service
- Public health nurses

Grants and allowances available include:

- Housing adaptation grant
- Mobility aids grant scheme
- Disability allowance
- Invalidity pension
- Mobility allowance
- Free travel pass
- Medical card
- Respite care allowance
- Carers' allowance
- Carers' benefit
- Exceptional needs payment
- Rent or mortgage interest supplement
- Bereavement grant

Your GP, public health nurse or social worker care team can help you apply for the grants and services for which you are eligible. As the level of funding and the availability of all of these services and payments changes regularly, the Citizens Information Board is also a very good organisation to contact for up to date information on how to apply for the various financial and other supports you and your family may need.

Other decisions

Making a will

- Making a will gives you the opportunity to make sure your assets are distributed according to your specific wishes after your death. A will can be as simple or as complex as you wish. It is not essential to get legal advice about making a will. However, getting advice from a solicitor will ensure that your will is valid and that you understand the terms and conditions those due to benefit will face. The cost is generally about €100.
- It is a good idea to keep a list of information such as where your will is kept, who the executors of your will are, contact details of your solicitor, details of your bank accounts, and investments or insurance policies. This will be very helpful to your loved ones after you have passed away. The Citizens Information Board has a useful form on which you can record this information. It is available on www.citizensinformation.ie

Pre-planning your funeral

- Some people choose to plan their funeral and some set aside money to pay the costs. Whether or not you want to do this is a very personal decision and varies greatly from person to person. You may want to let your family look after this. You may want to make very detailed plans or to let your loved ones know some of your wishes, such as whether you prefer burial or cremation. If you feel able to, talk to your close family about any specific wishes you have for your funeral. It can help your loved ones a little if they know they are marking your life and death as you wanted.
- You may want to talk to a funeral director. The Irish Association of Funeral Directors has lists of members throughout the country. Visit www.iafd.ie for more information.
- The web site www.rip.ie is another useful source of information.



We would welcome
feedback on this leaflet.
Please contact Tracy Egan,
Irish Heart Foundation,
50 Ringsend Road, Dublin 4,
tel: 01 6685001, email:
tegan@irishheart.ie with
comments.

More Information

If you need more information or are not sure where to get the information you need, you can also call an Irish Heart Foundation nurse at the National Heart and Stroke Helpline on locall 1890 432 787. This helpline is open Monday to Friday, 10am to 5pm.

You can contact the Irish Hospice Foundation on 01 679 3188.

Some of the contacts listed below may be helpful to you and your family:

Irish Heart Foundation

50 Ringsend Road,
Dublin 4

Phone: +353 1 6685001

Fax: +353 1 6685896

Web: www.irishheart.ie

Email: info@irishheart.ie

National Heart and Stroke Helpline

Phone: Locall 1890 432 787

Monday to Friday 10am to 5pm

Email: info@irishheart.ie

Irish Hospice Foundation

Morrison Chambers (4th Floor)
32 Nassau Street
Dublin 2

Phone: +353 1 6793188

Fax: +353 1 6730040

Web: www.hospicefoundation.ie

Email: info@hospicefoundation.ie

Citizens Information Board

Ground Floor
George's Quay House
43 Townsend Street, Dublin 2
Phone: +353 761 07 4000
Monday to Friday, 9am to 8pm
Web: www.citizensinformation.ie
Email: info@ciboard.ie

Health Services Executive (HSE)

Phone: Callsave 1850 24 1850
Monday to Saturday, 8am to 8pm
Email: infoline1@hse.ie

Irish Association of Funeral Directors

Mespil House
Mespil Business Centre
Sussex Road, Dublin 4
Phone: +353 818 935 000
Web: www.iafd.ie

The Carers Association

Market Square
Tullamore
Co Offaly
Phone: 1800 24 07 24
Fax: +353 57 9323623
Email: info@carersireland.com

Think Ahead, the forum on end of life

C/o Irish Hospice Foundation
32 Morrison Chambers,
Nassau Street, Dublin 2
Phone: +353 1 6793188
Web: www.thinkahead.ie
Email: Sarah.Murphy@hospice-foundation.ie

Useful web sites:

www.carers.ie

A web site from the Irish Hospice Foundation with practical information for carers

www.heartfailurematters.org

A web site from the European Society of Cardiology with practical heart failure information for patients, families and carers



Irish Heart Foundation,
50 Ringsend Road,
Dublin 4

Phone: +353 1 668 5001

Fax: +353 1 668 5896

Email: info@irishheart.ie

Web: www.irishheart.ie

Heart and Stroke

Helpline:

Locall 1890 432 787

Monday to Friday

10am to 5pm

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32 Nassau Street,
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