

Difficult Conversations

Making it easier to talk to people with heart failure about the end of life.



Funded by



THE
NATIONAL
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PALLIATIVE
CARE

Dying
Matters

*Let's talk
about it*

Foreword

The British Heart Foundation is delighted to introduce the Difficult Conversations guide, which has been written in collaboration with the National Council for Palliative Care. A diagnosis of heart failure has an enormous impact on the patient and their family. It gives rise to questions, emotions and treatment options that all require consideration at a time when people can feel prioritising and decision-making is impossible. We may think we know what's best for our patient and we will strive to deliver high quality care, information and support. But what are the priorities of the patient and their family who live with heart failure every day? And can we be sure that what we deliver really fits the needs of patients?

The future for patients with heart failure can be an unpredictable one, and this can make challenging conversations all the more difficult. This reinforces the importance of planning future care, respecting patient wishes, providing appropriate support in discussion with the patient and not making assumptions. Patient insights and views can only enhance our role in patient care, ensuring we can deal with our patients and their families with honesty, compassion and sensitivity at this time in their lives.

On the pages that follow, patients with heart failure and their families share with us the issues they have faced and are facing. They raise needs, regrets, observations, dilemmas and uncertainties that affect those living with heart failure. This guide aims to support those caring for people affected by heart failure, in particular healthcare professionals, by:

- **empowering healthcare professionals to understand needs from the patients, families and carers perspective**
- **supporting healthcare professionals to challenge their own assumptions of what they feel is best for their patients**
- **enabling healthcare professionals to learn from experience and to feel comfortable about approaching similar situations differently in the future.**

We hope you find this booklet will inspire you to build upon the communication skills you already possess and help you deal with the very difficult, and very necessary, conversations with patients and their families.

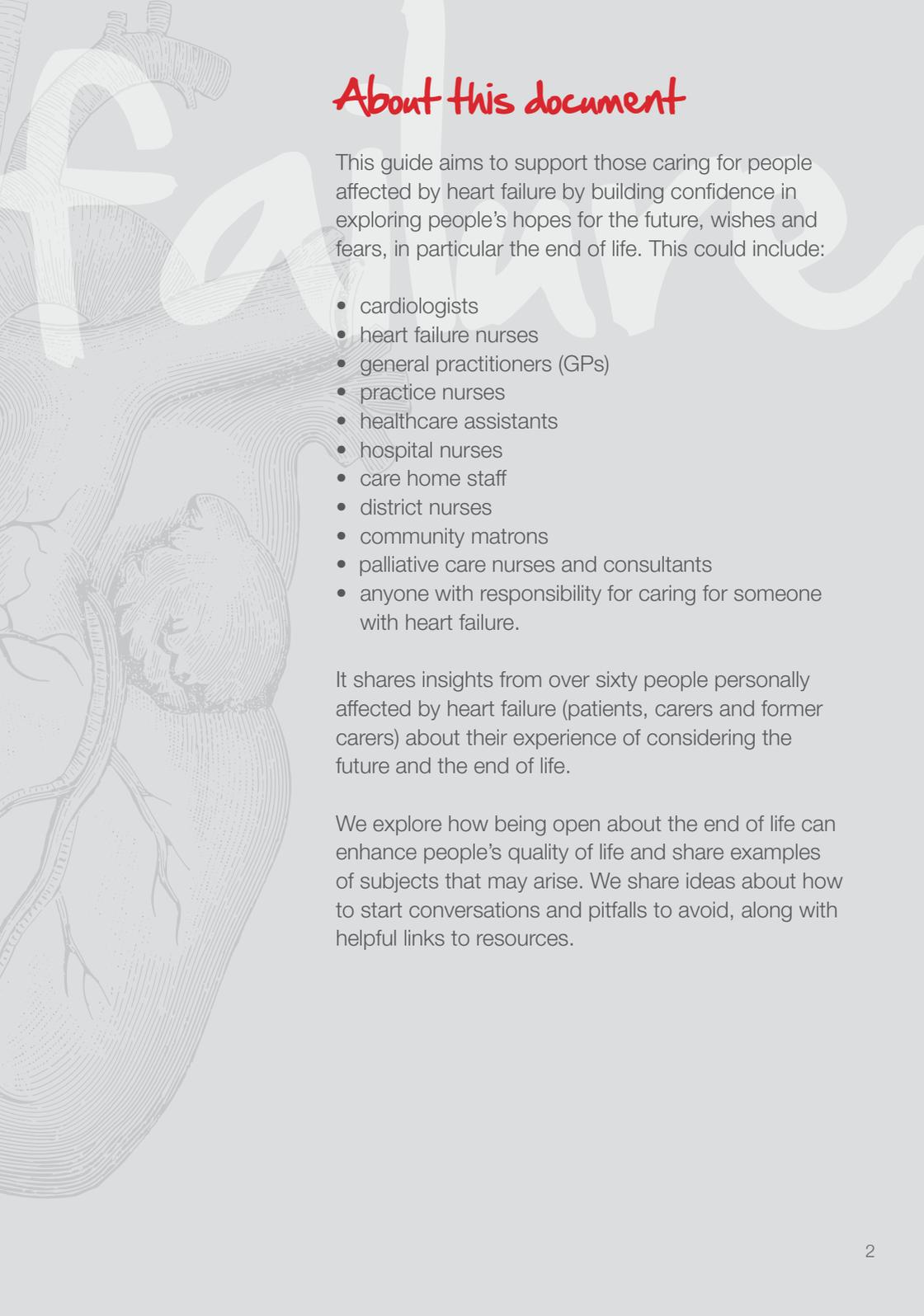
Producing this booklet has been a collaborative venture, and we would like to say thank you to all those who contributed to this work.



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About this document

This guide aims to support those caring for people affected by heart failure by building confidence in exploring people's hopes for the future, wishes and fears, in particular the end of life. This could include:

- cardiologists
- heart failure nurses
- general practitioners (GPs)
- practice nurses
- healthcare assistants
- hospital nurses
- care home staff
- district nurses
- community matrons
- palliative care nurses and consultants
- anyone with responsibility for caring for someone with heart failure.

It shares insights from over sixty people personally affected by heart failure (patients, carers and former carers) about their experience of considering the future and the end of life.

We explore how being open about the end of life can enhance people's quality of life and share examples of subjects that may arise. We share ideas about how to start conversations and pitfalls to avoid, along with helpful links to resources.

Introduction

Over 750,000 people have heart failure of variable severity in the United Kingdom¹. It predominantly affects older people. The end result of many cardiac conditions, this complex clinical syndrome tends to progress and is incurable.

Common symptoms include breathlessness, fatigue and congestion caused by fluid retention. Many people with heart failure, particularly those who are treated effectively, well supported and understand how to manage their symptoms have good quality of life.

Sadly some people die earlier than anticipated, sometimes suddenly², and are profoundly affected by their heart failure. Symptoms may fluctuate and be unpredictable, making it difficult to estimate prognosis. It can therefore be difficult to know how and when to discuss the future and, in particular, how they would like to be cared for at the end of their life.

The key, therefore, is to prepare for whatever the future may bring. This guide will help you to approach this in a sensitive and supportive way.

Why discuss the future, in particular the end of life?

Being open about the future can help people enjoy a better quality of life now. They may:

- feel less anxious and have an idea of what to expect
- receive better care and support
- make informed choices
- be more prepared (as much as one can be) for now and the future
- make things easier for those left behind by putting affairs in order.

“If someone else knows what my future could hold and I don’t, they’re in control, not me”

"If there are choices to be made, I want to make them"

"I found it very helpful and cathartic to be able to think, discuss and plan for the inevitable"

"Because our doctor was really clear about how Dad was, it meant that we were all able to spend time with him. We didn't miss out on that time together"

"MY UNCLE WROTE A LITTLE BOOK FOR HIS WIFE, CONTAINING INFORMATION ABOUT THINGS LIKE WHAT DO TO IF THE BOILER BREAKS DOWN. HE WAS CONCERNED ABOUT THE PRACTICALITIES AND WANTED TO MAKE THINGS EASIER FOR HER"

"I want to organise things now because I could feel too ill to do so in the future"

"Being told what could possibly happen in the future made us look at life differently. We make the most of each day within the limitations"

"It makes me feel happier knowing that my daughters won't be wondering what I would have liked to happen"

"TALKING ABOUT IT ALLOWS YOU TO REALLY SIT DOWN AND EVALUATE WHAT YOU WANT TO HAPPEN"

"It's easier to think about it because you can put it in a little box on the shelf and think 'that's done' and get on with enjoying life"

What can happen if you avoid the subject?

Although there will be times when people prefer not to think too far ahead or about a particular topic, avoiding the subject altogether can make life harder both now and in the future. We share some examples below.

Missed opportunities

"We've all got dreams. I'd love to go on a cruise. If I knew I didn't have long left I'd bring that cruise forward"

"The less honest professionals are, the more they limit people's opportunities and options"

Unnecessary stress and anxiety

"Dad didn't sort out his will or estate. He had a conflict with my brother and didn't reconcile, so my brother's now trying to sue me because he disagrees with the way I dealt with things after Dad died"

"IF YOU'RE NOT TOLD WHAT TO EXPECT:

1. YOU'RE NOT READY FOR IT
2. YOU DON'T UNDERSTAND IT"

"The reason why I'd like to have this conversation is that I get scared sometimes. My whole working career was teaching. During that time I could say what I was doing at 2pm on Tuesday 6th May! I know things don't always go according to plan but I'd like to know about my prognosis so that I can plan. I mean one day I was sitting on the settee reading the Sunday paper and the next minute I was wondering why my face was on the carpet. I hadn't felt faint or sick or in pain. I want to know 'what is dying like? And 'am I going to wake up dead one morning!' These things can't be planned but I'd rather be prepared"

Regrets

"IT IS SAD THAT DAD SPENT HIS LAST FEW DAYS IN THE WRONG PLACE, BEING DISTRESSED AND UNCOMFORTABLE. I'M LEFT FEELING GUILTY, WONDERING WHETHER I SHOULD HAVE DONE MORE"

"Because we weren't told how my husband's heart failure might progress, we made bad decisions. We put our life savings into a business. As the illness progressed, he became more and more reliant on me and there was no one to take care of the business. It was a nightmare. I'm still suffering financially now, even though he died some years ago"

"If conversations had taken place and a little bit of care put in place we could have kept Mum at home for longer, and avoided the dreadful and very sad end of life experience that she had"

Topics of conversation

These are some of the things that may be on people's minds.

Understanding heart failure and living well with it

People don't always know that they have heart failure and if they do know, they may not understand what it might mean for the future. They can be confused about how active they can or should be and how they could make life easier.

“The nurse used to say ‘have you been in touch with the heart failure team?’, but she never actually said ‘you have heart failure’. Months later, I said to her ‘I’ve got heart failure, haven’t I?’ and she looked at me as though I was daft!”



Some causes of heart failure can be inherited, such as hypertrophic cardiomyopathy, which naturally raises concerns and fear about what the future might hold for them and their children.

“Explain what’s wrong with your heart and why it’s not doing what it’s meant to”

“Am I going to just drop dead?”

"I HAVE HEART FAILURE AND MY DAD HAD IT TOO. I'M NERVOUS BECAUSE I SAW HOW DAD DIED"

“Nobody ever told me I had heart failure or that it is a condition in its own right”

“I live my life as fully as I can. When I have good days I enjoy them. I fight my way through, and on bad days I curl up on the settee and watch brain dead telly’.

Making decisions about future care and support (also known as advance care planning)

It is important that people are able to make informed choices about the kind of treatment and support they would like, particularly as there might come a time when they become unable to decide themselves.

"We were asked 'where do you want to be cared for when you die? Home, hospital or hospice'"

"He said he didn't want to be resuscitated"

"I don't want my husband to care for me. He's got no tolerance or patience. I'd much prefer to engage professional care"

"THE REAL WORRY ISN'T SO MUCH WHAT HAPPENS IF MY HUSBAND GOES DOWNHILL OR DIES, EVEN THOUGH HE'S THE ONE WITH HEART FAILURE, BUT WHAT WOULD HAPPEN IF I DID. I DO EVERYTHING - DEAL WITH THE FINANCES, ALL THE COOKING ETC. WHAT WOULD HE DO IF I DIED? HE COULDN'T POSSIBLY DO IT HIMSELF. HE GETS BREATHELESS MOVING FROM ONE CHAIR TO ANOTHER"

Implantable Cardioverter Defibrillators (ICD)

If people have an ICD implanted, it is important that they understand the implications. For example, it may be preferable to deactivate it if someone is nearing the end of life to avoid an increase in device shocks, which can be very distressing for the patient and those who support them. Providing printed information can allow people to read as much detail as they would like and come back to you with any queries. You will find more detailed guidance on ICDs in the resource section at the end of this guide.

"WHEN MY HUSBAND WAS DYING, I WAS ASKED WHAT WE WANTED TO DO ABOUT HIS ICD. I DIDN'T KNOW THERE MIGHT BE AN ISSUE. I ASKED WHAT THE OPTIONS WERE, AND WE AGREED THAT IT SHOULD BE DEACTIVATED, BUT THAT DECISION STAYED WITH ME FOR A LONG TIME. IF ONLY THIS HAD BEEN TALKED ABOUT. I WAS LEFT WITH THE BURDEN OF MAKING THE DECISION ON HIS BEHALF, BECAUSE I KNEW HE WOULDN'T RECOVER. PEOPLE SHOULD BE COUNSELLED BEFORE THE IMPLANT PROCEDURE ABOUT THIS"

Organ donation

Some people may wish to consider the possibility of becoming an organ donor so that they can help others after they have died.

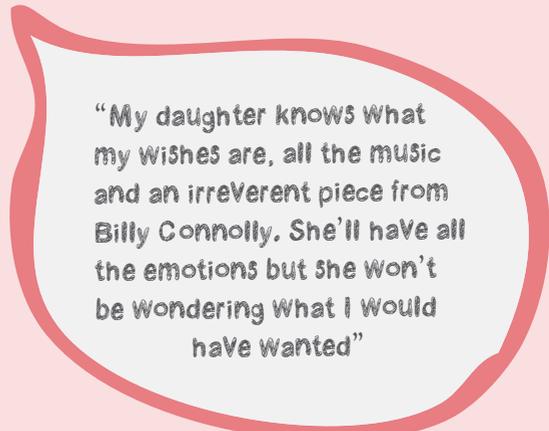
"My family know that if there are any bits of me that can be picked out that someone else could use then they should be completely comfortable with that, as I am"

Making things easier for those left behind

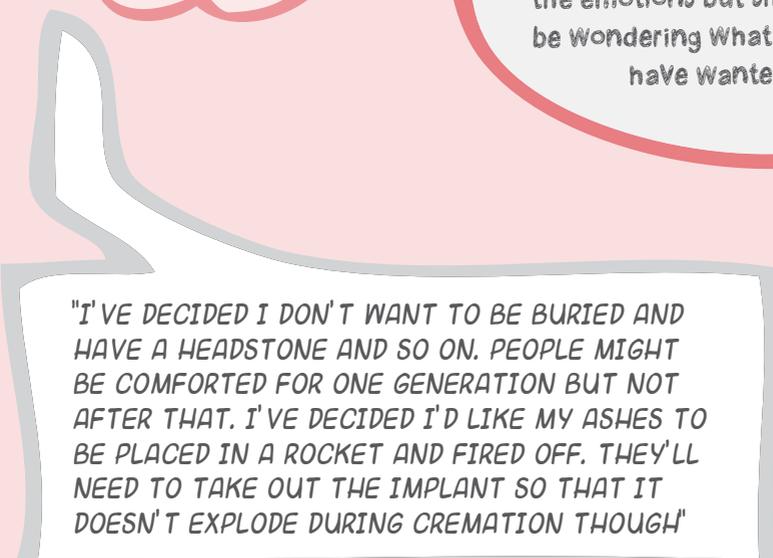
Attending to practical matters such as writing a will or planning a funeral can provide peace of mind for all involved. Families and carers can be comforted, knowing that they did everything possible for the person they were caring for. The person with heart failure can be reassured that they are making things slightly easier for those left behind.



“Who will look after my little girl when I die?”



“My daughter knows what my wishes are, all the music and an irreverent piece from Billy Connolly. She'll have all the emotions but she won't be wondering what I would have wanted”



"I'VE DECIDED I DON'T WANT TO BE BURIED AND HAVE A HEADSTONE AND SO ON. PEOPLE MIGHT BE COMFORTED FOR ONE GENERATION BUT NOT AFTER THAT. I'VE DECIDED I'D LIKE MY ASHES TO BE PLACED IN A ROCKET AND FIRED OFF. THEY'LL NEED TO TAKE OUT THE IMPLANT SO THAT IT DOESN'T EXPLODE DURING CREMATION THOUGH"

When to talk

Discussions are not one off occasions. It's important that talking about the future is never 'off-limits' and people know who they can talk to if they wish to.

The earlier the better

It is natural for people to decide that they will speak about the future when their condition is deteriorating or when things are becoming more difficult. However, it is not always possible to discuss things or put plans in place when someone is feeling very unwell or experiencing a crisis. Heart failure is also unpredictable so it can be difficult to identify when the situation is serious. Speaking as early on as possible, therefore, gives people time to think and control over their decisions.

"EVEN THOUGH WE
KNEW DAD WAS VERY
POORLY, WE DIDN'T
REALISE HIS DEATH
WAS SO IMMINENT"

"Because of the unpredictable decline,
the future should be discussed as soon
as possible, not to frighten people but
to give them time to think"

"I've got to the stage
when I can't dash
about, put things in
order and make sure
things are sorted"

What to discuss at diagnosis

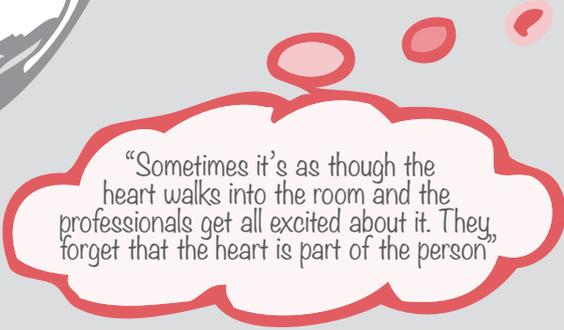
There is much to take in at diagnosis but it is important that the future, in its broadest sense, is openly discussed right from the start. You can lay foundations for further conversations by:

- ✓ Clearly explaining what heart failure is, what it can mean for the future and how to live well with it.
- ✓ Providing leaflets about heart failure which include information about planning for the future and end of life care, so that people can choose to read it if they wish to. Examples of helpful guides are included in the useful resources section, at the end of this guide.
- ✓ Using open questions (shared overleaf).
- ✓ Arranging a time to meet again to discuss any further questions or concerns.



What can help?

Understanding the person you are speaking to



“Sometimes it’s as though the heart walks into the room and the professionals get all excited about it. They forget that the heart is part of the person”

Having an understanding of the person you are speaking with, whether they have heart failure or care for someone who does, may help you to sensitively explore how they feel about the future. For example, it may be painful for someone younger to consider the future if they have a young family or have not had an opportunity to achieve the things they aspire to. Discussing the following can be helpful:

- their understanding of heart failure and what they expect in the future
- who or what is important to them (such as family or work)
- how they are feeling at the moment.

For example, you could ask:

“What do you understand about heart failure?”

“How did you expect things to be?”

Having empathy

Although people can live well with heart failure some people feel breathless, tired, depressed and generally unwell, especially as they often have other medical problems. It can be difficult to access the right support, which can result in people feeling isolated and alone. Relationships can change and the person with heart failure might be caring for someone else too. Being conscious of how life is for the person you are speaking to will help you to be compassionate and supportive.

"IT CAN FEEL AS THOUGH YOU'VE RUN LIKE MAD FOR A BUS BUT HAVE ACTUALLY DONE NOTHING"

"Being short of breath is so frightening. All of a sudden it hits you and you think you're going to die or suffocate"

"Fatigue doesn't only make you feel tired. It also makes you feel completely wiped out, emotionally, and takes away your motivation and energy to do anything. You can feel depressed too"

"It's hard for me because there are a lot of things my husband can't do any more and I have to go off and do things by myself. I suppose it's mourning a lifestyle loss and having to adjust to this as well as everything else. You can't do what you used to do and you're missing out"

"IT'S HARD TO THINK ABOUT AND HARD FOR SOMEONE OF MY AGE (29) TO ACCEPT."

"People see me and think I am lying about how ill I am. They think of heart disease and see little old ladies in their 70s – not a woman in her 40s wearing big showy jewellery which hides the scars, make-up and fantastic shoes, but there are days when I can't get out bed. Occasionally I need to use a walking frame"

Using open questions can be a way of allowing people to ask questions or express concerns in a way that is comfortable for them and help you to avoid, inadvertently, taking the conversation into a direction that is unhelpful. For example:

"What's important for you to speak about today?"

What are your worries? What are your fears?

"I've asked you a lot of questions. What would you like to ask me?"

Being honest, but kind

There will be times when you either need or wish to speak more directly about aspects of end of life care. This isn't always easy but a kind, practical and positive approach can help. Family members and those who are important to the person with heart failure may value an opportunity to speak to you separately.

"YOU DON'T NEED T SHIRTS SAYING 'YOU'RE GOING TO DIE' BUT YOU DO NEED TO TELL PEOPLE HOW SICK THEY ARE"

"My heart failure nurse is so positive, practical and matter of fact, which makes me feel that way too"

"Be honest but do it in a kindly manner"

"The consultant was wonderful. Her communication was honest, open and frank but with sensitivity. It was so lovely"

Providing written information can allow people to choose how much or little they would like to discuss, but be aware of how it may feel to read it. You might find it helpful to offer to talk it through with them. The British Heart Foundation and Pumping Marvellous have both produced helpful guides. Details are included in the useful resources section at the end of this guide.

“Things that we found difficult to talk about, such as what the last few days or hours might look like, were covered in some literature we were given. This meant I could read it, but Mum, who didn’t want to know, didn’t have to”

“I Was giVen a guide about heart failure, which Was really helpful. I Wish I’d been giVen this When I Was diagnosed. It Would have taken the fear out of it”

Making it clear that people can change their minds

Some people are fearful of ‘committing themselves’ by expressing or recording their wishes. It can be reassuring to understand that nothing is set in stone and that they can change their mind at any point.

"DAD WAS SCARED THAT IF HE TICKED A CERTAIN BOX HE WOULDN'T BE ABLE TO CHANGE IT"

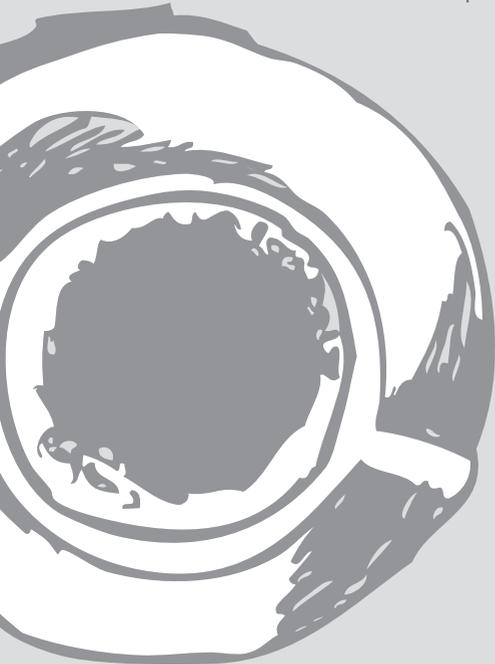
Discussing things more than once

It can be difficult to absorb information, especially when anxious or concerned. Offering further opportunities to discuss things can help.

“I’ve lost count of the number of times I’ve been driving home from an appointment and thought ‘hang on a minute – What does that mean?’”

Privacy

It is important that conversations can take place in a quiet, private place.



What NOT to say or do

We have shared some examples of approaches that people found difficult to help you avoid doing the same.

Making assumptions about the right time for someone to start thinking about these issues.

"I TRIED DISCUSSING MY WISHES FOR THE END OF LIFE WITH MY GP AT ONE POINT AND HE SAID THAT I WASN'T AT THAT STAGE YET. I DON'T KNOW AT WHAT POINT IT WOULD BE APPROPRIATE FOR ME TO DISCUSS IT"

Avoiding the subject when people directly mention issues to do with the end of life, or just not talking about it for fear of saying the wrong thing.

"Professionals often withhold information because of their own concerns, not the patient's"

"My husband was asking 'How am I going to die?' and the nurses said things like 'You don't need to worry about that', 'That's what we're here for' or 'That's something we can talk about later', but the problem is, there might not be a later"

"There still seems to be a real reluctance to talk about the end of life, even with someone of 101"

Being unclear, leaving people anxious or confused about the situation.

"THEY USED TO SAY THINGS LIKE 'THE HEART ISN'T DOING WHAT IT'S MEANT TO BE DOING', AND 'YOU HAVE TO THINK ABOUT THE ANGELS COMING DOWN...'. WE USED TO SAY 'CAN YOU EXPLAIN WHAT YOU MEAN?'"

"One week they'd say 'he's fine - he's got years left' and the next they'd say 'you need to start talking about things'"

Being blunt or insensitive; this isn't the same as being honest.

"Our consultant said 'That medication will kill you before your heart does'"

"THE MEDICAL PROFESSIONAL SAID, IN FRONT OF MY FATHER IN LAW 'THIS IS AN END OF LIFE SITUATION'. HE WAS STILL ABLE TO HEAR AND NOT WELL ENOUGH TO RESPOND. THEY SAID IT IN FRONT OF HIM BUT NOT TO HIM"

"The most distressing event was the Consultant Cardiologist telling her to 'get all affairs into order' when she went home, essentially, and clumsily, warning her of the seriousness of her condition and that it could lead to death. This was done on the ward, during visiting time. My friend described sobbing at the news, again still being in her bed on the very public hospital ward"

Saying 'there's nothing more we can do'.
Care and support are always an option.

"They said that there was nothing more they could do and that we should be preparing for the end of life. They said 'go home and enjoy the rest of your life'. That was it. It was like being shipped out of the office"

Being thoughtless

"MY GRANDMOTHER, WHO WAS 101, HAD BEEN TOLD THAT SHE HAD HEART FAILURE. I DIDN'T KNOW ANYTHING ABOUT HEART FAILURE AND THOUGHT IT MEANT THAT SHE WAS CLOSE TO DEATH. WHEN I ASKED IF SHE NEEDED AN END OF LIFE PLAN, THE DOCTOR SAID 'WELL, YOU CAN LIVE FOR YEARS WITH HEART FAILURE'. MY RESPONSE WAS 'ARE YOU SERIOUSLY TELLING ME THAT SOMEONE AGED 101, WITH A PACEMAKER AND HEART FAILURE, CAN LIVE FOR YEARS?'"

Who to speak with

Everyone, regardless of their role, has a part to play in providing opportunities for people to discuss their wishes and concerns for the future. It can be easier to speak with a professional or someone who is not personally involved in the situation and doing so can pave the way for discussions with close family and friends.

Identifying who will take the lead

Ideally, a named member of staff should take the lead on discussions and support the person at the end of life. This is flexible, but nominating someone to lead on this and liaise with the multidisciplinary team can help co-ordinate elements of professional care and respond to the person's preferences and choices.

What helps?

When considering who to have conversations with, people value speaking to those who:

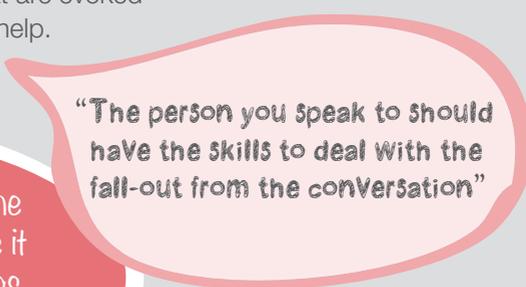
- they trust
- listen
- make the time to discuss things
- can cope with the feelings that are evoked
- can and will do something to help.



“The trouble is, everyone seems to think that everyone else is having the conversations”



“I would have liked someone outside the family to raise it with me to talk my feelings through before I shared them with my family”



“The person you speak to should have the skills to deal with the fall-out from the conversation”



What if you can't help?

If you are not able to respond to concerns or questions raised, try to refer them to someone who can. Passing on all the relevant information will save the person having to repeatedly share potentially sensitive or distressing information.

What if...

...it's not the right place or time?

If it doesn't feel like the right time or place to have a discussion try to acknowledge the person's concerns and arrange a more suitable time speak. It can help to write their question, verbatim, in their notes or fax them in a letter so that the conversation can be picked up in a way that is comfortable for the person concerned.

"I HAVEN'T GOT TIME TO GIVE THAT QUESTION THE TIME IT DESERVES BUT WILL MAKE AN APPOINTMENT TO FOLLOW IT UP"

...people don't want to talk?

People may not wish to discuss things when you raise the subject but it can be helpful for them to know that 'the door is always open' for them to speak to you another time, if they would like to.

"Sometimes people want to avoid it because it's too depressing, but that's just not the right time then. It doesn't mean that there will never be a right time. It's important to be clear that you're prepared to have a conversation with someone whenever/if ever they'd like to"

Where next?

Speaking openly about the future and the end of life can have a huge impact on people's quality of life, allowing them to do things that are important to them and give those left behind peace of mind and comfort.

“For some people, speaking openly about the future can be as important, if not more so, than the medical side of things”

“I think it's very helpful to think, discuss and plan for the inevitable time that one dies. We all will eventually but some of us will have early warning that our time will come a little sooner rather than later”

Whilst there will be times when people choose not to discuss the future, in particular about the end of life, your role is to offer opportunities and to make it clear that you are there for them if and when they feel they can.

Embracing this aspect of care for people affected by heart failure will enable you to provide more personalised and sensitive care. Don't delay in trying to be more open, however uncomfortable it may feel at first. Such communication is a learned skill.

¹ British Heart Foundation Mending broken hearts appeal www.bhf.org.uk

² Cowie MR, Wood DA, Coats AJ et al. (2000) Survival of patients with a new diagnosis of heart failure: a population based study. *Heart* 83: 505–10

² Hobbs FD, Roalfe AK, Davis RC et al. (2007) Prognosis of all-cause heart failure and borderline left ventricular systolic dysfunction: 5 year mortality follow-up of the Echocardiographic Heart of England Screening Study (ECHOES). *European Heart Journal* 28: 1128–34

Useful resources

Dying Matters has produced leaflets and materials to open up and support conversations around dying, death and bereavement. www.dyingmatters.org

The National Council for Palliative Care has produced a range of helpful publications about care for people with heart failure and the Mental Capacity Act. These are available from www.ncpc.org.uk/publications

Strengthening the relationship between heart failure nurses and specialist palliative care: Results from two national surveys (2005/2010)

Focus on heart failure (2006)

The Mental Capacity Act in Practice - Guidance for End of Life Care (2008)

The British Heart Foundation (BHF) has produced helpful information to support people affected by heart failure, available from www.bhf.org.uk

An everyday guide to living with heart failure (2010)

Caring for someone with a heart condition (2013)

One step at a time – Living with heart failure DVD (2011)

Implantable Cardioverter Defibrillator (ICD) deactivation at the end of life: Principles and practice (Sept 2013)

Role of the British Heart Foundation heart failure palliative care specialist nurse. A retrospective evaluation (2010)

Heart Failure Nurse Services in England - Executive Summary: Better Together: An end of life initiative for patients with heart failure and their families (2010)

BHF heart failure palliative care project report: the Glasgow and Clyde experience (2011)

Palliative Care: Principles of Practice. The palliative care module – Glasgow Caledonian University www.gcu.ac.uk

Pumping Marvellous is a charity that promotes awareness to heart failure patients and their carers surrounding the benefits of understanding and then utilising that knowledge to assist in the management of their condition. Pumping Marvellous promotes awareness of the symptoms of heart failure to the general public and medical profession to assist in early detection www.pumpingmarvellous.org

Heart Failure Matters provides practical information for patients, families and care-givers www.heartfailurematters.org

The British Society for Heart Failure provides education, information and support for those who are involved in diagnosing and managing heart failure www.bsh.org.uk

The Cardiomyopathy Association is a charity that provides information and support to families affected by the heart muscle disease, cardiomyopathy www.cardiomyopathy.org

NHS Blood and Transplant (NHSBT) is a special health authority, dedicated to saving and improving lives through the wide range of services they provide to the NHS www.nhsbt.nhs.uk

Planning for your future care - a guide explains advance care planning and outlines the different options available. Available to download from www.dyingmatters.org

Advance Care Planning: A guide for health and social care staff outlines definitions of advance care planning (ACP) and associated terms, highlights the key principles, issues and challenges of incorporating ACP into patient care and indicates how ACP links to the Mental Capacity Act (2005). Available to download from www.ncpc.org.uk/freedownloads

Preferred priorities for care is a patient held document, designed to facilitate patient choice in relation to end of life issues. Through good communication and by documenting patient and carers choices, they become empowered through the sharing of this information with all professionals involved in their care. Available to download from www.dyingmatters.org/gp and click on the section called 'How to help your patients plan'

Research

Gadoud, A. C. (2013). *A palliative care approach for people with advanced heart failure: recognition of need, transitions in care and impact on patients, family carers and clinicians*. PhD, The University of Hull and the University of York, Hull York Medical School.

Barclay, S et al (2011). *End of life care conversations with heart failure patients: a systematic literature review and narrative synthesis* Br J Gen Pract 2011; DOI: 10.3399/bjgp11X549018.

Natalie C. Momen and Stephen I.G. Barclay (2011). *Addressing 'the elephant on the table': barriers to end of life care conversations in heart failure – a literature review and narrative synthesis*. Current Opinion in Supportive and Palliative Care, 5:000–000

A summary report of the two articles above is available to download from www.clahrc-cp.nihr.ac.uk

Acknowledgements

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Richard Mindham, person with heart failure

About us

The National Council for Palliative Care is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters Coalition which aims to change public attitudes and behaviour around dying, death and bereavement.

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Coronary heart disease is the UK's single biggest killer. For over 50 years we've pioneered research that's transformed the lives of people living with heart and circulatory conditions. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease. But so many people still need our help.

From babies born with life-threatening heart problems to the many Mums, Dads and Grandparents who survive a heart attack and endure the daily battles of heart failure. Join our fight for every heartbeat in the UK. Every pound raised, minute of your time and donation to our shops will help make a difference to people's lives.

For further information, please contact

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