

Supporting carers in heart failure management: A qualitative study to identify carer needs

Dr Jennifer Wingham

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Aims of the presentation



- Outline the Rehabilitation Enablement in Chronic Heart Failure research project
- Describe the findings of the needs of caregivers in chronic heart failure project
- Present the family and friends resource in the REACH-HF programme

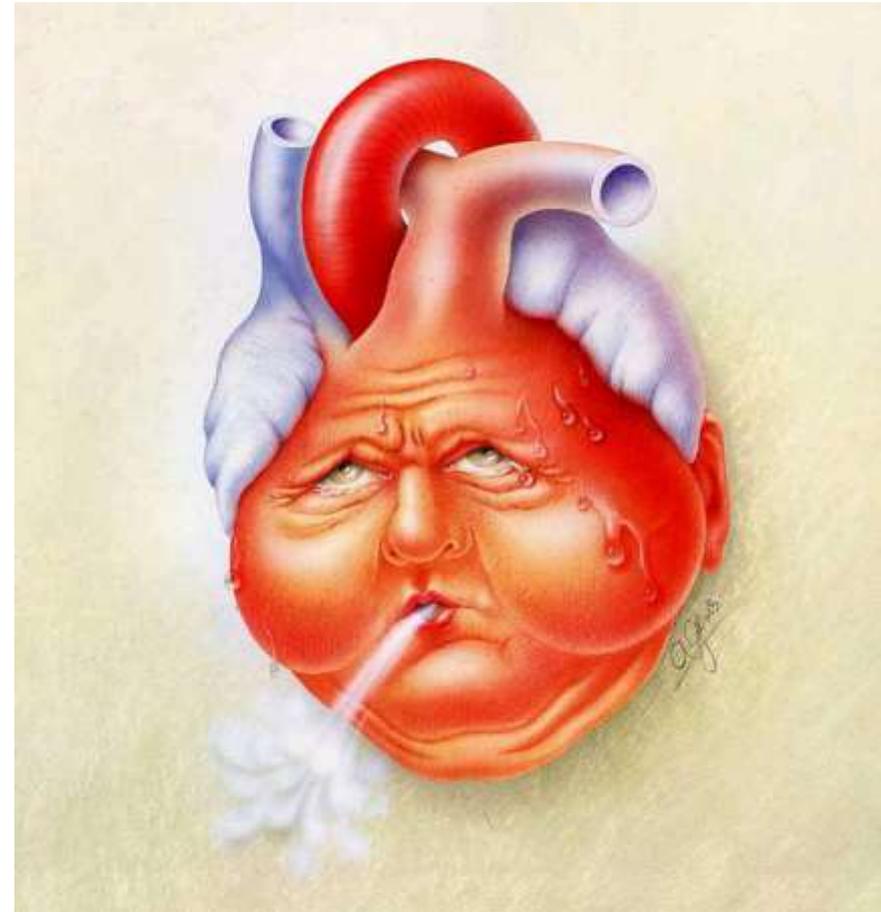
NIHR Programme Grant



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- The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Heart Failure

- Heart failure (HF) affects almost a million UK adults; symptoms include breathlessness, fatigue and swollen limbs
- Approximately 50% are supported by family and friends
- Carers provide much self management support



Self-management

- Prevention – exercise, vaccination, low salt healthy diet
- Monitoring - symptoms, e.g. weighing to monitor fluid balance
- Taking action when unwell – additional diuretic or seeking help
- Managing mental wellbeing
- Maintaining social role

Family support in HF

- “...because cognition and motivation – two factors essential for self-care behaviour – are interwoven with family and social situations, it is time to reconceptualise heart failure self-care as a family phenomenon.”
- Dunbar S, Clark P, Quinn C, Gary R and Kaslow N. Family Influences on Heart Failure Self-care and Outcomes. *Journal of Cardiovascular Nursing*. 2008; 23: 258-65.



Rehabilitation Enablement in Chronic Heart Failure



- A project to design and test a home based service for people living with heart failure and their families or friends
- A work book, a progress tracker, a friends and family resource, a relaxation CD and exercise DVD
- Supported by a trained health professional
- <http://www.rcht.nhs.uk/RoyalCornwallHospitalsTrust/WorkingWithUs/TeachingAndResearch/ReachHF/Homepage.aspx>

REACH-HF contributor locations



A NHS Lothian Heart Manual Office

Edinburgh

Louise Taylor

Wendy Armitage

Dr. Carolyn Deighan

B University of York (trial site) & York St. John University

Professor Bob Lewin

Professor Patrick Doherty

C University Hospitals NHS Trust Leicester

Professor Sally Singh

D University of Birmingham & Sandwell & West Birmingham Hospitals (trial site)

Professor Kate Jolly

Dr Russell Davis

E Aneurin Bevan Health Board (Abergavenny)

Dr Jackie Austin

F University of Exeter Medical School

Professor Charles Abraham

Professor Nicky Britten

Dr Colin Greaves

Dr Colin Green

Professor Rod Taylor

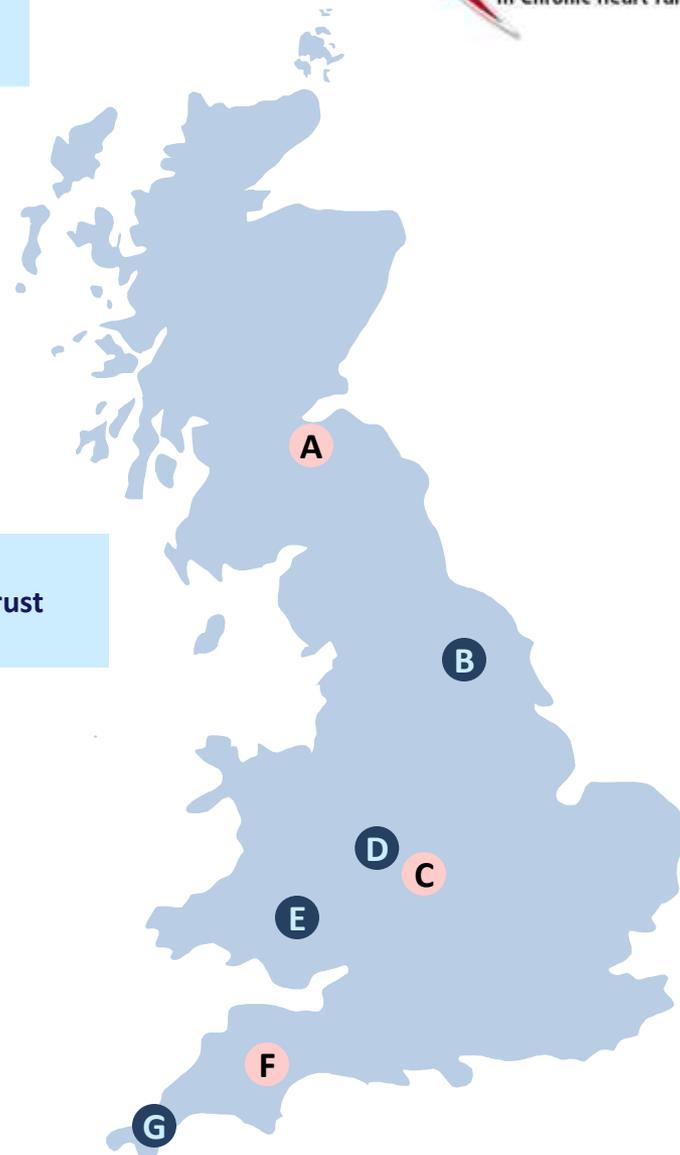
G Peninsula Community Health & Royal Cornwall Hospitals Trust (trial site)

Mrs Lorna Geach

Dr H Dalal

Dr Robin Van Lingen

Dr Jennifer Wingham



X Investigator location

X Investigator location and trial site

Development of the REACH-HF intervention



- Evidence-based approach
- Intervention mapping (6 step process)
- Psychological theory
- Behaviour change



Wingham J, Harding G, Dalal H, Britten N (2014) Heart failure patients' attitudes, beliefs and expectations of self management strategies: a qualitative synthesis. *Chronic Illness*. 2014.10(2) 135-54

Bartholomew et al. Planning health promotion programs. An intervention mapping approach. Wiley. 2011

Carer Study



Aim

To undertake a qualitative assessment of the needs of HF carers to inform an evidence-based self-help intervention ('REACH-HF manual') aimed at HF patients and carers.

Method

Qualitative study of 22 individual interviews across Cornwall, Birmingham and Leicester. Followed by a focus group of 4 different carers in Cornwall.

Informed by thematic analysis.

Demographics of carers

- 26 Participants (Cornwall, Birmingham and Leicester)
- Age range 39-84
- 6 males
- Mainly spouse/partner
- 3 were working
- 12 had some illness or disability



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Results



- Three distinct themes of needs identified to inform the development of the Family and Friends Resource

1 Providing Support

2 Becoming a caregiver

3 Getting help

Carers wanted to provide support but often lacked the information or skills. Many learnt by trial and error.

1 Providing Support

- Hyper-vigilance
- Many carers have seen the person they love close to death
- *“Definitely you, you watch. Definitely. Even... maybe from another room you watch, you know.”*

Need to know what to look for and how to provide support - how to support

Fear of doing something wrong

Medicines

- “...you slowly learn. Um, it’s like the tablets and getting the medication right; it took me a long time to realise that when it comes to water control it’s down to me to decide whether I’m going to give him any extra or not.”
- Feeling responsible

Community nurses were a good source of support



Medicines

- *“Have a system for giving medication because it’s easy to get in a muddle”*



Personal Pocket Medication Card

KNOW BETTER CARE

UConn Health Center

Medication Record	Pills/Dose	Time/Day	Reason for Taking	Date Started	Date Stopped
Drug Name & Strength Chlorzoxiprone 50 mg	2 pills	100 & 1/2 daily	Cholesterol	4/22/11	

Physical Activity

“Sometimes when he sleeps too much and he doesn’t move too much, I ‘gee’ him up and say, “Come on, we have to get you moving today.” Then he does find he does feel better for doing that.”

- **What exercise and when?**
- **Encourage/not nag/restrict**



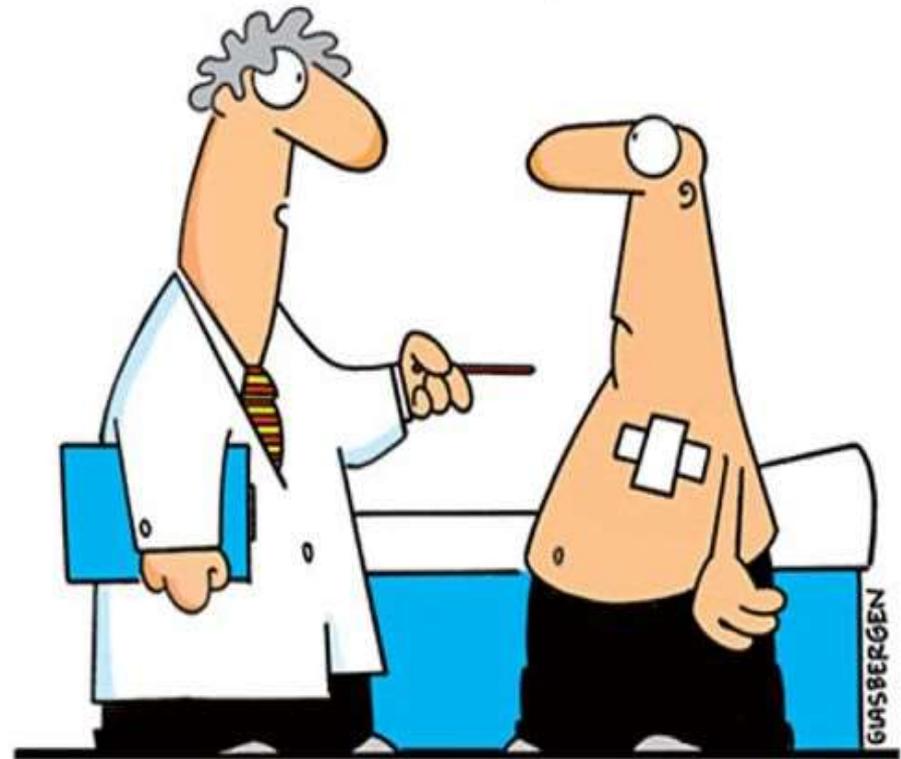
Providing emotional support

- *“I think there are the two particular things I do, allowing and encouraging to him to do as much as possible.”*
- Key part of the role
- Marking achievements
- Encouraging action



Other areas of providing support

- Providing personal care
- Living with a cardiac device
- Depression management



"It's a pacemaker for your heart. Plus, you can download apps for your liver, kidneys, lungs, and pancreas!"

2 Becoming a caregiver

Transition

- **Variety of reactions**
- Takes time (many months)
- Part of marriage and getting older
- Don't recognise self as carer.
- Complete shock. Stigma
- Development of skills takes time
- Support services

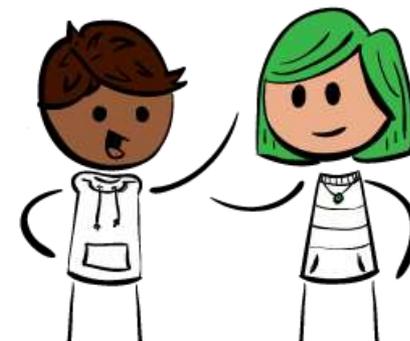
***Our greatest glory is
not in never falling,
but in getting up
every time we do.***



Communication

“He still wanted to be man of the family and when I said, “I’m coming with you”, he said “Oh, there’s no need”. Well, there is. I said, “When you come back and I say to you ‘What did they say?’ You can’t remember, it’s not intentionally, but you can’t remember, so how can you tell me?” Now we’ve grown to the stage where he expects me to go with him.”

Need to know how to communicate
Starting questions



Communication with health professionals



- Key part of the role when the person with heart failure is unwell or unable to remember past events
- May need to negotiate with the person with heart failure
- **Carers who did not cope well were in relationships where the cared for person excluded them from consultations or refused to talk about their heart failure**
- **Carers need courage and skills to communicate**

Managing mental health and wellbeing

*“I have a ‘chat night’ with a friend. So there’s just the two of us. And we just chat and have a cup of tea (**laughing**). But to me, that is the times when I know that I can get out for me, and it’s something that I enjoy doing.”*

- Often neglected
- **Need to inform GP**
- Stop avoid telling adult children
- Many have poor sleep



Managing Home and Work

- Need for prioritisation of what is important
- Involve the person they are caring for in task
- Caring is time consuming
- Need to be organised but also 'go with the flow'
- Worry at work
- Caring for children or other adults



3 Getting Help

- *“I have always been a bit independent and stubborn and... but you need to ask for help, and that is really hard ... Even if it’s from a really close relative or a friend, it’s really hard to make yourself ask for help once you’ve done it, it’s like Well I’m glad I did that.”*
- Use of text messaging – short and flexible
- Protection of adult children yet they are often good providers of support
- Fear of becoming a burden

Formal services

- Lack of knowledge about a 'Carers Assessment' –Care Act 2014
- Lack of knowledge about benefits
- Lack of knowledge about getting adaptations to the home or where to get equipment
- Access to carer support groups
- Voluntary services



Design of Friends and Family Resource

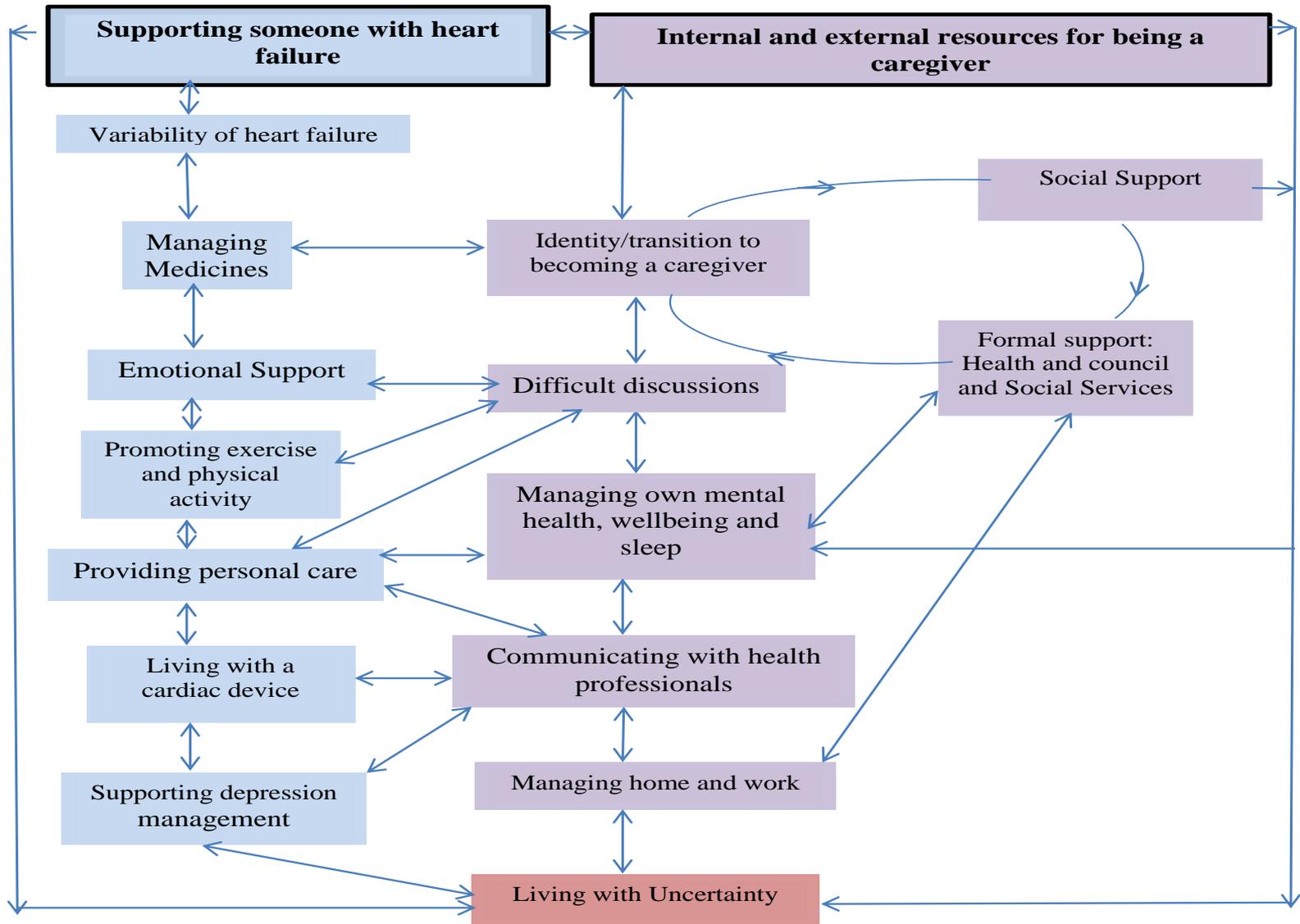


- ‘Dip in and out’ and short quick to read points
- Each chapter and section has a brief sentence or two about the content
- Includes quotes from the caregiver research
- Explains what are normal responses and actions
- Hints and tips from other caregivers and experts

Key messages

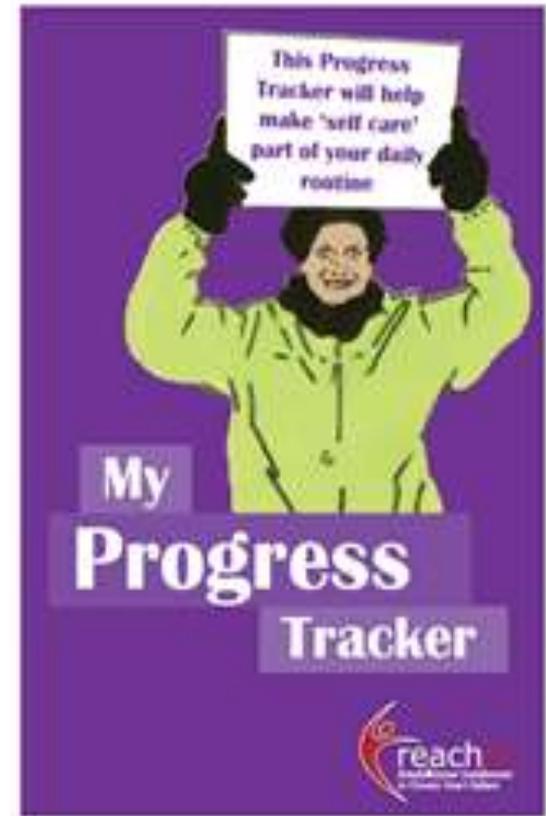
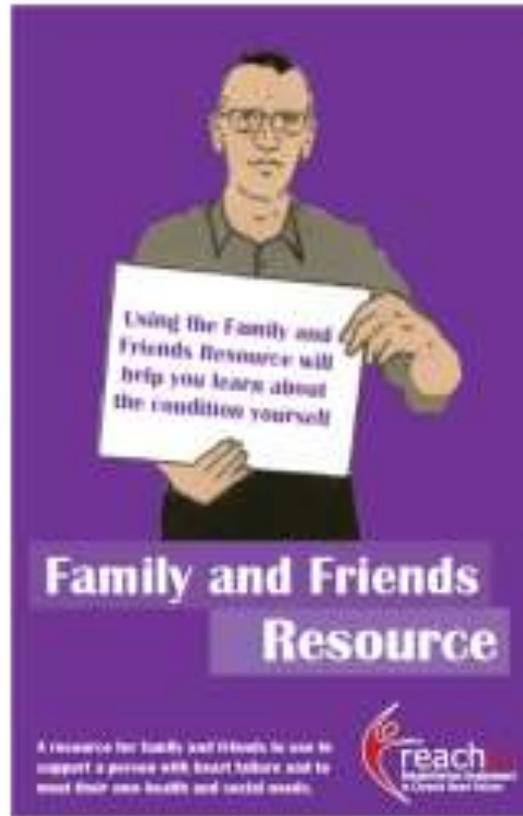
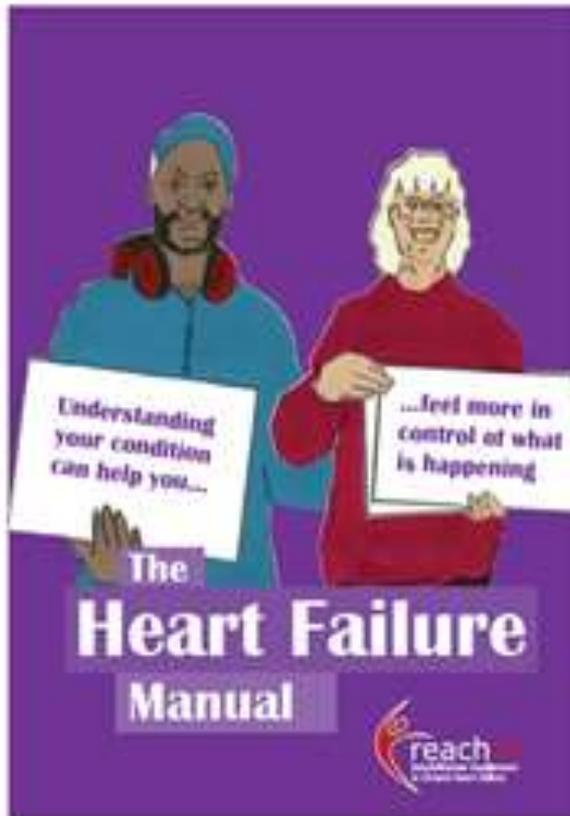
- Key message that their role requires flexibility and not to take over unless required
- Carers are sometimes uncertain if they should ask questions and be involved in care decisions
- Need for integrated care
- Need a change in care ethos -inclusivity

Figure 1: Conceptual Framework of Caregiver Needs in Heart Failure Management



- Legend:
- Actions and activities to support someone with heart failure
 - Internal and external resources required by the caregiver to support someone with heart failure
 - Living with uncertainty: affecting both the person with heart failure and the caregiver

REACH-HF Manual



Tack så mycket –Thank you



- Any questions?
- Wingham J, Frost J, Britten N, et al. Needs of caregivers in heart failure management: A qualitative study. Chronic illness. 2015; doi:10.1177/1742395315574765 First Published 19th March