



Family & Friends Training

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Aims and objectives

Aim

- ♥ Appreciate the benefit of involving family members in rehabilitation
- ♥ Know how to facilitate the supporter *Friends and Family Resource*

Objectives

- ♥ Define who is a caregiver/supporter
- ♥ Assess caregiver needs
- ♥ Develop skills of facilitation (esp for caregiver/supporter)
- ♥ Identify local sources of information to support caregivers



Caregiver/supporter –what does it mean?

♥ "A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems."

♥ <http://www.carers.org/what-carer>

♥ Any family member or friend even if caring is not obvious, may be living away and support by telephone

♥ Use the term **supporter** or better still by name



Break out activity 1

- Identify 3 'pluses' of (actively) involving "supporters" in management of people with HF
- and 3 possible 'minuses' (challenges) of such involvement



What do family members do?

- Can act as co-facilitators or supporters (see training pack)
- support your initial assessment (they often see themselves as 'telling the truth' about what is really happening on a daily basis)
- help set your plan – achievable and realistic
- support the patient to make changes to life style and heart failure management (sticking to the plan or make sensible adjustments)
- provide encouragement and help with tracking progress
- spot signs of clinical deterioration and get help if required



Principles of Facilitation

Invitation to be included in the intervention
"This is for you too"

Family Centred Care (see training pack)

- Respect and dignity
- Information Sharing
- Participation
- Collaboration

Top tips

- ✓ Avoid the term carer or caregiver especially in your early consultations.
- ✓ Actively invite the supporter to your consultations.
- ✓ You can contact the supporter separately from the patient.
- ✓ Assess knowledge, beliefs and fears
- ✓ Include the supporter in reviewing the action plan.



Practical Points

- Being involved may at first seem odd for supporters. They will need to **adjust** to a new 'model' of behaviour
- Set appointments with supporter (with person with HF or alone or a bit of both)
- **Not all supporters live with the cared for person** you may need to make contact separately
- **Follow up caregiver goals** in telephone and further visits and adjust the plan
- "How are you getting on with....."
- Problem solve and set new goals
- **Discuss** - experimentation is normal



Engaging Supporters – questions to use

- What does heart failure mean **to you**?
- Is there anything **you would like to know** about?
- It is **common for some family members to worry** about what they should do? What worries you? What do you think(name of patient) could do to achieve the goals?
- **What would you like to do to help**(name of p manage his/her condition?



Engaging Supporters – questions to use

- What do you do for relaxation or 'just for you'?
- What do you think about the future?
- Do you have any family members or friends who you can talk to or ask for help?



Case Studies

▶ **James Carmichael** 64y, OOHA, acute LVF and emergency CABG. CRT-D inserted



▶ **Lucy Poole** 31y, DCM of unclear origin. Young family and history of anxiety/depression




▶ **Joseph Brown** 78y, gradual deterioration but recent diagnosis of CHF. Background of COPD and reduced ex tolerance




Break out activity 2

- How would you approach the supporter?
- What do you think are their priorities?
- What methods would you use to help set goals and actions?
- How would you support the supporter /caregiver? *(Also think about what barriers you might face to trying to engage this supporter and what you would try to do to overcome those)*


 The Family and Friends Resource

- ‘Dip in and out’ – read what they need and when they want
- Divided into three sections

Providing Support
Taking Care of Yourself
Getting Help

 Welcome - Introduction


- **Facilitator task is to engage the supporter** in the intervention – this may be a new experience for
- Assess the caregiver’s needs (through whole intervention)
- Many will have health needs of their own and other responsibilities
- The role will vary from person to person
- Supporter **must not be made to feel guilty** if they are unable to be a supporter

 Chapter 1: Providing Support

- ▶ **Role as co-facilitator/supporter.** Priority chapter for many caregivers


What do I need to do to support?

- ▶ There will be many myths –ask what the caregiver knows about heart failure and make sure the information is accurate. They may have a **different understanding** from the person with HF
- ▶ Knowledge will depend on involvement in consultations at diagnosis and what the person with heart failure has told them
- ▶ Locus of control – who and when?


 Traffic Light Action Plan

- See the Heart Failure Manual and back of the Family and Friends Resource
- Lay people rely on facial expression and or pallor. “ He looks grey”
- They also look for changes in mood
- “ she gets snappy” or “He goes quiet”


Look at the TLAP



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 What to do in an emergency

- This section may lead to discussions about prognosis
- Emphasis is on **getting help quickly**
- Supporters may be anxious as they may have witnessed the person with heart failure close to death or had to call an ambulance
- **Find out where there are training courses in your area**

 Providing emotional support and stress management


- ▶ Supporter to use **Heart Failure Manual** as a resource as well as the **Family and Friends Resource**

Key Caregiver Messages

- ✓ Support/encourage but **don’t** smother/nag
- ✓ Focus on what has been achieved and goals for the future
- ✓ Step away when the person does not want to talk
- ▶ Providing emotional support will depend on the relationship between the pair and the supporter’s own wellbeing


Promoting exercise and physical activity

- Many caregivers have a positive view about physical activity but may be worried about how much and how often and how far the person with heart failure go
- **Their role should be negotiated with the cared for person and set as part of the treatment plan**
- This is a **key part** of the intervention
- May be best discussed in the second visit while you are there to do the exercise programme with them
- They will need to see what is normal breathlessness and recovery – **Borg scale**
- **Supporter should where able join in the exercise**



Dealing with depression

- Real challenge for supporters and a significant cause of resistance
- Caregivers often feel cut off, hurt and frustrated
- May be covering up depression because of fear of stigma
- **Key Message: Professional help is required**
- Caregiver to manage own stress



Progress Tracker


- Introduce the progress tracker in the first session
- Supporters can encourage use of the progress tracker – may spot improvements or symptoms before the person with heart failure
- Supporters can write their own questions in the tracker for the next contact
- Supporters may be the writer if the person with heart failure doesn't like writing
- **Use the tracker in each contact for discussions about progress**

Chapter 2 Taking Care of Yourself

- Transition (growing into the role) to becoming a supporter
- May or may not want the role
- May have been the cared for person but is now the least ill
- Sense of responsibility
- **Find out if there are any support services in your area**

Key caregiver messages

- **Role develops over time** (may be over months)
- Confidence grows through experience
- Learn together, they are not alone
- Ask for help and advice – formal and informal
- Goal: Accept that heart failure can be managed



Communication with health professionals


The PACE Framework

- ▶ **Presenting** detailed information. Symptoms, lifestyle, what you think is important and family history.
- ▶ **Asking** questions. For information or if something else can be done. This could include asking about medicines or exercise.
- ▶ **Checking** understanding of information that is given to you. Ask for clarification of what was meant, for example, about timing of medicines and how much should be taken.
- ▶ **Expressing** any concerns about the recommended treatment. Be honest so that you can work with the professional to find the right treatment.

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Supporter mental health and wellbeing

- Use a mental health screening assessment and refer on if required
- **Stop and think moment – reinforces engagement with the intervention**
- Get the caregiver to inform their GP about their role
- Use stress management section in the heart failure manual
- 'Me time' where possible
- Social role
- Carer's Assessment (chapter 3)
- Friends and family



Managing home and work

- Practical organisational tips
- Prioritisation of what is important- part of negotiating role
- Informing schools and employers
- **Carer's Assessment** is also designed to help caregivers remain at work if this is what they want to do


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Chapter 3 Getting help Friends, family and more

- ▶ Asking for help is really difficult
- ▶ **Fear of being a burden**

"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.'"

- ▶ Protection of adult children
- ▶ The resource has many practical tips
- ▶ Recommend use of the chart or carer app 'Jointly'




Social and council services

- Many caregivers do not know they are legally entitled to a 'Carer's Assessment' –also a good way of getting a home assessment and OT services
- Arranged through social services or local council – depends on your area –find out which
- For benefits, returning to or maintaining employment, support for caring, support groups, respite care
- Some councils will allow the refuse collectors to come to the house to collect the bins

Caregivers often feel they should be able to cope – manage sense of stigma, show the quote

Living with uncertainty

- Caregivers often worry about the future
- **Unless the caregiver asks this is not for the first consultation**
- Balance self-management message with reality
- It may come up on the second visit or by telephone
- Be led by what the caregiver asks and what they have been told
- Sensitivity with the person who has heart failure
- Make caregiver aware of palliative care services



Break out activity 3

- **what should the final visit be about?**

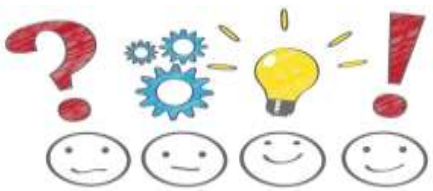
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Preparation for final visit

- Caregivers may come to rely on your service and there is a risk of 'bereavement' as you withdraw
- Get the patient and caregiver **to reflect on their progress** and what has been learnt – use questionnaires
- **Maintenance of self- management**
- **Manging set backs**
- Review the goals, praise achievement and plan for the future
- Refer to other services or support groups

 Any questions?

- Are you ready?



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