Caring Together Programme

British Heart Foundation, Marie Curie and NHS Greater Glasgow and Clyde working together to provide better palliative care for heart failure patients.

Use of Caring Together Holistic Assessment Tool

This holistic assessment tool has been specifically designed by the Caring Together Programme Team to support health care professionals to identify the unmet supportive and palliative care needs of patients and carers living with advancing heart failure. The holistic assessment tool has been developed and implemented by Caring Together as part of an integrated care model which includes specific referral criteria and core components.

Patients are referred if they meet the following **clear and concise referral criteria**:
- Have advanced heart failure (New York Heart Association classification categories III or IV)
- Have distressing or debilitating symptoms despite optimal medical therapy
- Have supportive or palliative care needs that may include a combination of physical, social, emotional, spiritual or psychological needs
- Further supplementary considerations are taken into account by clinicians referring patients, including the number of admissions in the last year and the surprise questions.

Patients who meet the referral criteria receive a **comprehensive assessment**:
- a cardiological review in outpatient or in-patient settings as appropriate
- a holistic assessment which looks at the physical, social, psychological and spiritual aspects of care is undertaken in order to address unmet patient and caregiver needs and inform future care planning and onward referral to other services **(incorporating the use of this tool).**

Each patient is **assigned a care manager**, who acts as their main point of contact for information and support. Care managers are responsible for leading and co-ordinating patients' care. They work closely with a patient's GP, cardiologist, district nurse and the wider multidisciplinary team to make sure they are getting the support they need.

An individualised medical anticipatory care plan is developed for each patient in partnership with lead clinician, patient and carer, which includes concise information on the patient's medical and palliative care needs. Anticipatory care plans are developed in partnership with the individual, family and carers, on how those needs can be met. Care plans are shared with the all involved in the care of the patient including unscheduled care providers.

Caring Together's **multidisciplinary approach** across the acute, community and out-of-hours care teams enables us to deliver consistent and coordinated services to patients and their carers in all care settings. The programme has also supported **joint learning** and increased awareness between health and social care professionals working across acute and community settings.

Caring Together is currently undertaking an independent evaluation. Implementation of tools outside such an integrated care model is undertaken at implementing organisation's own risk.

Caring Together Programme

British Heart Foundation, Marie Curie and NHS Greater Glasgow and Clyde working together to provide better palliative care for heart failure patients.

Holistic Assessment Tool

The holistic assessment tool has been specifically designed by the Caring Together Programme Team to support health care professionals to identify the unmet supportive and palliative care needs of patients and carers living with advancing heart failure illness. A person centred approach to assessment is encouraged whereby the Physical, Social, Psychological and Spiritual aspects of care needs are appraised and addressed where possible in partnership with other multidisciplinary professionals.

The assessment should take place at the point of referral to the Caring Together and can be completed in any care setting including outpatients and home. The assessment should always be regarded as an ongoing process and not a one of event. The need to repeat any aspects of the assessment including the ESAS-r, PHQ-9, GAD-7 and Carer Strain tools should be guided by clinical judgement to make certain that the changing needs of patients and carers are being addressed at appropriate intervals.

The assessment should be undertaken by the Care Manager who has an established relationship with the patient and an appropriate level of knowledge relating to the advancing disease. Aspects of the assessment may be carried out in partnership with other professionals (E.g. District Nurse, Palliative Care, Physician, GP or any other AHP).

Please note that the questions contained within the assessment document are there to act as prompts to support a person centred approach to discussion. A summary of the main assessment scores and outcomes **must** be documented and communicated to all other professionals involved in the patients care.

Background Information

Name of Patient: (Insert label if available)	**Name of GP:** (Insert label if available)	**Other Healthcare Professionals:**

If the following information is already documented elsewhere please indicate where this information is stored (e.g. HF Nurse Database)

………

	Review Date:	**Review Date if repeated:**
Date of Birth		
Age		
Post Code		
Gender		
Ethnicity		
Religion		
Sexual Orientation		
Marital status		
Next of Kin Contact details		
Dependants (yes/no) (If yes please specify)		
Patient's ability to participate in face to face assessment.	Able/Not Able	
Patient's willingness and consent for participation in assessment (explore any physical/cultural/other issues that may preclude patient participation).		
Preference for family member or other to be present during assessment.	Yes/No	
Preferred language (Please Specify)		
Communication Difficulties (E.g. Impaired Vision/hearing/ Intellectual/Cognitive Impairment)	Yes/No (If Yes Please Specify)	
Does the patient give consent for information to be shared with other Professionals/Family/Carer givers?	Yes/No (If No please specify)	

Social and Occupational Well-being

	Review Date	**Review Date if repeated**
Type of living accommodation	House / Flat / Bungalow / Sheltered / Care Home/ Other. (Please Circle) Stairs: Yes/No Internal/External. (Please Circle)	

	Review Date	**Review Date if repeated**
Disabled Access	Yes/No (please specify)	
Accommodation Concerns	Yes (please specify) No	
Mobility Concerns	Indoor: Yes/No (please specify) Outdoor: Yes/No (please specify)	
Personal Care Concerns	Yes (please specify) No	
Housekeeping Concerns	Yes (please specify) No	
Limitations relating to recreation/leisure activities	Yes (please specify) No	
Limitations/concerns relating to accessing healthcare services	Yes (please specify) No	
Financial Concerns	Yes (please specify) No	
Has an income maximisation assessment been offered?	Yes No (please specify) Declined (please specify)	
Family or close relationships concerns	Yes (please specify) No	
How does the patient usually travel to appointments?	Own car/taxi/ambulance seated/ambulance stretcher/ volunteer driver service/other.	
Does the patient live alone?	Yes No (please specify)	
Who is the patient's main carer?	Spouse/Partner/Sibling/ Child/ other (please specify)	
Does the carer live with the patient?	Yes No	
Are there any concerns relating to the role of the main carer?	Yes (please specify) No	
Has the main carer been offered a carers assessment by social services?	Yes/No Declined	
Is the carer the person that the patient relies on for daily support?	Yes No (please specify)	

Spiritual Well-being

The following questions have been designed to support you to identify the patient’s worries related to their spiritual well-being and the specific challenges that the patient perceives in being able to optimise their spiritual well-being now and for the future.

Review Date:

What is the patients **understanding** of their current illness?

....

....

....

Are there any specific worries or challenges related to their **understanding** of their illness and its likely progression?

....

....

....

Are there any specific worries or challenges related to their illness **now or in the future**?

....

....

....

Are there any specific **needs or restrictions** related to optimising the patient’s spiritual well-being? (E.g. someone to speak to: faith leader, minister or other person, immobility, housebound, cultural or ethnic background, belief system or requirements such as diet, fasting or others.)

....

....

....

Significant Conversations

Review Date:

From your own experience, what normally happens to you when your condition changes?

....

....

....

Bearing in mind that your condition is likely to change and may become more difficult to manage, where would you prefer to be cared for?

....

....

....

If your condition becomes too difficult to manage at home, what would be your preferred care option?

....

....

....

Referral to Other Health & Social Care Services

Profession/Service	Yes/No	Referral Date	Reason for Referral
District Nurse			
Palliative Care			
Home Care			
Personal Care			
Occupational Therapist			
LTC Financial Partnership			
Social Work			
Benefits Assessment			
Macmillan Finance Guidance			
Carer's Issues			
Childcare Issues			
Elderly Care Issues			
Housing Issues			
Fuel Tariff Review			
Work Focus for Patient			
Work Focus for Carers			
Vocational Rehabilitation			
Care and Repair Service			
*Voluntary Organisations			
*Other Services:			

Additional Information

……

……

……

*Voluntary/Other services may include: Befriending/Grant Applications/Visual or Hearing Services etc

Anticipatory Care Planning

"Patient anticipatory care plan" Communication Tool	**Yes/No**	**Review Date**	**Additional Comments**
Discussion regarding the aim, content and patient's voluntary involvement in completion of the "patient anticipatory care plan" document has been explained in full.	**Yes/No**		
"patient anticipatory care plan" document left with patient and their family.	**Yes/No**		
Review of the "patient anticipatory care plan" has been arranged: has taken place:	**Yes/No** **Yes/No**		
Professional assistance requested with completion of "patient anticipatory care plan" document.	**Yes/No**		
Individualised Anticipatory Care Management Plan completed by lead Clinician	**Yes/No**		

Patient anticipatory care document will be local initiative following "Thinking ahead and making plans model (Scott and Boyd, NHS Lothian)

Preferred Care Priorities		**Date**	**Comments**
Preferred place of care priorities identified	**Yes/No**		
DNA CPR discussion undertaken: DNA CPR document completed:	**Yes/No** **Yes/No**		
Device Deactivation Discussed:	**Yes/No/NA**		
Copy of DNA CPR form given to patient/carer	**Yes/No**		
Copy of Individualised Anticipatory Care Management plan/letter given to patient/carer	**Yes/No**		
Preferred Place of Care Documents shared with all other professionals	**Yes/No**		
Patient on the Palliative Care Register	**Yes/No**		

Additional Notes:

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Revised Edmonton Symptom Assessment System Recording

ESAS-r Graph

Date																					
Pain	10 0																				
Tiredness	10 0																				
Drowsiness	10 0																				
Nausea	10 0																				
Lack of Appetite	10 0																				
Shortness of Breath	10 0																				
Depression	10 0																				
Anxiety	10 0																				
Well Being	10 0																				
Other	10 0																				
Completed by																					

P= Patient, F = Family Caregiver, C = Caregiver Assisted, H = Healthcare Professional

	Marie Curie Care and support through terminal illness	British Heart Foundation	NHS Greater Glasgow and Clyde

Edmonton Symptom Assessment System:

Edmonton System Assessment System (revised version) (ESAS-r) (revised November 2010)

Patient Name:…………………………………… Date of Completion:…………………………

Please circle the number that best describes how you feel NOW:

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Pain**
No Tiredness	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Tiredness**
No Drowsiness	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Drowsiness**
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Nausea**
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Lack of Appetite**
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Shortness of Breath**
No Depression	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Depression**
No Anxiety	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Anxiety**
Best Wellbeing	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Wellbeing**
No __________ Other Problem	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible ________________**

Total symptom assessment score (from column totals) =

Specific Heart Failure Related Symptoms (included as part of Caring Together Programme)
Please circle the number that best describes how the patient feels NOW:

No nocturnal breathlessness	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible nocturnal dyspnoea**
No orthopnoea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible orthopnoea**
No fatigue	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible fatigue**
No oedema	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible oedema**
No thirst	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible thirst**
No itch	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible itch**
No cough	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible cough**
No bowel problems	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible bowel problems**
No urinary problems	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible urinary problems**
No weight problems	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible weight problems**
No skin problems	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst possible skin problems**

The ESAS was completed by Patient / Caregiver / Caregiver assisted / Healthcare Professional

	Marie Curie Care and support through terminal illness	British Heart Foundation	NHS Greater Glasgow and Clyde

What is the worst symptom that you are experiencing regularly that you would like me to help you with first?

....
....
....

What is the worst thing overall about living with your heart failure?

....
....
....

Please remember to discuss and document the ESAS scores with all relevant professionals involved in the patients care management.

Revised Edmonton Symptom Assessment Score (ESAS-r) Guidance

Purpose

The *ESAS* is a tool that was developed to assist in the assessment of nine symptoms that are common in palliative care patients: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and wellbeing (1). There is also a blank scale for patient-specific symptoms.

The ESAS has been revised to improve ease of understanding and completion for patients (2). The revised version of the tool is known as the *ESAS-r*. Changes include specifying a timeframe of "now", adding definitions for potentially confusing symptoms, modifying the order of symptoms, adding an example for "other symptom", and altering the format for improved readability.

The ESAS-r is intended to capture the *patient's perspective* on symptoms. However, in some situations it may be necessary to obtain a caregiver's perspective. The ESAS-r provides a profile of symptom severity *at a point in time*. Repeated assessments may help to track changes in symptom severity over time. The ESAS-r is *only one part of a holistic clinical assessment.* It is not a complete symptom assessment in itself.

General Information

How to do the ESAS-r

- It is recommended that the patient complete the ESAS-r *with guidance from a health care professional*, especially on the first occasion.
- The patient should be instructed to rate the severity of each symptom on a *0 to 10 scale*, where 0 represents absence of the symptom and 10 represents the worst possible severity. The number should be circled on the scale.
- The patient should be instructed to rate each symptom according to how he or she feels *now*. The health care professional may choose to ask additional questions about the severity of symptoms at other time points e.g. symptom severity at best and at worst over the past 24 hours.
- *Definitions* have been added to items that have been found to be more problematic for patients to understand or rate (3); it is recommended to review these with the patient:

Tiredness - lack of energy
Drowsiness - feeling sleepy
Depression - feeling sad
Anxiety - feeling nervous Wellbeing - how you feel overall

- With the previous version of the ESAS, patients often *reversed the scale for appetite* i.e. they considered "0" as "no appetite" and "10" as "best appetite". The scale has now been re-labeled as "lack of appetite". Coaching patients on the correct direction of the scale is still recommended.
- The *body diagram* on the reverse side of the ESAS-r can be used to indicate sites of pain.
- The circled numbers can be transcribed onto the *ESAS-r graph*.

When to do the ESAS-r

- In palliative home care, it is a good practice to complete and graph the ESAS-r during each telephone or personal contact. If symptoms are in good control, and there are no predominant psychosocial issues, then the ESAS-r can be completed weekly for patients in the home.
- In hospice and tertiary palliative care units, the ESAS-r should be completed daily.
- In other settings, palliative consultants will utilize this tool upon initial assessment and at each follow-up visit.

Who should do the ESAS-r

- It is preferable for the patient to provide ratings of symptom severity by himself/herself.
- If the patient cannot independently provide ratings of symptom severity but can still provide input (e.g. when the patient is mildly cognitively impaired), then the ESAS-r is completed with the assistance of a caregiver (a family member, friend or healthcare professional closely involved in the patient's care).
- If the patient cannot participate in the symptom assessment at all, or refuses to do so, the ESAS-r is completed by the caregiver alone. The caregiver assesses the remaining symptoms as objectively as possible. The following are examples of objective indicators:

  Pain – grimacing, guarding against painful maneuvers
  Tiredness – increased amount of time spent
  Drowsiness – decreased level of alertness
  Nausea – retching or vomiting
  Appetite – quantity of food intake
  Shortness of breath – increased respiratory rate or effort that appears to causing distress to the patient
  Depression – tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern
  Anxiety – agitation, flushing, restlessness, sweating, increased heart rate (intermittent), shortness of breath
  Wellbeing – how the patient appears overall

  If it is not possible to rate a symptom, the caregiver may indicate "U" for "Unable to assess" on the ESAS-r and ESAS-r Graph.

- The method of completion of the ESAS-r must be indicated in the space provided at the bottom of the ESAS-r and the ESAS-r Graph as follows:

Bottom of ESAS-r Numerical Scale
Completed by *(check one)*:
Patient
Family caregiver
Healthcare professional
Caregiver-assisted

Bottom of ESAS-r Graph
Insert letter from key in date column (date indicated at the top of form)
Completed by:
P = Patient
F = Family caregiver
H = Health care professional caregiver
A = Caregiver-assisted

Where to document the ESAS-r

- *The ESAS-r is always done on the ESAS-r numerical scale and the results later transferred to the ESAS-r Graph.* Graphing symptom severity directly onto the ESAS-r Graph without the use of the numerical scale is not a valid use of the ESAS-r, nor a reliable method of symptom assessment (attention to the graphed historical trend may affect the current scores and thus undermine one of the main purposes of the ESAS, i.e. to assess the current symptom profile as accurately as possible).

Please remember to discuss and document the ESAS score with all relevant professionals involved in the patients care management.

Patient Health Questionnaire (PHQ-9)

Patient Name:……………………………………….. Date of Completion:…………………………

A. Over the last 2 weeks, how often have you been bothered by any of the following problems?

Over the last 2 weeks, how often have you been bothered by the following problems?	**Not at all** **0**	**Several Days** **1**	**More than half the days** **2**	**Nearly every day** **3**
1. Little interest or pleasure doing things	☐	☐	☐	☐
2. Feeling down, depressed or hopeless	☐	☐	☐	☐
3. Trouble falling/staying asleep, sleeping too much	☐	☐	☐	☐
4. Feeling tired or having little energy	☐	☐	☐	☐
5. Poor appetite or overeating	☐	☐	☐	☐
6. Feeling bad about yourself – or that you are a failure or have let yourself or family down	☐	☐	☐	☐
7. Trouble concentrating on things, such as reading the newspaper or watching television	☐	☐	☐	☐
8. Moving or speaking so slowly that other people have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	☐	☐	☐	☐
9. Thoughts that you would be better off dead or of hurting yourself in some way	☐	☐	☐	☐
Total Score _____ =	+ _____	+ _____	+ _____	+ _____

B. If you have been bothered by any of the 9 problems listed above, please answer the following:

How difficult have these problems made it for you to do your work, take care of things at home, or get along with people?

Not difficult at all	**Somewhat Difficult**	**Very Difficult**	**Extremely Difficult**
☐	☐	☐	☐

GAD-7 Anxiety

Patient Name:……………………………………….. Date of Completion:…………………………

Over the <u>last 2 weeks,</u> how often have you been bothered by the following problems?	Not at all	Several Days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that its hard to sit	0	1	2	3
6. Becoming easily annoyed and irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Column totals: ________ + _______ + ________ + ________

= Total Score _______

Modified Caregiver Strain Index

(From Thornton, M and Travis, S.S (2003) Journal of Gerentology)

Patient Name:………………………………………….. Date of Completion:…………………………

Directions: Here is a list of things that other caregivers have found difficult. Please put a tick in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis = 2	Yes, sometimes = 1	No = 0
My Sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair: effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			

	Yes, on a regular basis = 2	Yes, sometimes = 1	No = 0
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behaviour is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

Total Score = ……………………………………………….

[Sum responses for “Yes, on a regular basis” (2 pts each) and “yes, sometime (1 pt each)]