

About Frailty

An introduction to frailty and its impact on those with cardiomyopathy

- Frailty is a syndrome characterised by weakness, fatigue, and increased vulnerability to bodily stresses.
- Although most often associated with aging, frailty is also a recognised component of chronic illnesses such as advanced heart failure (HF).
- Frailty can be easily missed by medical professionals in advanced heart failure patients and obtaining the right help and support for living in a timely fashion is key.

How is frailty clinically measured?

Frailty is a complex syndrome and there are at least 4 scales by which frailty brought about by advanced HF can be measured. The following are used as indicators:

- Slowness how slowly a person can walk, the speed and time in which they take to walk 5 metres.
- Weakness handgrip and knee extensor strength test, how firmly a person can grip with their hands and how easily they can lift their legs at the knee.
- Low physical activity how easily and quickly a person can complete a task like picking something off the floor.
- Exhaustion how easily a person becomes completely fatigued with or without completing a low-level physical activity.
- Shrinking this is how much decreased muscle mass the person has experienced. Generally, frailty is judged by unintentional weight loss of 10lbs or more in the previous twelve months. Do remember though that if you have advanced heart failure there is considerable likelihood that you will be carrying excess fluid which may not be immediately obvious, especially if it is in the abdomen. It is important that the nurse/clinician has taken this into account and assesses any loss of muscle bulk; otherwise the ensuing frailty may be missed if overall weight has remained the same or similar.

Frailty and advanced heart failure: only older people?

Whilst the symptoms of heart failure arising from a cardiomyopathy are well known to cause fatigue and breathlessness as well as feeling weak, developing advanced heart failure can lead to aspects of clinical frailty which present considerable challenges. This is as true for younger people as for those aged 70 plus and it is especially important that younger patients and their carers recognise this. Those people who are classed as IV (4) HF in the NYHA index will usually feel

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and demonstrate most of the signs of frailty.

NYHA Symptoms Class

- 1. No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnoea (shortness of breath).
- 2. Slight limitation of physical activity.
 Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea.
- Marked limitation of physical activity.
 Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnoea.
- 4. Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

What does frailty with HF look and feel like?

A cut or bruise can take much longer to heal than that of a person who does not have advanced HF or is not classed as being frail. Deterioration to the skin means that it can become paper-thin; livid bruising can occur at the lightest nudge, and the very fragile skin breaks and bleeds easily. Ulcers can follow unless such wounds are looked after carefully.

Certain medications may have an adverse effect, such as steroids, which can cause skin atrophy - (thinning of the skin). Prolonged exposure to steroids and NOAC blood thinners can cause skin lesions.

Changes to medication or environment can have a more sudden impact for frail people and it can take the frail person with advanced HF longer to adjust. Balance suffers, and the frail fall more frequently and have difficulty moving around, doing so more slowly; breathing is laboured.

Common illnesses such as a cold or upset stomach can have a more negative and prolonged effect on a person with frailty.

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Feeling frail and experiencing loss of capabilities, alongside the other debilitating symptoms, can make patients feel anxious or depressed in a way that is akin to grief in bereavement; it is so important that people are supported to manage their symptoms both physically and psychologically.

How is this frailty managed medically?

The key contribution that can be made aside from treating the advanced heart failure is to provide the support of expert Occupational Therapists (OT) to ensure that the home is a safe place to live. Such a referral will lead to provision of practical solutions to difficulties presented by the layout of the home and furniture.

Once all drug therapies have been attempted, some advanced therapies can be used for suitable patients who are frail (ideally, such interventions will have been considered at an earlier stage). In these cases, many aspects of frailty are reversible.

A Left Ventricular Assist Device (LVAD) is used either as a bridge to transplant, or in order to allow a damaged heart to recover, and for those judged suitable candidates, a heart transplant offers complete recovery from heart failure, although introducing a new range of challenges. The clinical team will assess each patient to see if these options are suitable for them.

For those people with advanced HF for whom these interventions would not be clinically appropriate, help and advice to manage symptoms of frailty will be overseen clinically within the community by palliative care specialists, supported by OTs.

Practical tips on coping with advanced HF and frailty

If you are affected by advanced HF and frailty it is important that you are supported to live well with your symptoms. This means ensuring that you keep your clinical team (GP, HF Specialist Nurse, cardiologist, and mental health practitioner) regularly informed of your wellbeing and communicate any concerns or needs you have as soon as practicable.

Here are some practical tips that may be helpful:

 Even if you are largely restricted to a chair, make a conscious effort to walk a given number of steps every hour or two. One patient measured

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the distance from his chair to his front door as 50 steps. Every 2 hours he walked 200 steps albeit very slowly, thus giving him a sense of achievement, a sense of at least some control over his situation, and much needed exercise and blood flow.

- Position a chair at strategic places around the house so that you can sit down when exhausted.
- Try to set up your living conditions so that you can live all on one floor, or if it is necessary to sleep upstairs, then only go up at bedtime.
- Take great care in the shower, if possible, position a low stool to sit whilst showering.
- If you are sitting in an armchair, boost the height of the seat cushion by inserting a foam pad underneath it. This makes getting up and down from the chair easier.
- Request a raised loo seat from your local OT department.
- Be willing to use a walking aid if you need it; whilst using a walking frame may do nothing for your morale, it can make moving around so much safer.
- Similarly, obtain a wheelchair so that you can still go out with help to cafes, garden centres or shops.
- Be sure to obtain a Blue Parking Badge so that trips out can become possible; and finally,
- Always carry a couple of plasters in a bag or wallet; the chances are your fragile skin is going to bleed all over your favourite shirt if you don't catch it in time!

If you are experiencing difficulties physical or emotional, let someone whom you trust know so that you can receive the support you need. Don't forget that you are not alone, Cardiomyopathy UK exists to provide clinical, practical, and emotional advice to people affected by HF. As well as our nurse helpline, we have online peer support groups and telephone peer support volunteers whom you can talk to and some of whom will have lived with and experience of advanced HF and frailty.

We are here for you

At Cardiomyopathy UK we offer help and support for you and your family. You can call our helpline to talk to our support nurses on 0800 018 1024. We can put you in contact with other people through our support groups, support volunteers and social media. Contact us for more about our services, or look online - www.cardiomyopathy.org

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