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“Can I do that?” How advice impacts on reengagement for patients with heart failure

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Joyce’s words

Anne (researcher); “How do you know what you can do, how much you can do?”
• “It’s trial and error and you pay for it if you do too much, feeling tired, fatigued, you just know. I was told I needed to take it easy so you do. Everyone knows not to rush or lift heavy things to not put a strain on my heart”.

Anne (researcher); “So you have had to try things out for yourself, and you got advice?”
• “No I did it really, well and Jeff [husband] he was very clear what I should stop doing, he took over. They can’t be clear really I asked but they say just pace yourself and take it easy so I did- but really you have to try things out. Your mind stops you though; you’re scared to push yourself too much. You can’t see your heart so you have to guess and go on how you feel. Pushing you just a little at a time. No one really gives clear answers.”
<table>
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<tr>
<th>Information Gathering</th>
<th>Processing</th>
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<td><strong>Medical Messages</strong></td>
<td>Beliefs.</td>
<td>IDCМ work</td>
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<tr>
<td>• General Advice “Pace yourself”</td>
<td>“This will get worse”</td>
<td>“I pace myself”</td>
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<tr>
<td>“Don’t lift heavy weights”</td>
<td>“Pace yourself”</td>
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<td>“Look after your heart”</td>
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<td>• CHD Prevention</td>
<td>Take exercise</td>
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<td>“The GP said that healthy eating and regular exercise such as walking would be good</td>
<td>“I always walk each day to build my heart up”.</td>
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<td>and I stick to that”.</td>
<td>“I do more now and have stopped smoking and eat better”</td>
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<td>• Specific advice</td>
<td>Eat a healthy diet</td>
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<td>“This is serious”</td>
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<td>“You could die”</td>
<td>Don’t drink</td>
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<tr>
<td>“This will get worse”.</td>
<td>“I can’t drink now so I don’t go out with my mate so much”</td>
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<td>• Inappropriate Advice/no advice.</td>
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<td>Reduced occupational performance</td>
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<td>“No-one explained”.</td>
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<td>“I cannot die and leave the kids so it would be good to have some clear guidance on</td>
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<td>what I should do</td>
<td>“No one was clear and said what I could do”</td>
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<td>“This will get worse”.</td>
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<td>• Breathlessness</td>
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<td>• palpitations</td>
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<td>“I could die”</td>
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<td>Isolation</td>
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<td></td>
<td>“no-one else like me”</td>
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<td></td>
<td>“I’m too young”</td>
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<td></td>
<td></td>
<td>Carer Pressure</td>
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<td></td>
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<td></td>
<td></td>
<td>“The family are different with me too; stop me doing things I don’t</td>
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<td></td>
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<td>bother now cos it causes to much upset”</td>
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These influences can be summarised as the main influences on occupational performance and are identified below:

- Anxiety or fear of causing damage to the heart.
- Carer or family pressure to stop or modify activities which they view will damage the heart.
- General advice given by clinical team, and from publications aimed at this group of patients, and also those with heart disease and heart failure.
- The beliefs held by the individual about IDCMI and what they need to do in order to “Guard their Heart”.
- The avoidance of what the participant views as symptoms which are often “fatigue” and “breathlessness on exertion”.
Constructed Grounded Theory

Guarding the heart

Seeking Information
"what can I do?", "Can I do that?" General advice/individual advice. "no-one can tell you"

Reduced Occupational Performance
"I pace myself", "don't lift heavy weights", "don't stress the heart"

Symptoms
Breathlessness and fatigue
"don't stress the heart", "damage"

IDCM Work
Medical Work appointments, tests. Advice "pace yourself", reduce CHD risk factors in lifestyle.

Fear
Isolation
Loss
Anxiety
This core category “Guarding the Heart

The main factors which describe the occupational performance of people with IDC M can be viewed as the following four concepts;

• **Seeking information**, the challenges that arise in the seeking and processing information about IDC M. This information is then processed and interpreted and impacts on occupational performance and increasing adherence to IDC M work.

• **Reduced occupational performance/participation**, reduced in the presence or absence of symptoms in everyday life. Adopting IDC M work; these are activities required for the medical management of the condition, ie, complying with medication, adopting a healthy lifestyle and pacing/avoiding activities.

**Symptoms**; which are provoked by activities and exercise and are viewed as damaging or ‘bad’ for the heart. Normal breathlessness and tiredness are interpreted as deterioration in the medical condition.
Influences on Occupational Performance.

Anxiety

Carer Pressure

General Advice

Reduced Occupational Performance

symptoms

beliefs