



## Exhale

### Palliative Physiotherapy Programme for Advanced Lung Disease in a Hospice Outpatient Setting

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## Background

- Hospices need to provide rehabilitation as part of the overall health service for advanced chronic conditions

(HSE: Palliative Care for All: Integrating PC into Disease management Framework)

- Government policy indicate that 25 % patients receiving SPC should have a non-malignant diagnosis
- Increasing number of non-malignant referrals
- Evidence to support the role of physiotherapy in end stage lung conditions

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## Advanced Respiratory Patients

- 95% of patients report that breathlessness is their most significant debilitating symptom
- Symptoms often include pain, fatigue, difficulty sleeping
- Decreased physical, social, and emotional functioning
- Become inactive: then chronically deconditioned
- High burden of poorly controlled symptoms

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## Developing the Programme

- Literature Review
- Evidence based practice
- Experience of developing other non-cancer programmes

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## Literature Review

- Pulmonary Rehab (PR)
  - Offered to COPD patients stage 1-4
- Extensive evidence
  - Improvements in HRQoL, exercise capacity, respiratory muscle strength, and exertional dyspnoea (COPD).
- Less evidence available for benefits of PR for Stage 3+4 patients with significant disease burden :
  - Excluded from studies
  - Fail to complete PR programme
  - Decline participation in PR

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## Stakeholder Involvement

- Meetings with
  - Respiratory teams in MMUH, BH, Connolly Hospital
  - Community COPD outreach teams Dublin North
  - Cardio-thoracic team in MMUH
  - Community Palliative Care Team, St. Francis Hospice

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## Referring patients

**Reasons patients not referred for Exercise programmes:**

- Fear of harm resulting from exercise
- Breathless at rest and deemed to be inappropriate
- Unable to physically attend programmes
- Patients not interested or unaware of benefits

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## Referral Pathway

- Referral pathway was developed following meetings
- Referrals directly to physiotherapy department with specific referral form
- Physiotherapy team managed and co-ordinated referrals

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## Inclusion and Exclusion Criteria

**Inclusion Criteria**

- Advanced lung disease
- Able to mobilise with or without aid , unassisted

**Exclusion Criteria**

- Cardiovascular instability
- Pulmonary hypertension
- Requires assistance to mobilise
- Cognitively unable to take part in class

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## Exhale Programme

```

    graph LR
      A[Initial Assessment] --> B[Education Patient & Carer]
      B --> C[Exercise Class Twice weekly x 5 Home Exercises]
      C --> D[Final Assessment Patient Feedback]
  
```

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## ASSESSMENT

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## Chronic Respiratory Questionnaire

Dyspnoea 5 Questions	Fatigue 4 Questions	Emotion 7 Questions	Mastery 4 Questions
<ul style="list-style-type: none"> <li>• 5 Priority ADL's</li> <li>• Score out 7</li> </ul>	<ul style="list-style-type: none"> <li>• Different terms</li> <li>• Low energy, Sluggish</li> </ul>	<ul style="list-style-type: none"> <li>• Impact of breathlessness</li> <li>• Frustration</li> <li>• Embarrassed</li> <li>• Impatient</li> </ul>	<ul style="list-style-type: none"> <li>• Control of breathlessness</li> <li>• Including fear &amp; panic</li> </ul>

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## 6 Minute Walk Test

- Standardised test to measure exercise capacity
- Participants walk at their own speed for 6 minutes and distance achieved is the result
  - Rest breaks are allowed
- Monitored oxygen and rate of perceived breathlessness

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## Timed up and Go

- Measure of functional ability and falls risk
- Participants stand up, walk 1.5m, turn around and walk back to chair and sit down
- Average time of 3 attempts to complete task is result

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## Hospital Anxiety and Depression Scale

- Validated measure to assess anxiety and depression
- Used routinely in pulmonary rehab programmes

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## Questionnaires

- SFH Physio department developed simple questionnaires for patient & carer.
- Attitudes and perceived barriers to exercise
  - What stops you from exercising?
  - What would you like to be able to do?
- Physical activity can help with my friend/relatives' overall wellbeing?

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## EDUCATION

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## Education

- Self-management education reduces the need for rescue medication for the symptom of breathlessness in COPD patients.
- Self-management education and exercise training more effective in improving self-efficacy in patients with COPD than self-management education alone.
- Self management education may reduce hospital admissions with exacerbations of COPD



## Education

- Individualised education session with participants and their family
- Based on questionnaire feedback
- Breathing techniques
- How to rate breathlessness
- Use of oxygen during exercise
- Education booklet provided

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## Borg Breathlessness Scale

Scale	Severity	Can you .....
0	No Breathlessness At All	Sing / Whistle
0.5	Very, Very Slight (Just Noticeable)	Sing / Whistle
1	Very Slight	Talk comfortably but aware of your breathing
2	Slight	Talk comfortably but aware of your breathing
3	Moderate	Talk in short sentences
4	Somewhat Severe	2 or 3 word sentences
5	Severe	Say one word answers
7	Very Severe Breathlessness	Difficulty talking
9	Very, Very Severe (Almost Maximum)	Unable to talk
10	Maximum	Gasping for air

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## CLASSES

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## Classes

- Twice weekly for 5 weeks
- Aerobic and strength training
- Individually paced for each participant
- Closely monitored
- Education re-iterated during classes
- Peer support and fun

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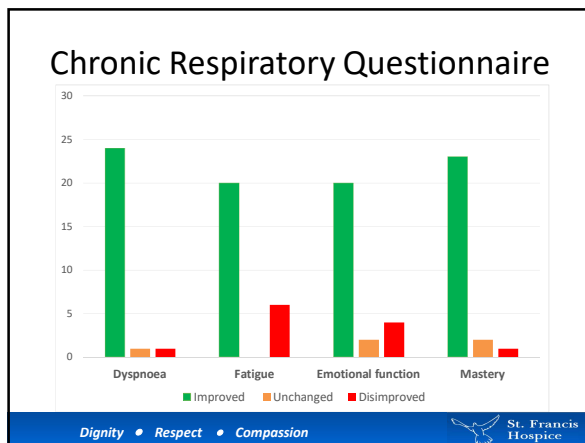
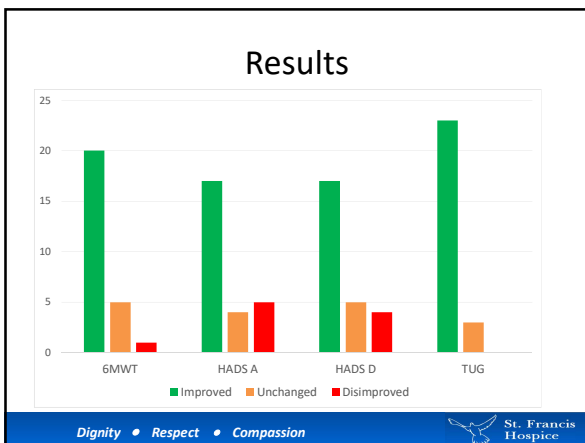
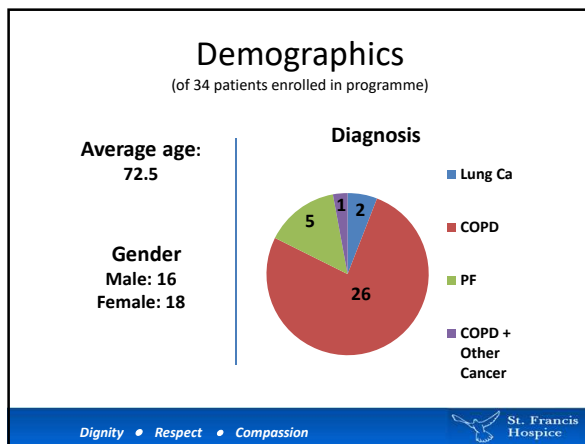
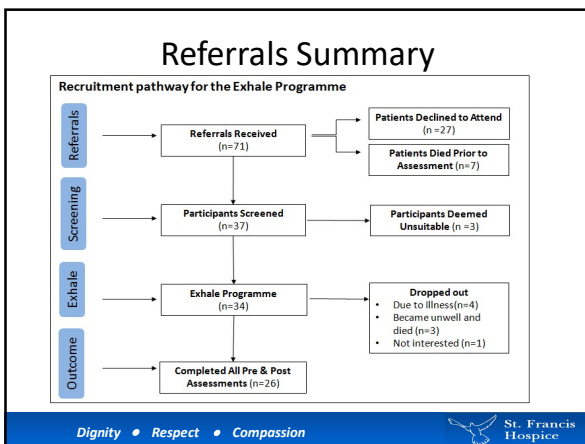
## Evaluation

- Participants repeated the outcome measures
- Feedback questionnaire completed

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## RESULTS

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### Patient Feedback

- “This was a great programme. I enjoyed that I was not pressurised to do the exercises”
- “I know what to do when I feel breathless with the breathing exercises and I am definitely doing more things at home”
- “I am more confident about managing my breathlessness. I have not been in hospital since the programme”

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### Family Feedback

- “I know now that we were minding Mammy too much.”
- “It’s great to see Dad taking so much more interest in the things he used to enjoy”

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### Referrer Feedback

- “Exhale is an excellent service. Our patients really enjoy it. It fills a serious gap in the service for very breathless patients”
- “We have a long list of suitable patients ready for referral to the next programme”

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### Facilitators to Success

- One point of contact throughout the programme
- Transport
  - Evidence that lack of transport is a barrier to attendance at rehab programmes

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### Unique Features

- Modified pulmonary rehab programme for unsupported patient group
- New pathway for these patients in the palliative stage of their disease.
- Education for family/carers
- Peer support to patients who were often socially isolated
- Transport provided where necessary
- Demystifying palliative care within this patient group

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### Transferability

- Design of this programme enables easy transferability to other physiotherapy settings with minimal equipment needs.
- Applicable to acute hospitals, community settings and hospices

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## Conclusion

- Rehabilitation has been described as the restoration of a patient to a person.
- Palliative care rehabilitation at its best is the transformation of the dying into the living.

Oxford Text of Palliative Medicine

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