

Planning for the future: addressing the information gaps for people living with COPD – Findings from a collaborative working group



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BACKGROUND & TIMELINE

- The palliative care needs of people with COPD was highlighted in the Palliative Care for All (2008) report and outlined further in the Advanced Respiratory Disease and Palliative care (2012) report.
- COPD Support Ireland (est. 2013) members reported an information gap in relation to future healthcare related decisions and end of life planning
- January 2016: COPD Support Ireland & Irish Hospice Foundation initiate project
- February 2016: Expression of interest from patients and carers to join a working group
- March, April, June, October 2016: 5 working group meetings

COLLABORATION

- Meaningful process of engagement through group work, discussions, feedback & reflection
- Homework & research by participants
- Involvement of local COPD support groups as 'sounding boards'
- Sharing of powerful stories
- Input from carers unable to attend through email & phone submissions

WORKING GROUP MEMBERS

- 7 people living with COPD
- 3 people caring for a family member with COPD
- 3 facilitators:
 - Advocate - COPD Support Ireland
 - Advocate - Irish Hospice Foundation
 - Nurse with respiratory & end-of-life care background

AIMS

1. To determine the existing information gaps in relation to planning for the future with COPD
2. To identify practical measures that can be developed & disseminated to fill the identified information gap

WORKSHOPS

Group achieved following in WS 1-5:

1. Developed a shared understanding of advance care planning & identified concerns & issues in relation to planning for the future when living with/supporting someone with COPD
2. Assessed available information materials & started to develop content for draft booklet
3. Review of 1st draft booklet in terms of content
4. Review of 2nd draft booklet and further decisions on content & design
5. Final content decisions & design work and planning of next steps



Pictures 1 & 2: During the workshops

NEXT STEPS

Planning for the future with COPD information booklet

- Final draft being prepared
- Publishing company (design & layout)
- Review of finished product by working group members & governing bodies
- **Official launch in 2017**

BOOKLET CONTENT

- Introduction
- What is COPD?
- Getting to know your COPD
- When a loved one has COPD
 - Information & support for carers
 - Tips on communication & well-being
- Managing your COPD
 - Maintenance & flare ups
- Planning for the future with COPD
 - What does planning for the future mean?
 - What is advance care planning?
 - Advanced healthcare directives
 - How do I create an advanced healthcare directive?
 - Planning legal affairs
- Palliative Care
- Talking about your wishes
 - With your family/someone you trust
 - With your doctor/healthcare team
- Glossary of terms
- Resources

"This is not a topic I like to talk about but I want to, I have to because I know what is ahead of me." Participant

"I need doctors and nurses to listen to what I have to say; don't avoid my questions, don't pass me on to someone else." Participant

"I want to know what happens next to me; how do you tackle this thing [COPD]? To look ahead it's important to know." Participant

Conclusions

The dissemination of the booklet has the potential to inform many people affected by COPD.

Using a partnership approach in addressing this challenging topic created a meaningful engagement with patients and carers.

Patients and carers have unique insider experience of what it is like to live with COPD. When their voice is heard they will get actively involved in shaping healthcare. Process outcomes from this project has implications for future patient-health carer collaboration.



Picture 3: Some members of the working group

Acknowledgements:

We wish to express our gratitude and appreciation to the working group members for their dedication and committed participation in the workshop series.

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