

# Supplement 1 overview of the 4 COSY instruments

**COSY: Communication leaflet** 1/2

## COSY COPD and Sexuality

### Let's start the communication!\*

**Important:**  
Ask EVERYONE, irrespective of their age, gender, the severity of their COPD or their sexual orientation, about limitations in their sex lives and how motivated they are to change the situation. Record the extent of the limitation (at least once a year).

**Introduction: Raising the issue and requesting permission to discuss it**  
"We haven't spoken about your sexuality yet, have we?"  
I understand, and other people affected by COPD report, that coughing, mucus and shortness of breath can result in limitations that may have a negative impact on sexuality. Perhaps this is the same for you.  
Is there anything else standing in the way of you enjoying a fulfilling sex life?"  
"Would you like to talk to me about it?"

**Record the limitation**  
\*On a scale of 0-10, to what extent is your sex life limited (0 = not at all, 1-3 = slightly, 4-7 = fairly, 8-10 = severely) by your ...

<b>Level 1</b>	... COPD symptoms: shortness of breath, coughing, mucus?"	<b>Motivation to take action</b> On a scale of 0-10
0	1 2 3 4 5 6 7 8 9 10	
<b>Level 2</b>	... general physical limitations?" (e.g. musculoskeletal pain, decompensated cardio-vascular disease, incontinence, sexual limitations)	<b>Motivation to take action</b> On a scale of 0-10
0	1 2 3 4 5 6 7 8 9 10	
<b>Level 3</b>	... external stress factors?" (e.g. psycho-social problems, relationship difficulties, stress in your personal life and/or workplace, fear)*	<b>Motivation to take action</b> On a scale of 0-10
0	1 2 3 4 5 6 7 8 9 10	
<b>Level 4</b>	... self-image?" (e.g. attractiveness, shame, inhibitions)*	<b>Motivation to take action</b> On a scale of 0-10
0	1 2 3 4 5 6 7 8 9 10	

\* For specific support in using this leaflet, refer to COSY: Communication leaflet guidance

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**COSY: Communication leaflet guidance** 1/8

## COSY COPD and Sexuality

**Objective:**  
It is time to start communication about sexuality in COPD care. Data shows that sexuality and intimacy are important contributing factors in quality of life and well-being. People with COPD have a proven need to talk about sex. Many health professionals have misconceptions about this issue and are uncomfortable talking about sexuality.

*"COSY" should support you to hold a relaxed, two-way dialogue about sexuality and intimacy. Where individuals do not experience a fulfilling sex life, it is particularly important to gain a joint understanding of the level of limitation (1-4) they currently experience.*

**IMPORTANT!**  
The primary purpose is to START A CONVERSATION. You do not need in-depth knowledge about sexuality nor should you expect to resolve individual difficulties right away.

If it becomes apparent in the course of the discussion that the reason for the limitation is not level 1, COPD, and that it can be attributed to a different level, then this is a useful outcome. The subsequent approach and course of action should be agreed with the individual concerned, taking account of their degree of motivation. It is important to outline the services available and the potential support offered by other providers (referral, self-referral).

**Approach:**  
A respectful and empathic approach forms the basis of an effective, trusting relationship between the professional and the individual concerned. The ability to listen actively is an important therapeutic skill: "Talking is good for your health".

Your own notes

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**COSY: Visual language sexuality**

## COSY COPD and Sexuality

It is not easy to find words to describe the broad spectrum of sexuality. Can I show you some images of how sexuality can be understood as a display and expression of intimacy, a way of affirming care and a physical act?

**Me with myself**

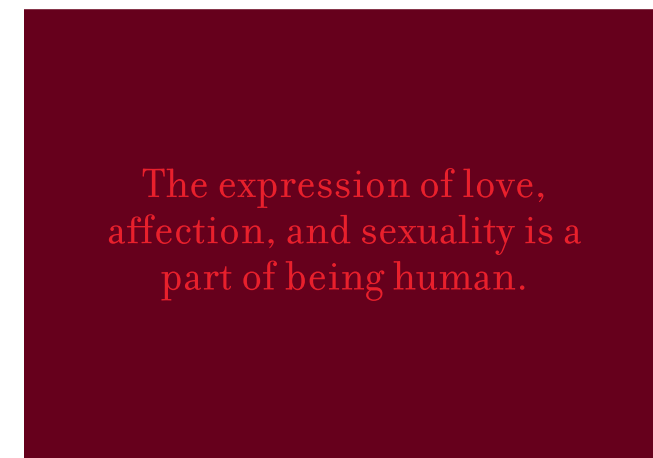
- smile at myself
- nurture myself
- spoil myself
- be with myself
- touch myself

**Me and ...**

- be connected
- talking – laughing – caring
- cuddle – be tender
- kiss
- having sex – making love

«What reactions and feelings do these images trigger in you?»  
 «Do you recognise your fulfilled needs in any of the images?»  
 «Do you recognise your UN-fulfilled needs in any of the images?»  
 «Are there any needs related to your sexuality and intimacy that are not shown here?»  
 «Do you see a connection between COPD and limitations in your sexuality?»

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## The diagnosis of COPD does not mean the end of sexual activity.

The spectrum of sexual activity is wide, the desires and possibilities are individual. Expressing intimacy with attention, affection, cuddling, bathing together, massages and touching, also with yourself can be just as important as sexual intercourse.

To discover how intimacy can be lived on a different level when sexual activity / arousal is limited, can be an exciting, beautiful task.

It can also be fun to be creative. Both as single person as well as a couple, you may find that you can discover yourself on a whole new level alone or together.

Take the time to think about what you desire and what you want to try for your sensual, intimate experience.

A fulfilling sex life is possible regardless of your age, marital status or stage of illness. It is an important element for the best possible quality of life, which you have the right to if you are ill (European Charter of Patients' Rights).

**Fears from the perspective of those affected**  
For people with COPD, the thought of having sex can be frightening. Perhaps it is the fear of getting short of breath during sex or disappointing their partner. Or the fear of being too tired and unattractive for sex. These are just some of the fears that can cause people with COPD to avoid intimacy and sexual activity in general.

**Fears from the partners' perspective**  
Partners of people with COPD may be concerned that sexual activity may lead to a worsening of symptoms or could even be dangerous.

There is no need to withdraw from intimacy, emotionally detach from their partner or give up sexual activity. There are positive ways to work around COPD.

COSY-Communication leaflet for health care professionals, page 1/2

COSY-Communication leaflet guidance for health care professionals, page 1/8

COSY-Visual language, page 1/1

COSY-Patient booklet, page 2&3/32

The four tools are available for free in German, French, Italian and English:  
<https://www.lungenliga.ch/fuer-fachpersonen/fachpublikationen-guidelines>

# My COSY-compass

Living well with COPD.

The expression of love, affection and sex is an important element for the best possible quality of life and holistic well-being, regardless of age or stage of the disease.

Touch caresses body and soul and has scientifically proven positive effects on health.

## My goal

A fulfilling emotional and intimate life in the sense of:



smile at myself



be with myself



nurture myself



spoil me



talk – laugh – care



cuddle – be tender



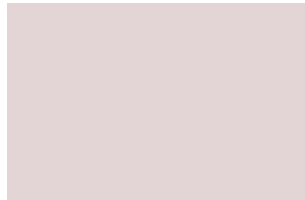
be connected



kiss



touch myself



.....



having sex – making love

- to receive
- to rediscover
- to discover anew
- to intensify
- .....

## My motivation

I wish for:

- more physical closeness
- to feel accepted as I am
- more pleasure and enjoyment in my intimate life
- Relaxation and lightness in my intimate life and less breathlessness
- more security and control in my intimate life

- .....
- .....
- .....
- .....

## My challenges

- .....
- .....
- .....

**COSY action Communication:** .....

.....

..... (what, when, how long/how often)

Supportive for me is: .....

My plan B when things get difficult: .....

.....

My confidence of implementation until the first follow-up contact on ..... is  /10

My confidence of implementation until the 2nd follow-up contact on ..... is  /10

My confidence of implementation until the end of the study ..... is  /10

10 = very confident  
0 = not at all confident

**Study weeks 1 – 15:**

Tick each day of weeks 1 – 15 on which you did the action.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Sun															
Mo															
Tu															
We															
Th															
Fr															
Sat															

Positive effect experienced

COSY Talks 1,2,3

Study end

**COSY action Physical activity:** .....

.....

..... (what, when, how long/how often)

Supportive for me is: .....

My plan B when things get difficult: .....

.....

My confidence of implementation until the first follow-up contact on ..... is  /10

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COSY Talks 1,2,3       Study end

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Positive effect experienced

COSY Talks 1,2,3

Study end

# Important elements for a better life with COPD

= Current stage of behaviour

## My own self, for example

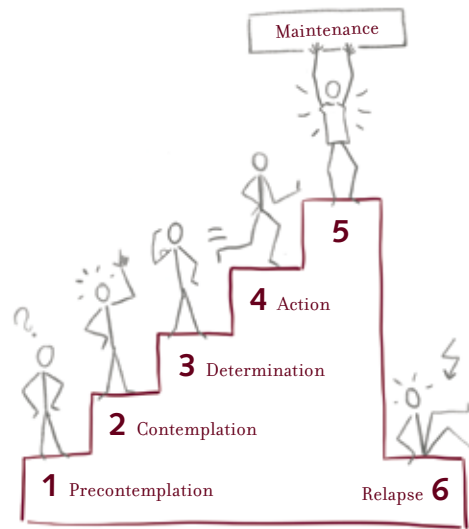
- Nurture myself
- Caring for myself
- Smile at my reflection in the mirror
- Realising my intimacy / sex

## Social area, for example

- Maintaining social contacts
- Pursuing hobbies
- Volunteering

## Psyche, for example

- Recognising and naming stressors and needs
- Talking about stressors and needs
- Listening
- Inspire the mind
- Doing regular relaxation exercises



Stages of change

## Lung / COPD

- 30 min of moderate endurance activity / day
- 2-3 / week strength training per muscle group
- Tackling Stop smoking
- Inhale regularly
- Possibly also inhale before exertion
- Pursed lip breathing during exertion
- Nasal breathing at rest and during light activities
- Use gentle coughing techniques when mucus accumulates
- Use relieving positions for easier breathing
- Use action plan on time
- Vaccinate
- Possibly oxygen in case of insufficient oxygenation

## Body in general, for example

- Discuss pain with a trusted specialist
- Discuss gynaecological and urological restrictions and other issues with the specialist
- Maintain a healthy body weight
- None or moderate alcohol consumption
- Sufficient and regular sleep, approx. 7 h / night

## Imprint

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Institute (EBPI)**



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**LUNG ZÜRICH**

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## Supplement 3

### **Interview about participants experiences with the COSY intervention**

I would like to ask you about your experiences with COSY.

➤ Please note that the questions relate only to the intervention (i.e. the personal consultations, the measures you discussed with the help of the COSY Compass and the support you received), but not to the accompanying study (i.e. not to the questionnaires you completed or the tests you took).

- 1) What did you like best and what did you like least about the entire COSY intervention?
- 2) Which elements of the COSY intervention (on-site conversation, telephone calls, COSY compass, COSY booklet) have motivated and supported you the most in communicating better or more easily about your needs for intimacy and sexuality?
- 3) Has your motivation for regular physical activity changed because of discussing your needs for closeness and intimacy? If yes, how?
- 4) Have you noticed any effects in your everyday life that you attribute to the COSY intervention? If yes, which ones?
- 5) This visit marks the end of the official study. How will you proceed to implement the knowledge and experience gained from the study in your everyday life?
- 6) What was the decisive factor that made you decide to take part in the study a year ago?
- 7) How much did you enjoy taking part in the COSY intervention?
  - 1 I really enjoyed taking part
  - 2 I enjoyed taking part
  - 3 Neutral
  - 4 I didn't enjoy taking part
  - 5 I didn't enjoy taking part at all

Thank you very much for your answers!

# COSY COPD and Sexuality

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«On a scale of 0-10, to what extent is your sex life limited (0 = not at all, 1-3 = slightly, 4-7 = fairly, 8-10 = severely) by your ...

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		<input type="text"/>
<div style="border: 1px solid black; border-radius: 50%; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center; margin: 0 auto;"> <div style="border: 1px solid black; border-radius: 50%; width: 20px; height: 20px; display: flex; align-items: center; justify-content: center; margin: 0 auto;"> <p>Level 2</p> </div> </div>	<p>... general physical limitations?" (e.g. musculoskeletal pain, decompensated cardio-vascular disease, incontinence, sexual limitations)</p>	<p><b>Motivation to take action</b></p> <p>On a scale of 0-10</p>
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		<input type="text"/>

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# COSY

## Level 1

Limitations in sex life due to COPD symptoms: shortness of breath, coughing, mucus

	1-3 slightly limited	4-7 fairly limited	8-10 severely limited
<b>Strategy</b> 	Develop and maintain relationship Give autonomy Provide information	Develop and maintain relationship Give autonomy Focus Gather existing knowledge and resources Advise, support	Develop and maintain relationship Give autonomy Focus Gather existing knowledge and resources Advise, support
<b>Action</b>	Offer help in case anything changes	Focus on specific symptoms and problems	Focus on specific symptoms and issues
<b>Questions</b>	"Can I give you some information?"  "Is it ok if I return to this issue at our next appointment or would you prefer to approach me?"	"What causes you limitations? Can you describe how you are affected by shortness of breath, coughing and mucus in your everyday life?  Is this a new situation? Has anything changed?  Is there anything that helps in your everyday life?"	"What causes your limitations? Can you describe how you are affected by shortness of breath, coughing and mucus in your everyday life?  Is this a new situation? Has anything changed?  Is there anything that helps you in your everyday life?"
<b>Customised interventions and options</b>	As necessary	Propose specific activities e.g. inhalation, breathing and coughing techniques, pursed-lip breathing or easier positions, oxygen, etc.	Propose specific activities e.g. inhalation, breathing and coughing techniques, pursed-lip breathing or easier position, oxygen, etc.
<b>Offer coaching as part of the "Living Well with COPD" programme</b>	Refer to the self-management programme "Living Well with COPD"  <a href="http://www.lungenliga.ch/copdcoaching">www.lungenliga.ch/copdcoaching</a>	Provide the "Living Well with COPD" handbook  Point out the relevant pages  (Self-directed study, start counselling or delegate)	Provide the "Living Well with COPD" handbook  Point out the relevant pages  (Self-directed study, begin counselling or delegate)  Identify the degree of urgency and take the lead, initiate pharmaceutical and non-pharmaceutical therapy, make adjustments
<b>Planning and proactive guidance</b>	Record your joint decisions	Follow-up appointments/telephone Check: Get in touch after three months or as agreed.	Follow-up consultations/telephone according to urgency Link with other professionals and specialists

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