

Online Supplement

Development of a Communication Instrument to Address Sexuality in COPD: COSY

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0.1	Date	_ _ _ _ _ _ _ _ _ _ _ _ _ _ _
1.1	Gender	<input type="checkbox"/> (1) male <input type="checkbox"/> (2) female
1.2	Birthday	_ _ _ _ _ _ _
1.3	Employment status	<input type="checkbox"/> (1) Working <input type="checkbox"/> (2) partial retirement <input type="checkbox"/> (3) pension <input type="checkbox"/> (4) unemployed
1.4	Years of education	<input type="checkbox"/> (1) ≤9 <input type="checkbox"/> (2) 10-12 <input type="checkbox"/> (3) ≥13
1.5	Living situation	<input type="checkbox"/> (1) living with a partner <input type="checkbox"/> (2) living alone <input type="checkbox"/> (3) assisted living at home <input type="checkbox"/> (4) community living in a home
2.1	Year of COPD Diagnosis	_ _ _ _ _ _ _
2.2	Severity of your breathlessness	<input type="checkbox"/> (1) never <input type="checkbox"/> (2) only during heavy exertion <input type="checkbox"/> (3) walking fast or walking on a slight incline <input type="checkbox"/> (4) When walking on level ground, I have to walk slowly (at my own pace) <input type="checkbox"/> (5) When walking on level ground, I need a break after about 100 meters <input type="checkbox"/> (6) I have too much shortness of breath to leave the house or have shortness of breath even when dressing
2.3	Breathlessness during sexual activity Sexual activity understood as: kissing, cuddling, sexual intercourse, masturbation	<input type="checkbox"/> (1) I have shortness of breath during sexual activity If yes since when ca..... <input type="checkbox"/> (2) I have no shortness of breath during sexual activity <input type="checkbox"/> (3) I avoid sexual activity because of breathing difficulties

		If yes, since when ca.....
3.1	Before Diagnosis of COPD How often were you asked about the topic of sexuality and sexual life in the practice or in hospital	<input type="checkbox"/> never (if never continue with question 3.3) <input type="checkbox"/> once <input type="checkbox"/> more than 1 time, how often ca?
3.2	Before Diagnosis of COPD Who approached you about the topic	<input type="checkbox"/> doctor/ GP, <input type="checkbox"/> lung specialist <input type="checkbox"/> non-physician professional <input type="checkbox"/> other.....
3.3	Before Diagnosis of COPD How often did you raise the issue of sexuality and your sexual life in practice or in hospital	<input type="checkbox"/> never <input type="checkbox"/> once <input type="checkbox"/> more than 1 time, how often ca?.....
3.4	Before Diagnosis of COPD With whom did you raise the issue of sexuality and sexual life	<input type="checkbox"/> doctor/ GP, <input type="checkbox"/> lung specialist, <input type="checkbox"/> non-physician professional <input type="checkbox"/> other.....
3.5	Since Diagnosis of COPD How often were you asked about the topic of sexuality and sexual life in the practice or in hospital	<input type="checkbox"/> never (if never continue with 3.7) <input type="checkbox"/> once <input type="checkbox"/> more than 1 time, how often ca?.....
3.6	Since Diagnosis of COPD Who approached you on the issue sexuality and your sexual life	<input type="checkbox"/> doctor/ GP, <input type="checkbox"/> lung specialist, <input type="checkbox"/> non-physician professional <input type="checkbox"/> other.....
3.7	Since Diagnosis of COPD	<input type="checkbox"/> never (if never continue with 3.7)

COPD und Sexuality questionnaire for persons living with COPD

	How often have you raised the issue of sexuality and sexual life in the practice or hospital?	<input type="checkbox"/> once <input type="checkbox"/> more than 1 time, how often ca?.....
3.8	<p>Since Diagnosis of COPD</p> With whom did you raise the issue of sexuality and sexual life	<input type="checkbox"/> doctor/ GP, <input type="checkbox"/> lung specialist, <input type="checkbox"/> non-physician professional <input type="checkbox"/> other.....
3.9	As a patient, would you like to be addressed on the subject of sexuality and your sexual life	<input type="checkbox"/> Yes <input type="checkbox"/> No (continue with 3.93) <input type="checkbox"/> Want to address it myself
3.91		<p>If Yes</p> <p>How would you like to be addressed?</p> <input type="checkbox"/> directly in an individual conversation <input type="checkbox"/> indirectly, e.g. questionnaire
3.92		<p>How regularly would you like to be addressed</p> <input type="checkbox"/> regularly, e.g. 1x /year <input type="checkbox"/> more frequently than 1x /year <input type="checkbox"/> less frequently than 1x /year <input type="checkbox"/> Other interval.....
3.93	In which life situation do you not want to be addressed	<input type="checkbox"/> if I do not have a partner <input type="checkbox"/> when I feel too ill <input type="checkbox"/> when I feel lonely <input type="checkbox"/> when I feel sad <input type="checkbox"/> Other.....

4.0	Is the gender of the interlocutor relevant for a relaxed conversation about sexuality and your sexual life?	<input type="checkbox"/> Yes <input type="checkbox"/> No If yes, do you prefer a same-sex interlocutor <input type="checkbox"/> opposite-sex interlocutor <input type="checkbox"/>
4.1	Is the age of the interlocutor relevant	<input type="checkbox"/> Yes <input type="checkbox"/> No If yes, do YOU prefer (compare to your age) A younger conversation partner <input type="checkbox"/> about the same age <input type="checkbox"/> an older interlocutor <input type="checkbox"/>
4.2	Do you prefer to be addressed on the topic of sexuality and your sexual life	With partner <input type="checkbox"/> without partner <input type="checkbox"/>
4.3	In addition to gender and age of the interlocutor, what factors do you think promote a trusting, relaxed and helpful conversation? (Multiple answers possible)	Enough time <input type="checkbox"/> Professional competence <input type="checkbox"/> Experience of the interlocutor <input type="checkbox"/> Sympathy <input type="checkbox"/> Trusting relationship <input type="checkbox"/> Empathy <input type="checkbox"/> Please name the 2 most important factors from your point of view..... Other factors that are important for you
4.4	What are YOUR barriers to addressing sexuality? please rate the factors on a scale from 0 to 5 Not at all true = 0 completely true = 5 Multiple answers possible	Too low a priority for me 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Too low a priority for my partner 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

	<p>What are YOUR barriers to addressing sexuality? please rate the factors on a scale from 0 to 5 Not at all true = 0 completely true = 5 Multiple answers possible</p>	<p>My self-esteem 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>My attractiveness 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>I can't talk about it with my partner 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Wording 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Shame 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Religion 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Upbringing 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Role expectations 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Embarrassment of doctor / health professional 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
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5.	<p>What are YOUR barriers to addressing sexuality? please rate the factors on a scale from 0 to 5 Not at all true = 0 completely true = 5</p> <p>Multiple answers possible</p> <p>General comments from you on this survey</p>	<p>Other barriers</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

	Date	_ _ . _ _ . _ _ _ _
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1. Basisangaben

1.1	Gender	<input type="checkbox"/> (1) male <input type="checkbox"/> (2) female
1.2	Year of birth	_ _ _ _
1.3	Ethnicity	<input type="checkbox"/> (1) Kaukasier <input type="checkbox"/> (2) Nicht-Kaukasier
1.4	Professional Activity	<input type="checkbox"/> GP <input type="checkbox"/> Lung specialist <input type="checkbox"/> Non-medical professional
1.5		since (year) _ _ _ _

2. Thema Sexualität bei COPD (alle Fragen beziehen sich auf COPD)

2.1	Is sexuality an issue in your professional work or in consultations with people with COPD?	<input type="checkbox"/> never <input type="checkbox"/> rarely <input type="checkbox"/> often <input type="checkbox"/> routinely/always
2.1.1	I do not address the issue of sexuality with patients with COPD in my professional practice	<input type="checkbox"/> Completely true <input type="checkbox"/> Partly true <input type="checkbox"/> Does not apply
2.2	What are the problems for you personally in addressing the topic of sexuality and sexual life? Multiple answers possible On a scale from 0 to 5 Does not apply = 0 Completely true = 5	Personal overload with the topic 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> own shame 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

	<p>What are the problems for you personally in addressing the topic of sexuality and sexual life?</p> <p>Multiple answers possible</p> <p>On a scale from 0 to 5</p> <p>Does not apply = 0</p> <p>Completely true = 5</p>	<p>Own uncertainty</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Insufficient priority</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Insufficient professional competence</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Difficulty in finding the entry point to conversation</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Difficulty in choosing the right words</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>My upbringing</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>My cultural background</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Religion</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Other.....</p>
2.3	<p>As a caregiver, do you consider the topic of sexuality and sexual life important for chronically ill people?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>

<p>In your opinion, what are the problems in addressing sexuality and sexual life from the patient's point of view?</p> <p>please rate the factors on a scale from 0 to 5 Not at all true = 0 to completely true = 5 0 1 2 3 4 5</p> <p>(Multiple answers possible)</p>	<p>Shame 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Insecurity 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Lack of self-esteem 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Dissatisfaction with physical attractiveness 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Low priority of the topic 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Uncertainty in the choice of words 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Generational (taboo subject) 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Culture-related (taboo subject) 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Religious reasons 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
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		<p>Upbringing</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Role expectations</p> <p>0 1 2 3 4 5</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Other.....</p>
2.9	<p>Why do you think the topic of sexuality and sexual life should be included in the consultation and the consultation interview?</p> <p>Multiple answers possible</p>	<p><input type="checkbox"/> Relevance for quality of life</p> <p><input type="checkbox"/> Relevance for self-esteem</p> <p><input type="checkbox"/> Relevance for self-image</p> <p><input type="checkbox"/> Reducing stress and anxiety about the issue</p> <p><input type="checkbox"/> Neutral conversation opportunity</p> <p>Other.....</p> <p>.....</p> <p>.....</p>
2.10	<p>Why do you think the topic of sexuality and sexual life should NOT be proactively included in the consultation and the consultation conversation?</p> <p>Multiple answers possible</p>	<p><input type="checkbox"/> Violation of privacy</p> <p><input type="checkbox"/> Risk of symptom exacerbation</p> <p><input type="checkbox"/> Could be life threatening</p> <p><input type="checkbox"/> presence of comorbidities</p> <p>e.g.....</p> <p>.....</p> <p>.....</p> <p><input type="checkbox"/> Insufficient evidence for benefit</p>

2.11		<input type="checkbox"/> insufficient emphasis in guidelines and curriculum Other
2.12	When do you think the topic of sexuality and sexual life should NOT be proactively included in the consultation and the consultation interview	<input type="checkbox"/> from a certain age, e.g.....years <input type="checkbox"/> Very severe COPD with oxygen therapy <input type="checkbox"/> Not living in a partnership
3.0	General comments on your part regarding this survey	

Sex & COPD

The expression of love,
affection, and sexuality is a part
of being human.

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

The spectrum of sexuality is wide, the desires and possibilities are individual. Expressing intimacy with 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.

Following these six helpful tips can help you to experience sex and

Perceive needs and talk about them

No one can hear your thoughts and know what makes you feel good or uncomfortable. Good communication is very important for improving your sex life. Do not wait too long to talk about it if you are not satisfied with your sex life.

Both you and your partner should be able to honestly express your feelings, desires and fears and find creative solutions to mutual satisfaction.

For example, the following statement can make it easier for you to address this issue: «It is not easy for me, but I would like to talk to you about our sex life.»

Do not be afraid to talk to your doctor or a trusted professional about sex and intimacy.

Get fit, stay fit

Regular physical activity taking part in a training program, e.g., as part of an outpatient rehabilitation program, will help you to reduce your fears about respiratory distress and increase your performance. During physical activity, a certain amount of shortness of breath is normal. Learn what is normal for you and your condition. With regular training, your condition will improve and you will be less breathless.

During sexual activity with moderate effort (such as cuddling on the sofa) is estimated to use up 2,0 METs*. This is equivalent, for example, to watering a lawn or being a dedicated spectator at a sporting event. An orgasm, which consumes considerably more sexual energy, is equated with >3 METs which is equivalent to climbing a flight of stairs, for example.

Remember! Physical activity is important and of great benefit to slowing the progression of your COPD. If you improve your physical activity and increase your fitness, your sexual activity will also benefit. Increased fitness means being able to experience fulfilling sexual activity with less breathlessness.

intimacy in a fulfilling way.

Listen to your body

Fatigue can be a result of COPD and can put a damper on intimate life. Pay attention to your body's signals to find out what time of day you feel the most energy. It can make a big difference if sex takes place at a time of day when your energy level is higher. Don't assume that you have to wait until bedtime to have sex.

If you feel rested and take breaks as needed during sexual activity, sex can be easier and more enjoyable.

Conserve energy

Managing your energy is fundamentally important, especially if you are affected by COPD. Avoid excessive alcohol consumption and heavy meals before sex.

The choice of sexual positions can also affect energy consumption. The partner, who does not have COPD, should take the more active role, if possible.

Inhale your bronchodilator and feel less shortness of

breath

Regular inhaling is part of the basic treatment. Additional inhalation prior to sex with a bronchodilator medication can, like inhaling before exercise, reduce your shortness of breath during exertion.

Oxygen reduces shortness of breath

If you use oxygen for daily activities, you should also use it during sex. This can make breathing easier. Ask the oxygen provider for extended oxygen tubing so there is more breathing room between you and the tank.

* MET is a «metabolic equivalent», or the ratio of work energy turnover to rest energy turnover. 1 MET is equal to the amount of energy used by an adult person sitting quietly.

It is not always easy to find words for the broad spectrum of intimacy and sexuality – and for one’s own needs.

On the following pages, we would like to inspire you with a selection of pictures to tune in to your individual sensuality and support you in feeling your needs and desires regarding intimacy and sexuality and to communicate them if necessary.

We sincerely wish that you find the kind of intimacy and sexuality that suits you best.

Me with myself...
Me and...



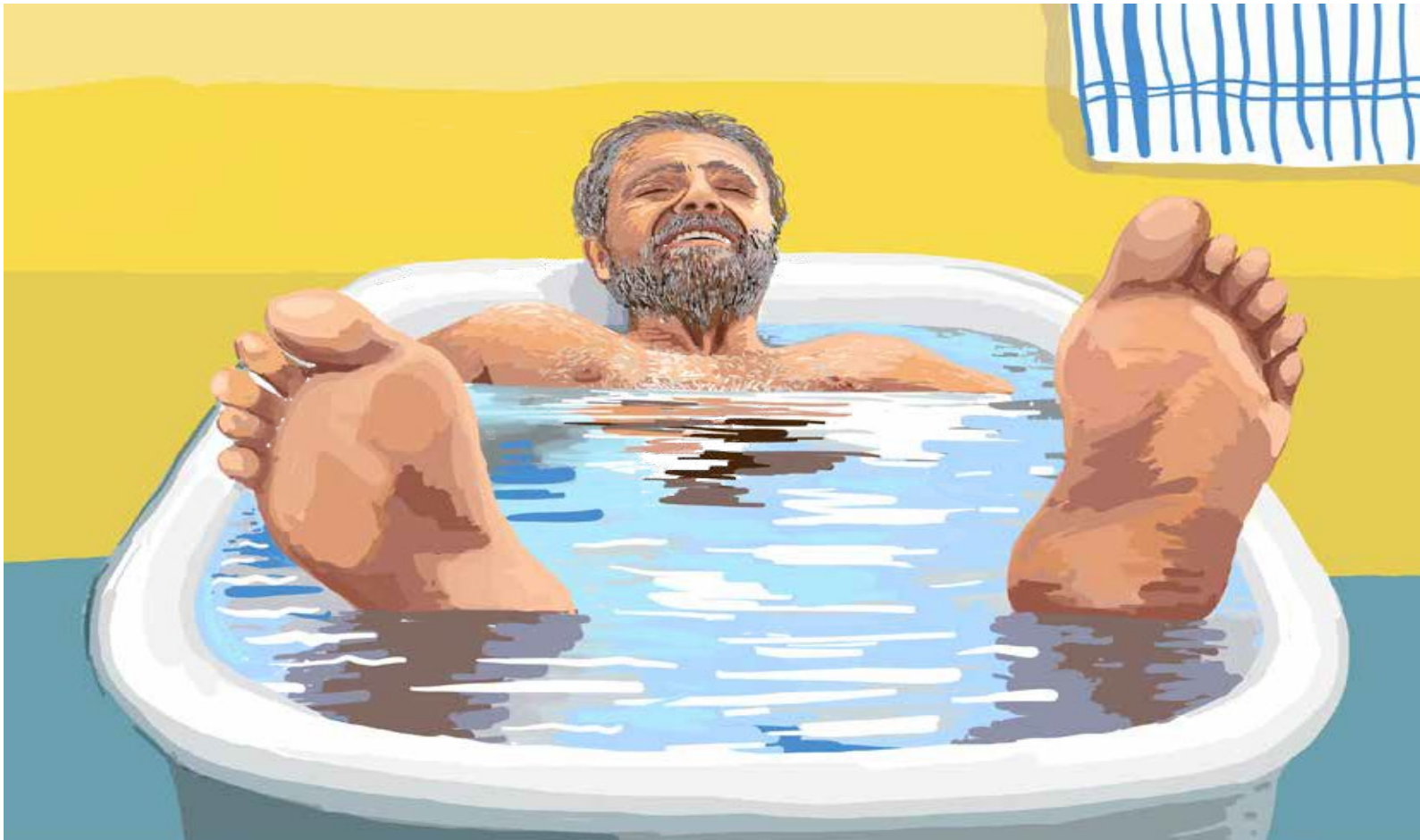
Me with myself...

smile at myself



Me with myself...

nurture myself



Me with myself...

spoil myself



Me with myself...

be with myself



Me with myself...

touch myself



Me and...

be connected



Me and...

cuddle – be tender



Me and...

kiss



Me and...

having sex – making love



Me and...

having sex – making love

energy saving position



Me and...

having sex – making love

oxygen can help

Words of Love

I enjoy being near you.

May I hold you in my arms?

I want to caress you

You make me feel good.

Thank you for being close to me.

I enjoy touching you.

A little cuddle would be nice!

Do you have 10 minutes just for the two of us?

I like the way you touch me.

I'm glad you're here.

It's nice to look into your eyes.

I love you.

May I give you pleasure

You are warm and soft.



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SCHWEIZERISCHE GESELLSCHAFT
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SOCIETÀ SVIZZERA DI PNEUMOLOGIA



LUNGENLIGA
LIGUE PULMONAIRE
LEGA POLMONARE



Imprint

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