



**ELF** EUROPEAN  
LUNG  
FOUNDATION

Tell us about your experience of having a lung condition during family planning and pregnancy

**This survey aims to find out more about the experiences of people with a lung condition, from considering starting a family to after childbirth.**

**Please only complete this survey if you have a lung condition and have considered having children, have been pregnant in the past or are currently pregnant. This may include people who have decided not to become pregnant because of their lung condition. Please complete as much of the survey as you are comfortable with or is relevant to you.**

**If you have been pregnant more than once, you might wish to answer this survey separately for each experience.**

**This survey has been designed by experts in women's and respiratory health and patient organisations. The survey is coordinated by the European Lung Foundation:  
<http://www.europeanlung.org/>**

**The anonymous survey responses will help healthcare professionals working with the European Respiratory Society (ERS) and the Thoracic Society of Australia and New Zealand (TSANZ) to understand how people with a lung condition are currently treated during pregnancy, and will help to highlight areas where more research is needed.**

**Please be aware that some sections of the survey address sensitive and very personal topics. These questions will help us to understand the different perspectives and experiences, and will help us to identify how people can be best supported.**

**The survey will take about 10-15 minutes to complete and you are free to exit the survey at any time. The survey will be open until Monday 14 May 2018.**

**Thank you for sharing your experience with us.**



Tell us about your experience of having a lung condition during family planning and pregnancy

## About you

### 1. Perspective

- I am a person with a lung condition and have not been pregnant
- I am a person with a lung condition and have been pregnant in the past
- I am a person with a lung condition and am currently pregnant
- I am completing this on behalf of someone else (please give details below)

Completing on behalf of e.g. wife, sister:

### 2. For people who are currently pregnant or have been pregnant in the past, when were you pregnant?

Please select all that apply.

- 1930s
- 1940s
- 1950s
- 1960s
- 1970s
- 1980s
- 1990s
- 2000s
- 2010s

### 3. What is your country of residence?



Tell us about your experience of having a lung condition during family planning and pregnancy

About your lung condition

**4. What is your lung condition?**

Please select all that apply.

- Asthma
- Bronchiectasis
- Chronic obstructive pulmonary disease (COPD)
- Cystic fibrosis
- Lung cancer
- Lung transplant recipient (please add details below of the primary lung condition leading to a lung transplant)
- Lung surgery (please add details below of the primary lung condition leading to lung surgery)
- Lymphangioleiomyomatosis (LAM)
- Pulmonary hypertension
- Sarcoidosis
- Sleep apnoea
- Tuberculosis (TB)
- Other lung condition (please give details below)
- Other health condition (please give details below)

Please give details

5. When was your lung condition diagnosed?

- I have been diagnosed and never pregnant
- Before your first pregnancy
- During your first pregnancy
- After your first pregnancy
- Other (please give details):



Tell us about your experience of having a lung condition during family planning and pregnancy

Pre-pregnancy and family planning

6. Before becoming pregnant, how important did you consider the impact of your lung condition on ...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important
Your fertility and ability to get pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The pregnancy (e.g. increased risk of premature birth)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to be a parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Before becoming pregnant, how important did you consider the impact of your lung treatments on...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important
Your fertility and ability to get pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your fertility treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Before becoming pregnant, how important did you consider the safety of changing or stopping your lung treatments...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important
For your health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Before becoming pregnant, how important did you consider the impact of pregnancy and labour on...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important
Your body and lungs while pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your body and lungs during labour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your future health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Before becoming pregnant, how important did you consider the possibility of...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important
Increased risks during pregnancy because of your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pregnancy accelerating or worsening your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Passing on your lung condition to the baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. Before becoming pregnant, how important did you consider the following lifestyle factors...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important
Diet (including vitamins and dietary supplements)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smoking (including quitting smoking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapies (e.g. yoga, meditation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. Before becoming pregnant, did you do any of following?

	Yes	No	Not applicable
Access genetic counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access genetic testing (e.g. pre-implantation genetic screening or diagnosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access assisted reproductive treatment (e.g. IVF, intrauterine insemination)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Yes	No	Not applicable
Access stop smoking support (e.g. counselling, nicotine replacement therapy or telephone helpline)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speak to a primary care professional (e.g. nurse, GP or family doctor) about becoming pregnant with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speak to a respiratory professional (e.g. respiratory consultant, respiratory nurse) about becoming pregnant with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speak to a pregnancy health professional (e.g. midwife, obstetrician) about becoming pregnant with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speak to another health professional (e.g. psychologist, physiotherapist) about becoming pregnant with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Search the internet to find information about becoming pregnant with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact a patient organisation to find information about becoming pregnant with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact other women with experience of your lung condition and pregnancy (e.g. through online discussion forums or social media)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please give details below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please give details			

13. How would you rate the information you received from the following sources about pregnancy and your lung condition before becoming pregnant?

	Very poor	Poor	Satisfactory	Good	Excellent	Not relevant to me
Partner, spouse or family member(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary care professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respiratory professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pregnancy health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other women with your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please add details below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please give details



14. To what extent did your lung condition influence your decision and options to have children?

- Not at all
- A little
- Moderately
- A lot
- It was the biggest factor
- Not relevant to me

15. Please share any other feelings, questions or considerations you had about managing your lung condition before becoming pregnant.



Tell us about your experience of having a lung condition during family planning and pregnancy

## Pregnancy

**The questions in this section are relevant for people who have had a lung condition during pregnancy. You can skip these questions if they are not relevant for you.**

16. When you were pregnant, how important did you consider the impact of your lung condition on...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important	Not applicable to me
The pregnancy (e.g. increased risk of premature birth)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to be a parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. When you were pregnant, how important did you consider the safety of changing or stopping your lung treatments...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important	Not applicable to me
For your health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. When you were pregnant, how important did you consider the impact of pregnancy and labour on...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important	Not applicable to me
Your body and lungs while pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your body and lungs during labour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your future health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. When you were pregnant, how important did you consider the possibility of...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important	Not applicable to me
Increased risks during pregnancy because of your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pregnancy accelerating or worsening your lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Passing on your lung condition to the baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. When you were pregnant, how important did you consider the following lifestyle factors...

	1 - Not at all important	2 – Not very important	3 - Moderately important	4 - Very important	5 - Extremely important	Not applicable to me
Diet (including vitamins and dietary supplements)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smoking (including quitting smoking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapies (e.g. yoga, meditation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. How would you rate the information you received from the following sources about pregnancy and your lung condition when you were pregnant?

	Very poor	Poor	Satisfactory	Good	Excellent	Not relevant to me
Partner, spouse or family member(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary care professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respiratory professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pregnancy health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other women with my lung condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please add details below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please give details

22. Please share any other feelings, questions, considerations or strategies around managing your lung condition during your pregnancy.

23. How would you rate the standard of care you received for your lung condition while you were pregnant?

- Excellent
- Good
- Satisfactory
- Poor
- Very Poor

Please tell us more about the standard of care and the professionals involved in caring for your lung condition while you were pregnant:



Tell us about your experience of having a lung condition during family planning and pregnancy

### Giving birth

**The questions in this section are relevant for women who have had a lung condition and given birth. You can skip these questions if they are not relevant for you.**

24. To what extent did your lung condition influence the decision of where you gave birth (e.g. hospital, home)?

- Not at all
- A little
- Moderately
- A lot
- It was the biggest factor
- Not relevant to me

Please tell us more about the decision of where you gave birth:

25. To what extent did your lung condition influence the decision of how you gave birth (e.g. water birth, pain management, caesarean section)?

- Not at all
- A little
- Moderately
- A lot
- It was the biggest factor
- Not relevant to me

Please tell us more about the decision of how you gave birth and who you discussed this with:



Tell us about your experience of having a lung condition during family planning and pregnancy

After birth and breastfeeding

**The questions in this section are relevant for people who have had a lung condition and given birth. You can skip these questions if they are not relevant for you.**

26. After giving birth, did you receive support and advice about breastfeeding with a lung condition?

- Yes
- No
- Not relevant to me

Please give details:

27. Did you receive support and advice about how breastfeeding can increase or reduce the chances of your baby developing a lung condition in future?

- Yes
- No
- Not relevant to me

Please give details:





Tell us about your experience of having a lung condition during family planning and pregnancy

Overall experience

28. How did your lung condition influence your overall experience of family planning, pregnancy and giving birth?



Tell us about your experience of having a lung condition during family planning and pregnancy

### Future pregnancies

29. To what extent is your lung condition influencing your decision or options to have children in the future?

- Not at all
- A little
- Moderately
- A lot
- It is the biggest factor
- Not relevant to me
- Prefer not to say

Please tell us more about your decision or options to have children in the future:



Tell us about your experience of having a lung condition during family planning and pregnancy

Support for people with a lung condition during pregnancy

30. Would you like more information about family planning and pregnancy to be available for people with your lung condition ?

Yes

No

If yes, what further information would you like?:

31. What other support would be beneficial?



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### Getting involved

**If you would like to receive the results of the survey and updates on the project please follow this link to enter your email address: <https://www.surveymonkey.co.uk/r/ELF-get-involved>**

**Please note that the European Lung Foundation will only contact you in relation to this survey and to send you updates about this project. We will not share your email address with any third parties. Your email address will be stored on our secure servers and we will retain your email only for as long as is necessary to provide you with the service stated above.**

**Please contact Courtney Coleman at the European Lung Foundation if you have any queries: [courtney.coleman@europeanlung.org](mailto:courtney.coleman@europeanlung.org).**