

# SJLIFE

## Women's Health Questionnaire

The following questionnaire addresses personal subject matter on topics including fertility, puberty, and sexual health/functioning. These important quality of life issues have not been well studied among survivors of childhood cancer. By completing this questionnaire, you will help us better understand these issues which could one day lead to improved prevention and treatment options.

All adult SJLIFE participants are being asked to complete this questionnaire. Be assured that your participation is voluntary and you may choose to answer all, some, or none of the questionnaire items. Your responses will be kept confidential so please do not put any identifying information (like name, age, or date of birth) on this questionnaire. Once completed, please seal the questionnaire in the attached envelope and drop it off in the questionnaire box in the SJLIFE clinic. Thank you in advance for your participation.

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Please! Do not mark below this line

## INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box.
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided.
5. Once you have completed the questionnaire, please place it in the attached envelope and drop it off in the SJLIFE questionnaire box in clinic.

### ESTROGEN THERAPY

Estrogen is the female hormone made by the ovaries. It can be given to patients to start puberty (puberty is defined as the physical changes that allow a girl's body to change into a woman's body) or can be used in older females who have low blood levels of estrogen. Estrogen can also be used with other female hormones as a form of birth control.

**A1. Have you ever been treated with estrogen?**

- Yes  
 No **→ Go to Question B1, next page.**  
 I don't know

**A2. Were you treated with estrogen therapy during puberty (puberty in girls is typically around ages 10-11 and leads to increase in size of breasts and development of pubic hair)?**

- Yes  
 No  
 I don't know

**A3. Were you treated with estrogen to prevent signs and symptoms of menopause (hot flashes, vaginal dryness, bone loss and/or decreased sex drive)?**

- Yes  
 No  
 I don't know

**A4. Were you treated with estrogen or other hormones to prevent pregnancy?**

- Yes  
 No  
 I don't know

**A5. Was your treatment with estrogen...**

- continuous  
 interrupted (stopped and started again)

A6. How many years (in total) have you been on estrogen? Do not count years in which your estrogen therapy was stopped.

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Years

A7. Are you currently on estrogen?

- Yes
- No

A8. How have you received estrogen treatments? *(Mark all that apply)*

- Injections (shots)       Skin patch
- Pills                               Vaginal ring
- Gel/Cream

A9. At what age did you start estrogen?

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Age in years

A10. If you took estrogen and it was discontinued, at what age did you last stop taking estrogen?

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Age in years

A11. If you stopped taking estrogen, why did you stop? *(Mark all that apply)*

- I stopped the medicine because I did not like taking it
- My doctor told me to stop
- I no longer had a prescription for the medicine
- Other reason

*If Other reason, explain.*

## BODY IMAGE

On this scale you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and mark the response which comes closest to the way you have been feeling about yourself during the past week.

		Not at all	A little	Quite a bit	Very much
<b>During the <u>past week</u> . . . .</b>					
B1. Have you been feeling <u>self-conscious</u> about your appearance? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B2. Have you felt <u>less</u> physically attractive as a result of your disease or treatment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B3. Have you been <u>dissatisfied</u> with your appearance when dressed? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B4. Have you been feeling <u>less</u> feminine as a result of your disease or treatment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B5. Have you been finding it <u>difficult</u> to look at yourself naked? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B6. Have you been feeling <u>less</u> sexually attractive as a result of your disease or treatment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B7. Have you been <u>avoiding</u> people because of the way you felt about your appearance? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B8. Have you been feeling the treatment has left your body <u>less</u> whole? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B9. Have you felt <u>dissatisfied</u> with your body? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B10. Have you been <u>dissatisfied</u> with the appearance of a scar(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>B11. At the present time, do you have any of the following?</b>					
	No	Yes			
Persistent hair loss. . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Scarring or disfigurement of the head or neck region (including the face). . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Scarring or disfigurement of the chest or abdominal region. . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg). . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Walk with a limp. . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Loss of an arm or a leg . . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Loss of an eye . . . . .	<input type="checkbox"/>	<input type="checkbox"/>			
Other. . . . .	<input type="checkbox"/>	<input type="checkbox"/>			

*If Other, specify.*



## RELATIONSHIP/MARITAL SATISFACTION SCALE

D1. Are you currently married or in a significant relationship?

Yes

No → **Go to Question E1.**

Please mark the number for each item which best answers that item for you.

D2. How well does your partner meet your needs?

1

2

3

4

5

Poorly

Average

Extremely well

D3. In general, how satisfied are you with your relationship?

1

2

3

4

5

Unsatisfied

Average

Extremely satisfied

D4. How good is your relationship compared to most?

1

2

3

4

5

Poor

Average

Excellent

D5. How often do you wish you hadn't gotten into this relationship?

1

2

3

4

5

Never

Average

Very often

D6. To what extent has your relationship met your original expectations?

1

2

3

4

5

Hardly at all

Average

Completely

D7. How much do you love your partner?

1

2

3

4

5

Not much

Average

Very much

D8. How many problems are there in your relationship?

1

2

3

4

5

Very few

Average

Very many

## FERTILITY AND FERTILITY PRESERVATION

The next set of questions will ask about your fertility, pubertal development, sexual development, and quality of life. You may feel these questions are personal. Please be reassured your responses will remain confidential.

E1. Do you know your fertility status?

Yes

No

E2. Have you and a partner ever tried to become pregnant?

Yes

No → **Go to Question E12, next page.**

E3. Have you ever had difficulty (it took more than 1 year) becoming pregnant with a partner?

Yes

No

I don't know

E4. Were you able to have all the children you wanted to have?

Yes → **Go to Question E6, next page.**

No



E4a. *If no*, which of you wanted more children?

I wanted more children but my partner(s) did not

My partner(s) wanted more children but I did not

We both wanted more children but we could not have more

E5. If more children were wanted, what were the reasons for not having more children? (Mark all that apply)

- I was unable to have more children (female infertility)
- I had other health issues related to my cancer treatment that made us decide not to have more children
- I had other health issues not related to my cancer treatment that made us decide not to have more children
- My partner was not able to help me conceive (male infertility)
- My partner had other health issues that made us decide not to have more children
- My partner and I tried but could not become pregnant, we do not know the reason why
- There were issues other than health that kept us from having more children (social/financial)

If there were other issues, please specify.

E6. Have you or a male partner ever been evaluated for infertility?

- Yes
- No → Go to Question E10.
- I don't know

E7. If you or your partner were evaluated for decreased fertility, was a problem identified?

- Yes. A fertility problem was found in my partner.
- Yes. A fertility problem was found in me.
- Yes. A fertility problem was found in both me and my partner.
- No
- I don't know

E8. Were you personally evaluated by a fertility specialist?

- Yes
- No → Go to Question E10.

If yes, which kind of physician?

If yes, how old were you at the time of evaluation?

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Age in years

E9. If you were evaluated by a fertility specialist, was a problem identified?

- Yes
- No

If yes, please specify.

E10. Have you/your partner engaged in treatment for fertility problems?

- Yes
- No → Go to Question E12.

E11. If yes, what type of treatment? (Mark all that apply)

- Insemination
- Ovulation Drugs
- In Vitro Fertilization (IVF)
- Other

If Other, please specify.

E12. Do you have any concerns about your fertility (your ability to have/produce biological children in the future)?

- No
- Yes
- Not sure

E13. Were you/are you at risk for premature ovarian failure (early menopause) due to cancer treatment?

- Yes
- No
- I don't know

E14. Did you undergo oocyte cryopreservation (egg freezing) before you received cancer therapy?

- Yes
- No
- I don't know

E15. Did you undergo oocyte cryopreservation (egg freezing) after you received cancer therapy?

- Yes
- No
- I don't know

E16. Did you undergo ovarian tissue freezing/cryopreservation before you started cancer treatment?

- Yes
- No
- I don't know

Please! Do not mark below this line

E17. Regardless of what you decided, were you offered fertility preservation before, during, or after your cancer treatment? (Mark all that apply)

- No
- Yes, before treatment
- Yes, during treatment
- Yes, after treatment

## PUBERTY AND SEXUAL DEVELOPMENT

F1. Was the onset of your puberty . . . (The onset of puberty in females is characterized by pubic hair and breast development.)

- Early compared to others your age
- Normal compared to others your age
- Late compared to others your age

F2. Were hormones needed to start your puberty?

- Yes
- No

F3. Have you had sexual intercourse?

- Yes
- No

If no, Go to Question F6.

If yes, at what age did you first have intercourse?

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Age in years

F4. Did you or your partner use a condom at last intercourse?

No

Yes

Go to Question F5.

F4a. If you did not use a condom at last intercourse, what method did you or your partner use to prevent pregnancy? (Select only one response.)

- No method was used to prevent pregnancy
- Birth control pills
- IUD (such as Mirena or ParaGard)
- Implant (such as Implanon or Nexplanon)
- Shot (such as Depo-Provera)
- Birth control patch (such as Ortho Evra)
- Birth control ring (such as NuvaRing)
- Sponge (such as Today Sponge)
- Spermicide
- Withdrawal or some other method

F5. In general, how often do you or your partner use a condom during sex?

(Select only one response.)

- Not applicable because I have never had sex
- Never
- Rarely
- Sometimes
- Often
- Always

F6. My previous sexual experiences have been with . . . (Mark all that apply)

- The opposite gender - men
- The same gender - women
- Both genders- men and women
- Myself- I have masturbated
- None of the above
- No reply

F7. My sexual experiences in the last year have been with . . . (Mark all that apply)

- The opposite gender - men
- The same gender - women
- Both genders- men and women
- Myself- I have masturbated
- None of the above
- No reply

F8. How many sexual partners have you had in the last month?

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F9. How many sexual partners have you had in the last year?

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F10. How many sexual partners have you had in your lifetime?

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# SEXUAL ACTIVITY

The following are questions commonly used by doctors to assess sexual function in females. They are standardized questions asked in a standardized fashion.

These next questions are sensitive and personal. They are very important in understanding how your medical illness or treatment affects your self and your body. Some questions ask about your own experiences, thoughts, and feelings, while others ask about how treatment has affected your intimate relationships. Please answer each question honestly and accurately. Be assured that your responses are totally confidential.

**G1. Have you been sexually active in the past year (alone or with a partner)?**

- Yes → Go to Question G3.
- No

**G2. I have not been sexually active in the last year because . . . (Mark all that apply)**

- I have never been sexually active → Go to Question G4.
- I am too tired
- I am not interested
- I have a physical problem that makes sexual relations difficult or uncomfortable
- My partner is not interested
- My partner is too tired
- My partner has a physical problem that makes sexual relations difficult or uncomfortable
- Other

*If Other, please specify.*

**G3. Have you been sexually active in the past month (alone or with a partner)?**

- Yes
- No

**G4. In the past month, how frequently have you had sexual thoughts, urges, fantasies, or erotic dreams? (Please mark the one item that is closest to your experience.)**

- Not at all
- Once
- 2 or 3 times
- Once a week
- 2 or 3 times a week
- Once a day
- More than once a day

**G5. Using the scale below, how frequently have you felt an interest or desire to engage in the following specific activities in the past month?**

*(This question is about your desire to engage, not about how you feel during sexual activity.)*

**(For each item, please mark the response that is closest to your experience):**

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Masturbation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Touching, hugging, holding, kissing . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Petting or foreplay . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Vaginal intercourse . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other sexual activity . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If Other, please specify.*



**G6. How frequently have you become aroused by the following sexual activity in the past month?**

*(By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexual.)*

**(For each item, please mark the response that is closest to your experience):**

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Masturbation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Touching, hugging, holding, kissing . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Petting or foreplay . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Vaginal intercourse . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other sexual activity . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If Other, please specify.**

**G7. In the past month, have you felt pleasure from any sexual activity?**

- I have had no sexual activity in the past month
- I have not felt any pleasure
- Seldom, less than 25% of the time
- Sometimes, about 50% of the time
- Usually, about 75% of the time
- Always felt pleasure

**G8. Using the scale below, how frequently have you engaged in the following activities in the past month?**

**(For each item, please mark the response that is closest to your experience):**

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Masturbation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Touching, hugging, holding, kissing . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Petting or foreplay . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Masturbation with partner . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Vaginal intercourse . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Other sexual activity . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If Other, please specify.**

**G9. In the past month, how often have you reached orgasm (climax) during sexual activity?**

- I have had no sexual activity in the last month
- I have not experienced orgasm
- Seldom, less than 25% of the time
- Sometimes, about 50% of the time
- Usually, about 75% of the time
- I always experienced orgasm

**G10. When you have orgasms (climax), how intense have they been in the past month?**

- I have had no sexual activity in the last month
- I have had no orgasms in the last month
- My orgasms were very mild
- My orgasms were fairly mild
- My orgasms were fairly strong
- My orgasms were very strong



For each item, please mark the response that is closest to your experience:

	Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
G18. Overall, how satisfied have you been with your sexual relationship with your partner? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G19. Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G20. Overall, how satisfied do you think your partner has been with your sexual relationship? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G21. Over the past 4 weeks, how satisfied do you think your partner has been with your sexual relationship? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**G22. Over the past 4 weeks, please rate how satisfied you have been with your ability to share warmth and intimacy with your partner by marking a number below from 0 to 10 (0=Not at all satisfied, 10=Extremely satisfied).**

0    1    2    3    4    5    6    7    8    9    10  
 Not at all Satisfied Extremely Satisfied

**G23. Over the past 4 weeks, please rate how comfortable you have been with touching, hugging or holding your partner by marking a number from 0 to 10 (0=Not at all comfortable, 10=Extremely comfortable).**

0    1    2    3    4    5    6    7    8    9    10  
 Not at all Comfortable Extremely Comfortable

**G24. I feel positive about my sexual relationship?**

- Not in a sexual relationship
- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**G25. I feel depressed about symptoms that keep me from enjoying sexual activity?**

- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**G26. I sometimes feel too distressed to engage in sexual activity?**

- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**G27. Problems with my sexual performance cause me distress?**

- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**Sexual Dysfunction Therapy**

**H1. Have you ever received medical treatment for sexual dysfunction like vaginal dryness, itching, or pain (not infection-related) during sex?**

- Yes
- No

*If yes, what medicine(s)?*

**H2. Have you ever tried/received complementary or alternative medical treatment (herbal supplements or acupuncture, for example) for sexual dysfunction?**

- Yes
- No

*If yes, what treatment(s)?*

**H3. Have you ever had psychological treatment (talk therapy) for issues related to sexual dysfunction?**

- Yes
- No

Please! Do not mark below this line

Finally a few questions about how you think survivors of childhood cancer and similar illnesses could best be informed about their risk (if any) of sexual dysfunction.

I1. Is there anything you wish you had been told at the time of your diagnosis and treatment regarding your future fertility or sexual functioning? (use additional pages if necessary)

I2. Is there anything you wish you had been told in a follow up cancer visit regarding your future fertility or sexual functioning? (use additional pages if necessary)

I3. Is there anything you wish to know now regarding fertility or sexual functioning? (use additional pages if necessary)

We are always interested in your input.

Use this space for any additional comments you may have:

**Thank you for participating.**