

St. Jude Children's Research Hospital

ALSAC • Danny Thomas, Founder

Finding cures. Saving children.

## SJLIFE

Behavior Survey Control

The questions in this booklet relate to:

Name

Person completing this questionnaire is:

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percomp text
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Your relationship:


Today's date:



St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678
Toll-free phone number:
1-800-775-2167
e-mail:
SJLIFE@stjude.org

## LIVING/MARITAL STATUS

A1. What is your current living arrangement? curliv (Mark all that apply)
$\square$ Live with spouse/partner curliv_spoLive with parent(s) curliv_par
Live with roommate(s) curliv_rm
$\square$ Live with brother(s) and/or sister(s) curliv_sibLive with other relative(s) (not including minor children) curliv_relLive alone curliv_alnOther Specify. curliv_oth
msspec text

A2. Have you ever been married or had a live-in relationship (lived as married)? evermNo
$\longrightarrow$ Go to Question B1a.
$1 \square$Yes

A3. Which of the following best describes your current marital status? curms

0
$\square$ Single, never married or never lived with partner as married


1Married

2Living with a partner as married

3Widowed

4Divorced

5Separated or no longer living as married

A4. How many times have you been married or lived as married? marnu


A5. How old were you at the time of your first marriage or when you first began living as married? marage


## SCHOOL HISTORY

B1a. What is the highest grade or level of schooling that you have completed? grade

11-8 years (grade school)9-12 years (high school), but did not graduate
3Completed high school/GEDTraining after high school, other than college
5Some college
6 पCollege graduate

7Post-graduate level

8Other

```
Specify.
gradespe text
```

B1b. What is the highest grade or level of schooling that your mother has completed? gradem

11-8 years (grade school)9-12 years (high school), but did not graduateCompleted high school/GED

4Training after high school, other than college

5Some college

6College graduate
7Post-graduate level
9Not Applicable

10UnknownOther Specify. grdmspe text

B1c. What is the highest grade or level of schooling that your father has completed? gradef

11-8 years (grade school)
29-12 years (high school), but did not graduate

3Completed high school/GED

4Training after high school, other than college

5Some college

6College graduate

7Post-graduate level

9Not Applicable

10Unknown

8Other Specify. grdfspe text

B4. If you were in a learning disabled or special education program, what grades were you in at that time? (Mark all that apply) specprog

| $\square$ K | $\square$ 5th | $\square$ 9th |
| :--- | :--- | :--- |
| specprog_k | specprog_5 | $\square$ specprog_9 |
| $\square 1$ st | $\square 6$ th | $\square 10$ th |
| specprog_1 | specprog_6 | $\square$ specprog_10 |
| $\square$ 2nd | $\square$ th | $\square 1$ th |
| specprog_2 | specprog_7 | $\square$ specprog_11 |
| $\square$ 3rd | $\square 8$ th | $\square 12$ th |
| specprog_3 | specprog 8 | specprog_12 |
| 4th <br> specprog_4 |  |  |

B5. Were you ever home schooled unrelated to medical issues? homesch

1Yes

2No

3Unsure

B2. If you have completed high school, did you receive a regular high school diploma or did you receive a high school equivalency certificate, also called a GED? ged

1High school diploma

2GED

B3. In elementary, junior, or high school were you ever in any of the following programs? (Mark all that apply)

Learning disabled or special education program? $\qquad$


If yes, were you in the program because of. . .
a. Missed school. $\qquad$ speced_a
b. Low scores on tests. $\qquad$ speced_b.
c. Problems learning or concentrating.
speced_c
d. Emotional or behavioral problems. . . .
rogram?
adplc
Homebound education for at least one school year due to a medical reason?. . . . .
homed

## EMPLOYMENT HISTORY

C1. Have you ever had a job? evjobNo $\longrightarrow$ Go to Question C4.Yes


C2. What is your current employment status? Include unpaid work in the family business or farm. empst (Mark all that apply)Not currently working empst_notWorking full-time (30 or more hours per week)empst_fullWorking part-time (less than 30 hours per week)empst_parCaring for home or family (not seeking paid work) empst_careUnemployed and looking for work empst_lookUnable to work due to illness or disability empst_disRetired empst_retireStudent empst_std| Other | Specify. |
| :--- | :--- |
| empst_oth |  |
|  | empsp |
|  | text |

C3. The following questions are about your present occupation. Please write your job title and brief details of what you do. If you have more than one job, please give the title of your main job (please give only one):

## C3a. Main job title:

mainj
text

C3b. Please briefly describe the primary tasks in your job:
no entry

C4. Have you ever applied for entry into the following services?
Military (Army, Navy, etc.) . $\qquad$ military 1 Yes 2 No$\square$

Police Department . . . . . . . . . . . . . . . . police. . .
Fire Department fire

C5. Have you ever not gotten a job or into military service because of your previous medical history?


## INCOME

D1. Over the last year, what was the total income of the household you live in? homeinc

1Less than \$20,000

2 \$20,000-\$39,999

3 \$40,000-\$59,999

4\$60,000-\$79,999

5\$80,000 - \$99,999

6Over \$100,000

9Don't know

D2. During the past year, how many people in this household were supported on this income? incsupn
11

2
34

5
66

77

88

99 or more

D3. Over the last year, what was your personal income?
1None

2Less than \$20,000

3\$20,000-\$39,999

4\$40,000-\$59,999

5\$60,000-\$79,999

6\$80,000-\$99,999

7Over \$100,000

D4. In the last 12 months, how have your finances usually worked out at the end of the month? endmo

1Some money left over

2Just enough to make ends meet

3Not enough to make ends meet

D5. In the past 12 months, was there ever a time when you did not have enough money to pay your monthly bills? bills

1 $\square$ Yes, a lot of times I did not have enough money to pay my monthly bills

2Yes, a few times when I did not have enough money to pay my monthly bills
$3 \square$No, I always had enough money to pay my monthly bills

D6. In the past 12 months, was there a time you needed to see a doctor or go to the hospital but did not go due to finances? needdr1

2No

1Yes

D7. In the past 12 months, was there a time anyone in your household (other than you) needed to see a doctor or go to the hospital but did not go due to finances? needdr2

2No

1Yes

## INSURANCE

## Health Insurance

E1. Have you ever had difficulty obtaining health insurance because of your health history? hltins
2 No $\longrightarrow$ Go to Question E2.Yes

E1a. What previous health history made it difficult for you to get health insurance?

Specify.
hltcov
E2. Do you currently have health insurance coverage?Non - U.S. resident/citizen

2No $\qquad$Yes

E3. How is this insurance provided? (Mark all that apply)Through your place of employment/education insprv_epmThrough your spouse's or parent's policy insprv_spoThrough a policy you have purchased yourself insprv_selAffordable Care Act (Obama Care)insprv_acaMedicaid or other public assistance program insprv_pubMedicare insprv_medMilitary dependent/Veteran's benefits (CHAMPUS)Other insprv_oth

| Specify. |
| :--- |
| insspe |
| text |

E3a. Does this health insurance plan have any exclusions or restrictions because of your health history? insexc
3Don't know

2No$\square$ Yes
Specify.
insexsp
text

E3b. Is there an extra premium charge on your health insurance policy because of your health history?
3Don't know

2No

1Yes

## Life Insurance

E4. Have you ever had difficulty obtaining life insurance because of your health history? lifins
2No $\longrightarrow$ Go to Question E5.$\square$ Yes$\square$ Never tried to obtain life insurance

E4a. What previous health history made it difficult for you to get life insurance?

Specify. reason_lifeins

E5. Do you currently have life insurance coverage? lifcov
2 No $\longrightarrow$ Go to Question F1, next page.Yes

E6. How is this life insurance provided? life (Mark all that apply)Through your employer life_empThrough your spouse's or parent's policy life_spoThrough a policy you have purchased yourself life_selOther

## Specify. <br> lifspe

text

E6a. Does this life insurance plan have any exclusions or restrictions? lifexcDon't knowNo

$\qquad$ Yes | Specify. |
| :--- |
| lifexsp |
| text |
|  |
|  |
|  |
|  |
|  |
|  |

E6b. Is there an extra premium charge on your life insurance policy because of your health history?

3Don't know
lifext
2No

1Yes

E6c. What is the total dollar value of your life insurance policy(ies)? lifval
1Under \$10,000

2\$10,000 - \$49,999

3\$50,000 - \$99,999

4\$100,000 or more

5Don't know

## SLEEP

Questions F1 to F8 relate to the past 7 days.




G20. Do you have any persisent or recurrent pain, more G20a. If yes, how long have you been experiencing this than aches and pains that are fleeting and minor? pain? longpain
$\square$ No $\longrightarrow$ Go to Question H1, next page.
$1 \square \mathrm{Yes}$ recurrentpain
$1 \square$ Less than 1 month
$2 \square$ 1-2 months
$3 \square$ 3-4 months
$4 \square$ 5-6 months
$5 \square$ More than 6 months
$6 \square$ Other $\qquad$

## SOCIAL BEHAVIOR

For questions H 1 to H 12 , please respond to each item by marking one box per row.
H1. Do you have someone to help you if you are confined to bed?
H2. Do you have someone to take you to the doctor if you need it?.
H3. Do you have someone to help with your daily chores if you are sick?
H4. Do you have someone to run errands if you need it? $\qquad$
H5. Do you have someone to prepare your meals if you are unable to do it yourself?
smeal
H6. Do you have someone to take over all of your responsibilities at home if you need it?
sresp.
sleftout
H8. I feel that people barely know me. . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .
H9. I feel isolated from others.
H10. I feel that people are around me but not with me.
sisol1
H11. I feel isolated even when I am not alone.
sisol?
H12. I feel that people avoid talking to me.
savoid


## WORRY



J1. Do you currently have anxieties/fears as a result of your cancer or similar illness, or its treatment? coanx
1 -No anxiety/fears

2 Small amount of anxiety/fearsMedium amount of anxiety/fearsA lot of anxiety/fears

5Very many, extreme anxiety/fears

J2. The next questions ask about problems you may have had after a very stressful experience. It could be something that happened to you directly, something you witnessed or something you learned happened to a close family member or close friend. Some examples include a serious accident, a death, or any event when you thought you (or someone close to you) might be hurt. Please answer a few questions about your most stressful event or the event that bothers you the most. In a few words or a phrase, please write down the event.

```
difev
text
```

J3. How long ago did the event described above happen? (please estimate if you are not sure)

```
difevtm
text
```


## Continue on next page.

## Keeping your most stressful event in mind, carefully read each problem below and mark one of the boxes on the right to indicate how much you have been bothered by that problem in the past month.

In the past month, how much were you bothered by:
K1. Repeated, disturbing, and unwanted memories of the stressful experience?
K2. Repeated, disturbing dreams of the stressful experience? ptsddrm
K3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?
K4. Feeling very upset when something reminded you of the stressful experience? ptsddups
K5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?
K6. Avoiding memories, thoughts, or feelings related to the stressful experience? ptsdavdm
K7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?

ptsdavdr
K8. Trouble remembering important parts of the stressful experience?
ptsdtrem
K9. Having strong negative beliefs about yourself, other people, or the world (for example, having
thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted,
the world is completely dangerous)? . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ptsdnegb
K10. Blaming yourself or someone else for the stressful experience or what happened after itptsddblm. .
K11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?
ptsdnegf
K12. Loss of interest in activities you used to enjoy? ptsdlos
K13. Feeling distant or cut off from other people?
ptsddis
K14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have
loving feelings for people close to you)? . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .
K15. Irritable behavior, angry outbursts, or acting aggressively? . . . . . . . . . . . . . . . . . . . . . . ptsdirb
K16. Taking too many risks or doing things that could cause you harm? . . . . . . . . . . . . . . . . .ptsdrsk.
K17. Being "superalert" or watchful or on guard? . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ptsdalt
K18. Feeling jumpy or easily startled?. . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ptsdjmp.
K19. Having difficulty concentrating?
ptsdcon
K20. Trouble falling or staying asleep?
ptsdslp

## L1. Have you ever been diagnosed with cancer? cancerdx_2

$\square$ No $\longrightarrow$ Go to Question M1, next page.Yes
## CANCER IMPACT

Looking back over time since your cancer diagnosis, how much of an impact did your cancer experiences have on the following areas of your life overall? Mark only one answer for each statement and try not to skip any items.

L2. Your educational plans (classes completed, degrees earned, goals achieved, etc.)


L3. Your work life or career (promotion, mobility, work environment, etc.) . . . . . . . . . . . . . . . . . cawr.
L4. Your diet
cadiet
L5. Your family plans (finding a partner, divorce, marriage, having children, etc.)
cafam
L6. Your social life (friendships, social activities)
calif
L7. Your living arrangements (moving in with relatives, selling a house, etc.)
calvg.
L8. Your financial situation
cafị!
L9. Your exercise activities
caexc
L10. Your love life
calve
L11. Your religious beliefs (e.g., belief in a higher power)
carelb
L12. Your religious activities (e.g., affiliation with a religious institution, participation in religious activities)
carela
L13. Other activities related to spirituality (e.g., meditation)
cas.p.pt
L14. Your retirement plans
cart
L15. Your ability to care or provide for your children
capry
L16. Your ability to be a caregiver to others (e.g., aging parents, sick spouse)
cacg.
L17. Your ability to retain or to change your health care insurance
cains
L18. Your emotional or psychological needs
caneed
L19. Other changes?
caoth

## Specify. <br> caspe

text
Below are some statements that people sometimes make when they talk about
their health. Please indicate how much you agree or disagree with each statement
as it applies to you personally by marking one box per row. Your answers should
be what is true for you and not just what you think others want you to say. If the
statement does not apply to you, mark N/A.

4

Disagree Strongly
M1. When all is said and done, I am the person who is responsible for taking care of my health hcresp
hcrole
M2. Taking an active role in my own health care is the most important thing that affects my health
M3. I am confident I can help prevent or reduce problems associated with my health. hcred
M4. I know what each of my prescribed medications does hc̣re.
M5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of the health problem myself ..... hegodr.
M6. I am confident that I can tell a doctor concerns I have even when he or she does not ask . ḥc.onc
M7. I am confident that I can follow through on medical treatments I may need to do at home ..... hectrt.
M8. I understand my health problems and what causes them hcundr
M9. I know what treatments are available for my health problems ..... hẹp̣t
M10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercisingcm!̣!
M11. I know how to prevent problems with my health
$\qquad$M12. I am confident I can figure out solutions when new problems arise with my health
$\qquad$ h.heṣol.
M13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress ..... helif̣e.
These questions ask about your feelings and thoughts during the last month. For each item, please indicate with a mark how often you felt or thought a certain way.
N2. In the last month, how often have you felt confident about your ability to handle your personal problems? handle.
N3. In the last month, how often have you felt that things were going your way? ..... going
N4. In the last month
overcome them? piling.
O. Below is a list of statements that describe problems people can have. We would like to know if you have had any of these problems over the past 6 months. Please complete all items. Please think about yourself as you read these statements and mark one response on each line.

3 Often a problem

7. I get frustrated easily.
prfft.
8. My mood changes frequently $\qquad$ prmood
9. I have trouble finding things in my bedroom, closet or desk.
prfind.
10. I forget what I am doing in the middle of things. prffrgt?
11. I have problems getting started on my own.
prstrt.
12. I am easily overwhelmed.
.prọṿ̣̣
13. I have trouble doing more than one thing at a time
14. My desk/workspace is a mess.
prmit
15. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.). ${ }_{\text {prremb }}$.
16. I have trouble prioritizing my activities. $\qquad$ prpiopert.
17. I read slowlythan others when completing my
prread
18. I am slower than others when completing my work ${ }_{\text {prwork }}$
19. I have trouble solving math problems in my head. prmath prpres
21. I have trouble staying on the same topic when talking
prtalk
22. I have a messy closet. prmesses
23. People say I am easily distracted. prdisst.
24. I have angry outbursts
25. I have a short attention span.
$\qquad$ prattụ
26. I overreact emotionally provract!
27. I have trouble organizing work.
28. I overreact to small problems.
$\qquad$ prorg?
29. I have problems organizing activities. $\qquad$30. I have emotional outbursts for little reason.provract?
31. I leave the bathroom a mess. $\qquad$ prmesss
32. I react more emotionally to situations than my friends.
33. I leave my room or home a mess.

If you answered "Sometimes" or "Often" to any of the questions in Section O, to what extent do the problems you may have checked interfere with your ability to function?


## OTHER ISSUES

Please rate how concerned you are about the following:


## Specify.

conspe
text
Please! Do not mark below this line

Have you been diagnosed with any of the following medical problems?
Q1. Depression
depdx $\quad 1 \square$ Yes $2 \square$ No

If yes, did you ever receive treatment? deptrt
$1 \square$
$\square$ Yes, in the past $2 \square$ Yes, currently $3 \square$ No
If yes, what type of treatment? (Mark all that apply) ydeptrt
$\square$ Behavior/talk therapy/counseling ydeptrt_talk
$\square$ Hospitalization ydeptrt_hosp
$\square$ Medication ydeptrt_med
List medications:
depmed1-depmed4 coded

## Q2. Anxiety <br> anxdx <br> $\square$ Yes $2 \square$ No

If yes, did you ever receive treatment? anxtrt
1Yes, in the past $2 \square$ Yes, currently $3 \square$ No

If yes, what type of treatment? (Mark all that apply) yanxtrt
$\square$ Behavior/talk therapy/counseling yanxtrt_talk
$\square$ Hospitalization yanxtrt_hosp
$\square$ Medication yanxtrt_med

## List medications:

anxmed1-anxmed4 coded

## Q3. Attention Deficit Disorder (with or without hyperactivity) <br> $\square$ Yes $2 \square$ No adddx

If yes, did you ever receive treatment? addtrt
$1 \square$ Yes, in the past $2 \square$ Yes, currently $3 \square$ No
If yes, what type of treatment? (Mark all that apply) yaddtrt
$\square$ Behavior/talk therapy/counseling yaddtrt_talk
$\square$ Hospitalization yaddtrt_hosp
$\square$ Medication yaddtrt_med
List medications: addmed1-addmed4 coded
Q4. Bipolar Disorder
biplrdx $\square$ Yes 2 No

If yes, did you ever receive treatment? biplrtrt
$1 \square$ Yes, in the past $2 \square$ Yes, currently $3 \square$ No
If yes, what type of treatment? (Mark all that apply) ybipirtrt
$\square$ Behavior/talk therapy/counseling ybiplrtrt_talkHospitalization ybipIrtrt_hosp
$\square$ Medication ybiplrtrt_med

## List medications:

biplrmed1-biplrmed4 coded

## Q5. Oppositional Defiant/Conduct Disorder odddx <br> $1 \square$ Yes $2 \square$ No

If yes, did you ever receive treatment? oddtrt
$1 \square$ Yes, in the past $2 \square$ Yes, currently $3 \square$ No

If yes, what type of treatment? (Mark all that apply) yoddtrt
$\square$ Behavior/talk therapy/counseling yoddtrt_talk
$\square$ Hospitalization yoddtrt_hosp
$\square$ Medication yoddtrt_med
List medications:
oddmed1-oddmed4 coded

Q6. Schizophrenia/Paranoia schizdx $1 \square$ Yes $2 \square$ No
If yes, did you ever receive treatment? schiztrt
${ }_{1} \square$ Yes, in the past $\quad 2 \square$ Yes, currently ${ }_{3} \square$ No
If yes, what type of treatment? (Mark all that apply) yschiztrt
$\square$ Behavior/talk therapy/counseling yschiztrt_talk
$\square$ Hospitalization yschiztrt_hosp
$\square$ Medication yschiztrt_med
List medications:

```
schizmed1-schizmed4 coded
```

Q7. Other psychiatric disorder (e.g. $\qquad$
If yes, please specify the disorder:
psydxsp coded

If yes, did you ever receive treatment? opsytrt
${ }_{1} \square$ Yes, in the past $\quad 2 \square$ Yes, currently $\quad 3 \square$ No
If yes, what type of treatment? (Mark all that apply) yopsytrt
$\square$ Behavior/talk therapy/counseling yopsytrt_talk
$\square$ Hospitalization yopsytrt_hosp
$\square$ Medication yopsytrt_med

## List medications:

opsymed1-opsymed4 coded

Do any of these medical conditions prevent you from attending work (or school) or engaging in leisure activities on a regular basis (more days than not)? psyint
$1 \square$
YesNo

If yes, which condition(s):
psyintsp1-psyintsp6 coded

