## ASPECTS OF CAREGIVING

### BOX AC1PRE

**QUESTION TEXT:**
If SP DECEASED flag = 1 (YES), go to AC5. Otherwise, go to AC1PRE.

### AC1PRE

**QUESTION TEXT:**
Now we have a few questions about your relationship with {SP}.
PRESS 1 AND ENTER TO CONTINUE

### AC1

**QUESTION TEXT:**
How much do you enjoy being with {SP}? Would you say a lot, some, a little, or not at all?

<table>
<thead>
<tr>
<th>CODES</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A LOT</td>
</tr>
<tr>
<td>2</td>
<td>SOME</td>
</tr>
<tr>
<td>3</td>
<td>A LITTLE</td>
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<tr>
<td>4</td>
<td>NOT AT ALL</td>
</tr>
<tr>
<td></td>
<td>REFUSED</td>
</tr>
<tr>
<td></td>
<td>DON'T KNOW</td>
</tr>
</tbody>
</table>

### AC2

**QUESTION TEXT:**
How much does {SP} argue with you? Would you say a lot, some, a little, or not at all?

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>A LOT</td>
</tr>
<tr>
<td>2</td>
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</tr>
<tr>
<td>3</td>
<td>A LITTLE</td>
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<tr>
<td>4</td>
<td>NOT AT ALL</td>
</tr>
<tr>
<td></td>
<td>REFUSED</td>
</tr>
<tr>
<td></td>
<td>DON'T KNOW</td>
</tr>
</tbody>
</table>

### AC3

**QUESTION TEXT:**
How much does {SP} appreciate what you do for {him/her}?
[Would you say a lot, some, a little, or not at all?]

<table>
<thead>
<tr>
<th>CODES</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A LOT</td>
</tr>
<tr>
<td>2</td>
<td>SOME</td>
</tr>
<tr>
<td>3</td>
<td>A LITTLE</td>
</tr>
</tbody>
</table>
AC4 \[cac7nerveslv\] \[C7 AC4 LEVEL SP ON YOUR NERVES\]

**QUESTION TEXT:**

How often does [he/she] get on your nerves?

[Would you say a lot, some, a little, or not at all?]

**CODES**

1. A LOT
2. SOME
3. A LITTLE
4. NOT AT ALL
   REFUSED
   DON’T KNOW

AC5 \[cac7moreconf\] \[C7 AC5A HLP SP U MORE CNF ABLTY\]
\[cac7dealbetr\] \[C7 AC5B HLP SP U DEAL W DIFF SIT\]
\[cac7closr2sp\] \[C7 AC5C HLP SP U R CLOSER TO SP\]
\[cac7moresat\] \[C7 AC5D HLP SP U STSFY SP CARED4\]

**DISPLAY INSTRUCTIONS:**

Use "Same Question Stem" display.

If at AC5a, do not display question text in brackets.
Otherwise, display question text in brackets.

If SP DECEASED flag <> 1 (YES), display “has” in AC5c.
Otherwise, use null display.

If SP DECEASED flag = 1 (YES), display “was” in AC5d.
Otherwise, display “is”.

**QUESTION TEXT:**

{} Next we have a few questions about your experience helping [SP]. For each statement I read, please tell me whether this describes your situation very much, somewhat, or not so much.{}

{variable text [a-d]}

RESPONSE [1] a. Helping [SP] has made you more confident about your abilities.
RESPONSE [3] c. Helping [SP] has brought you closer to [him/her].
RESPONSE [4] d. Helping [SP] has given you satisfaction that [he/she] [is/was] well cared for.

**CODES**

1. VERY MUCH
2. SOMEWHAT
3. NOT SO MUCH
   REFUSED
DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.

Display ‘variable text’ in the a-d sequence until all rows have been displayed.

<table>
<thead>
<tr>
<th>AC6</th>
<th>cac7diffinc</th>
<th>C7 AC6A FINANCIAL DIFF HELPING</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>cac7diffemo</td>
<td>C7 AC6B EMOTIONAL DIFF HELPING</td>
</tr>
<tr>
<td></td>
<td>cac7diffphy</td>
<td>C7 AC6C PHYSICAL DIFF HELPING</td>
</tr>
</tbody>
</table>

DISPLAY INSTRUCTIONS:
Use "Same Question Stem" display.
If at AC6a, do not display question text in brackets.
Otherwise, display question text in brackets.

If preloaded relationship of SP to Caregiver is 2 (spouse/partner), display "Helping a spouse or partner who has health problems can be difficult."

If preloaded caregiver is related to SP (relationship codes 3-29), display "Helping older relatives can be difficult."

Otherwise, use null display.

If SP DECEASED flag <> 1 (YES), display “Is helping {SP}”.
Otherwise, display “Has helping {SP} been”.

QUESTION TEXT:

{} [Helping a spouse or partner who has health problems can be difficult./Helping older relatives can be difficult.] {is helping {SP}/Has helping {SP} been}…{}

{variable text [a-c]}

RESPONSE [1] a. financially difficult for you?
RESPONSE [2] b. emotionally difficult for you?
RESPONSE [3] c. physically difficult for you?

CODES

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>YES</td>
</tr>
</tbody>
</table>
| 2 | NO
|   | REFUSED
|   | DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.

Display ‘variable text’ in the a-c sequence until all the rows have been displayed.

BOX AC7

BOX AC7

NOT ON FILE

If AC6a, 6b, and 6c = 2 (NO), RF, or DK, go to BOX AC8.
Otherwise, go to AC7.

<table>
<thead>
<tr>
<th>AC7</th>
<th>cac7diffinlv</th>
<th>C7 AC7A LEVEL FINANCIALLY DIFF</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>cac7diffemlv</td>
<td>C7 AC7B LEVEL EMOTIONALLY DIFF</td>
</tr>
</tbody>
</table>
CAC7C LEVEL PHYSICALLY DIFF

DISPLAY INSTRUCTIONS:
If AC6a = 1 (YES, FINANCIALLY DIFFICULT), display AC7a.
If AC6b = 1 (YES, EMOTIONALLY DIFFICULT), display AC7b.
If AC6c = 1 (YES, PHYSICALLY DIFFICULT), display AC7c.

Use "Same Question Stem" display.

If at first item, do not display question text in brackets.
Otherwise, display question text in brackets.

If SP DECEASED flag <> 1 (YES), display “is helping {SP}”.
Otherwise, display “has helping {SP} been”.

QUESTION TEXT:

{{Please tell me how difficult helping is by picking a number from 1 to 5. The number 5 means very difficult and the number 1 means a little difficult.}}{{

{variable text [a-c]}

{RESPONSE [1] a. How financially difficult {is helping {SP}/has helping {SP} been}?}
{RESPONSE [2] b. How emotionally difficult {is helping {SP}/has helping {SP} been}?}
{RESPONSE [3] c. How physically difficult {is helping {SP}/has helping {SP} been}?}

CODES

1 1 A LITTLE DIFFICULT
2 2
3 3
4 4
5 5 VERY DIFFICULT
   REFUSED
   DON’T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.

Display ‘variable text’ in the a-c sequence until all rows have been displayed.

BO0X AC7A  BOX AC7A  NOT ON FILE

If ((CA1 = 1 (HELPED WITH CHORES EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA2= 1 (HELPED WITH SHOPPING EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA3= 1 (HELPED ORDER MEDS)
or (CA4= 1 (HELPED WITH BILLS OR BANKING)
or (CA6 = 1 (HELPED WITH PERSONAL CARE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA7= 1 (HELPED GET AROUND HOME EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA9= 1 (HELPED DRIVE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA10= 1 (HELPED USE OTHER TRANSPORTATION EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or CA11A=1 (HELPED TRACK MEDS)
or CA11B=1 (HELPED WITH SHOTS OR INJECTIONS)
or CA11C=1 (HELPED MANAGE MEDICAL TASKS)
or CA11D=1 (HELPED WITH SKIN CARE)
or CA11A2A=1 (HELPED WITH EXERCISE)
or CA11A2B=1 (HELPED WITH SPECIAL DIET)
or LL1=1 (HELPED MANAGE PAIN LML)
or LL2=1 (HELPED WITH BREATHING LML)
or LL3=1 (HELPED WITH FEELINGS LML)
or LL6=1 (MADE MEDICAL DECISIONS FOR SP LML)), go to AC7A.
Otherwise, go to BOX AC7B.

AC7a

adic7choredif  C7 AC7AA LEVEL DIFFICULTY HELPING DO
chores
adic7shopdif  C7 AC7AB DIFFICULTY SHOPPING
adic7rxdif  C7 AC7AC DIFFICULTY ORDERING
medicine
adic7billsdif  C7 AC7AD DIFFICULTY BILLS BANKING
adic7caredif  C7 AC7AE DIFFICULTY PERSONAL CARE
adic7mobdif  C7 AC7AF DIFFICULTY GET AROUND
HOME
adic7drivdif  C7 AC7AG DIFFICULTY DRIVING
adic7transdif  C7 AC7AH DIFFICULTY USING
TRANSPORTATION
adic7medsdif  C7 AC7AI DIFFICULTY MANAGING
MEDICAL TASKS
adic7exrcsdif  C7 AC7AJ DIFFICULTY MANAGING
EXERCISE DIET
adic7painedif  C7 AC7AK DIFFICULTY MANAGING PAIN
adic7brethdif  C7 AC7AL DIFFICULTY MANAGING
BREATHING
adic7saddif  C7 AC7AM DIFFICULTY MANAGE ANXIETY
SAD
adic7decstif  C7 AC7AN DIFFICULTY MAKE MED
DECISIONS

DISPLAY INSTRUCTIONS:
If (CA1 = 1 (HELPED WITH CHORES EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display
AC7Aa.
If (CA2= 1 (HELPED WITH SHOPPING EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display
AC7Ab.
If CA3= 1 (HELPED ORDER MEDS), display AC7Ac.
If CA4=1 (HELPED WITH BILLS OR BANKING), display AC7Ad.
If (CA6 = 1 (HELPED WITH PERSONAL CARE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display
AC7Ae.
If (CA7= 1 (HELPED GET AROUND HOME EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display
AC7Af.
If (CA9= 1 (HELPED DRIVE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Ag.
If (CA10 1 (HELPED USE OTHER TRANSPORTATION EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display
AC7Ah.
If (CA11A=1 (HELPED TRACK MEDS) or CA11B=1 (HELPED WITH SHOTS OR INJECTIONS) or CA11C=1 (HELPED
MANAGE MEDICAL TASKS) or CA11D=1 (HELPED WITH SKIN CARE)), display AC7Ai.
If (CA11A2A=1 (HELPED WITH EXERCISE) or CA11A2B=1 (HELPED WITH SPECIAL DIET)), display AC7Aj.
If LL1=1 (HELPED MANAGE PAIN LML), display AC7Ak.
If LL2=1 (HELPED WITH BREATHING LML), display AC7Al.
If LL3=1 (HELPED WITH FEELINGS LML), display AC7Am.
If LL6=1 (MADE MEDICAL DECISIONS FOR SP LML), display AC7An.
If CA11A=1 (HELPED TRACK MEDS), display “medications” in AC7Ai.
If CA11B=1 (HELPED WITH SHOTS OR INJECTIONS), display “shots or injections” in AC7Ai.
If CA11C = 1 (HELPED MANAGE MEDICAL TASKS), display “medical tasks” in AC7Ai.
If CA11D = 1 (HELPED WITH SKIN CARE), display “skin care” in AC7Ai.
If more than one task displayed in AC7Ai, display commas between each one and "and" before the last task display text.
If CA11A2A = 1 (HELPED WITH EXERCISE), display “exercises” in AC7Aj.
If CA11A2B = 1 (HELPED WITH SPECIAL DIET), display “special diet” in AC7Aj.
If more than one task displayed in AC7Aj, display “and” between the two task display texts.

If SP DECEASED flag = 1 (YES), display “of [his/her] life” in stem question text.

Use "Same Question Stem" display.
If at first item (among those displayed), do not display question text in brackets.
Otherwise, display question text in brackets.

**QUESTION TEXT:**

{[}Next, for each task that you helped {SP} with in the last month {of [his/her] life}, please tell me if it was very, somewhat, a little or not at all difficult for you.[]}

{variable text [a-n]}

RESPONSE [1] a. doing chores around {his/her} home?
RESPONSE [2] b. shopping for {his/her} groceries or personal items?
RESPONSE [3] c. ordering {his/her} prescribed medicines?
RESPONSE [4] d. handling {his/her} bills and banking?
RESPONSE [5] e. providing personal care?

IF NEEDED: This includes help eating, showering, bathing, dressing or grooming, or using the toilet.

RESPONSE [6] f. helping {him/her} get around {his/her} home?

IF NEEDED: This includes getting out of bed, getting around inside, leaving home to go outside.

RESPONSE [7] g. driving {him/her} places?
RESPONSE [8] h. using transportation with {him/her}?
RESPONSE [9] i. managing {his/her} {medications} {shots or injections} {medical tasks} {skin care}?
RESPONSE [10] j. managing {his/her} {exercises} {special diet}?
RESPONSE [11] k. managing {his/her} pain in the last month of {his/her} life?
RESPONSE [12] l. managing {his/her} breathing in the last month of {his/her} life?
RESPONSE [13] m. managing {his/her} anxiety or sadness in the last month of {his/her} life?
RESPONSE [14] n. making medical decisions for {him/her} in the last month of {his/her} life?

**CODES**

1    VERY DIFFICULT
2    SOMEWHAT DIFFICULT
3    A LITTLE DIFFICULT
4    NOT AT ALL DIFFICULT
5    REFUSED
6    DON’T KNOW

**PROGRAMMER INSTRUCTIONS:**

Array the responses and variable text columns in the panel.
Display 'variable text' in the a-n sequence until all rows have been displayed.

**BOX AC7B**

If (HC1 = 1 (COMMUNICATED WITH PROVIDERS) or HC5a = 1 (MADE APPTS FOR SP) or HC5b = 1 (LOGGED IN ONLINE FOR MED INFO) or HC5c = 1 (COORDINATED SP’S CARE) or HC6a = 1 (HELPED CHANGE/ADD

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NSOC :: AC
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HEALTH INS) or HC6b = 1 (HANDLED OTHER HEALTH INS) or HC7 = 1 (HELPED AFTER OVERNIGHT STAY)), go to AC7B. Otherwise, go to BOX AC8.

AC7b        cac7talkdif  C7 AC7BA LEVEL DIFFICULTY COMMUNICATE PROVIDERS
             cac7coorddif  C7 AC7BB DIFFICULTY COORDINATE MED CARE
             cac7insurdif  C7 AC7BC DIFFICULTY HANDLE HEALTH INSURANCE
             cac7hospdif   C7 AC7BD DIFFICULTY TRANSITION POST HOSP CARE

DISPLAY INSTRUCTIONS:
If HC1 = 1 (COMMUNICATED WITH PROVIDERS), display AC7Ba. If HC5a = 1 (MADE APPTS FOR SP) or HC5b = 1 (LOGGED IN ONLINE FOR MED INFO) or HC5c = 1 (COORDINATED SP’S CARE), display AC7Bb. If HC6a = 1 (HELPED CHANGE/ADD HEALTH INS) or HC6b = 1 (HANDLED OTHER HEALTH INS), display AC7Bc. If HC7 = 1 (HELPED AFTER OVERNIGHT STAY)), display AC7Bd. Use "Same Question Stem" display. If at first item to be displayed and AC7Aa-n = NULL, do not display question text in brackets. Otherwise, display question text in brackets.

If SP DECEASED flag=1 (YES) display “of {his/her} life”.

QUESTION TEXT:
{}Next, for each task that you helped {SP} with in the last year {of {his/her} life}, please tell me if it was very, somewhat, a little or not at all difficult for you.{}
{}variable text [a-d]{}
RESPONSE [1] a. communicating with {his/her} medical providers?
RESPONSE [2] b. coordinating {his/her} health care?
IF NEEDED: This includes help with making appointments, checking results, and coordinating care across providers.
RESPONSE [3] c. handling {his/her} health insurance matters?
RESPONSE [4] d. transitioning {his/her} care after a hospital stay?

CODES
1 VERY DIFFICULT
2 SOMEWHAT DIFFICULT
3 A LITTLE DIFFICULT
4 NOT AT ALL DIFFICULT
REFUSED
DON’T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.
Display 'variable text' in the a-d sequence until all rows have been displayed.

BOX AC8
BOX AC8
NOT ON FILE
If preloaded relationship of Caregiver to SP is 2 through 12, go to AC8.
Otherwise, go to BOX AC9PRE.

**AC8**

**question text:**
In general, how much has your family disagreed over the details of (SP)’s care? Would you say very much, somewhat, or not so much?

**codes**

1. VERY MUCH
2. SOMewhat
3. NOT SO MUCH
4. REFUSED
5. DON’T KNOW

**AC8A**

**display instructions:**
If SP DECEASED flag <> 1 (YES), display “do”. Otherwise, display “have done”.

**question text:**
Families sometimes share responsibility for caring for an older relative. In general, do you think you do more than your fair share, less than your fair share, or a fair amount?

**codes**

1. MORE THAN FAIR SHARE
2. LESS THAN FAIR SHARE
3. FAIR AMOUNT
4. REFUSED
5. DON’T KNOW

**BOX AC9PRE**

**display instructions:**
Use “Same Question Stem” display.

If at AC9a, do not display question text in brackets.

Otherwise, display question text in brackets.

**question text:**

If SP DECEASED flag =1 (YES), go to SECTION SE – SUPPORT ENVIRONMENT.
Otherwise, go to AC9.
{} Please listen to a few more statements and answer whether this describes your situation very much, somewhat, or not so much.{}

{variable text [a-d]}

RESPONSE [1] a. You are exhausted when you go to bed at night.
RESPONSE [2] b. You have more things to do than you can handle.
RESPONSE [3] c. You don't have time for yourself.
RESPONSE [4] d. As soon as you get a routine going, {SP}'s needs change.

CODES
1       VERY MUCH
2       SOMEWHAIT
3       NOT SO MUCH
        REFUSED
        DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.

Display 'variable text' in the a-d sequence until all rows have been displayed.

Go to Section SE - Support Environment.