

C.A.R.E. Tool

An Assessment of

Caregivers' Aspirations, Realities and Expectations

Guberman, Keefe, Fancey, Nahmiash & Barylak

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Revised Edition – October 2003

Caregiver's name :

Care Receiver's name :

File number :

Assessor's name :

Date(s) of interview :

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Both the C.A.R.E. Tool and the Caregiver Risk Screen are available in French.

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C.A.R.E. TOOL

Introduction

Caregivers are people who provide ongoing assistance or support to a chronically ill or disabled family member, friend or neighbour. Caregivers' needs have too often been neglected by health and social service agencies, and their role in caring has generally been taken for granted. This tool has been developed to help remedy this situation.

Before conducting this assessment with caregivers, consider some of the factors that may impact on their situation, their feelings about their role, and their feelings about participating in an assessment.

Many people do not identify themselves as "caregivers."

Care relationships are built on prior experiences and relationships between the caregiver (CG) and care receiver (CR) that continue after the CR becomes ill. Many caregivers do not see themselves as a "caregiver," but rather as the mother, partner, son or friend of the person receiving care.

Caregiving can occur suddenly.

Meaning that caregivers have to deal with stressful situations with little preparation or prior experience.

Caregivers often provide care in isolation with little support.

Cutbacks in hospital beds and community programs have meant that most caregivers have few resources outside of home care to turn to. In addition, the primary caregiver often becomes isolated from her/his family and social networks.

Many issues pertaining to caregiving can be fraught with emotion.

It can be surprising where these issues emerge. It is important to be patient and allow the CG to express his or her feelings freely.

Caregivers are each unique individuals who cope with situations differently.

Each caregiver will have unique pressures and rewards derived from the caregiving situation. Each will draw on and provide care according to certain cultural, religious or family values or beliefs.

Potential stressors for the caregiver also exist outside of the caregiving relationship.

These stressors can impact on a caregiver's level of burden. For example, elderly caregivers frequently have health problems, while younger caregivers often have additional family/work responsibilities.

Caregivers often have trouble identifying their own needs and asking for help from services.

Since caregivers are rarely approached about their needs and are often totally focused on caregiving activities, it can be difficult to change the focus of their concern from the CR's needs to their own. Be patient as caregivers consider these questions.

Caregivers are often hesitant to use formal services and may be resistant to an assessment.

Fear of being judged on their caregiving, negative past experiences with formal services and personal values can all lead to hesitation in using formal services and accepting an assessment. It is important to discuss the purpose of the assessment openly.

Caregivers may not want to complete another assessment.

Caregivers may have already completed numerous assessments along with the care receiver and may find completion of another assessment overwhelming. Also, their needs are rarely taken into account in general agency assessments, so caregivers may feel frustrated by a lack of intervention geared toward previously identified concerns. You may want to discuss how this may give them their first opportunity to reflect on their own situation.

Using agency and community services can be overwhelming.

Locating appropriate information and using formal services can be very complex, particularly in a fragmented service system. It can often be stressful for a caregiver to consider the possibility of becoming involved in additional services for him or herself. The assessor can help relieve these feelings by explaining the role of case managers, if this is appropriate.

The C.A.R.E. Tool

Given the tremendous impact caring can have on caregivers and their lack of status and recognition with health and social service systems, the C.A.R.E. Tool was created to provide a method for practitioners to systematically evaluate the needs of caregivers themselves.

The C.A.R.E. Tool is composed of ten (10) sections that cover different aspects of a caregiver's situation, plus a summary section designed to pinpoint the key areas of difficulty being experienced by the caregiver. The summary section is to be filled out by the assessor alone, following the interview.

Sections are organized so as to start with more factual, less threatening issues, with more intimate issues nearer the end. Depending on the specific situation, the assessor may wish to modify the order. Each section is designed to elicit information from the caregiver's perspective. A "user guide" is provided on the facing pages of the tool to help explain questions and provide examples.

An important phase in the development of the tool was rigorous testing and validation carried out in collaboration with practitioners themselves. For more information on the reliability and validity results, please contact one of the authors listed below.

In summary, the purpose of the tool is...

- ♦ to enable a CG to discuss various aspects of her/his situation.
- ♦ to identify the specific services needed to support the CG.
- ♦ to provide the assessor with an understanding of the CG's daily experiences.
- ♦ to understand the conditions, context and consequences of caring situations.

When conducting the assessment...

- ♦ all answers should be recorded accurately and completely.
- ♦ all answers should reflect the CG's response.
- ♦ you will need to revisit sections in the assessment to complete the summary sheet. There is a box at the end of each page to allow you to record additional notes and to check areas that are causing difficulty and need consideration when doing the summary.
- ♦ the tool was designed for one primary CG with one primary adult CR. If there are two primary CGs, we recommend using the *C.A.R.E. Tool* with both of them separately (doing a separate assessment with each). If there is more than one primary CR we recommend filling out sections 2, 8 and 9 separately for each CR.
- ♦ we recommend that the assessment be done in private without the presence of the care receiver to allow the caregiver to speak freely on these subjects.

Remember...

- ♦ every caregiver has the right to refuse to answer a question or a section. If this happens, simply write "refused" in the space provided. If this happens more than once, you may want to verify the caregiver's desire to participate in the evaluation.
- ♦ issues raised can be very emotional for the caregiver.
- ♦ you may not be able or may not want to finish the evaluation in one session. Indeed, a comprehensive psycho-social assessment requires the building up of trust between the parties. This may take more than one session.
- ♦ the tool can be adapted to the specific situation of each caregiver. Not all sections are relevant to all caregivers. However, it is better to let the caregiver decide whether a section should be omitted or not. In the same way, the wording of certain questions may have to be adapted to the specific situation.
- ♦ you may want to share the tool with the caregiver rather than just posing the questions. In this way you can fill it out together.

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SECTION 1

CAREGIVER AND CARE RECIPIENT PROFILES

“Getting to know you and the caregiving situation”

1 A. Instructions

- ♦ the name, address, phone number, and sex of the CG can be filled out before the interview
- ♦ obtain the rest of the information from the CG

Definitions/Examples

Marital Status	the current status to which the CG identifies (e.g. single, divorced, married, common-law, widowed)
Ethnic Origin	the group of people holding similar customs, language, & characteristics to which the CG identifies affiliation; if the CG prefers, can state race or nationality
Language at Home	the language that the CG most commonly uses for communication
Approximate Distance	how close the CG lives to the CR (e.g. 2 blocks away, in the next town, 20 minutes away)
Who Else Lives with CG	anyone living with the CG whether or not CG lives with the care recipient
Length of Caregiving	total length of time providing care to CR if it has been a long time and more recent years have been more intensive, indicate length of more intensive years in brackets — e.g. 30 years (10 years intensive).

1 B. Instructions

- ♦ obtain the information from the CG
- ♦ some information you may know from the previous section and will not have to ask again (e.g. if CG and CR co-reside, who else lives with CR, language spoken)

Definitions/Examples

Illness / Disability	any diagnosed physical/mental condition, or a limitation caused by a physical/mental illness or episode (e.g. stroke, Alzheimer's Disease, schizophrenia, etc.)
Language Spoken	the language that the CR most commonly uses for communication; if the CR is unable to speak or has lost language abilities, please indicate
Interpreter	someone required if the care recipient does not speak the same primary language as either the CG or formal services, or both, and translation is required to assist with caregiving tasks; the interpreter could be the CG, a family member or service professional
Formal Services	assistance with physical tasks/emotional support that is received from volunteers or paid personnel from a service organization/program; identify the type of service being provided (e.g. homemaker, meals on wheels, etc.)

1. PROFILES

1 A. Caregiver Profile

Name	Address
Phone	
Sex <input type="checkbox"/> F <input type="checkbox"/> M	
Age	Marital Status
Ethnic origin	Language spoken at home
Relationship The Care Recipient is the.....of the CG.	
Does the CG live with the care recipient.....Yes No	
If no , approximate distance between CG's and CR's residences	
Who else lives with CG?	
Length of caregiving	Length of period of intensity (if applicable)

1 B. Care Recipient Profile

Name	Sex <input type="checkbox"/> F <input type="checkbox"/> M
Age	Marital status
Illness / disability	
Language spoken	
Ethnic Origin	
Does the CR require an interpreter? Yes No	
If yes , who acts as interpreter?	
Who else lives with CR?	
Is CR receiving any formal or community services? Yes No	
If yes , what type of service(s)?	

Notes: _____ Difficulties here/
_____ Review

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SECTION 2

DESCRIPTION OF CAREGIVING WORK AND SUPPORT

*"Helping others involves many activities...
understanding the help you provide and the difficulties that may exist"*

2.1

To understand...

- ◆ the types of activities the CG is helping with
- ◆ the types of help being provided with each activity
- ◆ the support others are providing with each activity
- ◆ the difficulty experienced with each activity or with the support provided

Instructions

1st column ask question and read activities

2nd column if YES, specify:

intensity.....(e.g. reminding, supervising, partial help)

frequency.....(e.g. daily, weekly, periodically)

3rd column if YES, specify:

relationship to CG (e.g. spouse, sister, nurse, volunteer)

4th column you can ask the question for the entire block of items without necessarily going back over each activity.

If YES, specify; could be related to:

ExamplesCR's dependence on CG for support

.....CR's behaviour (e.g. confusion)

.....lack of support (e.g. no help at night)

.....lack of services (e.g. in rural areas)

.....caregiver's health

Definitions/Examples

Feeding	e.g. spoon feeding, supervising CR feed self, G-tube feeding
Grooming	e.g. brushing hair, shaving
Incontinence care	ostomy care, changing urinary pads or catheter condoms
Mobility	supporting CR to walk, pushing CR's wheelchair
Transfers	helping CR in/out of wheelchair, bed, toilet, chair
PT/OT exercises	physiotherapy or occupational therapy exercises the CR does at home
Nursing/medical care	e.g. dressing changes, insulin injections glucose monitoring, monitoring oxygen
Household work	work done to support the functioning of the household (in cases where the CG and CR live apart, this refers to household work done only for the CR)

2.1.1 to 2.1.2

Instructions Indicate if CG is using any equipment

Definitions/Examples

- ◆ lift malfunctioning; glucose monitor inaccurate, discomfort using equipment, etc.

DESCRIPTION OF CAREGIVING WORK AND SUPPORT RECEIVED

2.1 List of caregiving tasks: intensity, support, problems or difficulties

Do you help or remind CR to do any of the following tasks?	Yes / No / N/A If yes , specify what you do.	Does anyone else provide help with this task? If yes , specify who.	*Are you having difficulties with any of these tasks? Yes / No If yes , specify how.
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Physical /Nursing care

Feeding			
Dressing			
Bathing / showering			
Grooming			
Incontinence care			
Mobility of CR			
Transfers			
PT/OT exercises			
Take medications			
Nursing/ medical care			

*This question can be asked after each activity or at the end of each block

2.1.1 Is equipment being used for any of this care? Yes No

If yes, does this cause any difficulties? Yes No

If yes, why _____

2.1.2 Do you need any other kind of equipment? Yes No

If yes, specify _____

Household Work

Preparing meals			
Shopping/errands			
Laundry			
Housecleaning			
Yard work / maintenance			
Banking /finances/ legal help			

*This question can be asked after each activity or at the end of each block

Notes: _____ Difficulties here/
_____ Review

2.2

To understand...

- ♦ the extent of support/supervision provided to the CR by the CG
- ♦ the extent to which the CG helps to coordinate activities & services that serve to benefit the CR

Instructions

1st column ask question and read first activity

2nd column if YES, specify:

details.....(e.g. stays home at night, monitors exits)

frequency.....(e.g. daily, weekly, periodically)

3rd column if YES, specify:

relationship to CG (e.g. spouse, sister, nurse, volunteer)

4th column you can ask the question for the entire block of items without necessarily going back over each activity.

if YES, specify; could be related to:

Examples..... CR's dependence on CG for support

..... CR's behaviour (e.g. confusion)

..... lack of support (e.g. no help at night)

.....lack of services (e.g. in rural areas)

.....caregiver's health

Definitions/Examples

Reassure CR	provide emotional support, understanding
Encourage CR	to participate in activities e.g. encouraging CR to go out to a program, to see friends
Prevention of injuries	e.g. ensuring CR does not operate stove, maintaining a lock on the door
Interpreting for CR	translating between CR and home care workers, medical professionals, etc.
Step in to improve relations	talking with landlords, neighbours, lawyers, bank on behalf of CR

2.2 Support and Coordination

Do you need to:	Yes / No / N/A If yes , specify what you do.	Does anyone else provide help with this task? If yes , specify who.	*Are you having difficulties with any of these tasks? Yes / No If yes , specify how.
-----------------	--	--	--

Support / Supervision

Stay in the house so that CR feels safe			
Reassure CR			
Correct or change dangerous, unwanted or difficult behaviours of the CR			
Encourage CR to participate in different activities			
Ensure prevention of injuries, accidents and wandering			
Check on CR at night			

*This question can be asked after each activity or at the end of each block

Coordination

Locate / set up/ check on services			
Organize and/or train support workers			
Make and accompany CR to appointments			
Interpret for CR			
Arrange / provide transportation			
Step in to improve relations between CR and others			
Other, specify			

*This question can be asked after each activity or at the end of each block

Notes: _____ Difficulties here/ Review

2.3

To understand...

- ♦ if the CG feels the current support is adequate in regard to specific activities
- ♦ if the CG feels that additional support is required for specific activities

2.4

To understand...

- ♦ if changes are required to the support currently received
- ♦ if there are reasons help was stopped in the past, that may affect receiving services now (e.g. CR's behaviour, conflict with family, dissatisfaction with services, etc.)

2.5

To understand...

- ♦ if the CG feels current support is adequate at specific periods of the day or in crises, rather than with specific activities

Instructions

- ♦ ask question, reading each period of time to the CG
- ♦ if no, ask CG to elaborate and record details (e.g. trouble scheduling home care, help unavailable on weekends)

Definitions/Examples**Crisis Situation**

- ♦ CR or CG becoming suddenly ill
- ♦ a sudden or dangerous change to CR's living environment (e.g. fire)
- ♦ CG becoming unable to provide care (e.g. being called away)
- ♦ CR wanders away or becomes lost

2.6 to 2.7

To understand how the CG perceives...

- ♦ how frequently she/he provides help to CR
- ♦ her/his level of personal involvement

① Occasional/part-time caregivers can also feel high levels of stress or be highly preoccupied with the caregiving role.

Definitions/Examples

24 hours/day ♦ provides most daily care and night care/supervision; most likely lives with CR

Full-time ♦ considers caring equals a full-time job (i.e. 30+ hours/week)

♦ may live with CR or spend bulk of time caring for CR at another residence; may receive some help

Part-time ♦ considers caring equals a part-time job (i.e. 10-30 hours/week)

♦ most likely does not live with the CR or is less involved in care provision; may work outside the home; may receive some help

Occasional ♦ provides care on a weekly basis or in times of crisis/psychosis of CR

♦ CR may be more independent; CG may also receive extensive additional help

2.8

To understand...

- ♦ how the CG first became involved in care and how this may impact on present situation

2.9 to 2.10

To understand...

- ♦ if there are other times when the CG feels support is not adequate

2.3 What would you like to have help for, or more help for? _____

2.4 Is there help that you have had in the past that has stopped? Yes No
If yes, why? _____

2.5 Do you have the help you need:

in the morning?	Y	N	If no , comments _____
in the afternoon?	Y	N	If no , comments _____
in the evening?	Y	N	If no , comments _____
at night?	Y	N	If no , comments _____
on weekends or holidays?	Y	N	If no , comments _____
in a crisis situation?	Y	N	If no , comments _____

2.6 Would you consider that your caregiving responsibilities are:

24 hours/day _____	Full-time _____	Part-time _____	Occasional _____
--------------------	-----------------	-----------------	------------------

2.7 Would you say your helping role preoccupies you:

All the time _____	Often _____	Sometimes _____	Rarely _____
--------------------	-------------	-----------------	--------------

2.8 How and why did you become the main person responsible for CR's care? _____

2.9 Who do you feel you can really count on for support? _____

2.10 Are there moments when you feel without help? Yes No
If yes, specify _____

Notes: _____ Difficulties here/

FOR REFERENCE ONLY

SECTION 3

CAREGIVER'S RELATIONSHIP TO FORMAL SERVICES

"Learning more about your relationship with others who provide help, such as doctors and other health professionals"

3.1 to 3.6

To understand...

- ♦ if the CG is involved in decisions regarding CR's medical treatment or service allocation
- ♦ if there are difficulties receiving/understanding such information (e.g. language/translation problems, poor access to information, discomfort with professionals)
- ♦ if there are difficulties discussing with medical personnel the use of non-traditional, alternative healing practices (e.g. faith healers, acupuncture, chiropractor)

SECTION 4

HOUSING

"Understanding how and where you live..."

4.1 to 4.2

To understand...

- ♦ if the CG is experiencing any difficulties with current living arrangements or housing conditions

Definitions/Examples

Living Arrangements	lack of privacy, tension in household
Housing/Structural	lack of accessibility, poor heating, too many stairs, repairs needed, etc.
Transportation	distance between residences, lack of a vehicle or driver's licence

4.3 to 4.4

To understand...

- ♦ if the CG is experiencing difficulty providing care due to where she/he lives or due to transportation problems

Definitions/Examples

Services	poor access to medical/emergency services
Transportation	high cost of transportation / poor transportation service
Driving	poor road conditions/complexity of city driving / distance to CR's home

4.5

To understand...

- ♦ if the CG anticipates any changes to the above due to providing care

3. CAREGIVER'S RELATIONSHIP TO FORMAL SERVICES

- 3.1 Who in your family has the final say in decisions about CR's care? _____
- If it is the caregiver, go to 3.2**
- 3.1.1 Is it a problem for you? Yes No
- 3.1.2 If yes, why? _____
- 3.2 Are you able to participate in decisions about the homecare or other services CR or you are receiving? Yes No
- 3.2.1 **If no**, is it a problem for you that you don't take part in the decision making? Yes No
- 3.3 Do you feel you are involved in decisions concerning medical treatment for CR? Yes No
- 3.3.1 **If no**, would you like to be? Yes No
- 3.4 Have you received information about CR's health? Yes No
- If no, go to 3.5**
- 3.4.1 **If yes**, do you understand this information? Yes No
- 3.4.2 Do you feel you have enough information about CR's health problems or conditions? Yes No
- 3.5 Do you feel comfortable asking the medical personnel, that is hospital staff or CR'S personal doctor, for information, or for more information? Yes No
- 3.5.1 Do you feel comfortable asking medical personnel about alternative helping practices? Yes No
- If no**, specify _____
- 3.6 Do you encounter any problems related to services due to the language spoken by CR or CR's culture (nationality, religion, values, different lifestyle, etc.) Yes No
- If yes**, specify _____

4. HOUSING

- 4.1 What difficulties, if any, do your living or housing arrangements cause? _____
- 4.2 What difficulties, if any, do you have concerning the condition of your house as it relates to caregiving? _____
- 4.3 Does the fact that you live in a (*rural, small town, suburban, urban*) area create any problems for you with regard to your caring role? Yes No
- If yes**, specify _____
- 4.4 Are there any specific concerns you have about transportation? Yes No
- What are they? _____
- 4.5 Do you foresee any changes in your living arrangements in the next year because of the care you provide to CR? Yes No
- If yes**, specify _____

Notes: _____ Difficulties here/ Review

SECTION 5

JUGGLING RESPONSIBILITIES

“Managing caregiving with the other responsibilities in life can also impact on your life...”

5.2

To understand...

- ♦ the extent of additional responsibilities assumed by the CG

Instructions

- ♦ read each category to the CG
- ♦ write in details as required

Definitions/Examples

Other Child Care	the provision of supervision, meals, and/or direct care to children outside of the CG's immediate family (e.g. grandchildren, neighbors children, paid babysitting)
Leisure/hobbies	any activity the CG does to relax or exercise (e.g. sports, bingo, art classes)
Other Care Responsibilities	occasional caregiving provided to someone besides the CR (can include relative who lives away or in institution)

If leisure/hobbies are the only commitment named but are negligible in terms of responsibilities, CG may be treated as having no other commitments.

5.3 to 5.4

To understand...

- ♦ how the CG copes with additional responsibilities
- ♦ the impact of having these responsibilities in addition to caregiving

5.5 to 5.7

To understand...

- ♦ if the CG has had to give up a job or significant commitments to provide care
- ♦ if quitting caused financial hardship or stress
- ♦ if the CG is considering modifying or leaving employment due to caregiving

5. JUGGLING RESPONSIBILITIES

5.1 Do you have children? Yes No If so, what are their ages? _____

Among these, how many do you provide care for? _____

5.2 Do you assume other important responsibilities or commitments?

Other child care? Yes No # of children _____

Education Yes No

Religious Activities Yes No

Volunteer Yes No

Paid work Yes No Hours per week? _____

Type of work? _____

Leisure/hobbies Yes No

Other care responsibilities Yes No For whom and where? _____

Hours per week? _____

Other Yes No Specify _____

If caregiver currently has no other commitments go to 5.5

5.3 How do you manage to juggle your responsibilities, commitments and caring for CR? _____

5.4 In terms of juggling your responsibilities including your caring for CR, what part of the day or week is the most difficult for you? Why? _____

5.5 Have you dropped or do you intend to drop any of your commitments or responsibilities because of your caring role?

No If now employed, go to 5.8

If not employed, go to 6

Yes What have you given up? _____

5.6 How has this decision changed or will it change your financial situation? _____

5.7 How has this decision affected or changed you or your caring role? _____

Notes: _____ Difficulties here/
_____ Review



5.8 to 5.12

To understand...

- ◆ the impact of the caregiving situation on the CG's employment
- ◆ whether the CG has had to make adjustments to current employment due to caregiving
- ◆ whether these adjustments have caused financial hardship or stress
- ◆ how adjustments to employment may have affected the CG's future finances

Definitions/Examples

Absences	CG needs to take days off to provide care
Less productivity	less work is accomplished because of preoccupation, stress, tiredness, or absences/interruptions
Changed Work Schedule	CG changes to a shared workload, changes status from full-time to part-time or casual, or changes hours of work (i.e. starting later and working more into the evening)
Financial situation	early retirement, purchase of house, savings, salary advancement, lower contributions to CPP, RRSP, investments, etc.

5.8 How often has your work been affected by your caring role in the following ways?

	Often	Sometimes	Rarely / never
Absences			
Interruptions			
Arriving to work later than usual			
Having to leave earlier than usual			
Lack of concentration			
Less productivity than usual			
Other, specify			

5.9 Have you made any of the following adjustments or changes to your paid employment as a result of your care responsibilities?

	Often	Sometimes	Rarely / never
Refused work			
Refused new responsibilities			
Reduced hours			
Changed work schedule/times			
Used vacation or sick days for care responsibilities			
Other, specify			

5.10 How have these adjustments affected you personally? _____

5.11 How have these adjustments changed your financial situation? _____

5.12 Do you think they will in the future? Yes No

If yes, explain. _____

Notes: _____ Difficulties here/
_____ Review

☐

SECTION 6

FINANCIAL COSTS OF CAREGIVING

"Providing care can involve numerous expenses..."

6.1

To understand...

- ♦ how the income of CG and CR is perceived
- ♦ if one person in the caregiving relationship is dependent on the other's income

Instructions

- ♦ check off the category that best represents this situation
- ♦ how it affects CG → try to establish if one is dependent on the other and any tension this may create

Definitions/Examples

Family Income any income goes into one general account to pay bills and care-related expenses

6.2

To understand...

- ♦ how frequently care-related costs occur → for either CR or CG
- ♦ if the cost is creating difficulty for the CG
- ♦ if the expenses are covered by a program or service (e.g. Veteran's Affairs)

Instructions

- ♦ read each item to the CG
- ♦ read each possible response to the CG → check one only as chosen by the CG
- ♦ Ask the CG each time if it creates problems → briefly record all answers given

Definitions/Examples

Medical Supplies	items required to complete physical or nursing tasks, or to assist with mobility (e.g. urinary pads, syringes, wheelchair, etc.)
General Supplies	items required to carry out caregiving tasks that are not considered medical supplies (e.g. plastic bibs, creams)
Special Diets	specific food or supplementation (e.g. "Ensure") required for the CR's particular health condition or to maintain the CR's general physical health
Home Adaptations	any structural modification/addition made to the residence where care is provided to accommodate the needs of the CR, or to ease caregiving tasks (e.g. widening doorways, building a ramp, etc.)
Transportation	specialized vehicle (e.g. wheelchair van) transportation service (e.g. wheelchair accessible bus, ambulance, taxi) cost of fuel for transport to/from caregiving or to/from care-related appointments
Additional Groceries	any grocery items separate from dietary supplements required to maintain CR's diet requirements, that may have been added since assuming care
Additional Heating/Utilities	services which may have been added since CR moved in to CG's home
Respite	a temporary intermission from caregiving activities to provide opportunities for rest or attendance to personal activities (including in home respite/day program)

6.3 to 6.6

To understand...

- ♦ if the CG is aware of financial programs/tax benefits regardless of any financial problems
- ♦ if the CG may need assistance from these programs in the future

① It is helpful to have on hand brochures or information on benefit programs/tax credits.

6. FINANCIAL COSTS OF CAREGIVING

Please note the following to the CG:

- ◆ Caregivers often assume many costs associated with care, and for some, these costs can be a source of considerable difficulty. However, money can be a delicate issue.
- ◆ Caregiver is not obliged to answer any questions if she/he would prefer not to.

6.1 Which of the following choices best describes your and CR's income situation?

- ☐ Our income is considered as family income (everything is together)
 ☐ You and CR have separate incomes
- ☐ CR has only income
 ☐ CG has only income

6.1.1 Does the situation you described cause any problems for you or for CR?.....Yes No

If yes, What are they? _____

6.2 We would like to look at the financial cost of care and whether this causes any problems for you.

How often do you or CR pay for the following?	Often	Sometimes	Rarely / never	Does this create any problems for you?
Medical supplies or equipment				
Medication				
General supplies				
Special diets				
Home adaptations				
Transportation				
Additional groceries				
Additional heating/utilities				
Cost of respite/day centre				
Cost of hiring private help				
Moving costs				
Legal/notary fees				
Unforeseen expenses				
Other, specify				

6.3 Are you or CR reimbursed for any of these expenses? Yes No

If yes, specify which items, and by whom _____

6.4 Are you aware of financial programs to assist in the purchase of some of these items? Yes No

6.4.1 Do you know about available tax credits for caregivers? Yes No

6.4.2 **If yes**, are you or CR benefiting from these programs? Yes No

6.5 Are there medications, supplies or treatments that CR should have, but that cannot be afforded? Yes No

If yes, specify _____

6.6 In the next year, what new expenses will be necessary for caregiving (renovations, moving, wheel chair)? Yes No

If yes, specify _____

Notes: _____ Difficulties here/ Review

SECTION 7

PERSONAL HEALTH

"Taking care of someone can affect your health..."

7.1 to 7.3.1

To understand...

- ◆ whether the CG has any health problems
- ◆ how the CG perceives her/his current level of health
- ◆ how the CG perceives poor health as affecting her/his life in general → not necessarily in relation to caregiving

Definitions

Physical Health	state of well-being of the body; including but not limited to experiencing illness
Emotional Health	frequency of negative emotions and the quality of spiritual and social well-being

7.4

To understand...

- ◆ whether the CG has experienced a change in her/his physical health

Instructions

- ◆ in long term caring situations (e.g. mother caring for adult child) → ask if changes have occurred within 5 years
- ◆ read each item to the CG and allow her/him to choose from the responses given
- ◆ ensure the answer is given by the CG → not your interpretation

Definitions/Examples

General Nutrition	the CG's eating habits (frequency and type of food)
Medical Condition	an illness or disease that has been diagnosed by a medical physician/psychiatrist and is currently being treated/monitored
Doctor/Dentist	if the CG is able to keep up routine check-ups and attend to personal health concerns
Medication	any prescribed or over-the-counter medication; CG may be abusing meds or may need to use more to relieve headaches, backaches, etc. or any other drug, either legal or illegal
Sexual Life / intimacy	the quality of the CG's sexual relations or intimacy with partner
Weight	refers to either a weight loss or gain → as defined as problematic to CG

7. PERSONAL HEALTH

7.1 Do you have any specific medical or mental health conditions? _____

7.2 Is your physical health:

Excellent _____ Good _____ Fair _____ Poor _____

7.2.1 **If fair or poor**, how does this affect you? _____

7.3 Is your emotional health or morale:

Excellent _____ Good _____ Fair _____ Poor _____

7.3.1 **If fair or poor**, how does this affect you? _____

7.4 Physical health

7.4.1 Since you have become involved in caring for CR, (**OR** In the past five years), have you experienced changes in any of the following areas:

	Better	Worse	No change
Sleeping			
General nutrition			
Headaches			
Backaches			
Tiredness			
Previous medical condition			
Doctor / Dentist Attention			
Use of medication and/or drugs			
Alcohol consumption			
Cigarette smoking			
Sexual life / intimacy			
Weight			
Exercise			

Notes: _____ Difficulties here/
 _____ Review

7.5.1

To help the CG...

- ♦ discuss their emotional health and stress level.
In general → not necessarily in relation to caregiving

Instructions

- ♦ read each item to the CG
- ♦ read each possible response to the CG → check one only as chosen by the CG
- ♦ this is not a clinical diagnostic scale; it is used to define the various emotions experienced and to give an idea of the impacts of the situation on the CGs' emotions

① Terms in this table may seem redundant, but people do not always identify their emotions with identical terms; it provides numerous terms that may allow the caregiver to identify the word that best represents her/his feelings.

Definition

Depression this is meant to be a subjective statement; it does not necessarily refer to a clinical diagnosis

7.5.2 to 7.5.5

To focus on...

- ♦ the most prevalent feelings in the CG's life (those noted as "all the time" or "often")
- ♦ the potential sources of negative feelings
- ♦ how the caregiver copes with these feelings and if she/he needs further support

7.5.3

- ♦ this question refers to the feelings identified in 7.5.2

7.5 Emotional Health

7.5.1 In the past three months, how often have you had the following feelings?

	All the time	Often	Sometimes	Rarely	Never
Boredom					
Nervousness					
Exhaustion					
Isolation					
Sadness					
Worry					
Guilt					
Helplessness					
Feeling unappreciated					
Anger					
Feeling overwhelmed					
Loneliness					
Frustration					
Feeling discouraged					
Loss, grief or mourning					
Depression					

7.5.2 Which of these feelings cause you the biggest concern? _____

7.5.3 What are each of these feelings related to? _____

7.5.4 Are you able to find ways to relieve these feelings? Yes No
If yes, how, and is this enough? _____

7.5.5 Have you recently had a major stress in your life such as a death, job loss, divorce or illness? Yes No
If yes, specify, and how has this affected you? _____

Notes: _____ Difficulties here/ Review

☐

SECTION 8

CAREGIVER – CARE RECEIVER – FAMILY RELATIONSHIPS

“Taking care of someone can also impact on your relationships with others...”

8.1 to 8.2.3

To understand...

- ◆ the possible changes/conflicts occurring in the CG/CR relationship

Examples

Relationship Change	<ul style="list-style-type: none">◆ pre/post caregiving, e.g. parent/child role change◆ over course of caregiving, e.g. CR more abusive/demanding, increased tension
Areas of Tension	<ul style="list-style-type: none">◆ expectations of the CG◆ quality or amount of care provided/time spent caregiving◆ CG going out or socializing/paying attention to others◆ receiving outside help
Issues in the Past	<ul style="list-style-type: none">◆ abuse◆ unresolved dispute◆ traumatic/stressful event

8.3

To understand...

- ◆ If the CR has any behavioural issues that cause stress for the CG

Definitions/Examples

Inappropriate behaviour	screaming, sexual gestures, etc.
Memory problems	general difficulty reading, remembering, understanding others, etc.
Wandering off	particularly for dementia sufferers; leaving supervision without notice; getting lost
Repeating self	repeating actions or words, generally due to short-term memory problems
In need of much attention	wanting attention from the CG or others frequently; being demanding

8. CAREGIVER - CARE RECEIVER -FAMILY RELATIONSHIPS

- 8.1 Has your relationship to CR changed since you have started assuming responsibility for his/her care (OR in the past five years)?..... Yes No

If yes, how _____

- 8.2 Are there areas of tension between you and CR regarding the care you provide? Yes No

If no, go to 8.3

- 8.2.1 **If yes,** what are they? _____

- 8.2.2 Do they stem from issues in the past? Please explain: _____

- 8.2.3 How does this affect you? _____

- 8.3 Do you experience difficulties because of certain behaviours or needs of CR like:

	Often	Sometimes	Rarely / Never
Shouting, sexual gestures or other inappropriate behaviour			
Memory problems or trouble understanding others			
Wandering off			
Repeating self			
In need of much attention			
Other situations			

- 8.3.1 How does this affect you? _____

Notes: _____ Difficulties here/
 _____ Review

8.4 to 8.5

To understand...

- ♦ if the CR has specific behavioural issues that cause stress for the CG or place her/him at risk of abuse/injury
- ♦ how this affects the CG and if she/he needs help

Instructions

- ♦ read each item to the CG
- ♦ if YES; ask CG who it is directed to (e.g. CG, home care workers, etc.) and how often it occurs
- ♦ record all responses the CG gives to how it affects her/him (i.e. stress, injury, fear, embarrassment, etc.)
- ♦ note if CG wants assistance with this or not (if necessary, record type of aggressiveness needing help with)

Definitions/Examples

Verbally aggressive	to use words, intentionally or unintentionally, which provoke emotional pain or fear
Physically aggressive	to use physical actions (e.g. slapping, hitting, biting), intentionally or unintentionally, that provoke physical pain, discomfort, or injury
Sexually aggressive	to use physical actions, words, or gestures in a sexual manner, intentionally or unintentionally, which provoke fear, discomfort, or injury
Uncooperative	to resist receiving care, or refuse to participate in care activities

8.6 to 8.8.2

To understand...

- ♦ the possible areas of tension for the CG caused by family/friendship conflicts
- ♦ if the CG feels appreciated for the caregiving work she/he does → from friends, family, or CR

Definitions/Examples

Areas of tension	<ul style="list-style-type: none"> ♦ lack of support from family ♦ past conflicts/arguments ♦ expectations placed on CG ♦ quality of care provided by CG ♦ receiving outside services ♦ friends/family wanting/not wanting to place CR in facility care ♦ friends/family not understanding caregiving experience
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8.9 to 8.10

To understand...

- ♦ the positive side of caregiving as viewed by the CG
- ♦ the attributes that enable the CG to contribute to and strengthen the caregiving situation

Definitions

Personal Qualities/Skills	anything that the CG feels she/he does to enhance the caregiving situation or help her cope with caregiving (e.g. organizational skills, patience, understanding, nursing skills from a previous job, etc.)
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① Record anything identified by the caregiver in these questions, even if you personally do not feel it is something rewarding or positive.

① If CG cannot identify any qualities she or he has, you may suggest some you have seen from the questionnaire (e.g. patience, compassion, organisation, courage).

8.4 Can the person you care for sometimes be: **If yes, does this happen:**

			To whom?	Often	Sometimes	Rarely/ Never
Verbally aggressive	Y	N				
Physically aggressive	Y	N				
Sexually aggressive	Y	N				
Uncooperative	Y	N				

8.4.1 How does this affect you? _____

8.5 Do you feel you need assistance dealing with these behaviours? Yes No

8.6 Is there tension between you and other family members (*spouse, siblings, children*) or close friends about the care you provide for CR? Yes No

If no, go to 8.7

8.6.1 **If yes**, with whom? _____

8.6.2 What are they? _____

8.6.3 Do they stem from issues in the past? _____

8.6.4 How does this affect you? _____

8.7 Has your relationship with other family members (*spouse, siblings, children*) or close friends changed because of your role in caring for CR? Yes No

If yes, with whom and how? _____

8.8 Do you feel appreciated for the work you do? Yes No

8.8.1 **If yes**, who do you receive appreciation from?

Care receiver _____ Relative _____ Others (specify who) _____

8.8.2 **If no**, how does this make you feel? _____

8.9 What is the most rewarding thing for you about caring for CR? _____

8.10 What qualities and personal strengths do you bring to your caring role? _____

Notes: _____ Difficulties here/
 _____ Review

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SECTION 9

PLANNING ISSUES, CRISES AND THE FUTURE

"Preparing for emergencies and the future..."

9.1 to 9.2

To determine...

- ♦ if the CG has sufficient plans in place for CR and her/himself in the event of a crisis

Instructions

- ♦ read each item as they apply to the situation
- ♦ check YES or NO as stated by the CG
- ♦ if YES, ask the CG to specify the plan and briefly write in the details

① The CG may have a plan in place, but it may not be a plan that will work or that is well thought out.

Definitions/Examples

Crisis Situation

- ♦ CR or CG becoming suddenly ill
- ♦ a sudden or dangerous change to CR's living environment (e.g. fire)
- ♦ CG becoming unable to provide care (e.g. being called away)
- ♦ CR wanders away or becomes lost
- ♦ need for emergency evacuation (e.g. CR uses oxygen and there is a risk of fire)

9.3 to 9.4

To determine if the CG...

- ♦ has thought about possible changes to the situation (e.g. CG becoming ill or passing away)
- ♦ has thought about the future care of the CR (e.g. facility care)
- ♦ needs help making future plans or improving existing ones

Definitions/Examples

Future Care of CR

care/supervision for CR should illness worsen or the CG is unable to provide care for the long term (i.e. nursing home or facility placement)

Future

a subjective interpretation for the CG; refers to an indefinite period of time, could be short term or long term future outlook

9.5 to 9.6.1

To understand...

- ♦ if the CG is interested in continuing caregiving
- ♦ how the CG sees her/his future involvement in caregiving

9. PLANNING ISSUES, CRISES AND THE FUTURE

Please note the following to CG:

♦ A crisis situation refers to a sudden, unexpected change, while future care refers to planning.

9.1 How do you deal with a crisis situation? _____

9.2 Do you have a plan in place to deal with the following crises?

If yes, specify

Sudden illness of CR	Y	N	_____
Sudden illness of CG	Y	N	_____
Being suddenly unable to provide care	Y	N	_____
CR wanders away or gets lost (if applicable)	Y	N	_____
Need for sudden evacuation	Y	N	_____

9.3 Do you have any plans in place for the future care of CR? Yes No

9.4 Do you have any other specific worries about the future with regards to your caring?..... Yes No

If yes, specify _____

9.5 Thinking about the future, and given all that you have said about the impacts of caring on your life, do you think you have the mental energy and strength necessary to continue caring for CR?..... Yes No

Comments _____

If no, go to 9.6.1.

9.6 I am going to read you two statements describing how you might see your ongoing involvement in care, and I would like you to tell me which one best describes the way you feel. (circle letter)

- A. I want no changes in the way the care is organized and in the work and responsibilities I am assuming.
- B. I would think about changes in the way care is organized and in the work and responsibilities I am assuming.

If A, go to 10.1

If B, ask:

9.6.1 I am going to list a number of ways that changes could occur. Please tell me which of these best represents your feelings (CG can choose more than one):

I would like to:

- _____ Share my responsibilities with formal service providers
- _____ Share my responsibilities with other family members
- _____ Consider moving CR to a long term care facility
- _____ Reduce significantly my care responsibilities but remain involved
- _____ Discontinue my involvement in CR's care

Notes: _____ Difficulties here/ Review

SECTION 10

SERVICE AND SUPPORT NEEDS

"Exploring the services that could help if available..."

10.1

To explore...

- ♦ the types of services the CG feels would be most beneficial for the situation

Instructions

- ♦ ask which type of help she/he feels would best help

- ① Ensure the caregiver understands that identifying services does not mean necessarily that services will or can be arranged.
- ① Try to focus on what would improve the well-being of the CG (many caregivers will focus on CR's well-being only).

10.2

To identify...

- ♦ the type of service or support the CG feels would enable her/him to have personal time

- ① Ask this even if caregiver already feels she/he has sufficient time for her/ himself; the present time may be available but not taken advantage of.

10.3 to 10.5

To identify...

- ♦ if the CG is uncomfortable accepting/discussing formal services
- ♦ the types of service(s) the CG feels would be most helpful to the situation

- ① Read all the services in the list even if they do not exist in your area; this can assist with identifying future areas of program development for caregivers.

Instructions

- ♦ read each item from the possible list of services
- ♦ under "comments", identify any aspects of the service that are necessary for this CG (e.g. respite at night only)
- ♦ under "other", specify any services named by CG or that apply to situation, that are not in table
- ♦ if many services are identified, ask which of those would be most helpful
- ♦ check if this service is available in your area

Definitions/Examples

Information Services	resource centers, 1-800 numbers, or libraries that could provide information on the CR's illness or on caregiving (e.g. Alzheimer's Society)
Training for Tasks	e.g. how to lift properly, how to prevent choking, specific nursing care, etc.
Medical Assistance	services for CR that currently are not received
Support for Emergencies	help provided in situations of crisis to ensure the safety and well-being of CG and CR
Financial Aid/Benefits	any extra income, funding for equipment and supplies, or compensation for services
Counseling	psychological or psychiatric, one-on-one counselling
LTC options/facility	e.g. nursing home, group home (<u>not</u> a senior's apartment or supported living apartment)
Abuse Services	counselling/shelter/information for either the CR or the CG

10. SERVICE AND SUPPORT NEEDS

Please note the following to CG:

- ◆ Caregivers are not always aware of services that might be available to them.
- ◆ However, the services which we will be talking about may not be currently available here.
- ◆ Knowing what they would need will be helpful to agencies for service development.

10.1 Given all the issues we have discussed, and given what you have just said, what kind of help or resources do you think you need? _____

10.2 What do you need to ensure that you take time **just for you**? _____

10.2.1 How is taking time for your needs viewed in your or CR's culture? _____

10.3 How do you feel about accepting services from an agency? _____

10.4 If it were possible to have access to all the following services, which ones would be most useful to you in your caring role? (*Assessor should check if services named are available to the caregiver.)

	✓	Comments	*Availability ✓
Information services			
Training for specialized tasks that you assume			
Training/organizing support workers			
Nutritional services			
Homemaker services			
Nursing care			
OT/PT/Rehab services			
Medical assistance/specialist services			
Professional assistance with arranging services			
Equipment/home adaptation			
Respite			
Adult Day care			
Prescription assistance			
Support for emergencies			
Support groups			
Counselling			
Religious/Spiritual advisor			
Legal services/notary public			
Financial aid/benefits			
Housing assistance			
Transportation services			
Helping in considering LTC options/placement			
Abuse services			

Other Specify:			
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FOR REFERENCE ONLY

10.6

To explore...

- ♦ the ways the CG may be interested in becoming involved in the community/service sector

To focus...

- ♦ on the CG as a partner in the caregiving process

To validate...

- ♦ the CG's experience and strengths

Instructions

- ♦ read each item and check off any that the CG agrees with

SECTION 11

OTHER INFORMATION

"Is there anything else you would like us to know?"

11.1

To provide the caregiver with an opportunity...

- ♦ to share additional information with the assessor about the caregiving situation that may not have been covered in the assessment questions, in particular with regard to family dynamics, cultures, religions

① Information such as cultural beliefs that influence caregiving, additional information on family relationships, etc., may help to understand the answers previously given in the assessment.

SECTION 12

CAREGIVER'S COMMENTS AND RECOMMENDATIONS

"Your thoughts on the interview would be helpful to us..."

12.1 to 12.2

To record ...

- ♦ questions the CG felt were unclear
- ♦ questions the CG felt were inappropriate
- ♦ if the CG felt the questions were relevant to her/his situation
- ♦ any other feedback from the CG

FOR REFERENCE ONLY

If several services have been indicated (previous table 10.4), ask the caregiver to prioritize their service needs by asking:

- 10.5 Of everything you have named, what would be the most helpful for you? _____

- 10.6 If you had the time, would you like to become involved in any of the following ways? **(read all responses)**
- _____ Be able to take part, as an equal, in the decisions made by professionals about CR's care
 - _____ Represent caregivers on agency committees
 - _____ Be involved in community groups for caregivers
 - _____ Be part of groups consulted on government policy concerning caregivers
 - _____ Be involved in research on caregiving
 - _____ Other (specify) _____

11. OTHER INFORMATION

- 11.1 We have covered all of the areas in the assessment but is there anything else we should know about you, about CR or your family which that would help us understand your situation in particular with regard to family dynamics, cultural background or religion beliefs? _____

- 11.2 Of all the resources we discussed today are there any options that would be unacceptable or impermissible for you or your family because of cultural or religious beliefs? _____

12. CAREGIVER'S COMMENTS AND RECOMMENDATIONS

- 12.1 Do you have any comments or recommendations concerning the interview or specific questions? _____

- 12.2 Is this the first opportunity you have had to really discuss your situation? _____

- 12.3 Other comments? _____

FOR REFERENCE ONLY

13. ASSESSOR'S COMMENTS

13.1 Assessor's comments on interview _____

13.2 Assessor's comments on tool _____

Instructions – C.A.R.E. Tool Summary Sheet

- ♦ complete this section alone following the interview
- ♦ purpose is to identify the key areas where the caregiver is experiencing difficulty
- ♦ answers to be based on information from caregiver *and* your perspective of the situation

Step 1 circle the number that best represents the difficulty being experienced by the caregiver

For the areas of Caregiving task-Relationships:

0. no difficulty.....requires no support
1. little difficulty.....requires no immediate support
2. some difficulty.....requires some support
3. significant difficulty.....requires a comprehensive intervention plan
4. extreme difficulty.....requires immediate and/or extensive support (within 2 weeks)

For the areas of *Planning*:

0. no difficulty.....plan in place and sufficient
1. little difficulty.....plan in place, but some issues/concerns
2. some difficulty.....plan in place, but not sufficient
3. significant difficulty....recognizes issues but no plan
4. extreme difficulty.....no recognition of issues/no plan

Step 2 indicate if there is a potential for deterioration within the next couple of months

Step 3 write in your reason for that rating (except for a rating "0")

Key Areas of Concern

- ♦ refer to areas marked 1, 2, 3, or 4 in the table, and those marked as having potential for deterioration
- ♦ identify the three areas that are the primary concern for the caregiving situation

Service Recommended

- ♦ refer to Section 10 of the assessment and use your own knowledge of services
- ♦ identify the formal services that would best help each key area of concern

Urgency of Service

- ♦ urgency should be considered in cases where you had rated an area as a "4"/extreme difficulty in the table
- ♦ urgent means that there is an emergency situation and services are required within 48 hours to prevent a breakdown of the situation

Identified by

- ♦ check whether this service was identified by the caregiver (in Section 10), by you, or by both of you

Interest in Continuing Care

- ♦ refer to questions 9.5 and 9.6 in the assessment to help guide your answer
- ♦ check whether it is "No" or "Yes"; if yes, write in any conditions that apply (e.g. only with services, only for 6 months)

To inform your answers in each area, refer to the corresponding sections of the assessment indicated below. You should also consider information provided in the overall assessment when circling your answers.

Caregiving Tasks	Section 2
Formal Services	Section 3
Housing & Transp.	Section 4
Juggling Resp.	Section 5
Financial Costs	Section 6
Personal Health	Section 7
Relationships	Section 8
Planning	Section 9

C.A.R.E. Tool Summary Sheet

Summary of Situation

Assessment Area	How much difficulty is experienced?					Potential for deterioration? Y/N	Why did you rate it this way?
	No	Little	Some	Significant	Extreme		
Caregiving Tasks							
♦ physical/nursing care	0	1	2	3	4	Y N	
♦ household work	0	1	2	3	4	Y N	
♦ supervision/support	0	1	2	3	4	Y N	
♦ coordination	0	1	2	3	4	Y N	
♦ help received from others (informal & formal)	0	1	2	3	4	Y N	
Relationship with Formal Service Providers	0	1	2	3	4	Y N	
Housing	0	1	2	3	4	Y N	
Juggling Responsibilities	0	1	2	3	4	Y N	
Financial Costs	0	1	2	3	4	Y N	
Personal Health							
♦ physical health	0	1	2	3	4	Y N	
♦ emotional health	0	1	2	3	4	Y N	
Relationships							
♦ with care recipient	0	1	2	3	4	Y N	
♦ with family	0	1	2	3	4	Y N	
Planning							
♦ crises	0	1	2	3	4	Y N	
♦ future	0	1	2	3	4	Y N	

Key Areas of Concern	Service Recommended	Urgent? Y/N	Identified by :	
			Caregiver	Assessor

Is caregiver interested in continuing care provision? Yes No

If yes, conditions: _____