
C.A.R.E. Tool

Short Version

Caregivers' Aspirations, Realities and Expectations

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CAREGIVER'S NAME: _____

CARE RECEIVER'S NAME: _____

ASSESSOR'S NAME: _____

DATE(S) OF INTERVIEW: _____ FILE NUMBER: _____

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2. DESCRIPTION OF CARE GIVING WORK AND SUPPORT RECEIVED

2.1 List of care giving tasks: intensity, support, problems or difficulties

Do you help the CR in the following areas? If yes, specify what you do.

PHYSICAL/NURSING CARE:

Yes No

Feeding: _____

Dressing: _____

Bathing/Showering: _____

Grooming: _____

Incontinence Care: _____

Mobility of CR: _____

Transfers: _____

PT/OT Exercises: _____

Take Medications: _____

Nursing/Medical Care: _____

What other types of help does the CR have with these tasks? _____

Thinking of all the physical and nursing care you do and all the help the CR has, are you having difficulty in any of these areas?

HOUSEHOLD WORK:

Do you help the CR in the following areas? If yes, specify what you do.

Yes No

Preparing Meals: _____

Shopping/Errands: _____

Laundry: _____

Housecleaning: _____

Yard Work/Light and Heavy Maintenance: _____

Banking/Finances/Legal Help: _____

Offering Financial Help: _____

What other types of help does the CR have with these tasks? _____

Thinking of all the household work you do and all the help the CR has, are you having difficulty in any of these areas? _____

SUPPORT/SUPERVISION: "DO YOU NEED TO"

Do you need to do any of the following? If yes, specify what you do.

Yes No

Stay in the House So That CR Feels Safe: _____

Offer Emotional Support/Reassure CR: _____

Correct or Change Dangerous, Unwanted or Difficult Behaviors of the CR: _____

Encourage CR to Participate in Different Activities: _____

Ensure Prevention of Injuries, Accidents or Wandering: _____

Remain Vigilant at Night: _____

What other types of help does the CR have with these tasks? _____

Thinking of all the emotional support and supervision you do for the CR and all the help the CR has, are you having difficulty in any of these areas?

COORDINATION/MEDIATION

Do you need to do any of the following? If yes, specify what you do.

Yes No

Locate/Set up/Check on Services: _____

Organize and/or Train Support Helpers: _____

Make and/or Accompany CR to Appointments: _____

Interpret for CR: _____

Arrange/Provide Transportation: _____

Step in to Improve Relations Between CR and Others: _____

Advocate for CR: _____

Other, Specify: _____

What other types of help does the CR have with these tasks? _____

Thinking of all the mediation and coordination you do and the help CR has for this, are you having difficulty in any of these areas? _____

2.2 Are there other things that you do for CR that we haven't discussed and that you'd like to talk about? _____

2.3 In your family, who has the last word with regard to decisions concerning CR's care? _____

Is this situation causing you any trouble? Yes No

If yes, specify? _____

2.4 How long have you been care giving? _____ Length of intense care giving (if applicable). _____

2.5 Would you consider that your care giving responsibilities are:

24 Hours/ Day Like a Full-Time Job Like a Part-Time Job Occasional

2.6 Would you say your helping role preoccupies you:

All the Time Often Sometimes Rarely

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

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

2.9 On a scale of 1 to 10, where would you put your need for support in your care giving work?

1 = No Need **and** 10 = Very High Level of Need _____

3. CAREGIVER'S RELATIONSHIP TO FORMAL SERVICES

3.1 Would you like to be more involved in decisions around homecare, medical care or other services? Yes No

3.2 Do you feel you are getting enough information from professionals about CR's health problems or condition?

Yes No

3.3 In your relationships with professionals do you encounter any problems due to language, culture, lifestyle choices, values, etc.? Yes No

If yes, specify? _____

4. HOUSING/TRANSPORTATION

4.1 Does the CG live with the CR? Yes No

If no, approximate distance between CG's and CR's residences. _____

Who else lives with CG? _____

4.2 What difficulties, if any, do your living or housing arrangements cause? _____

4.3 What difficulties, if any, do you have concerning the condition of your /CR house as it relates to care giving? _____

4.4 Does the fact you live in an area (rural, small town, suburban, urban) create any problems for you with regard to your caring role? Yes No

If yes, specify. _____

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. _____

4.6 Are there any specific concerns you have about transportation? Yes No

If yes, what are they? _____

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 What other responsibilities or commitments do you have (e.g. employment, child care, education, volunteer employment, leisure)?

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

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

Yes No

If yes, what have you given up? _____

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

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

5.6 FOR EMPLOYED CAREGIVERS ONLY:

5.6.1 How has your work been affected by your care giving role? _____

5.6.2 Have you any concerns about your work? _____

5.6.3 How have adjustments at work affected you or your financial situation? _____

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.
- Only CR has income.
- Only CG has 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 Are you having any problems with out of pocket expenses related to care giving? (E.g. medication, housing expenses, special diet, helpers or services, etc.)

If yes, what are they? _____

6.3 Are there medications, supplies or treatments that CR should have, that she/he or you can't afford? Yes No

If yes, specify. _____

6.4 Are you aware of financial and tax-related programs, which you or your CR might benefit from? Oui Non

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

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

7.3 Is your emotional health or morale:

Excellent Good Fair Poor

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 recent years), have there been any negative changes in the following areas:

Sleeping	<input type="checkbox"/>	Doctor/Dentist Attention	<input type="checkbox"/>
General Nutrition	<input type="checkbox"/>	Use of Medication and/or Drugs	<input type="checkbox"/>
Headaches	<input type="checkbox"/>	Alcohol Consumption	<input type="checkbox"/>
Backaches	<input type="checkbox"/>	Cigarette Smoking	<input type="checkbox"/>
Tiredness	<input type="checkbox"/>	Weight	<input type="checkbox"/>
Previous Medical Condition	<input type="checkbox"/>	Exercise	<input type="checkbox"/>

7.4.3 Has your sexual/intimate life changed in any way and how has this affected you? _____

7.5 Emotional Health

7.5.1 Over the past few months, have you experienced any of the following feelings?

Boredom	<input type="checkbox"/>	Feeling Unappreciated	<input type="checkbox"/>
Nervousness/Worry	<input type="checkbox"/>	Anger	<input type="checkbox"/>
Exhaustion	<input type="checkbox"/>	Feeling Overwhelmed	<input type="checkbox"/>
Isolation/Loneliness	<input type="checkbox"/>	Frustration/Discouragement	<input type="checkbox"/>
Sadness	<input type="checkbox"/>	Loss, Grief or Mourning	<input type="checkbox"/>
Guilt	<input type="checkbox"/>	Depression	<input type="checkbox"/>
Helplessness	<input type="checkbox"/>		

7.5.2 Which of these feelings are related to your care giving? _____

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

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 the death, job loss, divorce or illness? Yes No

If yes, specify. And how this affected you? _____

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 5 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 and how do they affect you? _____

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

Shouting, Sexual Gestures or Other Inappropriate Behaviors	<input type="checkbox"/>	Being Uncooperative	<input type="checkbox"/>
Memory Problems or Troubles Understanding Others	<input type="checkbox"/>	Verbally Aggressive	<input type="checkbox"/>
Wandering off	<input type="checkbox"/>	Physically Aggressive	<input type="checkbox"/>
Repeating Self	<input type="checkbox"/>	Sexually Aggressive	<input type="checkbox"/>
In Need of Much Attention	<input type="checkbox"/>		

8.3.1 How does this affect you? _____

8.4 Do you feel you need assistance dealing with these behaviors? Yes No

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

8.5.1 If yes, what are they and how do they affect you? _____

8.6 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, in what ways? _____

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

8.7.1 If yes, who do you receive appreciation from?

Care Receiver Relative Service Provider Others (specify who)

8.7.2 If no, how does this make you feel? _____

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

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

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?

Sudden Deterioration of the Situation/Sudden Increase in CRs' Needs Yes No

If yes, specify. _____

Being Suddenly Unable to Provide Care. Yes No

If yes, specify. _____

CR Wanders or Gets Lost (If Applicable). Yes No

If yes, specify. _____

CR Attempts Suicide. Yes No

If yes, specify. _____

Need for Sudden Evacuation. Yes No

If yes, specify. _____

9.3 Have you discussed with CR the current or future legal aspects of your care giving role, such as wills, guardianship, power of attorney, advance directives? Yes No

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

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

If yes, specify. _____

9.6 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 _____

9.6.1 If yes, what do you need in terms of skills or support to help you continue caring for CR?

9.6.2 If no, which of the following best represents the changes that you would like to see?

I WOULD LIKE...

Share my responsibilities with formal service providers.

Share my responsibilities with other family members.

Consider moving CR to a residence or alternative housing.

Consider moving CR to a long term care facility.

Reduce significantly my care responsibilities but remain involved.

Discontinue my involvement in CR's care.

9.7 Because caregivers may not be aware of all the resources and services that can be available to them, here is a list of potential supports that may be useful to you. If it was possible to have access to all the following services which would be most useful to you in your caring role?

- | | | | |
|---|--------------------------|---|--------------------------|
| Information | <input type="checkbox"/> | Prescription Assistance | <input type="checkbox"/> |
| Training for Specialized Tasks That You Assume | <input type="checkbox"/> | Support for Emergencies | <input type="checkbox"/> |
| Training/Organizing Support Workers | <input type="checkbox"/> | Support Groups | <input type="checkbox"/> |
| Nutritional Services | <input type="checkbox"/> | Counseling (Individual or Family) | <input type="checkbox"/> |
| Homemaker Services | <input type="checkbox"/> | Religious/Spiritual Advisor | <input type="checkbox"/> |
| Nursing Care | <input type="checkbox"/> | Legal Services/Notary Public | <input type="checkbox"/> |
| OT/PT/Rehab Services | <input type="checkbox"/> | Financial Aid/Benefits | <input type="checkbox"/> |
| Medical Assistance/Specialist Services | <input type="checkbox"/> | Housing Assistance | <input type="checkbox"/> |
| Professional Assistance with Arranging Services | <input type="checkbox"/> | Transportation Services | <input type="checkbox"/> |
| Equipment/Home Adaptation | <input type="checkbox"/> | Helping in Considering Supported Living/Placement | <input type="checkbox"/> |
| Respite | <input type="checkbox"/> | Abuse Services | <input type="checkbox"/> |
| Adult Daycare | <input type="checkbox"/> | Other, specify. | <input type="checkbox"/> |

Comments _____

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

9.8.1 Which of these resources and services will ensure that you take time just for yourself? _____

9.9 Would you like to be involved in the following?

- Represent caregivers on agency committees.
- Be involved in advocacy groups for caregivers.
- Be part of groups consulted on government policy concerning caregivers.
- Be involved in research on care giving.
- Other, specify. _____

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

10. OTHER INFORMATION

10.1 We have covered all of the areas in the C.A.R.E. Tool but is there anything else we should know about you, about CR or your family which that would help us understand your situation? For example, with regard to family dynamics, cultural background or religion beliefs?

C.A.R.E. TOOL SUMMARY SHEET

Summary of Situation _____

ASSESSMENT AREA	DEGREE OF DIFFICULTY					POTENTIAL FOR DETERIORATION
	NONE	LITTLE	SOME	SIGNIFICANT	EXTREME	YES
CAREGIVING WORK						
Physical/Nursing Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Household Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supervision and Support of CR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HELP RECEIVED FROM OTHERS (INFORMAL & FORMAL)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
RELATIONSHIP WITH FORMAL SERVICE PROVIDERS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HOUSING/TRANSPORTATION	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
JUGGLING RESPONSIBILITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FINANCIAL COSTS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PHYSICAL HEALTH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EMOTIONAL HEALTH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
RELATIONSHIP WITH CARE RECIPIENT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
RELATIONSHIP WITH FAMILY MEMBERS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PLANNING FOR CRISES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PLANNING FOR FUTURE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

KEY AREAS OF CONCERN	RECOMMENDED INTERVENTIONS	IDENTIFIED BY	
		CG*	A**
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>

CG*: Caregiver A**: Assessor

Is caregiver interested in continuing to provide care? Yes No

If yes, under which conditions? _____

Date of Reassessment: _____