Our Family Our Way

Person With Care Needs
Individual Tools

These tools belong to:_____

Date:_____

Our Family, Our Way: A Communication and Care Coordination Guide for Caregiving Families

Created by Scripps Gerontology Center, Miami University
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Contents

Reminder:

Everything you write in these Individual Tools will be shared with your family members at your family meeting.

Before You Begin……What Matters Most?

The care and support arrangement affects everybody's life — persons with care needs and caregivers alike. Before you begin, take a moment to reflect on what matters most to **you, in your own life**, on a daily basis. Keep this in mind while you and your family discuss your unique care and support arrangement.

WHAT MATTERS MOST to you about how you spend your time and with whom? What's important to you about the flow of your day? What are you most eager to preserve as life goes on?

For example, some people might say:

- I'm an early riser. I like to get things done in the morning.
- I have an exercise routine that is important to me.
- Spending time with my grandchildren makes my day.
- I need downtime to unwind before bed.
- I need some alone time.
- I want to get out to see my friends.

Use this space to describe.

WHAT'S NEEDED?

This first section is designed to help you think about **what is needed** in your family's care and support arrangement. To do this, you'll complete several tools with questions about:

- Underlying Health Considerations that limit your ability to carry out daily self-care activities
- Environmental Considerations related to the home in which you currently live
- What help you require and who's helping now
- When care and support is being provided
- How the current care and support arrangement affects you

Underlying Health Considerations

This tool helps you and your family think and talk about underlying health conditions that limit your ability to carry out daily self-care activities. By keeping these in mind, you'll be better able to talk about which limitations might be improved and which need to be considered when making decisions about care. Check the column that best describes your current health situation. If you are not sure whether you experience limitations in a certain area, check the "I'm not sure" column.

How do limitations in the following areas affect your ability to carry out daily living and self-care activities?

Health Consideration	I'm not sure	No limitation	Some limitation	Major limitation
Hearing				
Vision				
Taste/Smell				
Dental health				
Bladder or bowel control				
Hand dexterity				
Physical mobility				
Balance				
Strength				
Sleep				
Energy				
Pain				
Decision-making/judgement				
Depression				
Anxiety				
Substance use disorder/addiction				
Other physical or mental health considerations. Please describe.				

Environmental Considerations

This tool helps you and your family think about your current living environment. If you generally agree with the category, check the "yes" column. If you generally disagree with the category, check the "no" column. If you're not sure, check "not sure." If the category is not applicable (for example, there are no stairs), check N/A.

The neighborhood...	N/A	I'm not sure.	Yes	No	Notes
Is safe.					
Is convenient.					
Is near family and/or friends.					
Other. Please describe.					

The home...	N/A	I'm not sure.	Yes	No	Notes
Has rooms and hallways clear of clutter.					
Has non-skid rugs.					
Has safe stairways (clutter free, handrails, clearly marked, well lit).					
Has easy to use furniture.					
Has adequate indoor lighting.					
Has adequate outdoor lighting.					
Has adequate heating.					
Has adequate cooling.					
Has a phone within reach or easy to get to.					
Has an emergency response system. (e.g., Lifeline)					
Has smoke alarms installed, tested.					
Has carbon monoxide detector installed, tested.					
Has window bars or locks.					
Has working doorbell or knocker that can be heard.					

The home...	N/A	I'm not sure.	Yes	No	Notes
Has a peephole or window to see out front door.					
Has exterior in good repair.					
Has accessible interior doorways.					
Has accessible exterior doorways.					
Has lawn care/snow and ice removal when necessary.					
Has an accessible mailbox.					
Has a visible address marker.					
Is free of pests (roaches, bed bugs, etc.)					
Other. Please describe.					

In the kitchen...	N/A	I'm not sure.	Yes	No	Notes
Frequently used items are accessible on the shelves.					
The stove is easy to use and safe.					
The microwave is at a good height/ is accessible.					
The floor is skid free.					
Other. Please describe.					

In the bathroom...	N/A	I'm not sure.	Yes	No	Notes
The tub or shower is accessible.					
The tub or shower floor is slip-proof.					
There are grab bars for getting in and out of the tub/shower.					
There is a hand-held shower or shower seat.					
There are grab bars for getting up from the toilet.					

In the bathroom...	N/A	I'm not sure.	Yes	No	Notes
Other. Please describe.					

If there are pets...	N/A	I'm not sure.	Yes	No	Notes
They are safe underfoot.					
They are easy to feed.					
They are easy to let out/clean up after.					
They are friendly with people.					
They are friendly with other animals.					
They are in good health.					
There is a plan to get them to/from the veterinarian.					
There is a plan if the PWCN cannot care for them. (e.g., hospital stay)					
Other. Please describe.					

Are there any other environmental concerns unique to life in the home (oxygen, shared spaces, etc.)? Name them here.

_____

_____

_____

_____

What Care and Support is Required and Who is Helping Now?

This tool helps you and your family members think about what care and support is required and who is helping now.

For the **"what personal help is required"** section, identify the amount of **personal** help you require by checking a box for each care or support activity. By "personal help," we mean help you require from another person.

For the **"who is helping now"** section, identify who is assisting with the activity. **Don't forget to include yourself, if applicable!**

For the **"what devices are used and needed"** section, indicate what kinds of equipment or devices (like a wheelchair, walker, a lift, adjustable bed, or special tools) are used and what kinds of equipment or devices could be helpful

If the activity does not apply to you, check "not applicable" (N/A). (For example, if no medical or nursing tasks are needed, or if there are no pets, these are not applicable.)

If you are not sure about what help is required, who is helping, or what devices are used or could be helpful, check the "I'm not sure" box in each of those sections.

Care or support activity		What PERSONAL help is required?				Who is helping now?			What DEVICES are used and needed?		
How much personal help do you require with the following activities:	N/A	I'm not sure	I require no help	I require some help	I require much help	I'm not sure	Who provides the help?	No one is helping, but I need help.	I'm not sure	What devices are USED?	What devices could be helpful?
Bathing or showering											
Dressing											
Grooming (e.g., hair care, shaving, teeth-brushing, nail care)											
Getting to the toilet, using a bedpan, or other toileting needs											
Eating or drinking											

Care or support activity		What PERSONAL help is required?				Who is helping now?			What DEVICES are used and needed?		
How much personal help do you require with the following activities:	N/A	I'm not sure	I require no help	I require some help	I require much help	I'm not sure	Who provides the help?	No one is helping, but I need help.	I'm not sure	What devices are USED?	What devices could be helpful?
Getting in/out of bed/ chair											
Getting around the house											
Managing medications											
Medical or nursing tasks (e.g., changing bandages, injections, colostomy/catheter)											
Preparing meals											
Making telephone calls											
Transportation											
Communicating and coordinating with health and service providers											
Going to medical appointments											
Doing essential shopping (e.g., grocery, pharmacy)											
Writing checks and paying bills											

Care or support activity		What PERSONAL help is required?				Who is helping now?			What DEVICES are used and needed?		
How much personal help do you require with the following activities:	N/A	I'm not sure	I require no help	I require some help	I require much help	I'm not sure	Who provides the help?	No one is helping, but I need help.	I'm not sure	What devices are USED?	What devices could be helpful?
Managing insurance or legal matters (e.g., estate planning, POA, etc.)											
Doing laundry											
Doing light house or yard work											
Taking out trash/ bringing in trash cans											
Doing heavy house or yard work											
Doing home modifications											
Caring for pets											
Social contact (e.g., visits, telephone calls)											
Emotional support (e.g., reassurance, encouragement)											
Other. Please describe:											

Care or support activity		What PERSONAL help is required?				Who is helping now?			What DEVICES are used and needed?		
How much personal help do you require with the following activities:	N/A	I'm not sure	I require no help	I require some help	I require much help	I'm not sure	Who provides the help?	No one is helping, but I need help.	I'm not sure	What devices are USED?	What devices could be helpful?
Other. Please describe:											

When do you need Care and Support?

In every family, different people provide different types and amounts of care and support -- and at different times. This tool will help you and your family members think and talk about when care and support is being provided.

When are the times that you need care and support? In the space below describe the care or support you need. Examples include hands on help, phone check-ins, transportation, paperwork assistance, communication with health and service providers, etc.

_____

_____

_____

_____

_____

Below, shade in the times you generally need help.

	Early Morning	Late Morning	Early Afternoon	Late Afternoon	Early Evening	Late Evening	Overnight
MONDAY							
TUESDAY							
WEDNESDAY							
THURSDAY							
FRIDAY							
SATURDAY							
SUNDAY							

How Does the Current Care and Support Arrangement Affect You?

This tool helps you and your family think and talk about the impact the care and support arrangement has on each other so you'll be able to keep this in mind as you make decisions about care and support.

For each area, circle the number from 1 to 5 that best reflects how much you think the care and support arrangement affects you overall in that area, then use the box below each rating to give examples of what influenced your rating.

Overall physical strain

1 2 3 4 5

No physical strain — Extreme physical strain

What are those physical strains?

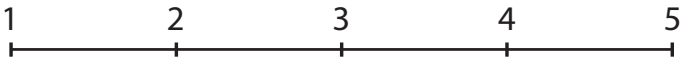
Overall emotional stress

1 2 3 4 5

No emotional stress — Extreme emotional stress

What are those emotional stresses?

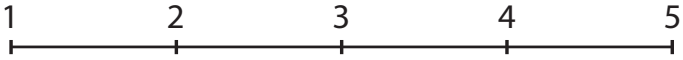
Overall loss of social time (for work, school, volunteering, recreation, family, and friendships)



No social loss — Extreme social loss

What are those social losses?

Overall financial hardship



No financial hardship to me — Extreme financial hardship to me

What are those financial hardships?

Adapted from: National Alliance for Caregiving and AARP, Family Caregiving in the U.S.: Findings from a National Survey, 1997. http://www.caregiving.org/pdf/research/finalreport97.pdf (page 39)

Benefits

We know that family care can create some stresses and strains, but families also report experiencing benefits from the care and support arrangement. These include physical, emotional, social, and financial benefits. Use the space below to identify any benefits of the care and support arrangement you may be experiencing.

_____

_____

_____

_____

_____

Strengths

Each person — you and your caregivers alike — brings a different set of strengths to the care and support arrangement. What are the strengths you bring or have the potential to bring to your family's care and support arrangement? (Examples include: patience, sense of humor, knowledge about illness/disability, particular caregiving skills, financial resources, etc.) Name your own strengths here.

_____

_____

_____

_____

_____

What's Needed – My Notes for Our Family Meeting:

Use this space to write additional notes about What's Needed in your family's care and support arrangement.

WHAT'S WANTED?

Now that you have thought about what's needed and what's happening, it's important to think about what is wanted when it comes to the care and support arrangement. You can think about **what's wanted** in two ways:

- What is your ultimate goal for the care and support arrangement?
- What changes do you want in the care and support arrangement?

When you complete these tools it's important to be as specific as you can.

The more specific you are, the easier it will be for others to understand what you want.

What is your ultimate goal for the care and support arrangement?

Before you can start to think about what's possible in your family's care and support arrangement, it helps to have a clear vision of what you want to happen as a result of your arrangement. Often, family members have different ideas about what they want to happen, so before you meet with your family, take some time to think about your goal for the care and support arrangement and write it here:

My ultimate goal for our family's care and support arrangement is:

_____

_____

During your family meeting, you and your family members will work together to create a shared goal statement(s) for your family.

What changes do you want in the care and support arrangement?

Now that you have determined what you want, think about what needs to change in the care and support arrangement in order for that to happen.

Below, list 3 changes that could be made (by you or your caregivers) to help achieve your ultimate goal. Be realistic.
It may help you to think of the 3 simplest or easiest changes that could be made to bring you closer to your goal.

1. _____

2. _____

3. _____

What's Wanted – My Notes for Our Family Meeting

Use this space to write additional notes about What's Wanted in your family's care and support arrangement.

WHAT'S POSSIBLE?

This section is designed to help you think about what is possible in your family's care and support arrangement. To do this, you'll think about **what's possible** in two ways:

- Care and support you could provide as part of the care and support arrangement
- Extended family, friends, or community services who may be able to provide care and support

What's Possible? – Part One

This tool helps you and your family members think about care and support you could provide as part of the care and support arrangement. For each care or support activity, check whether you are "willing and able to do" the activity, "able and willing to share," "able only with other help on hand," "unable to do," "prefer not to do," "could learn to do," or "could contribute money/resources toward." If the care or support activity is not needed, check "not required now." You may check more than one box in each row.

Even if the care or support is not required now, this is a good opportunity for you to think about what might be possible should the need arise in the future.

Note: There are many reasons you may be unable to complete a care activity and this is the time to clearly name your limitations. Here are some examples:

- You lack the physical strength or ability.
- The care activity is too emotionally difficult.
- You don't have needed skills or knowledge.
- You don't have needed equipment.
- Personality differences or conflicts.

Care or support activity	Not required now	Able and willing to do	Able and willing to share	Able only with other help on hand	Unable to do	Prefer not to do	Could learn to do	Could contribute money/resources toward
Bathing or showering								
Dressing								
Grooming (e.g., hair care, shaving, teeth-brushing, nail care)								
Getting to the toilet, using a bedpan, or other toileting needs								
Eating or drinking								

Care or support activity	Not required now	Able and willing to do	Able and willing to share	Able only with other help on hand	Unable to do	Prefer not to do	Could learn to do	Could contribute money/resources toward
Getting in/out of bed/chair								
Getting around the house								
Managing medications								
Medical or nursing tasks (e.g., changing bandages, injections, colostomy/ catheter)								
Preparing meals								
Making telephone calls								
Transportation								
Communicating and coordinating with health and service providers								
Going to medical appointments								
Doing essential shopping (e.g., grocery, pharmacy)								
Writing checks and paying bills								
Managing legal matters (e.g., estate planning, POA, etc.)								
Doing laundry								
Doing light house or yard work								

Care or support activity	Not required now	Able and willing to do	Able and willing to share	Able only with other help on hand	Unable to do	Prefer not to do	Could learn to do	Could contribute money/resources toward
Taking out trash/bringing in trash cans								
Doing heavy house or yard work								
Home repairs or modifications								
Caring for pets								
Social contact (e.g., visits, telephone calls)								
Emotional support (e.g., reassurance, encouragement)								
Other. Please describe:								
Other. Please describe:								

What's Possible? – Part Two

This tool helps you and your family think about extended family (that is, family other than the spouse/partner and adult children) or friends or community services who may be able to provide some of your care and support. Identify the individual or the service and the type of care and support they might provide. Your local Area Agency on Aging or other resources in the **Helpful Caregiving Resources** booklet (located on the OFOW website) can assist you in identifying community services available in your area.

Who else is available to provide care and support?			
Extended family or friends	**What might they do?**	**Community Services**	**What might they do?**

What's Possible – My Notes for Our Family Meeting:

Use this space to write additional notes about What's Possible in your family's care and support arrangement.

You've completed your Individual Tools!

Next Steps:

- Review pages 10 - 12 in the **Family Meeting Guide** to help you get ready for your family meeting.
- Bring your completed **Individual Tools** with you to your family meeting.