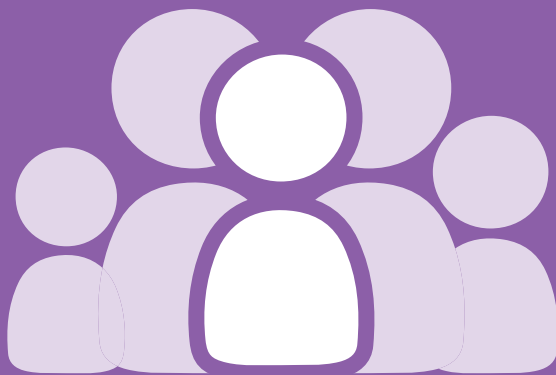


# Charting the LifeCourse



## Respite: Short Breaks for Caregivers

Being a caregiver can be one of the most rewarding and most challenging times we face. In order to continue to care for family members who require additional support, we must remember to care for ourselves as well.

This guide is meant to help caregivers and those who support them to understand the meaning and importance of respite/short breaks, see real life examples, understand the possibilities and options that exist for respite, within and outside the formal, paid service system, and create a successful plan that uses these short breaks to enhance the lives of all family members.

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### LIFE DOMAIN



ALL Life Domains

### LIFE STAGE



ALL Stages

### DEVELOPED BY

**MISSOURI**  
FAMILY TO FAMILY  
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

### IN PARTNERSHIP WITH

**ARCH**  
**National  
Respite  
Network**  
And Resource Center

*Charting the LifeCourse: Respite*

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# RESPITE GUIDE

What is it and who is it for?



## About the Guide

This guide is one in a series of Charting the LifeCourse guides developed by and for families and professionals who interact with and support families. These guides include information and tools for planning a quality and meaningful life for all family members, especially among families that include a member who requires additional support to live in their community and to reach their good life. To find out more about how these guides are developed and the topics currently addressed, please visit [lifecoursetools.com](http://lifecoursetools.com).

The *Charting the LifeCourse: Respite Guide* and accompanying toolkit are intended for anyone in a family or relationship that is providing the majority of care or support to a person who needs additional support, and are also referred to as “caregivers” or “carers” throughout this guide. It is focused on the topic of respite, or short breaks for caregivers. The purpose of this guide is to provide:

- information on the importance of respite for the well-being of a caregiver and of finding the right fit for all family members;
- tools for thinking about and planning respite; and
- additional resources for finding respite outside the formal paid service system in the community or from other family members and friends.

In this document, caregiver refers to the more commonly used term “family caregiver”. Family caregivers include family members, neighbors, or friends who provide informal care to children or adults with one or more special needs, including, but not limited to, chronic mental, neurological or physical health conditions, cognitive, intellectual or other developmental disabilities or delays; physical disabilities, and functional limitations. “Care receivers” refer to children and adults with one or more special needs who are cared for by caregivers. This guide interchangeably uses the terms “care recipient,” “loved one,” and “person receiving/needing care.”

This guide provides the questions to ask or think about, and strategies to get the answers and move closer to the desired result. It is meant to be used as a way for families to start conversations as they begin to think about and plan for respite.

## CONTENTS

1. GETTING STARTED
2. EXPLORING
3. PLANNING
4. NEXT STEPS
5. RESOURCES

# RESPITE

## What is it and why is it important?



### What is it?

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to, or a short break for, family caregivers who are caring for that child or adult (archrespite.org).

Traditionally, the word “respite” has been used to describe a paid service provided outside the family home, often in a formal care facility setting, community-based respite program, or in-home care using paid professionals or other individuals. As we continue to learn about the many benefits of respite for families, we are also learning that it matters where and how these short breaks are spent for both the individual receiving support, their caregiver and family. As a result, there are a growing number of respite options and resources outside the traditional paid options, including supports in the family home, local community options, and resources for identifying people and places caregivers already know and trust who can provide breaks as well as meaningful interactions and experiences for the care recipient.

### Why is respite important?

Caring for a loved one can be very rewarding, but can also be stressful, and even overwhelming at times, due to a lack of balance. Everyone needs time to do the things they need to do, like go grocery shopping or to an appointment. However, it is also important to make time to do the things you want to do and that are meaningful to you and your family, such as hobbies or activities with friends. For many families, especially those with loved ones who require intensive care, it can be difficult to think about spending time apart from one another. As a caregiver, entrusting the care of your loved one to someone else can cause feelings of anxiety, and for the individual requiring support, the very thought of going somewhere new, without their typical caregiver, can be unsettling. They may refuse to participate in any discussion about the subject. However, recognizing the importance of short breaks for everyone can provide many positive benefits for all family members.

Caregivers, and their families, who do not take regular and sufficient amounts of respite time to do the things they want and need to do, often experience greater stress, which can take a toll on their mental and physical health. Importantly, research shows that respite which is personalized and purposely planned, benefits not only caregivers, but all family members, including siblings or a spouse or partner.

Some benefits of taking short breaks include<sup>1,2,3,4</sup>:



#### FAMILY UNIT

- More time spent together
- Improved relationship quality with other children, spouse or partner
- Improved relationship with, and better able to relate to, the care recipient
- Ability to live ‘a more ordinary life’



#### CAREGIVER

- Have time for everyday activities, like sleeping or running errands, and for taking care of own health
- More time to spend with other family members, such as a spouse or partner or children
- Freedom to do something for themselves, like visit friends or read a book
- Better overall physical and emotional health
- Reduced stress, exhaustion, and anxiety
- Feeling a ‘sense of renewal’ or relief



#### CARE RECIPIENT

- Meaningful, and potentially new, experiences
- Greater independence by spending time away from the caregiver
- Socialization and keeping active (depending on activities during respite time)
- Improved interactions with caregiver (because caregiver is less stressed)
- Increased happiness and self-esteem
- Improved physical and mental health

1. Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 43(11), 2604-2616.

2. Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health & social care in the community*, 23(1), 51-63.

3. Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., & Emerson, E. (2011). The impacts of short break provision on families with a disabled child: an international literature review. *Health & social care in the community*, 19(4), 337-371.

4. Theis, S. L., Moss, J. H., & Pearson, M. A. (1994). Respite for caregivers: An evaluation study. *Journal of Community Health Nursing*, 11(1), 31-44.

# EXPLORING RESPITE

## What are the possibilities?

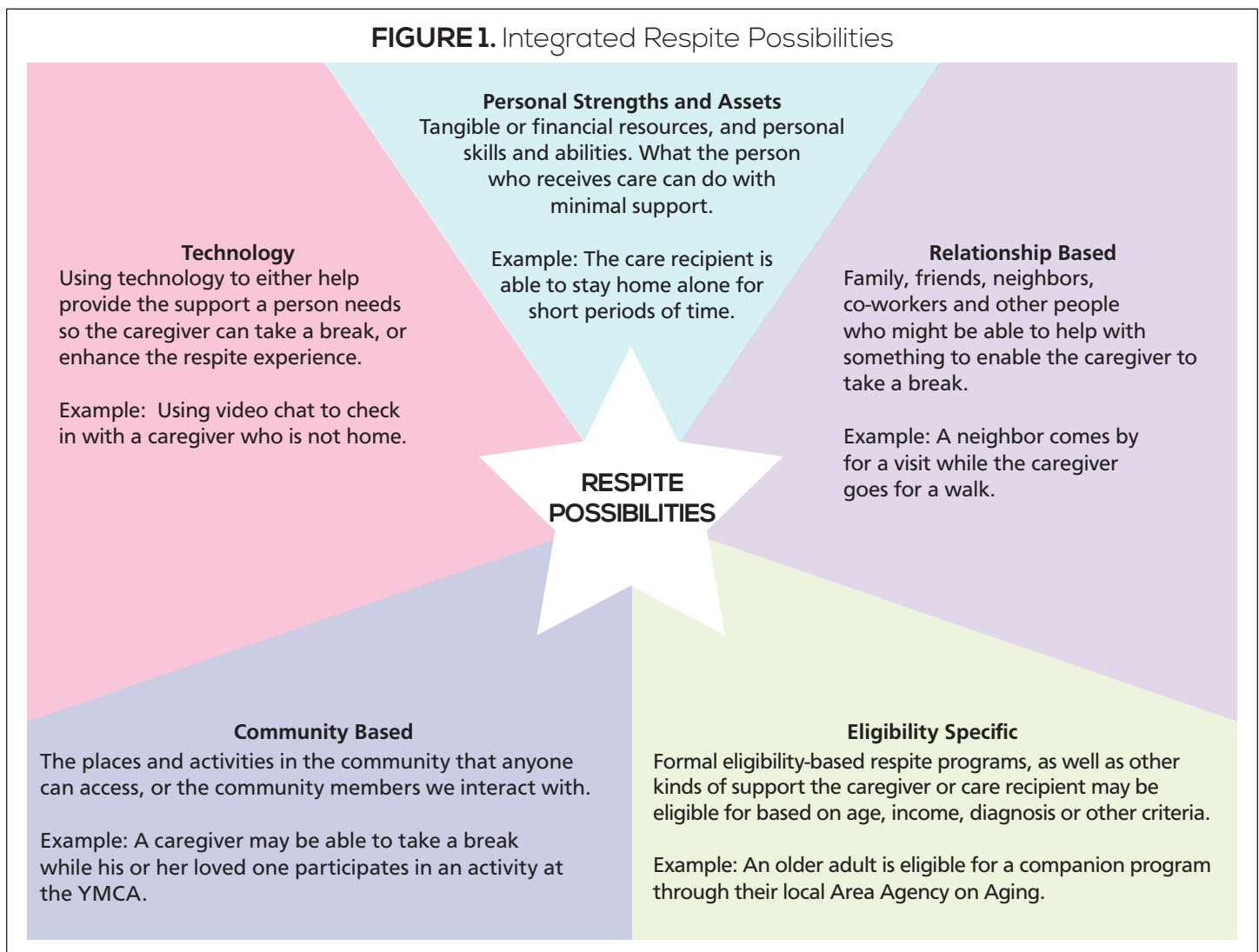


Everyone uses a variety of resources and supports to get through their day-to-day routine. People build on their own strengths, assets, skills and capabilities. Some people have friends or family in their lives that do things for them (and vice versa). Community groups, clubs, organizations or resources can also be a source of support, and who doesn't use technology these days?

When someone in the family has different abilities or support needs, the caregiver may be able to access formal government services, such as paid respite. Sometimes, caregivers are told to use natural supports, but it's hard to know what that means. It is important to consider all of the various sources of support anyone else might use, and how they may be adapted to your unique situation. There are often ways for a caregiver to get respite (a short break) even when paid supports or traditional funding sources are limited or not available. Even if formal respite services are available and being accessed, these services can be enhanced or maximized by incorporating other types of support along with them. By not relying solely on paid formal supports, if something should happen that those paid services are no longer available or are limited, the caregiver will still have options for taking a respite break.

The Integrated Supports Star for Respite, pictured below, is a visual way to help you think differently about support options for respite, and to understand the different elements of the Star. Later in this guide, (pages 8-9) you will use the Star to think about your own respite needs and resources.

**FIGURE 1.** Integrated Respite Possibilities





# PLANNING RESPITE

## What is a portfolio?



As caregivers, it is easy to become so focused on the person needing care, that we lose sight of our own wants, needs and identity, as well as that of other family members. We can begin to experience anxiety or guilt at the very thought of entrusting the care of our loved one to another individual or organization.

It is important for caregivers and their families to make a plan to incorporate respite into their lives long before exhaustion, isolation and feelings of being overwhelmed have set in. Advanced planning also allows for respite to be customized to meet the unique needs of the family members and provide enjoyable and meaningful experiences for everyone.

### My LifeCourse Respite Portfolio

The LifeCourse Respite Portfolio is a set of tools to help you make a plan for respite. In the next few pages, we will take you step-by-step through filling out your own LifeCourse Respite Portfolio. Each section of the Portfolio is identified by headers in bold. The headers correspond with the section in the guide containing directions for that part of the Portfolio, as well as examples to help get you started. Below are images of the tools you will need. All Charting the LifeCourse Respite materials can be downloaded, free of charge, at [lifecoursetools.com](http://lifecoursetools.com).

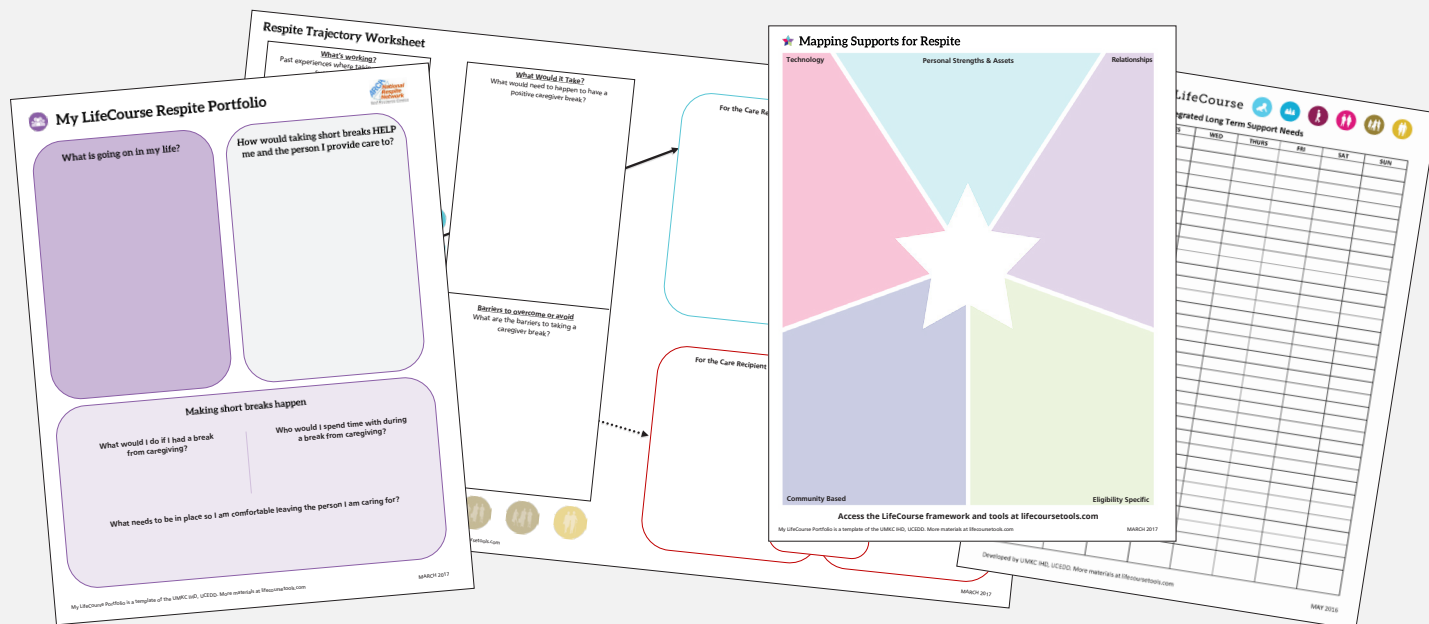
The LifeCourse Respite Portfolio is designed to lead you through planning for respite by:

- helping you explore the need for and benefits of respite for you, your loved one, and your family,
- leading you through the development of a plan that balances the support needs of your loved one with those of the family or caregiver,
- helping you identify specific opportunities or times for respite that can fit into your schedule, and
- assisting you in exploring strategies and resources available to you for respite within and outside the formal paid system.

Once completed, this portfolio can be used to:

- problem solve with professionals on how to meet the needs of the person receiving care, the caregiver and family members during formal planning meetings,
- train or coach staff providing respite, in or out of the home,
- plan or coordinate logistics of day-to-day activities,
- and help others in the community understand how to support your loved one while they are receiving care or participating in a community activity.

Download your own LifeCourse Respite Portfolio at [lifecoursetools.com/respite](http://lifecoursetools.com/respite)



# PLANNING RESPITE

## What's going on now?



Having a clear picture of your current situation can help you know where you are starting, how using respite could improve your life, think about what you would do with a short break, and identify what needs to change.

To begin, you will need the blank LifeCourse Respite portfolio that came with this guide or you downloaded at [lifecoursetools.com/respite](https://lifecoursetools.com/respite).

The first page of the portfolio is designed to provide a snapshot of your current situation related to respite as well as help you identify the benefits of respite to you, your loved one and other members of your family, if you are able to take a break from your caregiver role while your loved one is in trusted care. Take a few moments to reflect or even have honest conversations with other family members about the impact of caregiving and consider your own needs as well as those of others in your family. Try to let go of any guilt and think factually about your unique situation.

### What is going on in my life?

List some of the ways that caregiving impacts you, your loved one, and your family as a whole. Think about factors that are unique to your situation.

Examples: loved one requires 24/7 care; being sole caregiver; juggling care-giving with full time job; lack of sleep; caregiver health issues.

### How would taking short breaks HELP me and the person I provide care to?

List some of the SPECIFIC benefits to you, your loved one, and your family.

Examples: relieve stress; improve caregiver mental health; improve relationship of caregiver and loved one; caregiver keeping their job.

## Making Short Breaks Happen

### What would I do if I had a break from caregiving?

List ideas of places you might want to go, activities in which you'd like to participate, or hobbies you might pursue.

Examples: attend faith or other community events; host sleepovers or family events; take a yoga class.

### Who would I spend time with during a break from caregiving?

Think about who you would like to spend time with if you had respite from caregiving.

Examples: reconnect with family or friends; make a new friend; have some alone time.

### What needs to be in place so I am comfortable leaving the person I am caring for?

List some of the conditions/specific supports that you and your loved one feel are necessary to feel comfortable being apart and truly enjoying a short break from caregiving.

Examples: specific training needed; unique care needs; preferred way of being supported.

# PLANNING RESPITE

What is our vision?

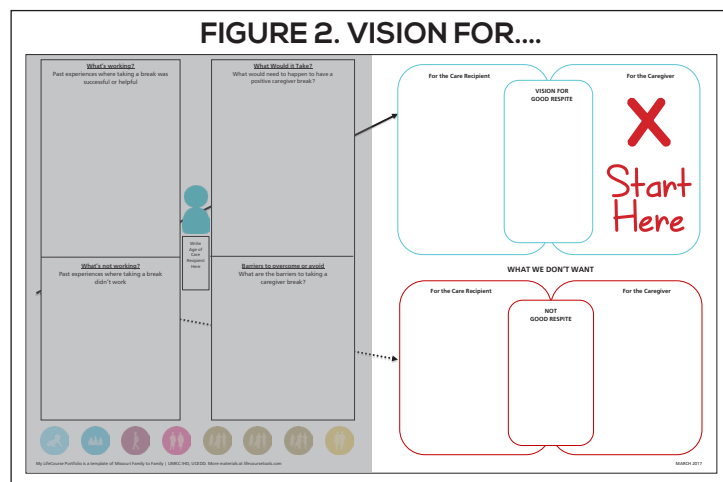


## Respite Trajectory Worksheet

Good respite planning starts with a clear vision for a good life and for a good respite experience. Having a vision of what good respite looks like for you and your loved one, and keeping that vision in mind, can help guide you as you make decisions about whether choices or experiences draw you closer to that vision or further away.

Exploring your vision could mean thinking well into the future or focusing on the here and now. Identifying a vision will help you have a target to aim for, as well as a way to communicate with others what you want good respite to look like. Most caregivers will only take a break if they are sure their loved one is happy, safe, and well cared for in their absence.

The Respite Trajectory Worksheet is located on the inside of your LifeCourse Respite Portfolio. You will begin this exercise on the right-hand side of your Respite Trajectory Worksheet. You will begin by identifying an "overall" good life for both you (the caregiver) and the person receiving care, as well as what you both don't want in life. This will help you keep in mind a target for your lives, and avoid pitfalls that might take you in an undesirable direction.



### CARE RECIPIENT

#### Vision for a Good Life

Ask the person receiving care (if possible) to define their good life and LIST in this section. It could be similar or different than what you identify. What makes them happy or puts a smile on their face?

Example: friends, family, a favorite item or food

### CAREGIVER

#### Vision for a Good Life

LIST what needs to be present or happening to make a good life for YOU, the caregiver. You can think long or short term.

Examples: friends, family, fun, good job, or having enough money to do the things you like

### RESPITE

#### VISION FOR GOOD RESPITE

LIST what makes a good respite experience for both you and your loved one. What needs to be happening or in place so you can both relax and have a positive experience?

Examples: Respite providers trained in CPR/first aid, care recipient does enjoyable activity

**Note:** Sometimes it is easier to know what you want by FIRST identifying "What We Don't Want" below.

#### What We Don't Want

LIST outcomes or experiences that your loved one wishes to avoid or would make their life "not good" in this section.

Examples: being bored, loneliness, no money

#### What We Don't Want

List what would make your life not so good. What do you want to avoid or prevent?

Examples: poverty, poor health, or loss of job.

#### WHAT IS NOT GOOD RESPITE

LIST things that would make respite a negative experience for either the caregiver and/or care recipient.

Examples: care recipient is frightened, caregiver worries the entire time



# PLANNING RESPITE

## What is our trajectory?



### Trajectory

The 'trajectory' is the path in life that will either lead you toward your good life or push you toward what you don't want. Life experiences and events affect the trajectory. Some experiences help move the trajectory toward the desired good life outcomes. Others might move the trajectory toward unwanted results. It's important to reflect on past life experiences, both positive and negative, to know what to continue or build upon, and what to avoid or stop doing. With every choice, decision, experience, or interaction with others, consider which direction it nudges the trajectory. You will need your Respite Trajectory Worksheet (pictured).

FIGURE 3. RESPITE TRAJECTORY WORKSHEET

Planning is beneficial at any age. First, on your Respite Trajectory Worksheet, write your loved one's current age or the date in the box under the icon of the blue person.

### Past Experiences

#### What's working?

Reflecting on past experiences that were positive can help you to know what worked well and plan more positive experiences in the future. LIST times you felt comfortable taking a break, things that resulted in a positive respite experience, or situations where your loved one was successfully supported by someone other than you, the caregiver.

#### What's not working?

It is also important to acknowledge past barriers to good respite or what has moved you or your loved one toward unwanted results. By knowing what didn't work in the past, you can identify situations to avoid. LIST past negative experiences, situations that made you feel uneasy about taking a break, or resulted in a stressful situation for you or your loved one.

### Current and Future Experiences

#### What would it take?

Keeping the Good Life and Respite vision in mind and considering the trajectory up to this point, think about moving forward. LIST what would need to happen for you to feel confident and comfortable taking a short break, additional steps that need to be taken, or supports needed to move you and your loved one toward the vision of good respite?

#### Barriers to Overcome or Avoid

Considering potential barriers to you or your loved one having a successful respite experience can help you plan and address/avoid issues that are preventing your good respite vision. LIST potential barriers that might get in the way of you or your loved one having a successful respite experience.

# MAPPING RESPITE

## What are our options?



### Integrated Star Worksheet

In this section, you will create your own Respite Integrated Supports Star “bank.”

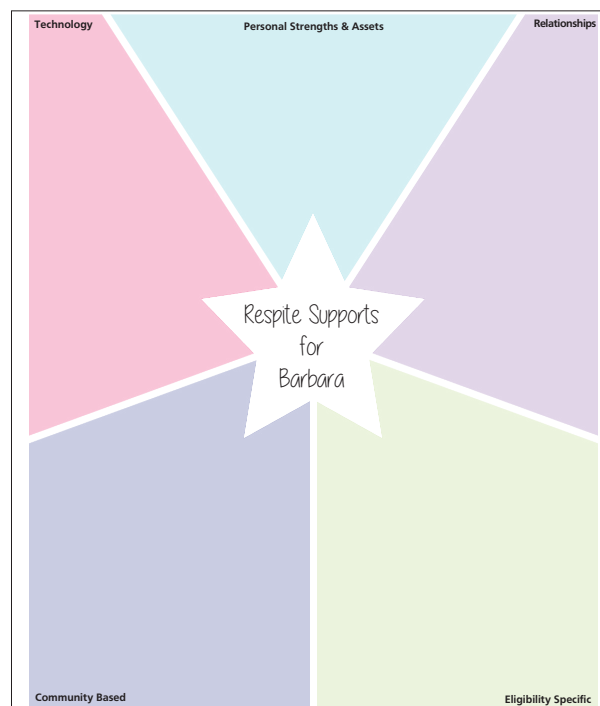
Completing the star will help you think about your own life and the supports and resources you have available in each of the star categories that could help make respite possible or a better experience for you and your loved one.

You will need your LifeCourse Respite Portfolio, turning to the Integrated Star Worksheet on the back page.

First, in the center of the star, write “Respite Supports for” and the care recipient’s name.

The descriptions and examples that follow in this section will guide you through each part of the Integrated Supports Star.

FIGURE 4. MAPPING SUPPORTS FOR RESPITE



### Personal Assets and Strengths

It’s important to consider what the caregiver and the person receiving care bring to the table – what are the possessions, assets, skills, traits, knowledge and talents of you and your loved one that could make respite possible and a positive experience?

List you and your loved one’s knowledge, skills, personality traits, and material or financial resources that enable or could enable you to take a break in the light blue part of the star.

#### Examples:

- ability to stay home alone
- ability to dial 911
- doesn’t wander
- knows/communicates address
- ability to use public transportation
- money to pay for respite

### Technology

Everyone uses technology as part of daily life these days. How can technology be used to help make respite possible for you and a positive experience for your loved one?

List the technology you and/or your loved one have available or use now in the pink part of the star. Remember, technology can be high tech, like a smart phone, or low tech, like a digital watch.

#### Examples:

- Medical Alert or Safety ID
- Remote monitoring
- Facetime/Skype
- GPS locator
- Smart device (phone or tablet)
- Computer

## Relationships

Most of us rely on others in our life to give us advice, lend a hand, or be there for us when we need some support. How can relationships help you take a respite break and/or make it a positive experience for the care recipient?

List the people in your life (and if you'd like, their relationship to you or your loved one) right now that either do or could do even one thing that would enable you to take a short break in the purple part of the star.

### Examples:

- Immediate or extended family members
- Friends
- Volunteers/Mentors/Interns
- Teachers/Coaches
- Spiritual leaders and fellow worship congregants
- Co-workers, employers, carpool participants
- Other caregivers

## Community-Based Resources

There are many places and activities that can be accessed simply by being a member of that particular community. Could participating in a community activity provide an opportunity for a caregiver break?

In the dark blue part of the star, list the places you and/or the person receiving care go and activities you participate in.

### Examples:

- Parks and recreation, community center
- Public transportation
- Schools
- Camps
- Faith-based resources
- Parent/family cooperative
- Sitter-companion services

## Eligibility Specific

Eligibility specific supports are resources the caregiver or care recipient may be able to receive because of income, age, diagnosis, disability, or other criteria. This might include formal respite supports, but can also consist of other options either or both of you might be eligible to receive based on various factors.

List the supports both you and the person receiving care are eligible for or currently receive in the green part of the star.

### Examples:

- Medicaid, Medicaid waiver, SSI, SSDI
- Rehabilitative services
- Center-based respite, ie: adult day centers
- Family care homes or host homes
- Home-based service programs
- State lifespan respite care programs
- Older Americans Act- Family Caregiver Support Program
- Respite voucher
- Consumer directed respite

## Integrated Supports in Action: Nicole

Nicole is a busy mom of three, including two young children with special health care needs. She also cares for her aging mother. She works part time and leads a parent support group. Nicole does a lot of giving during her day and often finds herself coming up empty.

One of her children requires position adjustments on a regular basis. Nicole found herself stopping in the middle of tasks or making sure she was always nearby to be able to reposition her.

Nicole sat down and used the Integrated Supports Star Worksheet to help her think through her

supports and create short breaks for herself. When she filled out the star, Nicole began to look at her relationships differently.

She realized that her older daughter, who was home from college for the summer, could help reposition her younger sister as well as spend some time with her. This allowed Nicole to work on projects around the house as well as run occasional errands. By utilizing her relationship-based supports, Nicole greatly reduced the amount of stress that she had been feeling and allowed her to take care of things she needed to do. ★



# PLANNING RESPITE

Can we find time?



You and your loved one have worked hard to make plans for successful respite and identify resources that can help you reach your vision of good respite. With today's busy lifestyles, you may feel it is difficult to fit respite time into your schedule. Sometimes, you may not even realize how much you could really use some respite time in your life. This section will show you two ways you can use the Integrated Respite Support Schedule. If you don't already have one, download a copy for free at [lifecoursetools.com](http://lifecoursetools.com). Since the colors used to color the schedule are the same as the Integrated Supports Star colors, you may want to have your Respite Integrated Star bank closeby.

The schedule can help you see the need to take a break as well as find time to incorporate respite into your life. Fill out your own schedule as it is now so you have a good visual of when you are providing care and when you are meeting other life obligations.

The schedule can also help you see how and when your loved one is supported by yourself and others, and find windows of time when it might make sense for you to create respite opportunities. Fill in your loved one's schedule and write who supports him/her during specific times. It is helpful to shade the timeslots the same color as the type of support it corresponds to on the Integrated Supports Star.

**FIGURE 5. CAREGIVER  
INTEGRATED RESPITE SUPPORTS SCHEDULE**

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM							
6:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM							
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM							
1-1:30 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM							
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

Example: If you work 8:30am to 5:00pm each day, color in those times as shown in the example above on the left. If you provide care for your loved one evenings and weekends, shade those times as shown. Maybe you have other family that you need to do something with. Add those times to the schedule (and if it overlaps some of the other times, that's okay), as that will help identify times when you need support with caregiving.

You can see in this example, the caregiver has little time to do other things she needs to do, and illustrates the need for finding time and supports for respite.

**FIGURE 6. CARE RECIPIENT  
INTEGRATED SUPPORTS SCHEDULE**

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM							
6:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM							
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							
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9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

Example: If your loved one stays home by themselves during the day Monday through Friday, shade that time light blue, as that shows a personal strength. If they have a weekly meeting (like a Bible study or card game), shade that time based on who is supporting them.

Once filled in, you can look for times and ways to incorporate different supports so you can take a break, and your loved one can be supported to have good respite experiences and a good life.

# NEXT STEPS

## Making respite happen



Congratulations! You've completed your Charting the LifeCourse Respite Portfolio! We hope the process helped you understand the need and benefits of taking short breaks from caregiving, and identify resources and opportunities to make it happen. We hope you discovered and identified different options to get respite and plan to make it a successful experience for both you and the person for whom you provide care.

So now what? There are a number of ways you can put the information in your portfolio to good use.

The Charting the LifeCourse Respite Portfolio can be used:

- To help others provide good supports to your loved one while you are taking a break or are not around. Paid staff, volunteers, family, friends, or others who might be providing care in your absence can use the front page of the portfolio as a quick reminder about what's important and how to best support the person receiving care.
- To train and coach people on how to best provide support when you are taking a respite break, and understand your vision for a good life and a good respite experience for your loved one. It could be kept in a notebook that can be easily accessed and used as a reminder when someone new or who hasn't spent time with the care recipient recently is providing support.
- To help people know how to best support your loved one when he/she is participating in an activity or event in the community.
- To advocate with professionals in formal planning meetings for your loved one's support needs and your needs as a caregiver and family member. The vision and trajectory pages can help you articulate to others what is important, what has worked or not worked in the past, and how you and your loved one want to move forward. The Integrated Star can be used to help both you and professionals think about how paid services can be enhanced by using some of the other types of supports you identified in the LifeCourse Respite Integrated Supports Star, or if paid services aren't available, decide how to best meet the support needs of your loved one, and your need to have some time for yourself.
- As a good organizing tool. It can help with planning and coordinating the logistics of everyday life for you and your loved one. The Integrated Schedule can be used when planning and scheduling who is providing support and when. It can help you find time for yourself to get a break from caregiving. The Integrated Support Star Worksheet can help you find solutions when challenges arise around respite and other life issues.

You may want to update the information in the Respite Portfolio from time to time, especially as life circumstances change for you, the person you provide care for, or your family. To see examples of how portfolios are used for respite needs, visit [lifecoursetools.com/respite](http://lifecoursetools.com/respite). You can also submit your own examples and stories if you wish!

### Integrated Supports in Action: Susan and Jackie

Susan is the primary caregiver for her mom, Jackie, who is in the moderate stages of dementia. A couple of years ago, Susan became concerned about her mom's safety when she began doing things like leaving the stove on and letting strangers in her house. Since they did not have resources to pay for in-home support and any family members that could help care for her mother lived far away, she decided to bring her mom home to live with her.

Jackie now requires more intensive support. A couple of months ago, Susan decided to quit her job to stay home full time with her. She now cares for Jackie on a daily basis and rarely gets a break.

Susan recently used the Integrated Support Star to think through the resources they had available to help her have a break.

When she filled out the star, Susan noticed that they did not participate in many community activities. She was able to find a church-run volunteer program for people with dementia that met twice a week for a couple of hours. Jackie now attends that group and Susan uses that time to run errands, go grocery shopping, or just stay home and take a nap. She says that those small two-hour breaks during the day have really helped recharge her batteries. ★



# RESOURCES FOR RESPITE



The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community, the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the Lifespan Respite Technical Assistance Center which is funded by the Administration for Community Living in the US Department of Health and Human Services.

The resources below, arranged by the categories of the Integrated Supports Star you just learned about, are just a few examples of national resources to get you started, and help you to make respite happen.

To find even more resources, visit [archrespite.org](https://archrespite.org).

## PERSONAL ASSETS & STRENGTHS

### [VolunteerMatch.org](https://www.volunteermatch.org)

Search engine with hundreds of thousands of opportunities for individuals to give back and share their time and talents with their community.

### [National Center for Creative Aging](https://www.creativecaregiving.org)

[creativecaregiving.org](https://www.creativecaregiving.org)

Free resource providing creative lessons to address the needs of family and caregivers of adults living with Alzheimer's disease and related cognitive disorders.

## COMMUNITY RESOURCES

### [YMCA.net](https://www.yymca.net)

YMCAs offer recreation and exercise programs for individuals of all ages and abilities.

### [Public Libraries](https://www.usa.gov/libraries)

Public libraries lend books, movies, music, and offer recreational and educational programs year round.

## TECHNOLOGY

### [State Assistive Technology Projects](https://www.ata.org)

Listing of statewide programs helping people with disabilities and their families select and acquire assistive technology devices for all types of settings.

### [LotsaHelpingHands.com](https://www.lotsahelpinghands.com)

Manage care schedules online for individuals of all ages.

### [AARP Technology](https://www.aarp.org/technology)

Provides information, webinars, and resources for older Americans and their caregivers to learn more about technology for entertainment, support, and more.

## RELATIONSHIP-BASED

### [Parent to Parent USA \(P2PUSA\)](https://www.p2pusa.org)

Find your state P2P to connect with someone who's 'been there' and find out how they made respite happen for their family.

### [AARP.org Caregiving](https://www.aarp.org/caregiving)

Tips and advice for caregivers at all stages, including articles, online discussion boards for caregivers to connect, and links to resources.

## ELIGIBILITY SPECIFIC

### [ARCH National Respite Locator Service](https://www.respitelocator.org)

Search engine of local respite programs and providers serving family caregivers of individuals with any disability or chronic condition, or of any age.

### [ARCH Respite Fact Sheets](https://www.archrespite.org/productspublications/arch-fact-sheets)

Provides an overview of the different types of respite programs available and how to access them.

### [Eldercare.gov](https://www.eldercare.gov)

Find your local Area Agency on Aging or Senior Center and additional resources.

### [Family-to-Family Health Information Centers](https://www.fv-ncfpp.org)

Federally funded centers that provide information and referral, training through workshops, and family-friendly materials to help you navigate life.

# THE Charting the LifeCourse FRAMEWORK



This guide was developed using the *Charting the LifeCourse*, a framework created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to think about life experiences that will help move them toward an inclusive, productive life in the future.

Even though it was originally created for people with disabilities, this universally-designed framework may be used by any person or family making a life plan, regardless of life circumstances.

## FOUNDATION OF THE LIFE COURSE FRAMEWORK

The following are the building blocks of the charting the Charting the LifeCourse framework. They are the core principles and values that are important as we begin to think differently about what it means to support individuals with disabilities and their families to have good lives.

**Core Belief:** All people have the right to live, love, work, play, and pursue their life aspirations.



### ALL People

ALL people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families.



### Life Stages and Trajectory

Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory. It is important to have a vision for a good, quality life, and have opportunities, experiences and support to move the life trajectory in a positive direction.



### Life Outcomes

Individuals and families plan for present and future life outcomes that take into account all facets of life and have life experiences that build self-determination, social capital, economic sufficiency and community inclusion.



### Family System and Cycles

People exist and have give-and-take roles within a family system. Roles adjust as the individual members change and age. Individuals and families need supports that address all facets of life and adjust as the family ages through family cycles and the roles and needs of members change.



### Life Domains

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. These include daily living, community living, safety and security, healthy lifestyles, social and spirituality, and citizenship and advocacy.



### Individual and Family Supports

Supports address all facets of life and adjust as roles and needs of all family members change. Types of support might include discovery and navigation (information, education, skill building); connecting and networking (peer support); and goods and services (daily living and financial supports).



### Integrated Delivery of Supports

Individuals and families access an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility; community supports that are available to anyone; relationship-based supports; technology; and that take into account the assets and strengths of the individual and family.



### Policy and Systems

Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Every program, organization, system and policy maker must always think about a person in the context of family.

To learn more about the Charting the LifeCourse framework, visit [lifecoursetools.com](http://lifecoursetools.com).

Connect with us



[archrespite.org](http://archrespite.org)