



Charting the LifeCourse
Framework and Tools

Charting the LifeCourse Raising the Bar for Respite

May 23, 2024

www.lifecoursetools.com

About Barb

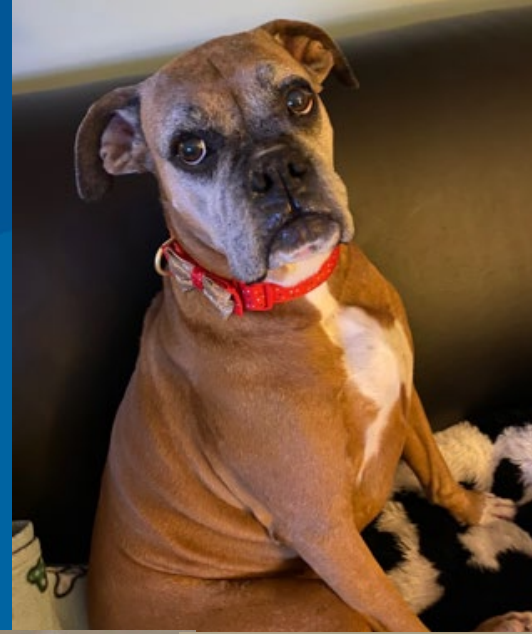
- 48+ years Human Services
- Consultant
- CtLC Coach
- PCT Trainer/Mentor
- Family Member
- Family Caregiver
- Sister, Partner,
Daughter, Aunt



www.lifecoursetools.com

About Jane

- Mom of 3 sons, “Ben’s mom”
- Wife, mom, grandma, daughter, sister
- CtLC Nexus at UMKC-Institute for Human Development, UCEDD
 - Product Development and Training
 - Trainer/Coordinator of SDM activities



Objectives for Today

- Raise the bar in how we think about short breaks
- Introduce LifeCourse tools and training for Respite
- Explore short breaks through an interactive activity



Charting the LifeCourse



www.lifecoursetools.com

What is Charting the LifeCourse?

Created for people and families of all abilities and all ages to:

- *Explore life possibilities and discover options*
- *Problem-Solve to find solutions and identify resources*
- *Plan Goals and Action Steps for Now and the Future*
- *Advocate and navigate for vision*
- *Access a variety of integrated supports*



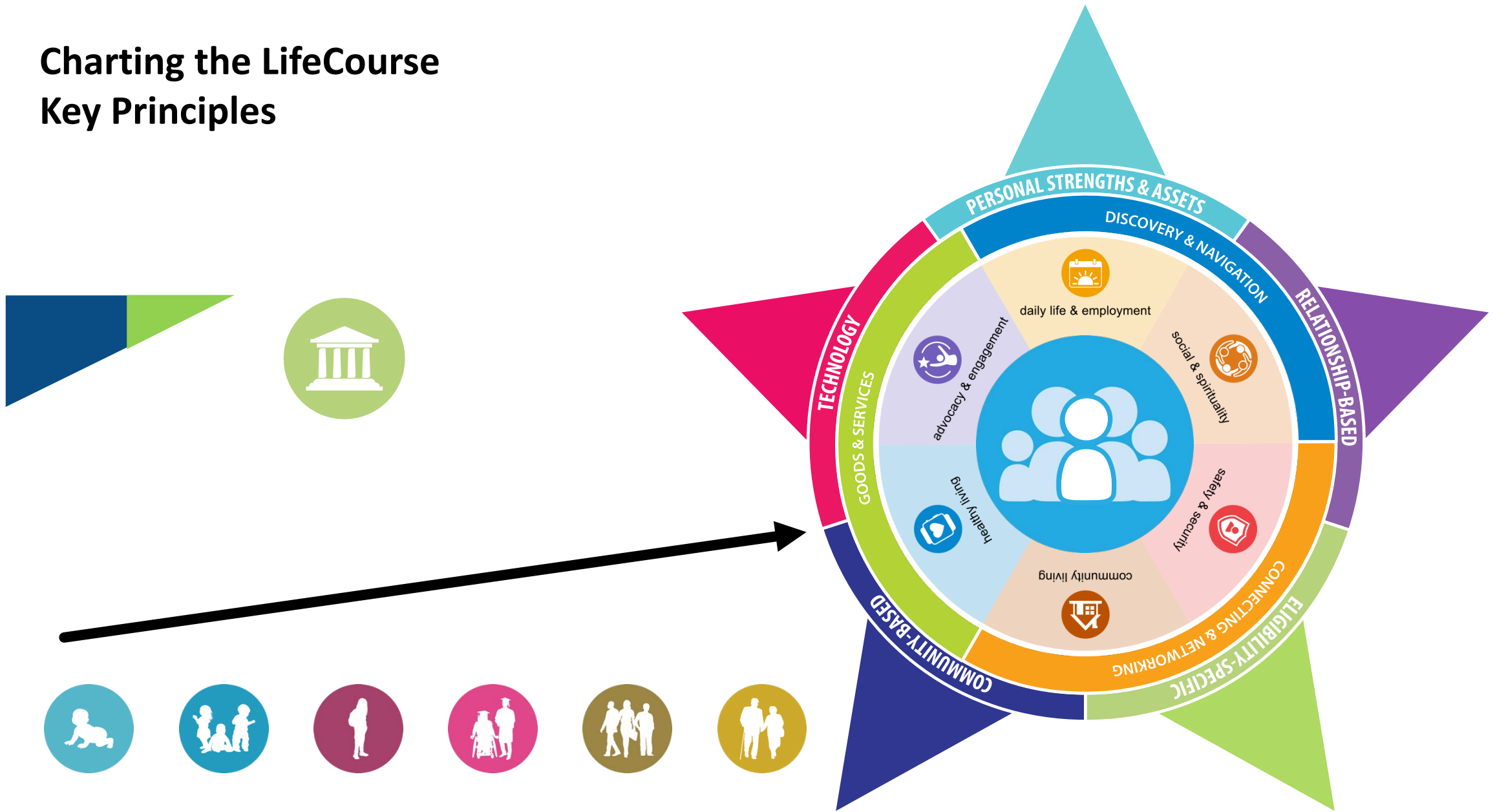
CORE BELIEF

All people and their families have the right to live, love, work, play, learn, and pursue their life aspirations in their community.



Charting the LifeCourse

Key Principles





Respite: Setting the Stage

Beyond traditional understanding



www.lifecoursetools.com

Traditional Respite Definition

- Paid service
 - Outside family home
 - Formal care facility setting
 - Community based respite program
- OR
- In-home with paid professionals



Respite: Practical Application

- “Coordinated systems of community-based respite for family caregivers of children or adults regardless of special need.”*
- Short breaks that benefit both the caregiver and care recipient
- Can be in a variety of settings, including in-home, community places and more
- Respite can be a “formal service” or informal supports

*Lifespan Respite Care Act

wellness

short breaks

rest and recharge

friends

*trusted places
and people*

extended family

balance

Doing Everyday Things

Sometimes caregivers need respite to handle some kind of business....

Caregiver may need short breaks to work on these kinds of things:

- Medical appointments
- Grocery shopping
- “Fighting city hall”
- Handling household issues
- Paying bills
- Job obligations



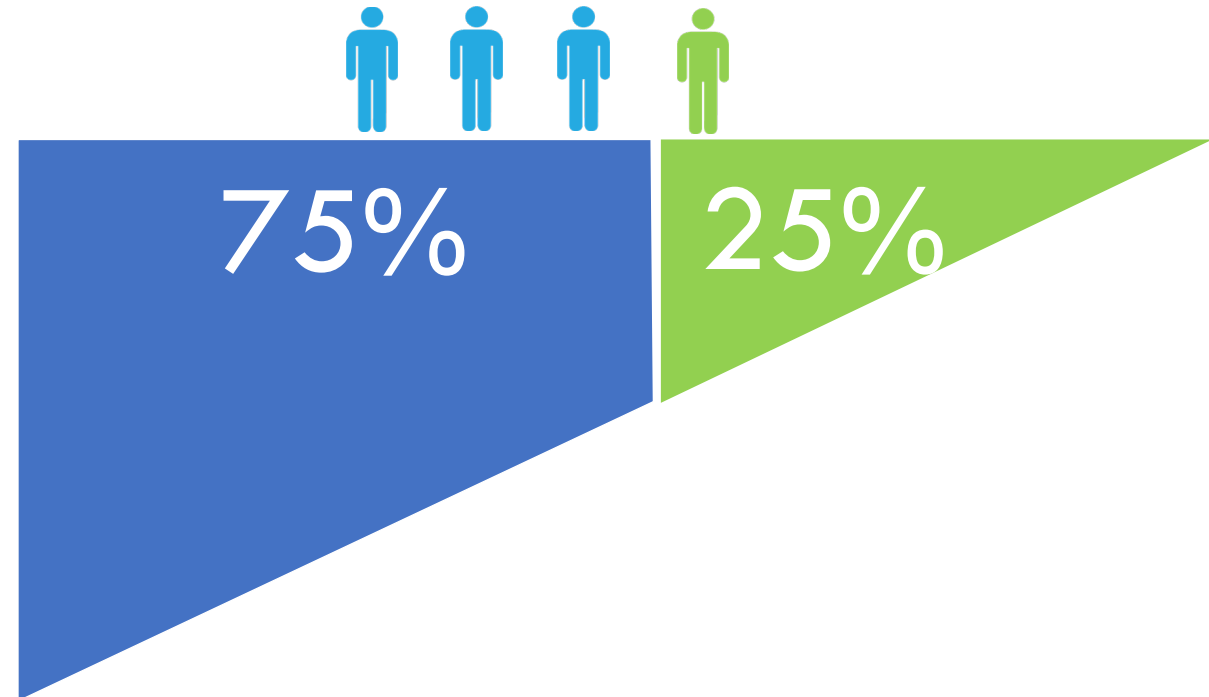
Changing Roles

May not recognize, acknowledge or identify as a caregiver

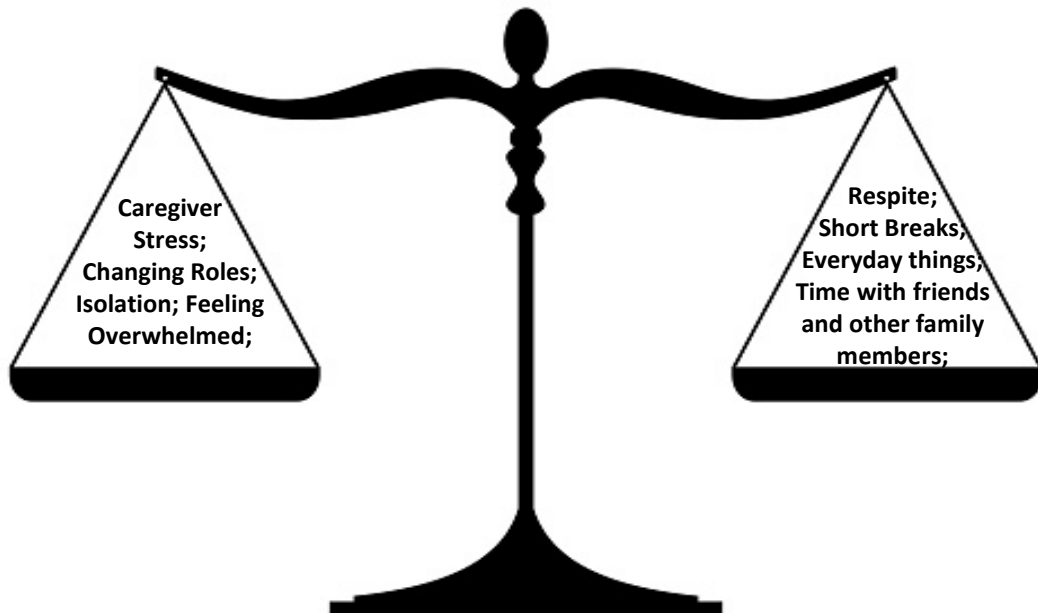
- Change in roles (for example, caring for a spouse or aging parent)
- Not acknowledging the “extra” care, beyond the typical role
- Not recognizing the stress and “overwhelm”

Why Think Differently About Respite?

- Not everyone gets respite funding – think about the ALL
- Respite funds are often very limited – how can we make them stretch?
- Short breaks don't have to be a formal service – how do we incorporate into everyday life?



Finding Balance



Caregiving can be:

- Rewarding
- Stressful
- Overwhelming

Important to find
BALANCE

Why Respite is Important

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.



Benefits of Respite

Caregiver:

- Rest and recharge
- Relieve caregiver stress
- Spend time with other family member(s)
- Catch up with friends
- Do things they enjoy

Care Recipient:

- Break from caregiver
- Chance to spend time with others or do things they enjoy

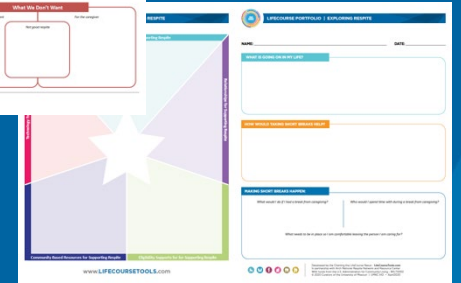
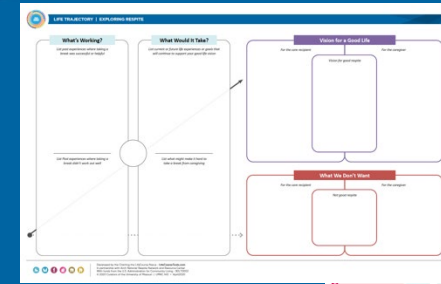
“Good Respite for All ”



The Care Recipient will have greater independence by spending time away from caregiver, improved interactions with caregiver (due to decreased stress), increased happiness and self-esteem.



Caregivers will be supported to take planned short breaks where they can focus on self care, spend time with friends or other family members, read a book, do everyday things, or just relax and re-charge.



Charting the LifeCourse Respite Guide and Tools



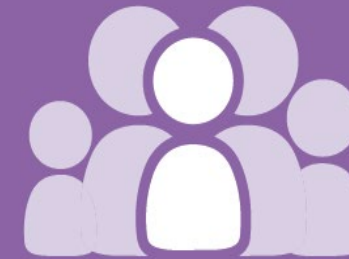
www.lifecoursetools.com

Respite Guide

<https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respite/>

- Free to download and use

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.

UMKC INSTITUTE FOR HUMAN DEVELOPMENT, UCEDD

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

LifeCourse Portfolio: Exploring Respite

LIFECOURSE PORTFOLIO | EXPLORING RESPITE

NAME: _____ DATE: _____

WHAT IS GOING ON IN MY LIFE?

HOW WOULD TAKING SHORT BREAKS HELP?

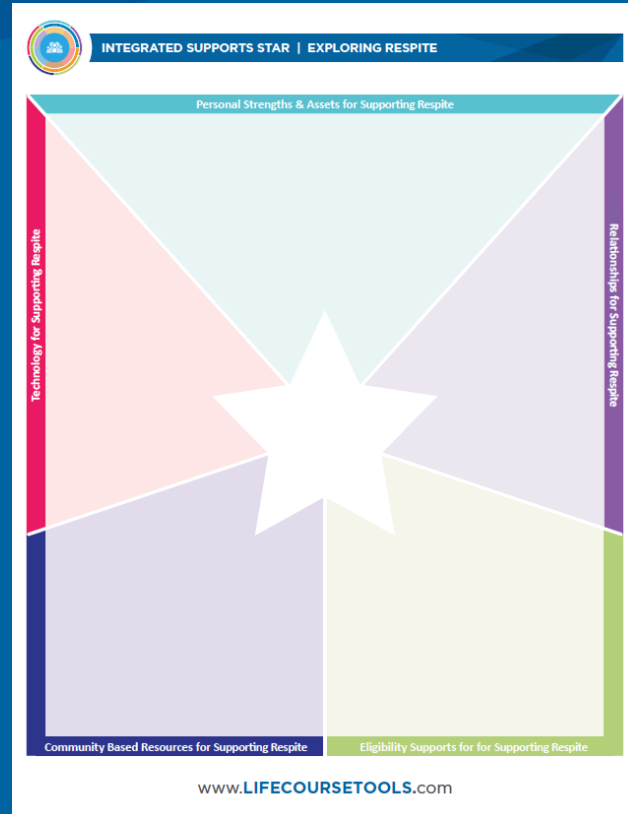
MAKING SHORT BREAKS HAPPEN:

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

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

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

Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com
 In partnership with Arch National Respite Network and Resource Center
 With funds from the U.S. Administration for Community Living - 90L10002
 © 2020 Curators of the University of Missouri | UMMC 810 • April 2020



LIFE TRAJECTORY | EXPLORING RESPITE

What's Working?
 List past experiences where taking a break was successful or helpful

What Would It Take?
 List current or future life experiences or goals that will continue to support your good life vision

Vision for a Good Life
 For the care recipient: _____
 For the caregiver: _____
 Vision for good respite: _____

What We Don't Want
 For the care recipient: _____
 For the caregiver: _____
 Not good respite: _____

Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com
 In partnership with Arch National Respite Network and Resource Center
 With funds from the U.S. Administration for Community Living - 90L10002
 © 2020 Curators of the University of Missouri | UMMC 810 • April 2020

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 could improve your life, think about what you would do with a short break, and identify what needs

To begin, you will need the blank LifeCourse Respite portfolio that came with this guide or you download at lifecoursetools.com/respites.

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

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

Examples: relieve stress; improve caregiver health; improve relationship of caregiver and 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 on a break from caregiving?

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

Examples: reconnect with family or friends; meet 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 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?

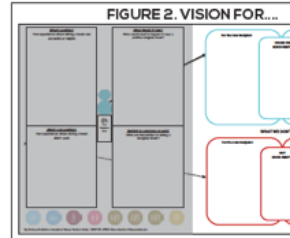


Respite Trajectory Worksheet

Good respite planning starts with a clear vision for a good life and for a good respite experience. Having a clear vision of what good respite looks like for you and your loved one, and keeping that vision in mind, can help 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	CAREGIVER	RESPITE
<p>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</p>	<p>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</p>	<p>VISION FOR GOOD LIFE LIST what makes a good life for you and your loved one. What are you doing or in place so you can relax and have a positive experience? Examples: Respite provided in CPR/first aid, care that is enjoyable activity</p>
<p>Note: Sometimes it is easier to know what you want by FIRST identifying "What We Don't Want" below.</p>		
<p>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</p>	<p>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.</p>	<p>WHAT IS NOT GOOD LIST things that would be a negative experience for caregiver and/or care recipient. Examples: care recipient caregiver worries the</p>

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

MAPPING RESPITE

What are our options?



Integrated Star Worksheet

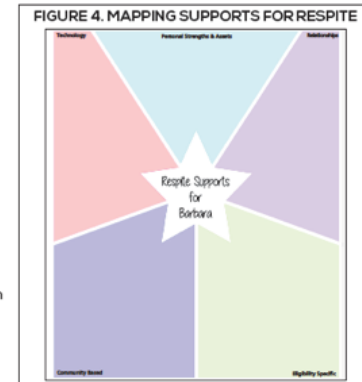
In this section, you will create your own Respite Integrated Supports Star "bank."

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.



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

- Faith-based resources
- Parent/family cooperative
- Sitter-companion services

- State lifespan respite care programs
- Older Americans Act - Family Caregiver Support Program
- Respite voucher
- Consumer directed respite

breaks for herself. Nicole began to look for respite services.

daughter, who was summer, could help her as well as spend some time with Nicole to work on as well as run occasional relationship-based respite. This reduced the amount of time Nicole spent caregiving and allowed her to do other things she wanted to do. ★



Questions to Ask or Discuss

- What is going on in your life?
- How would taking short breaks HELP you and the person you provide care for?
- What would you do if you had a break from caregiving?
- What are things you enjoy doing?
- Who would you spend time with during a break from caregiving?
- What are some of the everyday things you don't have time to do?
- What needs to be in place, so you are comfortable leaving the person you are caring for?

Let's Try It!



www.lifecoursetools.com

Each person take a few minutes to think about the questions and write something in each box. Then spend some time sharing and discussing in your group how you could apply to the people you navigate with, plan with, etc.

If you are NOT a caregiver, think about it in terms of what is going on in your life

- Where could you use a short break (parenting, job, obligations, etc.)?
- How would a break in _____ help me?
- What would it take/what would I do if I had a break?

Fill it out for YOU

LIFECOURSE PORTFOLIO | EXPLORING RESPITE

NAME: _____ DATE: _____

WHAT IS GOING ON IN MY LIFE?

HOW WOULD TAKING SHORT BREAKS HELP?

MAKING SHORT BREAKS HAPPEN:

<i>What would I do if I had a break from caregiving?</i>	<i>Who would I spend time with during a break from caregiving?</i>
<i>What needs to be in place so I am comfortable leaving the person I am caring for?</i>	

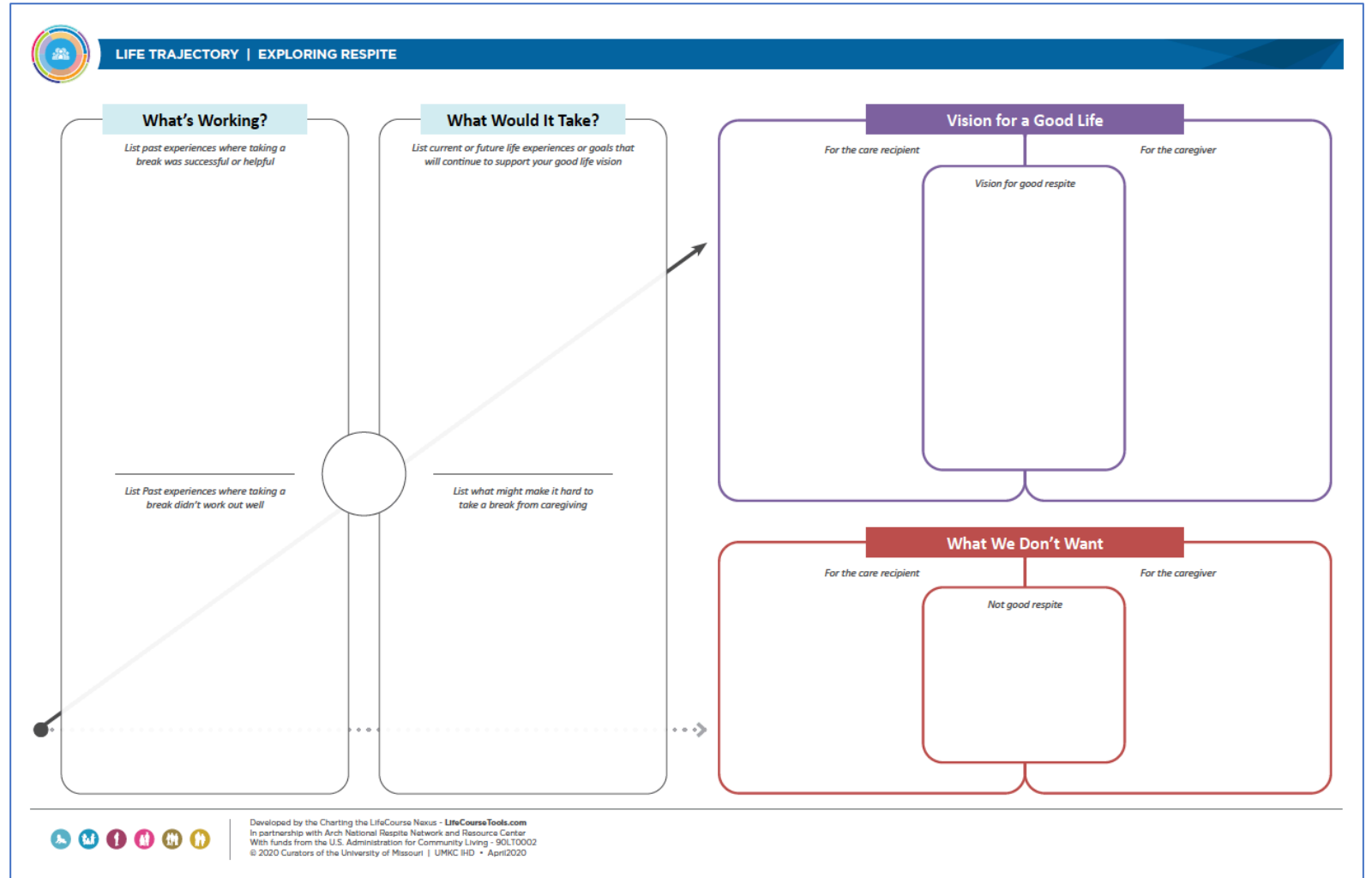
Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com
In partnership with Arch National Respite Network and Resource Center
With funds from the U.S. Administration for Community Living - 90LT0002
© 2020 Curators of the University of Missouri | UMKC IHD • April 2020

Welcome Back!

- What were some of the key takeaways or “aha moments” from your activity and discussion?
- What did it feel like to do this for yourself?
- What would it be like to use this to support a caregiver to take a short break?

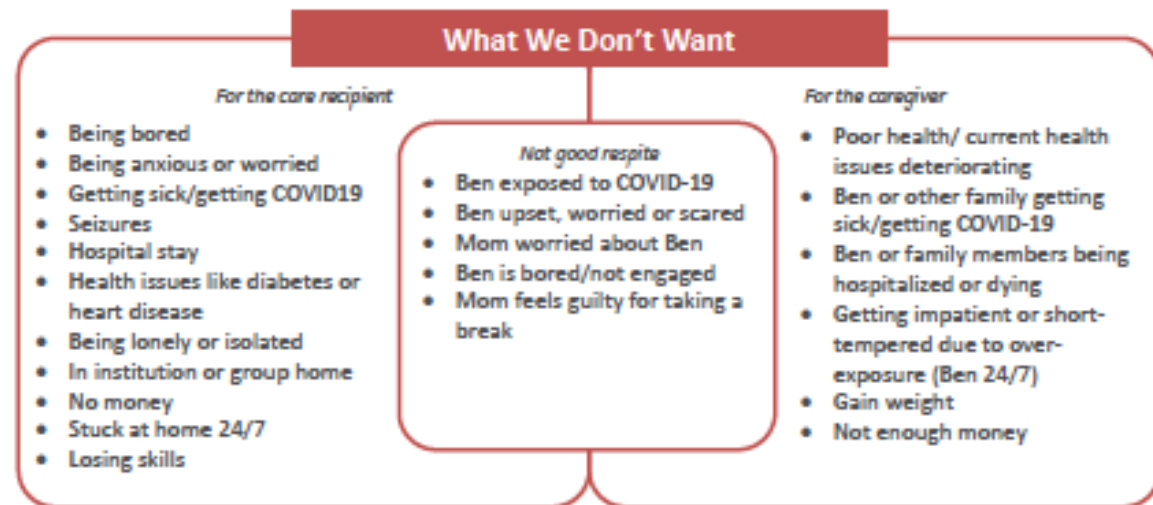
Why Use the Respite Trajectory?

- Learn about vision, fears, barriers
- Identify goals for caregiver and care recipient for short breaks/life



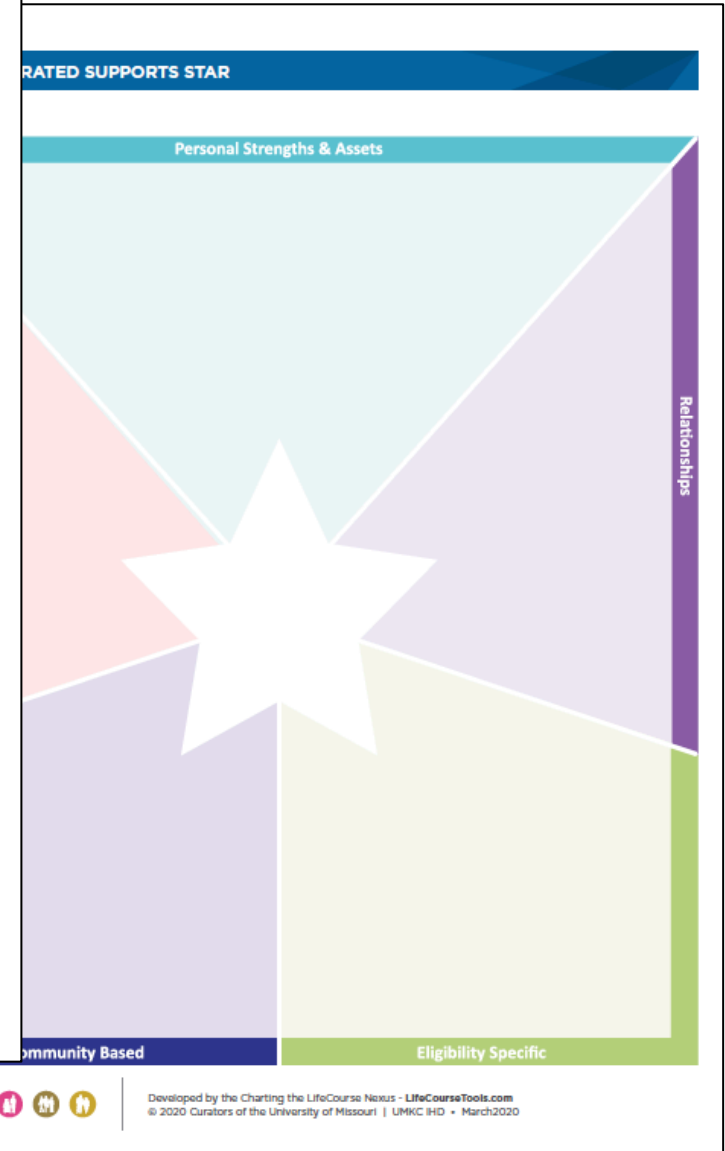
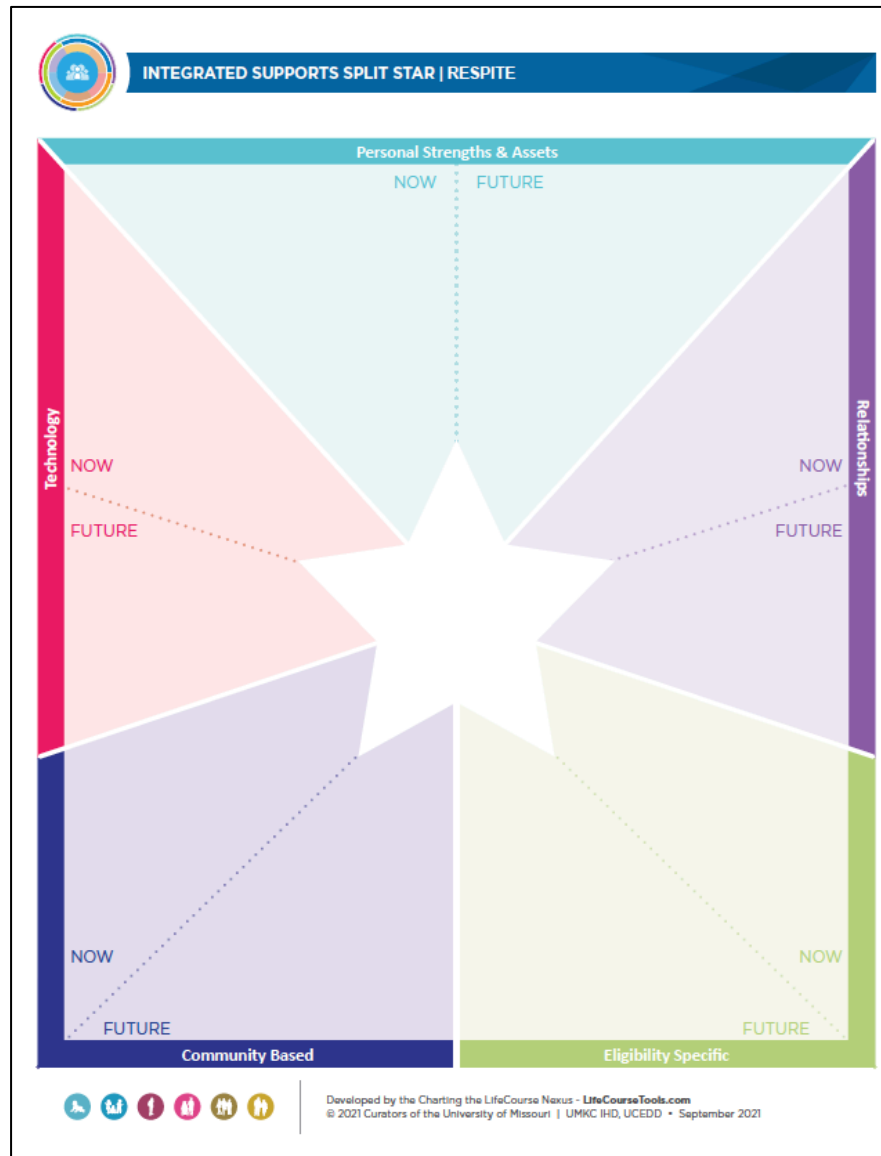
Vision for Good Life and Good Respite

And what we don't want....



Why Use the Respite Support Star?

- Not everyone gets paid respite supports (think about the ALL)
- Paid respite funding is often not enough (make it stretch)
- Can offer more targeted and personalized support (incorporate in everyday life)



Respite Resources and Ideas - when in-person or formal respite services aren't available or enough



Planning for Supporting Ben's Caregiver(s) if Parents Aren't Available



Charting the LifeCourse Respite Series

What is it?



www.lifecoursetools.com

Respite Skill Building Series

4-part Interactive Skill Building Training

- Session ONE – Explore respite/short breaks; building trust; getting to know caregiver/family
- Session TWO – Trajectory - discover vision/fears; identify barriers; identify GOAL(s) for short breaks/life in general
- Session THREE – Integrated Supports – mapping and planning variety of supports for respite; moving beyond traditional paid respite
- Session FOUR – Respite Schedule – using to map care giver and care recipient needs and life schedule

Questions & Final Reflections



www.lifecoursetools.com

THANK YOU!

stjohnj@umkc.edu

Barbara.Sapharas@umkc.edu

<https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respite/>



www.lifecoursetools.com