

2022 NATIONAL CONFERENCE



American
Brain Tumor
Association®

Providing and pursuing answers®

Living Your Best Self...as a Caregiver



Jamie Jacobs, PhD

Program Director, Center for Psychiatric Oncology & Behavioral Sciences
Director of Caregiving Research, Cancer Outcomes Research Program

Massachusetts General Hospital | Cancer Center

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01

I have no stocks, patent rights or employment with any company

02

I have no consulting/advisory board agreements

03

I have funding from the following sponsors:

National Cancer Institute

American Society for Clinical Oncology Conquer Cancer Foundation

ARE YOU...HAVE YOU...



Taking care
of a loved
one



Ever provided
care for
someone else
(a parent,
child, friend,
spouse)



Being taken
care of by a
loved one



Congratulations

...on taking the next hour to focus on

YOU

“UNMET NEEDS”

01

Caregivers
have more
unmet care
needs than
patients

02

Caregiver's
needs are
considered
secondary or
overlooked

03

We need to
better
understand
the needs of
caregivers of
people with
brain tumors

A DAY IN THE LIFE...

Personal care

Mobility

Transportation

Communication with supports

Housework and meal preparation

Management and coordination of medical care

Administration of medication and therapies

Monitoring and managing of side effects

Emotional support

Managing finances

Care for other departments

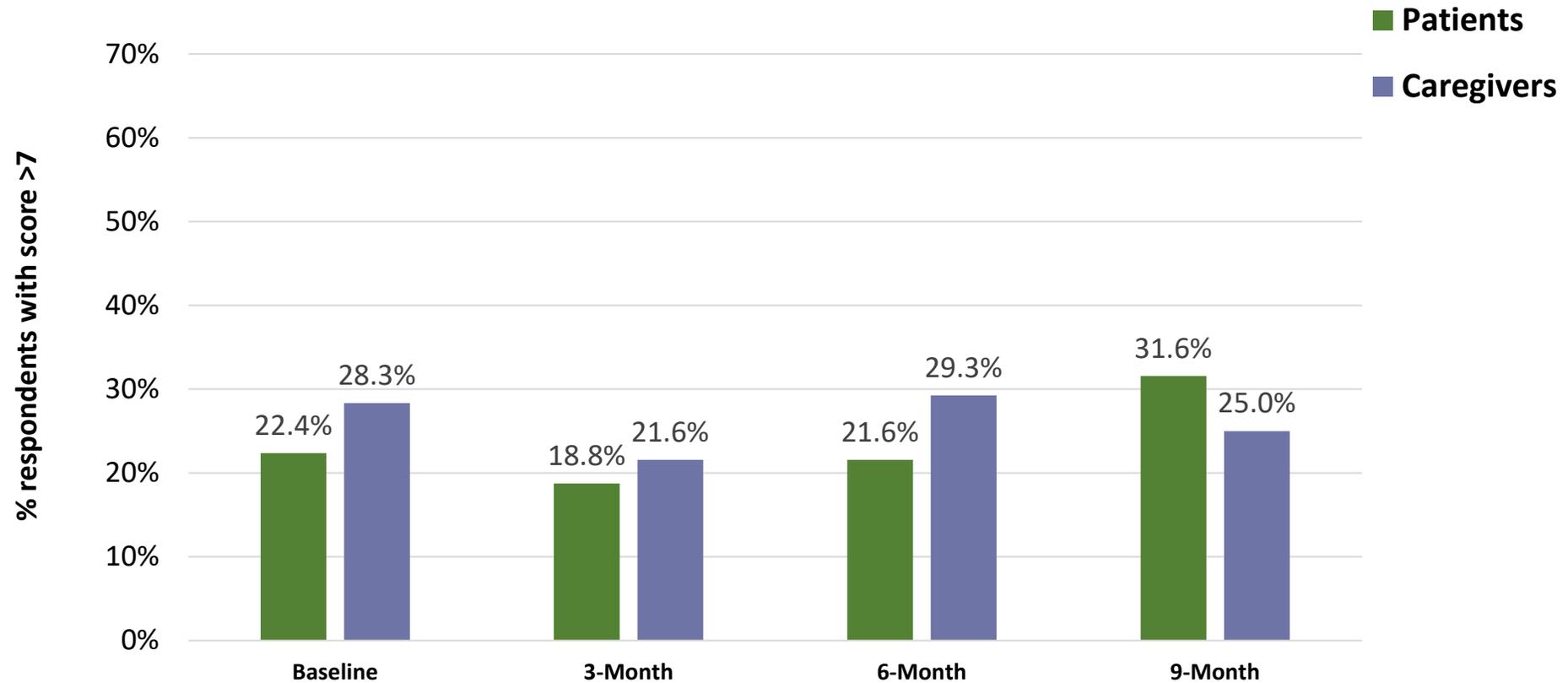
Maintain job or other responsibilities

Self-care?????

CAREGIVER

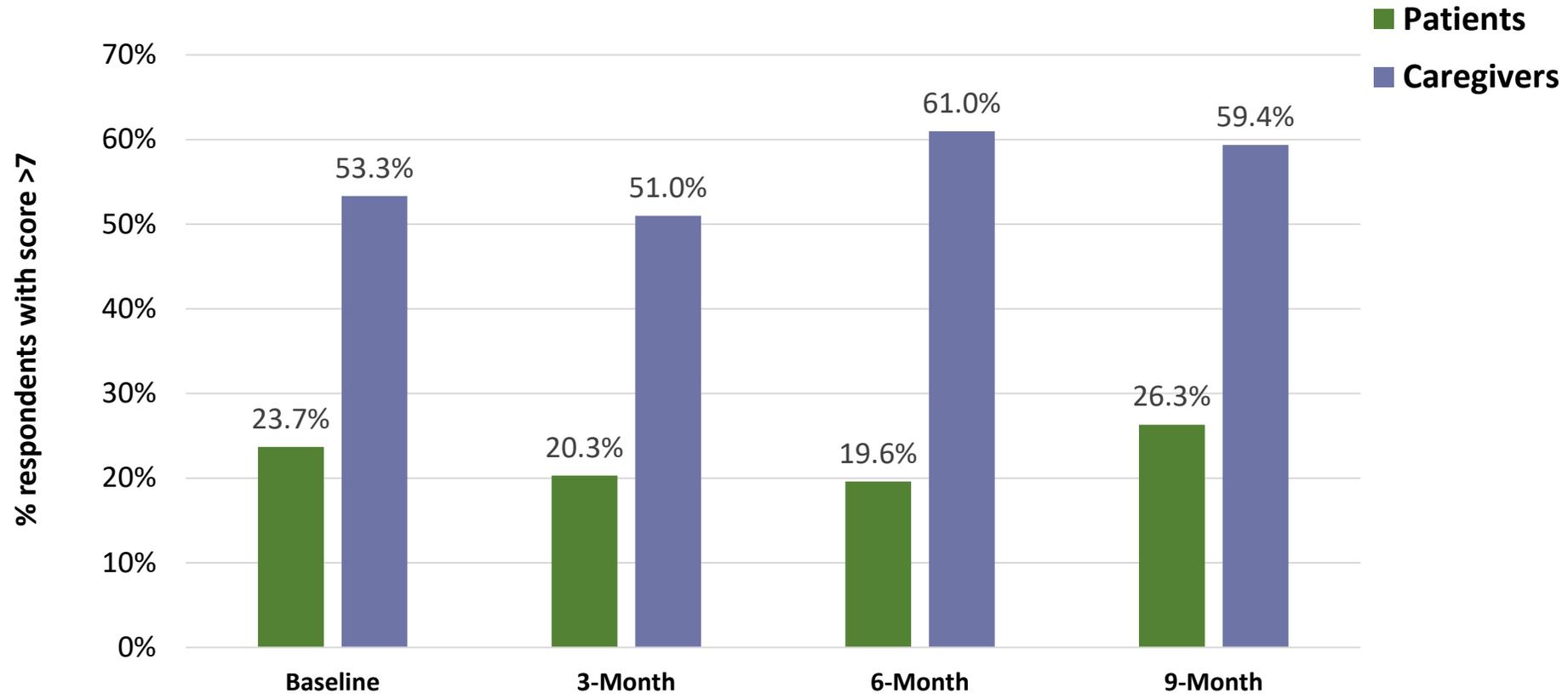
“I don’t go out with my friends by myself as much as I used to because I don’t want to leave him here by himself.”

DEPRESSION SYMPTOMS



Forst et al., 2017

ANXIETY SYMPTOMS



Forst et al., 2017

THREE COPING STRATEGIES

1

**Enhancing
Communication**

2

**Intention for
Self-Care**

3

**Building
Relaxation Skills**

THREE COPING STRATEGIES

1

Enhancing
Communication

SHARING FEARS AND WORRIES

01

If the situation were reversed and someone else was caring for you, would you want him/her to keep their worries from you or share them with you?

03

What advice would a good friend give to you?

It is common for people to want to “protect” each other from their fears, worries, or sadness during this time. Ask yourself these questions:

If a friend were in your situation, what advice would you give them?

02

What is the worst that can happen if you shared some of your fears with the person you are caring for?

04

COMMUNICATION: THE THREE Fs

01

STATEMENT OF FACT

When I see that you are running late and haven't called.

02

STATEMENT OF FEELING

I feel nervous and worried.

03

STATEMENT OF FAIR REQUEST

I would like if you would call or text next time you are running late so that I know everything is okay and when to expect you home.

ENHANCING SOCIAL SUPPORT

How to ask for or optimize the support you need:

01

ASSESS

Assess the situation

02

IDENTIFY

Identify the type of support you need

03

IDENTIFY

Identify who might be best equipped to provide you with that type of support

04

NOTICE

Notice any barriers associated with asking for and receiving support

- Am I willing to ask for help?
- Am I willing to receive help?
- Do I think that asking for help makes me seem weak?
- Do I believe that I should be able to do it all by myself?
- Do I think that I am burdening others by asking for their help?

05

CHALLENGE

Challenge yourself as to whether your beliefs about asking for and receiving support are accurate.

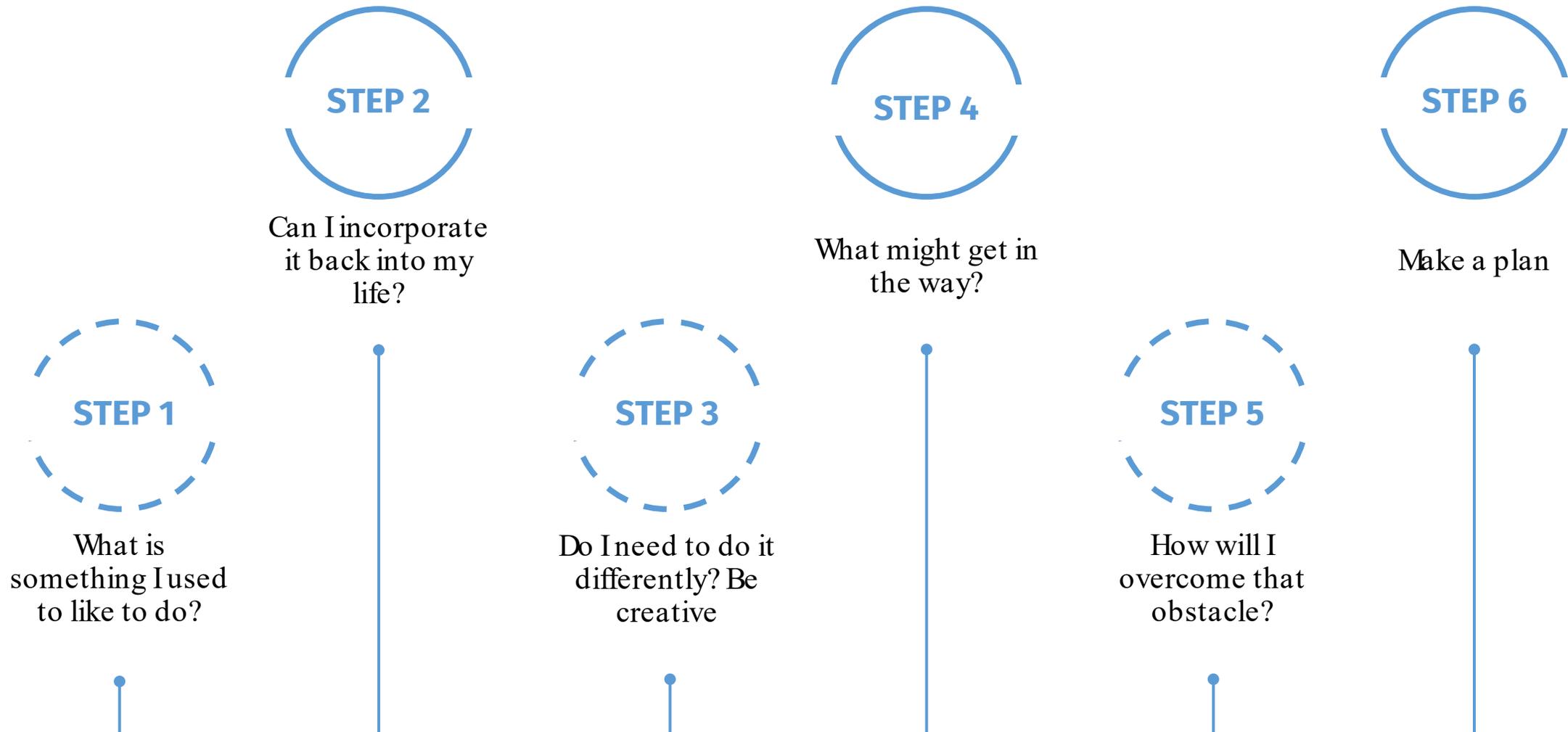
For instance, is receiving support really a sign of weakness? If someone asked you for support, would you label him/her as weak? What would you tell a friend to do?

THREE COPING STRATEGIES

2

Intention for
Self-Care

INTENTION FOR SELF-CARE: 6 STEPS



INTENTION FOR SELF-CARE: EXAMPLE 1

1. What is something I used to like to do?

Workout at the gym

2. Can I incorporate it back into my life?

Maybe, but not at the gym

3. If not, can I do it differently? Be creative

Take a walk or jog around the neighborhood

4. What might get in the way?

Weather, can't leave my loved one

5. How will I overcome that obstacle?

Have a backup exercise video at home or on YouTube

6. Make a plan

This week, Tuesday, 30-minute walk in the morning, if raining, YouTube exercise videos and choose one in advance

INTENTION FOR SELF-CARE: EXAMPLE 2

1. What is something I used to like to do?

Travel to new places

2. Can I incorporate it back into my life?

No, we cannot feasibly travel right now

3. If not, can I do it differently? Be creative

Watch a travel show on a country/city and order that country's cuisine for dinner while we watch

4. What might get in the way?

Not enough time

5. How will I overcome that obstacle?

Block out one night every other week or once a month

6. Make a plan

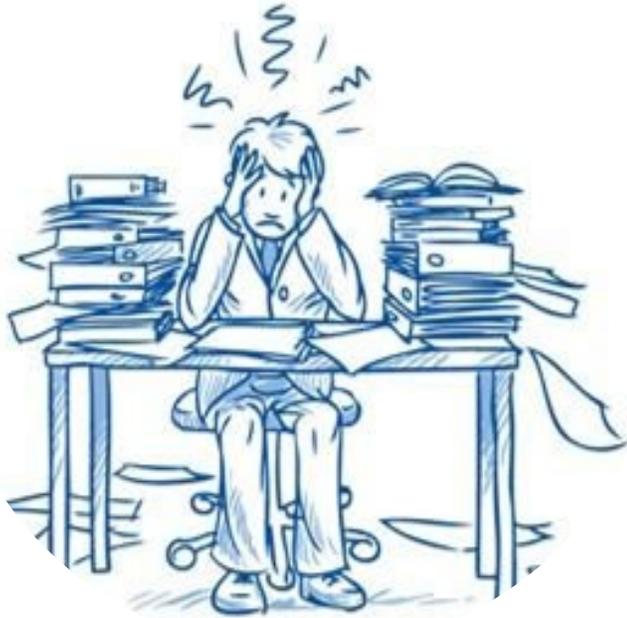
This week, Wednesday night, mother will watch kids, we will choose a show on Greece and eat food from a Greek restaurant while we watch

THREE COPING STRATEGIES

3

Build Relaxation
Skills

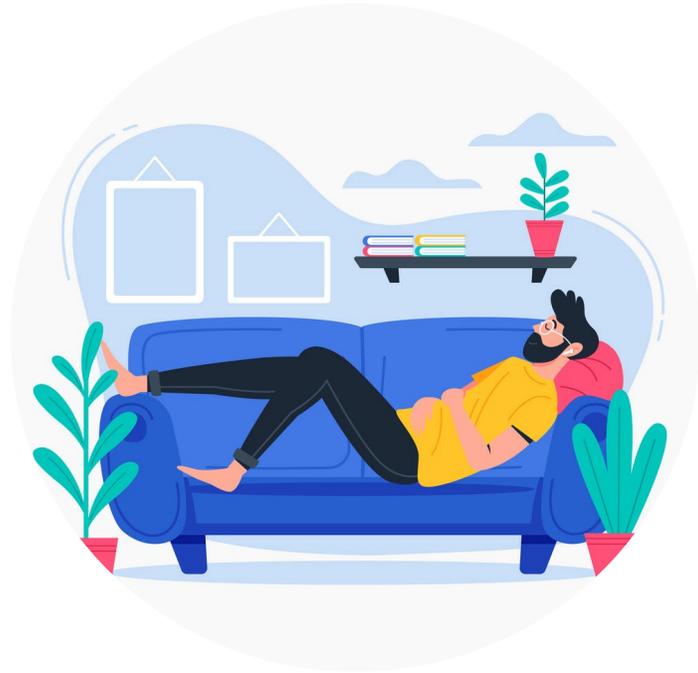
THE FIGHT OR FLIGHT RESPONSE



↑ Adrenaline
↑ Cortisol
↑ Sick

↑ Inflammation
↑ Sleep issues
↑ Stress on body

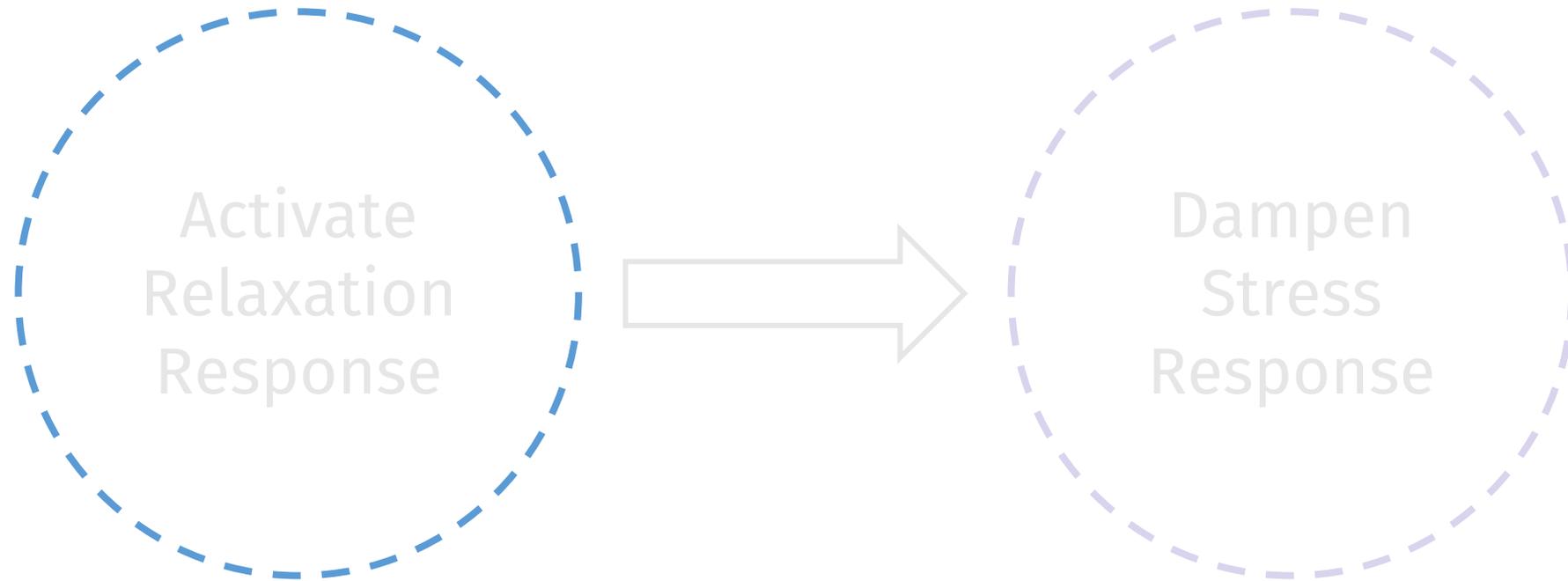
THE RELAXATION RESPONSE



↓ Adrenaline
↓ Cortisol
↓ Sick

↓ Inflammation
↓ Sleep issues
↓ Stress on body

GOAL OF BUILDING RELAXATION SKILLS



PROGRESSIVE MUSCLE RELAXATION (PMR)

01

HANDS
AND
ARMS

Hold arms at a 45-degree angle and make fists.

02

FACE
AND
NECK

Raise eyebrows, squint eyes, wrinkle nose, bite down lightly, pull back corners of mouth, and pull head slightly down to chin.

03

CHEST,
SHOULDE
RS, BACK

Take a deep breath, hold it in, pull back the shoulders and puff out chest. Careful of back issues.

04

THIGHS,
CALVES,
FEET

Lift your feet off of the floor, flex slightly, and turn toes inward.



Progressive Muscle Relaxation (PMR)

ADDITIONAL RESOURCES

[Caregiver Resource Center](#)

[Caregiver Handbook](#)

[Connections](#) – ABTA’s online brain tumor support community for patients, survivors, and caregivers

[CommYOUity Connect](#) – ABTA’s peer mentoring program for patients, survivors, and caregivers

www.cancercare.org (caregiver groups online and over the phone)

MGH Program for parents: <http://www.mghpact.org/forparents/parents>

https://livehelp.cancer.gov/app/chat/chat_launch (NCI live free information)

Caregiver Support Video Series: (<https://www.cancer.org/treatment/caregivers/caregiver-support-videos.html>)

Cancer Support Community: <https://www.cancersupportcommunity.org/MyLifeLineMemberStories>

Mobile Apps:

Insight Timer

Calm

Headspace

Stop Breathe and Think

Full Catastrophe Living by Jon Kabat-Zinn

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THANK YOU

Any questions?



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