



Facilitating Conversations About *Acceptance and Grief*

1

Sign In!

- If you are joining as a group, each individual **MUST** sign in separately from their own account to receive CEU credit.
- You do not need to stay signed in; please join for a few minutes in order for the system to log you as an attendee.

2



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3

Financial Disclosure

Anna Reeve is an employee of Lingraphica
and thereby receives financial compensation
from the Lingraphica Company.

Carole Starr is the author of the book mentioned in
this course (*To Root & To Rise: Accepting Brain Injury*)
and manages the website <https://starrspeakerauthor.com>



4

Learning Objectives

- Discuss the importance of conversations about grief and acceptance with survivors of brain injury, stroke, and/or neurodegenerative conditions.
- Identify 4 possible stages of grief and statements associated with each.
- Define the SLP's role in identifying communication supports that facilitate conversations related to both grief and acceptance.
- State 3 clinical resources available to assist an AAC device user to discuss their current and/or past feelings about their rehabilitation journey.



5

TTO

Agenda

- Meet Carole Starr
- A long-term survivor's perspective on accepting brain injury
- What might acceptance look like?
- Discuss the SLP's role in facilitating conversation about acceptance and grief
- Impacts of grief on moving forward with life and use of communication supports
- Navigating through stages of grief and barriers to acceptance
- Conclusion — Q & A



6

Slide 6

TT0 Shorten 6th bullet to "Navigating through stages of grief and barriers to acceptance"
Teresa Thompson, 2023-01-18T18:25:18.573

CM0 0 agree
Caitlin Mueller, 2023-01-19T22:45:33.789

Carole J Starr, MS



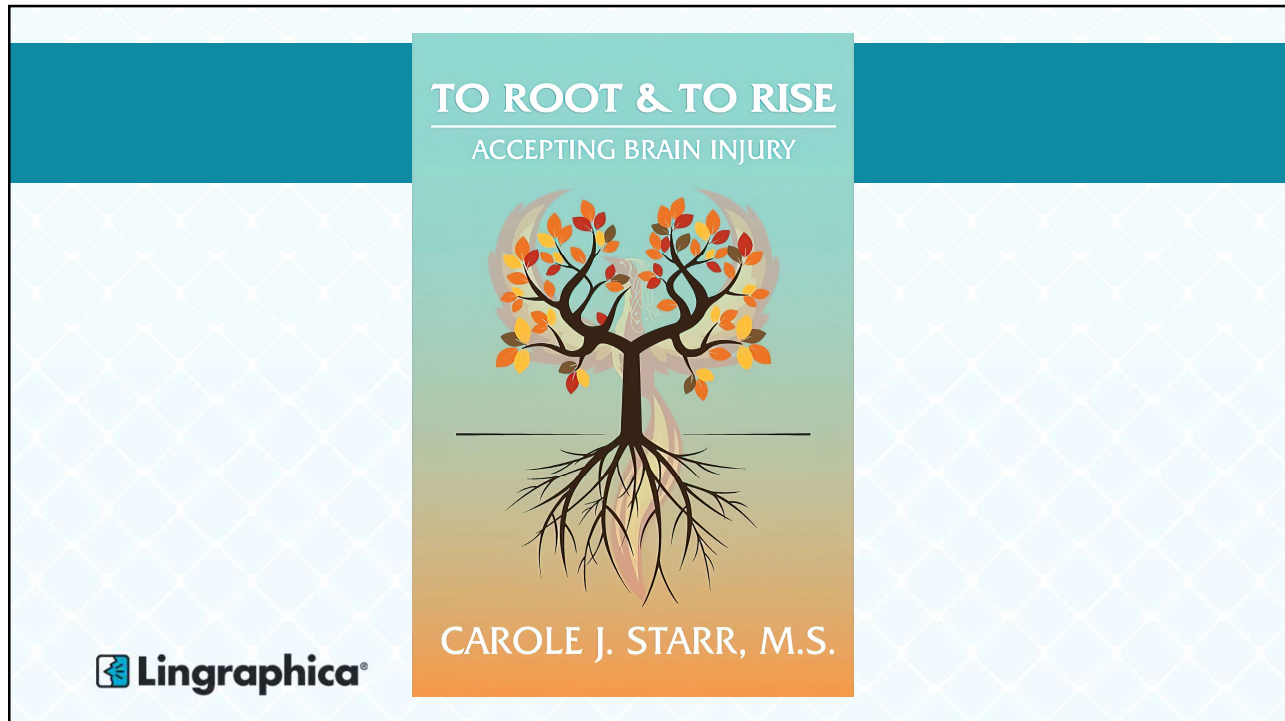
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Carole's Brain Injury Journey from Surviving to Thriving

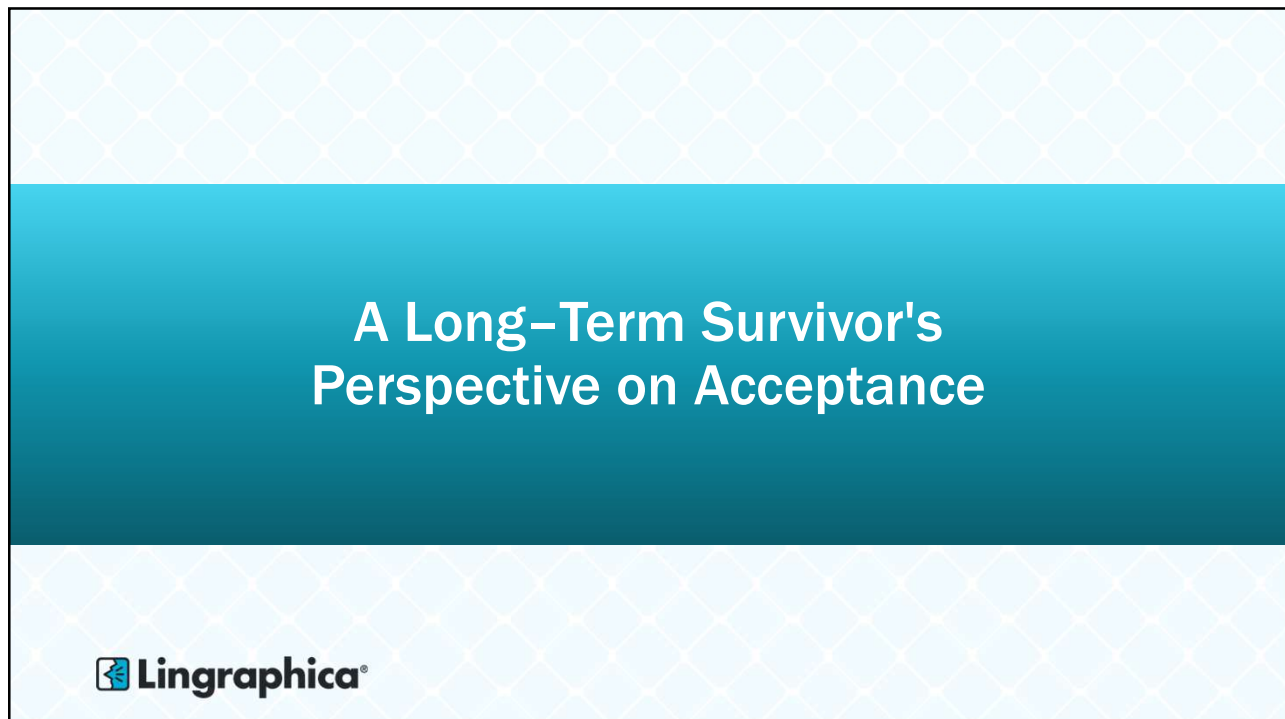
- From loss of self to embracing new identity
- From grieving the losses to celebrating progress
- From looking backward (what was) to looking forward (what is)
- From feeling useless to finding a new purpose



8



9



10

“Acceptance is acknowledging the reality of a situation. It’s about recognizing the difference between what can be changed and what cannot.”
– Carole Starr



To Root & To Rise: Accepting Brain Injury, p. 1

11

Misconceptions About Acceptance



- Giving up or resigning
- “The end of the road”
- Things will always be this way
- I’m OK with the way things are



Adapted from To Root & To Rise: Accepting Brain Injury, p. 2

12

Acceptance Is...

- Not a one-time event
- Not agreeing with or liking what's happened
- Knowing that this injury has changed the person forever
- Working with limitations, not fighting them
- Recognizing the need for help
- Letting go of control
- Understanding life is different, not over



Adapted from *To Root & To Rise: Accepting Brain Injury*, p. 2-3

13

The Spiral Path Moving Toward Accepting Brain Injury



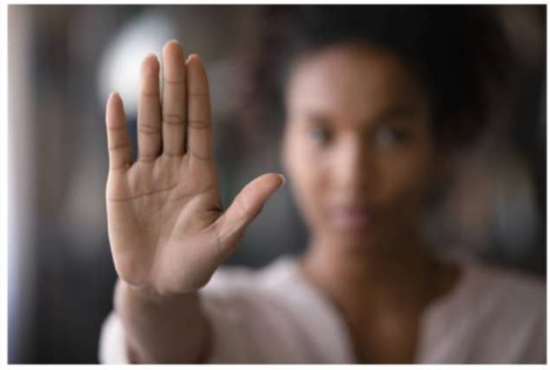
- Denial & lack of awareness
- Feeling lost & confused
- Sadness, anger, & loss
- Growing toward acceptance



To Root & To Rise: Accepting Brain Injury, p. 23

14

Denial & Lack of Awareness



What it looks like

- "This can't be real"
- Magical thinking — tomorrow I'll wake up "normal"
- Unwillingness to listen to family, friends, medical professionals
- Refusal to use strategies
- Push to return to "old life," certainty about recovery



15

ISO

Denial

Psychological Denial vs Organic Denial

- You may observe:
 - Overestimating abilities
 - Unwillingness to use strategies despite effectiveness
 - Pushing Forward — headstrong despite negative effects
 - Pushing Back — resistance to change or acceptance
 - Minimizing symptoms or condition
 - Embarrassment or shame



16

Slide 16

JSO This was very helpful to me as a clinician. I had seen those types of denial in practice but hadn't been able to define them quite like this. Very impactful.

Jen Stanley, 2023-01-25T21:07:09.133

“Awareness of the issue is the first step in overcoming denial. You have to work your way through it, at your own pace and in your own time.”
– Carole Starr



To Root & To Rise: Accepting Brain Injury, p. 33

17

Feeling Lost & Confused



What it looks like:

- Awareness of failures
- Sense of self crumbles
- Uncertainty about the future
- Grief



18

GU0

Sadness, Anger, & Loss



What it looks like:

- Drowning in painful emotions
- Comparing new self to old self
- Frustrated by limitations
- Doubting that life can ever be happy, meaningful, or productive again

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19

Growing Toward Acceptance



What it looks like:

- Finding activities the new self can succeed at
- Embracing strategies
- Believing that a life changed is not a life ruined
- Looking for silver linings
- Choosing gratitude
- Letting go

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20

Slide 19

GUO This is Carole--I noticed that all the people pictures are of white people. What about adding more diversity?

Guest User, 2023-02-01T14:31:17.025

“I couldn’t control the brain injury, but I did have some control over how I thought about it.”

– Carole Starr



To Root & To Rise: Accepting Brain Injury, p. 57

21

5 Mindsets that Can Help to Move Forward

1. Stop comparing.
2. Recognize and celebrate my progress.
3. Be gentle with myself in times of failure.
4. Find & focus on what I’m good at.
5. Trust that my life can still be good.



Adapted from To Root & To Rise: Accepting Brain Injury, p. 57-58

22

The SLP's Role



23

Identify and Address Barriers

- Start the conversation
 - Inquire about identity, feelings about communication changes
 - Depression screening
 - Visual aids
 - Motivational interviewing
 - Build “therapeutic alliance”
- Referrals
- Resources
- Fatigue



Ackerman & Hilsenroth, 2003

24

Depression Visual Aids

Patient Health Question (PHQ)-9
Przeworski R, Spitznagel EL, Williams JB. The PHQ-9: validity of a brief depression severity measure. Journal of General Internal Medicine. 2001;16(3):372-81.

For each symptom identified by the patient, use the time options on page 5 to identify the frequency it is experienced over a two-week period. Scoring can be completed on page 6.

1. Little interest or pleasure in doing things
2. Feeling down, depressed or hopeless
3. Sleep problems — trouble falling asleep, trouble staying asleep, sleeping too much
4. Feeling tired or having little energy

Depression Visual Aids

Once a symptom is identified by the patient, using the pictures and verbal questions above, use the visual options below to inquire about the frequency of each symptom.

Not at all

Several days

More than half

Nearly every day

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Depression Intensity Scale Circles

Most severe depression

10 Most severe depression

9

8

7

6

5

4

3

2

1

0 No depression

No depression

The Numbered Graphic Rating Scale (NGRS) and the Depression Intensity Scale Circles (DISCs) are displayed on separate laminated cards.

L Turner-Stokes et al. J Neurol Neurosurg Psychiatry 2005;76:1273-1278

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JNNP

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26

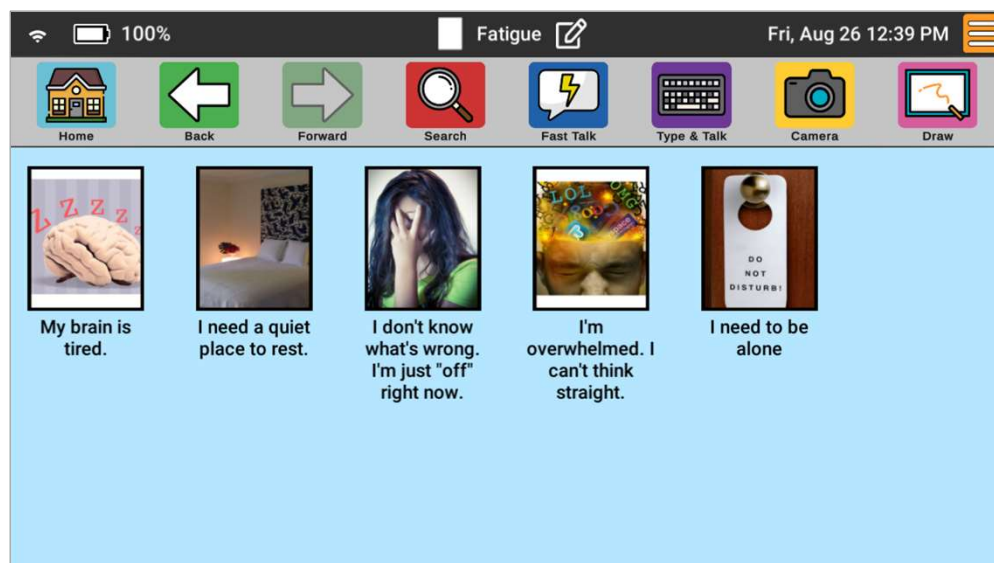
The Role of Fatigue



- Depression vs fatigue
- Tracking symptoms and triggers
 - *Aphasia friendly monitoring*
- Routines
- Communication strategies and tools help the person:
 - Set boundaries
 - Self-advocate
 - Plan ahead



27



28

Grief: Impacts on Life & AAC



29

What might grief look like?

- Low motivation
- Depression
- Denial
- Isolation
- Anger
- Frustration
- Resistance
- Rigidity



30

AAC Resistance & Device Abandonment

- Unfamiliarity
- Denial
- Poor understanding of AAC benefits
 - Progress
 - Improved communication
 - Increased social interactions
- Not enough training or support (Crema, 2009)
- Not involved in decision making, goal setting
- Lack experience with using device in conversation for **connection**



31

Considerations for AAC users

- Collaborative treatment and programming
- Adding positive statements and “truths” about acceptance to their device
- Providing choices can increase expression and discussion of feelings
- Closely observe their reactions and responses for opportunities for
 - Elaboration
 - Personalized statements
 - Triggers



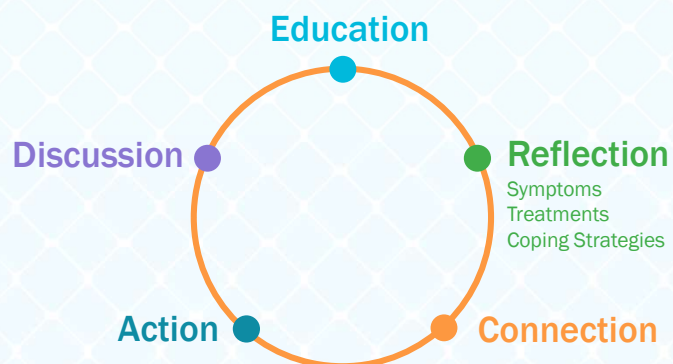
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AAC Supports for Clinical Conversations



33

A Clinician's Guide to Facilitating Conversations About Acceptance and Grief



34

Clinical Conversations

Example: How do they feel about these statements?

- Acceptance means I'm giving up on my brain
- Acceptance means, how I am now is how I will ALWAYS be
- Acceptance means that this stroke has ruined my life FOREVER
- Acceptance means I like what has happened to me



35

Suggested Activities

- Practice words/phrases
- Add high priority phrases to their device
- Develop scripts and stories
- Locate support or conversation groups
- Provide light tech note cards
- Search for photos in magazines or the internet
- Help them plan & break down steps toward long-term goals



36

Recovery Stages Mon, Aug 29 4:24 PM

Home Back Forward Search Fast Talk Type & Talk Camera Draw

Everything is fine. I don't need help.

I'll be back to my normal when I go home.

I do not accept this

I hate the person I am now

My old ways of doing things just don't work anymore.

I can't change what is.

Lingraphica® Denial

37

Overcoming Denial Tue, Aug 30 9:27 AM

Home Back Forward Search Fast Talk Type & Talk Camera Draw

I want to learn more about my brain injury.

I want to meet other people with Aphasia.

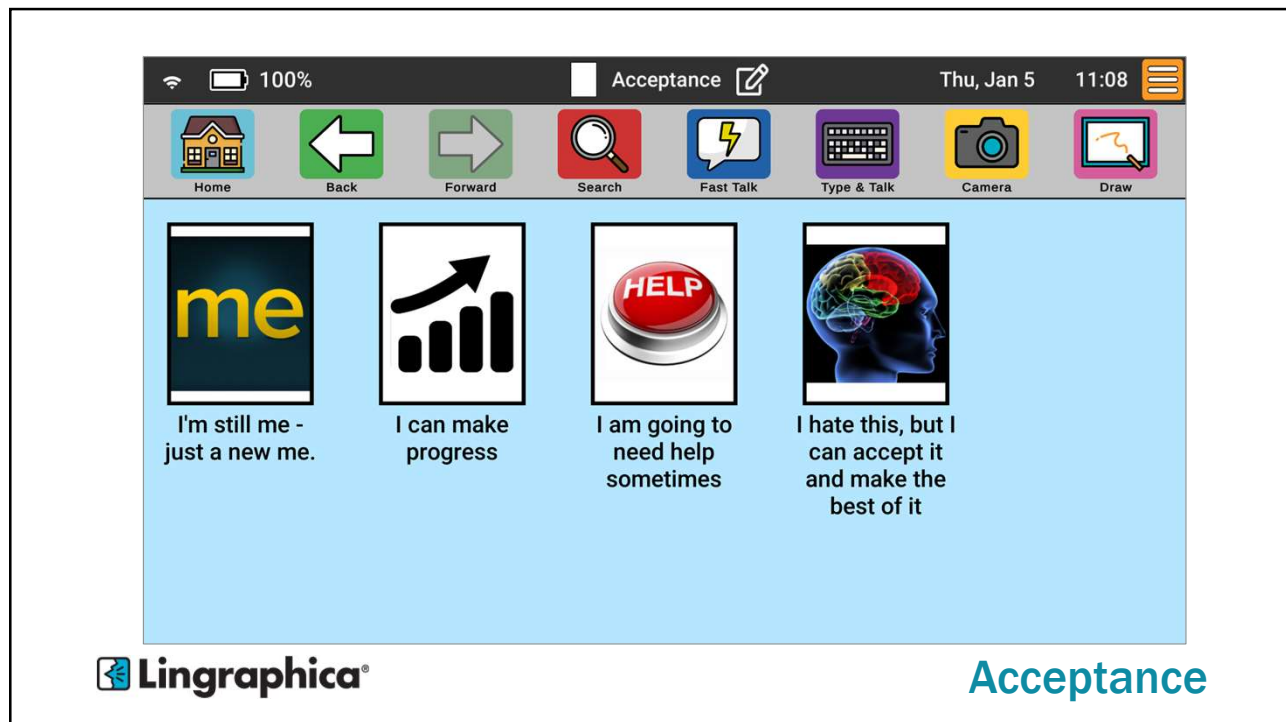
Let's talk about what was difficult today.

I'm ready to talk to someone.

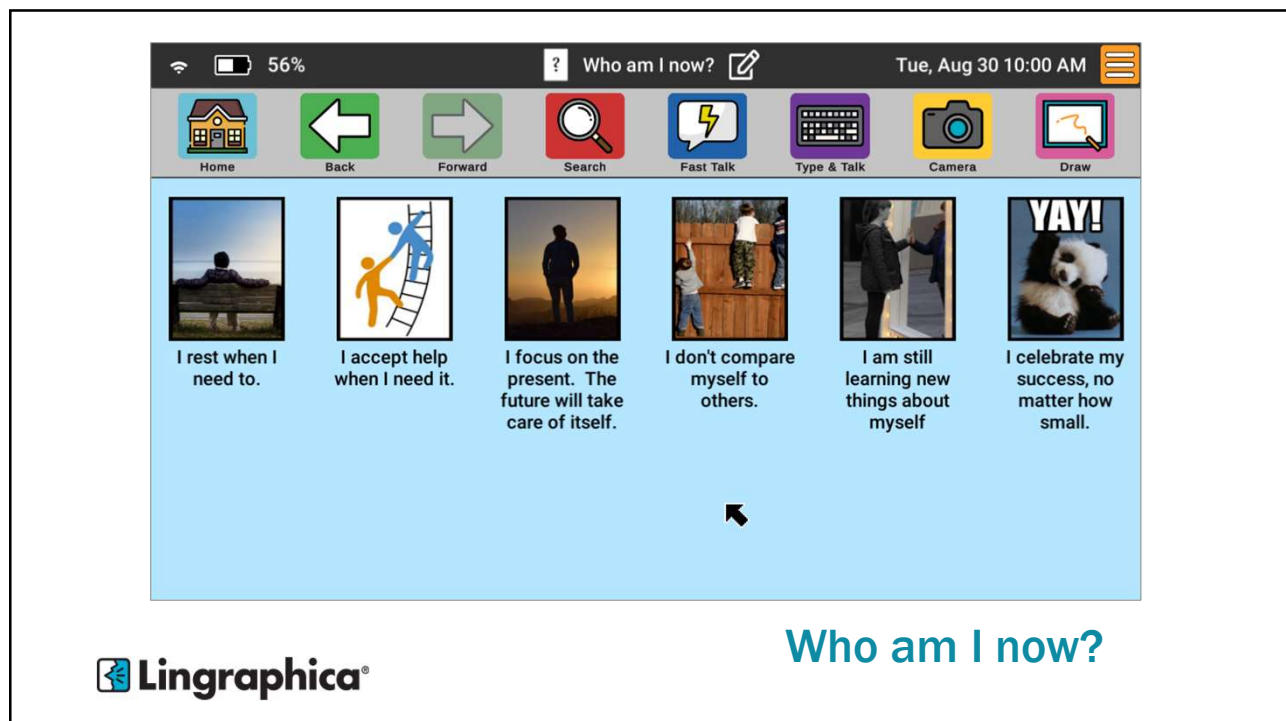
My old ways of doing things aren't working anymore.

Lingraphica® Growing Towards Acceptance

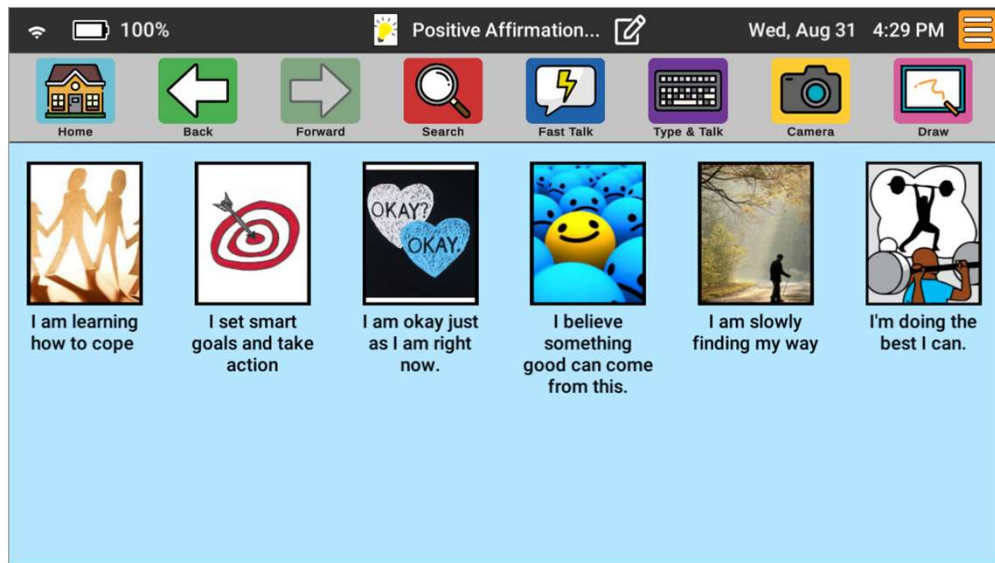
38



39



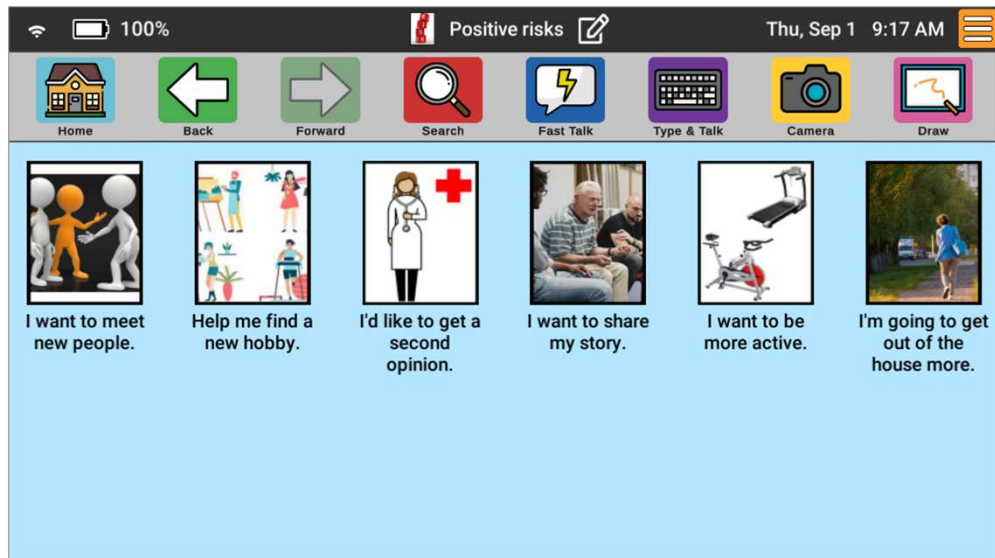
40



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The Power of Positive Words

41



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Exploring Positive Risks

42

100% Giving to others Wed, Aug 31 5:25 PM

Home Back Forward Search Fast Talk Type & Talk Camera Draw

Can I give you a hug?

Compliments

Will you help me send a card?

I'd like your address.

Can I read you a story?

What's your email address?

I'd like to come visit you.

I'd like to order some flowers.

Let's bake!

Thank you for all you do for me.

How can I help?

I want to volunteer.

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Giving to Others

43

100% grateful Mon, Aug 22 11:25 AM

Home Back Forward Search Fast Talk Type & Talk Camera Draw

I'm grateful for you

THANK YOU
Thank you for helping me

I am grateful to be alive

I am grateful to be making progress

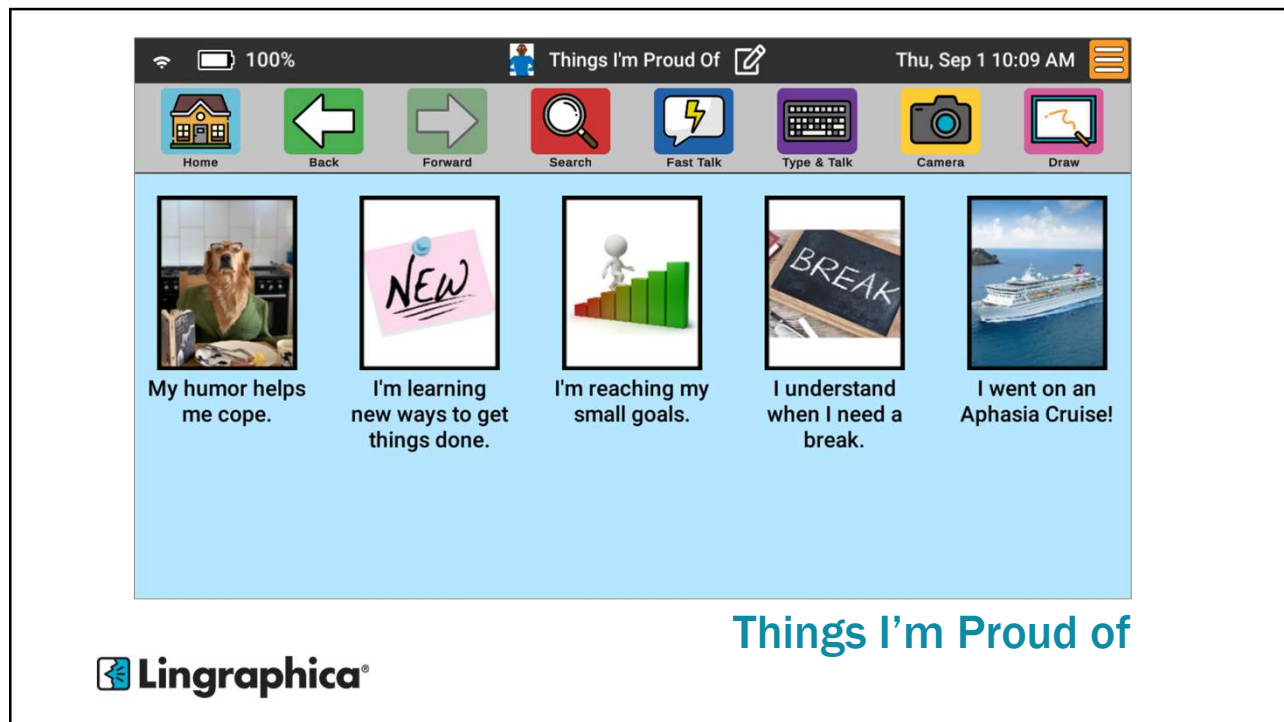
I am grateful for the doctor.

I am grateful for my family.

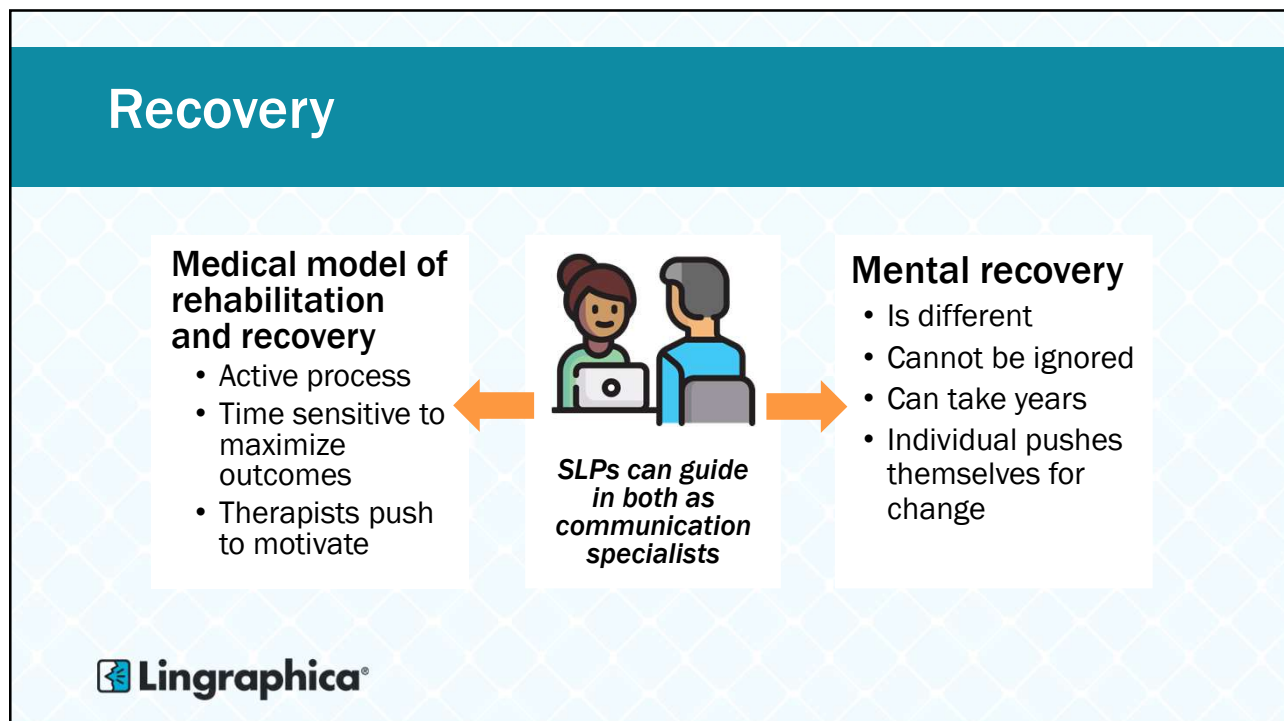
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Gratitude

44



45



46

Conclusion

We've discussed

- The SLP's role in facilitating conversation about acceptance and grief
- Impacts of grief on moving forward with life and use of communication supports
- What might acceptance look like?
- A long-term survivor's perspective on accepting brain injury
- Navigating through stages of grief and barriers to acceptance



47

Next Steps

- Visit starrspeakerauthor.com
 - Get your copy of *To Root & To Rise- Accepting Brain Injury* for your clinic!
- Register for the live course: **Tackling the Psychosocial Impacts of Aphasia: The SLPs Role**
 - 2/16 10:00 am ET
 - 2/22 3:00 pm ET
 - 2/28 7:00 pm ET



48

Next Steps



Schedule a device demo

www.lingraphica.com/clinical-aac-device-demo/



Start a trial

www.lingraphica.com/start-trial/



49

Earn CEUs for Today's Course

- Return to learn.aphasia.com
- Go to your learning center
- Look in the "current" tab and find this course
- Launch post-work (learning assessment and course eval)
- When finished, it will show in "completed" tab
- Please complete within 48 hours



50

Questions & Answers



51

Thank You!

52

References

Crema, Christopher. Augmentative and Alternative Communication in the Geriatric Population: A Review of Literature. Perspectives on Gerontology. American Speech-Language-Hearing Association. Volume 14, Issue 2, Pages 42-46, <https://doi.org/10.1044/gero14.2.42>.

Lanzi AM, Ellison JM, Cohen ML. The "Counseling+" Roles of the Speech-Language Pathologist Serving Older Adults With Mild Cognitive Impairment and Dementia From Alzheimer's Disease. Perspect ASHA Spec Interest Groups. 2021 Oct;6(5):987-1002. doi: 10.1044/2021_persp-20-00295. Epub 2021 Jun 29. PMID: 35647292; PMCID: PMC9141146.

Starr, Carole J. *To Root & Rise: Accepting Brain Injury*. Spiral Path Publishing, 2017.

Steven J. Ackerman, Mark J. Hilsenroth. A review of therapist characteristics and techniques positively impacting the therapeutic alliance. Clinical Psychology Review. Volume 23, Issue 1, 2003, Pages 1-33, ISSN 0272-7358, [https://doi.org/10.1016/S0272-7358\(02\)00146-0](https://doi.org/10.1016/S0272-7358(02)00146-0).

