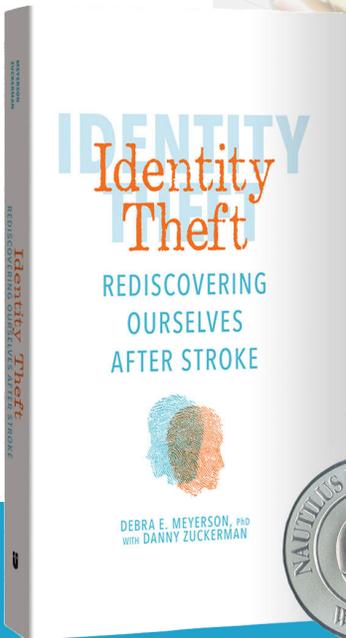




Rebuilding Identity and Rewarding Lives

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman



Facilitator Overview: Aphasia Friendly Book Guide

Facilitator Overview: Aphasia Friendly Book Guide

Introduction

After a medical trauma like stroke, survival is job one. Job two is working to regain as many and as much of former capabilities as possible. But there is another less visible and sometimes even more challenging aspect of recovery— **the emotional journey to rebuild identities and rewarding lives**. Survivors with ongoing physical or communication challenges like aphasia often face dramatic changes to their lives and opportunities — impacting relationships with family and friends, work and income, activities and hobbies, and more. Even survivors who recover all, or virtually all, of their capabilities often say they are “a different person” after a stroke. Their identities are often shaken, if not shattered. They are faced with what can be overwhelming and even paralyzing questions: Who am I now? How do I move forward with my life?

[Stroke Onward](#) is a non-profit organization co-founded by Debra Meyerson and her husband Steve Zuckerman to provide stroke survivors, families and carepartners with more resources to help them navigate the emotional journey to rebuild identities and rewarding lives. One of our early key initiatives has been the development of a series of reader guides to help deepen and personalize the impact of Debra’s foundational book, [Identity Theft: Rediscovering Ourselves After Stroke](#). Readers have told us that reviewing the book has been beneficial, but that the opportunity to discuss it and engage with fellow survivors has been even more meaningful. As one survivor who participated in our process to develop this guide commented, the most valuable part of the experience was, “Realizing that I am not alone.”

Terms of Use

This book discussion guide is just that—a tool to help individuals and groups reflect on their reading of *Identity Theft – Rediscovering Ourselves after Stroke*, as well as summaries of that book provided by Stroke Onward. It is intended to be used in a book club or peer-to-peer support group run by skilled facilitators. The guide is not and must not be considered a form of or replacement for medical advice and/or mental health support.

This guide and all associated material are provided by Stroke Onward as a free resource for the community. Materials developed by Stroke Onward may not be altered without explicit written permission. With the exception of facilitators who may distribute materials to their group members, materials may not be used by anyone who has not downloaded them directly from the Stroke Onward website in accordance with its policies. All rights are reserved and all use must be non-commercial.

Continuous Improvement

Should you have any questions about our support materials or any suggestions for how to improve them, please let us know. We welcome and encourage candid feedback about your user experience as



we would like to enhance and improve our resources over time with your help. In addition, we request that all group members, facilitators, and any student clinicians utilizing these materials complete a brief voluntary online survey at the completion of the book group (which may be submitted anonymously if desired).

To obtain a site-specific online survey link, or to share input or a question, please reach out to programs@strokeonward.org.

Acknowledgements

Stroke Onward is deeply indebted to the following individuals and institutions for their leadership on guide development, generous collaboration, and extremely impactful contribution to our community:



Boston University, College of Health and Rehabilitation Sciences: Sargent College

California State University East Bay, Speech, Language and Hearing Sciences

Elizabeth Hoover, PhD, CCC-SLP, BC-ANCDS
Clinical Associate Professor, SLHS
Clinical Director, Aphasias Resource Center

Ellen Bernstein-Ellis, MA, CCC-SLP
Director, Aphasias Treatment Program
Norma S. and Ray R. Rees Speech, Language and Hearing Clinic

Anne Carney, MS, CCC-SLP
Lecturer, SLHS

Sophia Kanenwisher, MA, CCC-SLP
Lecturer and ATP Interim Co-Director

In addition, we would like to thank our fabulous team of student clinicians who supported this project with commitment, creativity, and sensitivity:

Sarah Charbonneau
Grace Gahan
Roxanne Segina

Maya Jacobs
Yasmin Jacobs
Shika Narayan
Carmina Sanchez
Haleigh Stevenson
Michelle Valdez

Prior to public release, materials were field tested by and improved with thoughtful feedback from an extraordinary pilot group of facilitators, and their associated group members and student clinicians. We would like to publicly thank each organization below for their important contributions:



Book Access:

Identity Theft: Rediscovering Ourselves After Stroke by Debra E. Meyerson, PhD, with Danny Zuckerman (Andrews McMeel Publishing, 2019, ISBN 978-1-4494-9630-2) is available through [Amazon](#), [Barnes & Noble](#) and independent booksellers in paperback, hard cover, e-book ([Kindle](#)) and audiobook ([Audible](#)) formats. Additional audio access may also be obtained through [Google Play](#), [Apple Books](#), [Libro.fm](#), [Scribd](#), or [Rakuten/Kobo](#).

In addition, *Identity Theft* is available through many public libraries, including Hoopla and Libby/Overdrive streaming services although inclusion may need to be requested locally. Note that local library patron policies may make it difficult to utilize a loaned version for book club purposes unless a special extended borrowing term may be negotiated. Ask!

One strategy we might recommend is for a facilitator/program to purchase a quantity of books to create an internal library for ongoing book club use. For individuals on limited income and otherwise unable to access a book, Stroke Onward may be able to assist in some cases; please reach out to programs@strokeonward.org with any questions or requests.

All author proceeds from book sales benefit the work of Stroke Onward.

Reading Support Materials:

Supplemental resources have been developed to support and enhance the reader and group experience. There are a variety of ways to utilize these materials, and each facilitator should explore and carefully consider what approach(es) will work best to meet group and individual needs. While we are happy to share ideas, we do not prescribe or require any one size fits all solution. The goal is to find a comfortable and effective way for all participants to connect with the book's content-- and most importantly, each other.

- **Materials Provided by Stroke Onward:** Resources currently available from the website for download and distribution by facilitators include:
 - **Chapter Materials** (packaged per chapter):
 - **Summary:** Typically a one-page summary in paragraph format;
 - **Highlights:** Typically a two-page summary in bullet point format with additional detail and heavier use of bolding;
 - **Points for Reflection:** Approximately 10 questions per chapter in a range of multiple choice, scaled and short answer formats;
 - Questions are intended to spark meaningful discussion; they are not intended in any way as a test;
 - Scaled and other questions should be considered a starting point; facilitators are encouraged to deepen the discussion through the use of additional non-scripted questions and probes where appropriate.
 - **Additional Audio and Video Recorded Resources** (links may be shared directly with group members):
 - Voice recorded [Chapter Summaries](#) in WAV format
 - Voice recorded [Survivor Biographies](#) (Appendix I from the book) in WAV format

- A brief [video introduction to book groups provided by Debra Meyerson](#)
 - A brief [video introduction to Stroke Onward](#).
- **Community Resources:** With special thanks to Ellen Bernstein-Ellis, MA, CCC-SLP, we are honored to share with you a growing list of additional tools and guidance contributed by highly experienced facilitators. The intent of sharing Community Resources is to help new users avoid reinventing the wheel and to continuously increase the range and quality of available support material as group experience grows. All Community Resources may be found on the Stroke Onward website and a current list is below:
 - Introduction PowerPoint template
 - Identity Word Cloud activity
 - Book Club Session Suggestions, including:
 - Considerations for:
 - First day
 - Typical sessions
 - Last session
 - Sample:
 - Activities and icebreakers
 - Day one schedule
 - Post session email
 - Facilitator References and Resources

Should you develop additional book group resources that you would like to offer to future aphasia guide users, please do share them with programs@strokeonward.org. We cannot guarantee that all submissions will be posted, but we do guarantee they will be appreciated. By submitting your material, you grant permission to Stroke Onward to utilize your material and distribute it to others, with appropriate attribution and our thanks.

- **Notes on Usage:**
 - **Content Flexibility:** While some groups may prefer to focus on each chapter with equal emphasis, other groups may choose to spend more time on particular topics or issues. Each group's agenda and pace may also vary based on member age range, work status, interests, time post onset, and many other factors. That's perfectly okay. For planning purposes, note that some chapters typically are more lengthy or discussion rich, e.g. in our experience Chapter 9, "Stroke Is a Family Illness."
 - **Use of Materials:** Experience to date suggests that materials may be used successfully in a wide variety of ways. While most groups distributed all chapter materials each week, some shared only a couple questions from the Points for Reflection or none at all. Some groups made it a point to address explicitly all questions each week, while other groups just let the conversation roam. In multiple reported examples, the materials were used independent from the group to guide private discussions with carepartners and mental health professionals. Materials were also used within and outside the group to support individual SLP treatment goals. In the words of one student clinician,
 - *"In our group specifically, members self-selected goal areas. These turned out to be so functional for the clients and we were blown away each week by their hard*

work.”

- **Summaries vs Highlights:** Our development team elected to create and offer both recap formats to meet different accessibility needs and style preferences. They may be used interchangeably or together. In addition to supporting individual readers, some groups enjoyed reading the chapter Summary aloud as a kickoff to discussion.
- **Points for Reflection:** While some groups have preferred to do so, there is no expectation that groups will cover every question included or necessarily use the order provided. Facilitators may freely modify usage to best meet the needs and interests of your group. In essence, the Points for Reflection should serve as a question bank to guide the discussion; it is fine to add additional prompts, skip and also repeat question content when beneficial. Some questions are applicable across multiple chapters or can be saved for a wrap up session too.
- **Use of the Term “Identity”:** Individual identities are dynamic and multiple. Throughout our materials, even though we may refer to identity in the singular form, the plural is always implied to encompass both the multiple facets of an individual’s identity and how these evolve over time.

Planning and Implementation Recommendations:

Just as each stroke is different, each book group is different. While these materials are newly launched to the public, they have already been implemented successfully in a range of settings accommodating varied logistics, preferences, and constraints. We encourage experienced facilitators to utilize provided materials in any thoughtful and responsible way that best serves your group members’ experience and goal of self-discovery in a supported and safe environment.

The guidance below is based on our experience to date:

Participation:

- **Intended Audience:** Debra Meyerson’s aphasia was caused by her stroke. As a result, the book and associated materials are written from that perspective. We encourage you to be inclusive and customize discussion and references to recognize group members who may have developed aphasia due to injury or other causes. Our hope is that these materials may be a resource for those with aphasia, other communication challenges, or anyone who might simply benefit from the availability of more accessible materials.
- **Know Your Members:** Due to the nature of this activity, it is important that all group members be well known or carefully assessed prior to participation. It is equally important that facilitators be vigilant to observe all members over the course of group meetings. Be on the watch for members who may need you to check in privately and/or potentially refer out for professional mental health support. For some, this book group may require or trigger very challenging inner work.

- **Member Readiness:** After potential members are informed of the nature of this book group, we suggest that each person make an active choice to participate. This experience will not equate to the average book discussion group and every individual is different. There may need to be particular sensitivity for survivors in the earlier stages of healing following stroke. Our guidance in this area is best summarized in this lightly edited quote from one early group member:
 - *“I found this book club was very supportive and (it) respected and treated (me) as an adult. I am glad I found this book at this time of my recovery. I am now in my 5(th) year after stroke and (I have) aphasia. I am now working on my new identity. I think the first two years I would not have enjoyed or appreciated the book at that time, because I was working so hard at getting my old self back together and (I wasn’t) ready to step into my new (life) or Identity. To be honest I would have probably (thrown) the book at the wall. Over all it was a great experience”*

Facilitation:

- **Facilitator Preparation:** It is recommended all facilitators read *Identity Theft* in advance of their group both to be familiar with content and to help plan and structure sessions appropriately. In addition, please be sure to check our website not only for Stroke Onward provided materials, but also for tools developed by prior facilitators and generously contributed to our growing list of Community Resources.
- **Facilitator Role:** A facilitator’s role is to provide a safe, supportive, and effective environment for group discussion. It is to ensure that the discussion stays on track and all are heard respectfully. A facilitator should ensure that group norms are established around confidentiality, participation, and other expectations.

A facilitator’s role is not to provide answers or offer medical/counseling advice—but rather to make sure that the right questions get asked at the right time in the right way for the group. In our ideal scenario, groups would be co-led by an SLP and a social worker or other mental health professional. If the facilitation will be led by a student clinician, additional guidance regarding appropriate SLP counseling skills may be needed.

- **Supervision/Training:** We recommend that anyone choosing to facilitate this book group have deep experience supporting both groups and individuals with aphasia; if this is not the case, please seek additional training or support as needed. When facilitators will be student clinicians, we recommend 100% supervision especially as some topics like intimacy and grief may be more challenging for students to navigate alone. Student clinicians may also benefit from additional guidance, role play, and other focused training opportunities.

Student clinicians engaged with early groups consistently reported that while facilitating groups was not always easy, the rewards far outweighed any challenges. As one pilot student clinician commented:

- *Where do I begin? I loved every minute of this experience. I knew a lot of our participants already through my work... but this gave me the opportunity to get to know them and their stories on such a deep level. I loved watching the participants continually bond over their shared experiences, no matter how painful, and to make light of their struggles, too. They encouraged each other frequently which was heartwarming to witness.*

Although not the most fun in the moment, it was also an honor to provide space for difficult conversations. I am so grateful that the participants were not only willing to discuss the book but to share their personal journeys with us, even if it was hard emotionally and/or linguistically. Our participants were also very supportive of us as students- I received a lot of encouragement about my career goals and words of wisdom from people who have been on the patient side of therapy! I consider it an honor to have had this opportunity; I felt like facilitating the Identity Theft book group taught me more about the ups and downs of stroke recovery than any textbook ever could. I am SO grateful for the impact this experience had on me as a clinician.

- **Reference Materials:** A sample resource/citation list developed by aphasia program supervisors at California State University East Bay and Boston University as a manageable set of introductory materials for student clinicians is provided as a Community Resource. Reading materials focus on expanding clinicians' understanding of the role of identity in recovery from aphasia, as well as providing support when discussing the chapter on intimacy and relationships as this can require additional sensitivity and facilitator skill. You may wish to supplement or select other materials based on student needs.

During early book discussions we found that few group members had previously received any support or materials related to intimacy post stroke from other healthcare providers. As a result, the reference list also includes a few select resources with additional background that you may choose to share with group members directly.

If you are aware of other resources that might benefit future facilitators or group members, please do share them with programs@strokeonward.org.

- **Mental Health Referral Plan:** As with any impactful self-work and discovery, some participants may request, need, or benefit from additional individualized support best provided by a mental health professional. We recognize that it can be difficult to identify local mental health professionals experienced with stroke recovery and especially those familiar with how to successfully support individuals with aphasia. Some settings may have affiliated mental health resources available and that is ideal. For others, we encourage you to identify appropriate local resources and familiarize them with this project in advance in case the need for additional support does arise.

Additional national mental health resources are noted below:

- Warmlines: Created to give people support when they just need to talk to someone <https://screening.mhanational.org/content/need-talk-someone-warmlines/>
- Crisis Text Line: Text 741741 for support. More information at <https://www.crisistextline.org/>.
- National Suicide Prevention Lifeline 1-800-273-8255 is a national network of local crisis centers that provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week.

Group Structure:

- **Group Size:** We'd suggest a group size of 5-10 participate in each book/support group. Include enough members to provide meaningful interaction and not so many that the conversation becomes difficult to manage; of our five initial groups, most had 8 participants. This number is in part reflective of the current need to rely on Zoom and avoid multiple gallery screens-- we think it is important that the facilitator be able to see all participants at all times to gauge reactions, facial expression, level of involvement, etc.
- **Group Ground Rules:** All participants should be encouraged to attend all sessions in order to build a supportive network and ensure continuity. Ground rules for participation around respectful interactions, confidentiality, and other group expectations should be established in the first session. A sample set of ground rules is provided in the Introduction PowerPoint found in Community Resources.
- **Group Composition:** There are benefits to establishing groups of individuals mixed by age, life experience, length of time post-stroke, reading abilities and more, especially to facilitate peer to peer learning and encouragement. Other groups may find discussion more productive when members face similar life challenges or stages; for example, a survivor group composed primarily of retirees may prefer not to focus on book content about career impacts in the same way as a group of young survivors. However you choose to proceed, set member expectations and your session plans accordingly.
- **Do Not Underestimate Peer Power:** In the words of a few participants:
 - *"I learned from the book that the feelings I experienced following my stroke were not strange, but rather 'normal.' It opened my eyes and helped me to handle a lot of those feelings, and to realize that while the effects of a stroke are very different person to person, the fears and hopes are basically the same."*
 - *"I have had the opportunity to look back, soothe and heal some of my ghosts from the past, particularly my self-identity and all that comes with it. I love that this book has given me a framework to feel and discuss reconciling my past and present self. I also feel that I need to be part of helping others who are facing similar aphasia journeys. Maybe through advocacy I can connect people to resources and support. We will see."*
 - *"It was very interesting to hear about others' experiences in recovering from a stroke. It gave one a sense of belonging. I enjoyed the discussion very much."*
- **Inclusion of Carepartners:** Creating dedicated survivor-only discussion groups may allow for more candid and beneficial discussion for group members who might hesitate or rarely have a chance to convey information or feelings without a carepartner present. For some, carepartner involvement may be needed to participate or desired and that's okay too. Note that we are also in the process of developing a book guide specifically for carepartner groups; for additional information or if you might like to collaborate with us on this project, please reach out to programs@strokeonward.org.

Session Logistics

- **Ideal Number of Weeks:** We'd suggest a minimum of 12 weeks where possible. This would allow for an introductory session the first week, review of two chapters most weeks with one chapter the final week to cover all 19 chapters, and possibly a wrap up/celebratory/evaluation session. Our initial sessions ran 10 weeks and felt too rushed and tight. One pilot group that had planned to run for 12 weeks chose to slow the pace even more to allow time for deeper discussion based on member requests midway through the pilot. To quote one group member's feedback:
 - *"I loved the BU book group. I know it could only be for a short time since there are semesters, but I would have liked to have more time to discuss the issues and challenges brought up in the book."*
- **Ideal Session Length:** We'd suggest 90 minutes to allow a reasonable amount of discussion time, especially if you plan to cover multiple chapters a week. Our initial groups met once a week. In one pilot group, sessions were limited to 45 weekly minutes so they chose to pre-select and discuss only 2-3 questions each week; while members expressed a desire for more time, the sessions were still reported to be very valuable.
- **Group Member Preparation:** In our initial groups, all participants were asked to read or listen to the book chapters in advance to prepare for each week's discussion, although this was not possible for everyone. Chapter materials were distributed in advance to allow a review of one or both chapter summary formats as an alternative or supplement as best met the needs/goals of each individual.

Home use of the Points for Reflection document varied significantly. In some groups, questions were not distributed in advance and were simply used by facilitators to guide conversational flow. In most groups, questions were distributed in advance to allow time for members to self-reflect and consider responses prior to group discussion. In some cases, individuals prepared for group discussions with the support of carepartners or as part of individual treatment sessions. Some individuals chose to prepare written responses to key questions. Whether the main self-discovery value is derived before, during or after discussion matters less than finding ways to support each person to benefit. In the words of one early participant:

- *"I was a bit reserved and didn't share what I really wanted in the group. I did learn from a few others. However, writing down my answers to the discussion questions and writing my reactions to many things discussed in the book were extremely helpful to me to process what I went through and plan for the future."*
- **Session Format:** Those that have run groups previously know that each group is unique based on the sum of its individual personalities and communication needs. As such, some groups may require a more structured, facilitator-driven format with others enjoying more open dialogue. Some of our initial groups had strong member involvement with individuals participating in question selection, session co-facilitation and also the development of additional new questions for discussion. In multiple early groups, facilitators chose to slow the planned pace of discussions mid-course because members became engaged in very rich discussion and asked to continue. Finding the sweet spot between productive adaptability and time management is key.

- **Group Dynamics:** While there is no one “right” way to manage group sessions, key points to keep in mind as a facilitator especially while sessions remain virtual:
 - As with any group, it may not always be possible to provide each group member equal access to the discussion, but it is the facilitator’s job to ensure equitable participation to the extent possible. Group members may help with this responsibility as well. In the words of two student clinicians,
 - *“I was surprised by how well the group members facilitated the group themselves. They all asked one another follow-up questions and made sure everyone participated equally.”*
 - *“As a facilitator you have to become comfortable with shifting focus from one group member to another and stopping them from continuing too long. Some individuals speak more than others but the goal is to give everyone an equal chance to speak so the facilitators must develop some strategies to maintain this balance.”*
 - PowerPoint slides: Minimizing the use of slides will maximize participant visibility when utilizing virtual meeting platforms. If slides must be used, share them briefly and turn them off so that the focus remains on all participants. This also allows the facilitator to see when a participant is about to initiate communication and also allows all participants to observe the head nods, smiles, “reactions” (e.g. thumbs up, applause) and other visual cues that can be so informative.
 - Mute function: Minimal use of the mute function will help keep the group engaged and allow people to share spontaneously the supportive comments, laughter, and other emotions that build bonds and understanding between group members.

- **Additional Session Guidance, Tools and Resources:** Especially for those new to the book group experience, we strongly recommend you review the Community Resources contributed by experienced facilitators. For example, an excellent companion resource to this Facilitator Overview, Book Club Session Suggestions, as well as an Introductory PowerPoint template, are available with special thanks to Ellen Bernstein-Ellis, MA, CCC-SLP and her team of student clinicians.

Thank You

Thank you for the important work you do. We hope this book group will be a meaningful and rewarding experience for both you and your group members as you work together to navigate the emotional journey to rebuild survivor identities and rewarding lives. We look forward to your feedback-
programs@strokeonward.org!