

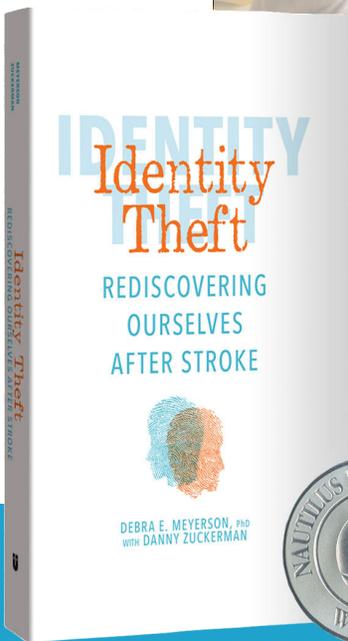


Rebuilding Identity and Rewarding Lives

Identity Theft:

Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman



Facilitator Overview: Carepartner Book Guide

Facilitator Overview: Carepartner 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?

Carepartners walk down a parallel path as they work to both support their survivor and also cope with their own life changes and associated emotional journey. We have heard from many carepartners that a critical question for them is whether it is just their lives that have been impacted, or if their identities have changed too. We hope that in reading [*Identity Theft: Rediscovering Ourselves After Stroke*](#), and with your help to facilitate discussion amongst groups of carepartners, participants will be encouraged not only to think about their partners’ recovery in new ways, but also open the door to thinking about their own identities—how they have changed, or how they might want them to change in the future.

[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 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 peers 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***. 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.

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Carepartner Content:



Opening the door to a brighter tomorrow

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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:** We know that carepartners typically have very little time. We also know that their needs and feelings often take a back seat to allow for other priorities. As a way to address these divergent demands and needs, we elected to create two different versions of carepartner book support material.

Resources currently available from the website for download and distribution by facilitators include:

- **Carepartner Discussion Prompts:**
 - An abbreviated list of questions geared for those groups with less time to devote or that prefer a less intensive experience;
 - Facilitators may elect to focus on one or a small number of questions based on the interests and goals of the group. Alternatively, some groups may choose to cover all discussion prompts over the course of 2-3 sessions.
- **Carepartner Chapter by Chapter Points for Reflection:**
 - An extensive list of questions more closely tied to the text of the book;
 - Questions are provided for each chapter, although facilitators are encouraged to select a subset of questions that will be most relevant for the group;

- Generally, groups will cover at most 2-3 chapters per session, allowing for in depth discussion and significantly more time for peer sharing and support.
- **Additional Resources** (links may be shared directly with group members):
 - A brief [video welcome and introduction to carepartner book groups](#) provided by Steve Zuckerman, Debra Meyerson's husband.
 - A brief [video introduction to Stroke Onward](#).
 - [A conversation with Debra and Steve](#), hosted by Liz Hoover, PhD, CCC-SLP, BC-ANCDs, Boston University Aphasia Resource Center.
- **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:
 - An Identity Word Cloud icebreaker activity
 - A sample set of Group Ground Rules
 - Facilitator References and Resources

Should you develop additional book group resources that you would like to offer to future carepartner group 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 survivor's stroke onset, and many other factors. That's perfectly okay. For planning purposes, note that some chapters typically are lengthier or more 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 some groups may prefer to distribute a short targeted list of questions prior to each meeting to allow advance contemplation or encourage personal journaling, other groups may choose to distribute all questions at once. Alternatively a facilitator may choose to let the conversation roam independently and hold the questions in reserve. Materials may also be used independent from the group to guide private discussions with survivors, family and friends, and/or mental health professionals.

- **Prompts/Points for Reflection:** Regardless of the question resource selected, all questions are intended to spark meaningful group discussion; they are not intended in any way as a test. All 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.

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. 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:

- **The Power of Peer Support:** In the words of our pilot Carepartner group participants:
 - *“Only caregivers truly understand what it takes to care for a stroke survivor and we need a very safe space to share very difficult challenges.”*
 - *“Much food for thought. An opportunity to think about and discuss issues that either had not previously occurred to me or, if they had, I’d not had time to consider.”*
 - *“Gave me some insights into things I was dealing with but could not face alone.”*
 - *“Brought closer to others in the group. Verbalized many things never vocalized before. Was able to discuss and not receive a pity party; people understood. Brought up discussions that prompted discussion (sometimes limited) between caregiver and survivor. Let me understand what the survivor might be thinking”.*
 - *“A discussion group with others, especially our stroke survivors, would be a very different discussion - possibly also valuable, but very different, as it would focus on the survivors’ identity issues and not the care partners’.”*
 - *“It affirmed my need for solidarity with other caregivers facing the same challenges, and that we need to sustain these connections going forward.”*

- **Intended Audience:** We encourage you to be inclusive and customize discussion and references to recognize the life situations of carepartners whose survivors may have different recovery profiles due to stroke, brain injury or other trauma.
- **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 in observing 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 lead to 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. There may need to be particular sensitivity for carepartners with survivors in the earlier stages of healing. While it may be natural and beneficial for carepartners to share aspects of this experience with their survivors, please consider both carepartner and survivor readiness carefully. Our guidance in this area is best summarized in this lightly edited quote from one participant in an early survivor-focused book group:
 - *“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 that 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 a carepartner and a social worker or other mental health professional.

- **Supervision/Training:** If the facilitation will be led by a student clinician, additional guidance regarding appropriate counseling skills may be needed. We recommend 100% supervision for student clinicians, 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 working with survivors and their families 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 understanding of the role of identity in recovery from stroke and 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 your or 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 meaningful 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.

Some excellent general carepartner support resources may be found on the [Resource Page](#) of the Stroke Onward website. 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 suggest a group size of 5-10 participants in each book/support group. Include enough members to provide meaningful interaction and not so many that the conversation becomes difficult to manage. 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 our Community Resources.
- **Group Composition:** There are benefits to establishing groups of individuals of mixed age, life experience, length of time as carepartners, 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 carepartner group composed primarily of retirees may prefer not to focus on book content about career impacts in the same way as a group of younger members. Whichever way you choose to proceed, set member expectations and your session plans accordingly.
- **Inclusion of Survivors:** Creating dedicated carepartner-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 survivor present. For some carepartners, survivor involvement may be needed to make participation possible or desired for other reasons, and that's okay too. Note that we have also developed a book guide specifically for survivor groups; for additional information, please visit our website or reach out to programs@strokeonward.org.

Session Logistics

- **Ideal Number of Weeks:** For those utilizing the chapter by chapter resource materials, we 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.
- **Ideal Session Length:** We suggest 60-90 minutes to allow a reasonable amount of discussion time, especially if you plan to cover multiple chapters a week. Our initial carepartner group met once a week but only discussed the book every other week to allow time for other types of group discussion, social activity and support.
- **Group Member Preparation:** In our initial groups, all participants were asked to read or listen to the book chapters in advance in order to prepare for each week's discussion, although this was not always possible for everyone.

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 through private advance journaling. Whether the main self-discovery value is derived before, during or after discussion matters less than finding ways to support each person so they may 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:** Some groups may require a more structured, facilitator-driven format while others prefer 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 if sessions are 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 spontaneously share the supportive comments, laughter, and other emotions that build bonds and understanding between group members.

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 carepartner and survivor identities, and rewarding lives. We look forward to your feedback- programs@strokeonward.org!