

Aging with Parkinson's Disease

Guidelines for Living Positively as we near End of Life

Introspection - Questions to Ask Yourself

Are you comfortable having a conversation about end of life?

Leaving a Legacy

Continue your on-going "Bucket List"

Discussion with Family and Friends

Telling your Life Story

Writing your Memoirs – Can use Dragon dictation program if difficulty typing/writing

Life Review Therapy/Dignity Therapy

Facing End of Life with Parkinson's

Importance of staying positive with advancing PD and end of life.

Creating bonds - important to be close to at least one special person.

Respect your body: accepting where we are and doing what we can to stay healthy.

Create any project that allows for self-expression.

Frank Church: <https://journeywithparkinsons.com/author/frankchurch2015/>

Contributions you can make - for others and for yourself.

“People grow a lot when they are faced with their own mortality.” Thinking about one's mortality can be an opportunity. This outlook of terminally ill patients allows them to make choices around how to live their remaining days. They can address old grudges, tell their friends and family how much they are loved, and take pleasure in small things, and recognizing that all any of us have is the present moment.

What is Life Review Therapy?

While the idea of sharing memories may seem commonplace today, this therapeutic approach wasn't always practiced. Psychiatrist Dr. Robert Butler theorized in the 1960s that having an older adult think back on their life's events could be therapeutic. Mental health experts consider Dr. Butler's ideas the foundation for life review therapy.

Life review therapy has adults refer to the past to achieve a sense of peace or empowerment about their lives. Doing this can help put life in perspective and even reveal important memories about friends and loved ones.

What Are the Features of Life Review Therapy?

Therapists center life review therapy around life themes or by looking back on certain time periods. These include childhood, parenthood, becoming a grandparent, or working years.

Other themes include:

- education and schooling
- experiences in aging
- health
- literature
- milestones such as marriage
- major historical events
- major turning points
- music
- purpose
- values

You may be asked to bring mementos to enhance the life review therapy. These can include music, photos, letters, possessions, or even family trees.

Although the term "life review therapy" is often used interchangeably with the term "reminiscence therapy," there are some small differences. For example, reminiscence therapy is often about describing a memory itself. Life review therapy is based on discussing what a memory means to you. The life review therapy approach can also help you deal with difficult memories or unresolved concerns that may be keeping you from feeling at peace. Mental health specialists may use life review therapy for groups or individuals.

Who Can Benefit From Life Review Therapy?

Life review therapy can have several purposes: therapeutic, educational, and informational. The therapeutic benefits are specific to the person reflecting upon their life. The therapy can help with feelings about end-of-life and help illuminate the greater meaning in life. The following people may especially benefit from life review therapy:

- people with dementia or Alzheimer's disease
- older adults suffering from depression or anxiety
- those diagnosed with a terminal condition or progressive disease
- those who have experienced the loss of a loved one

Teachers often ask their students to conduct life reviews with older adults or loved ones. Students may wish to record, write, or videotape these sessions for sharing purposes in the future. There can be benefits for families when their loved one participates in life review therapy. The family

may learn things they never knew before. Saving these memories through video, audio, or writing can be a treasured piece of family history.

What Are the Benefits of Life Review Therapy?

The therapy itself is intended to empower older adults and those facing end-of-life issues to find hope, value, and meaning in their lives.

Therapists also use life review therapy to treat depression in older adults. A doctor may also use life review therapy to accompany other medical treatments, such as taking medications to reduce anxiety or depression.

Life review therapy can promote improved self-esteem. People may not realize the significance of their accomplishments — from raising children to being the first person in their family to earn a college degree, looking back can help people feel proud of what they have accomplished.

Dignity Therapy Questions:

- Tell me a little about your life history, particularly the parts that either you remember most or think are the most important? When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other(s))?
- Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?

Leaving a Legacy
Questions to Share with Family

- What would you like to see change in the world over the next ten years?
- What do you want us to know and to do after you are gone?
- What do you remember most about your Mom and Dad and what was most important to each of them?
- What 3 events most shaped your life?
- How did you know your wife was the one, how would you describe them, and what message do you have for them?
- What 3 words best describe who you have tried to be in life?
- What are you most proud of? What has been your greatest accomplishment?
- What are you most thankful for?
- What were times in our life you were truly tested and what did you learn about yourself?
- How would you describe each of your children?
- Is there any unfinished messages to pass on to others?
- What do you wish you had asked your Mom or Dad before they died?
- Who are your mentors? What did they teach you?
- What do you think is the meaning of life?
- What was your first memory?
- What is your greatest regret?
- What quality do you want us to remember about you?
- What were your hopes and dreams as a child?
- What was the most rebellious thing you did as a young person?
- What can you remember about your first kiss?
- How did you choose your work and what was your favorite part?
- What 3 words describe your parenting style?
- What do you think the world needs more of right now?
- What do you believe people want the most is life?
- What were the 3 best decisions you have ever made?
- What comes to mind when you think of your hometown?
- What did you believe about yourself that helped you become successful?
- What do you think about each of your siblings? How would you describe them?
- What strength do you wish you had possessed in earlier parts of your life --- such as teens? or 20s?
- What are you thinking about now...about death?
- What one thing would make you feel better today?

Recommendations

Websites:

- seniorplanet.org
- <http://legacyproject.human.cornell.edu/give-your-advice/> (advice from oldest americans)
- <https://thischairrocks.com/> (older adult american who has a site on fighting ageism)
- <http://seniorplanet.org/seniors-rise-up-and-teach-the-world-to-wise-up/>
- <http://legacyproject.human.cornell.edu/>
- https://en.wikipedia.org/wiki/Maggie_Kuhn
- https://en.wikipedia.org/wiki/Gray_Panthers

Videos:

- <https://youtu.be/j9WhqZ0BNas> (cornell university gerontologist - longterm study on a legacy project)
- <https://youtu.be/Xz4R6Rzf1KU> (Eileen Kramer - 101 and still performing)
- <http://seniorplanet.org/old-a-thought-provoking-film-asks-what-it-means/>
- <http://goodnewsshared.com/2014/11/15/positive-news-awards-media-coverage-older-peoples-issues/>

Movies and Documentaries Released in 2015 voted for displaying older adults positively:

- I'll See You in My Dreams
- Grandma
- Seymour: An Introduction (directed by Ethan Hawke)
- Rikki and the Flash
- Danny Collins
- Iris
- Heart of a Dog

Resources:

- http://www.huffingtonpost.com/karl-a-pillemer-phd/listening-to-elders_b_4200329.html
- <https://www.washingtonpost.com/news/inspired-life/wp/2016/03/29/its-no-longer-okay-to-be-sexist-or-racist-she-asks-why-its-still-okay-to-be-ageist/>
- <http://www.sandiegouniontribune.com/news/2016/mar/28/advocates-redefine-aging/>
- Consider the Conversation - A documentary on a taboo subject.
(www.ConsidertheConversation.org)

Books/Articles:

- Being Mortal by Atul Gawande
- The Tibetan Book on Living and Dying by Sogyal Rinpoche
- Final Gifts by Maggie Callanan
- How We Die: Reflections of Life's Final Chapter by Sherwin Nuland
- Knocking on Heaven's Door: The Path to a Better Way of Death by Katy Butler
- The End of Your Life Book Club by Will Schwalbe
- Internal Medicine by Terence Holt
- *This Chair Rocks: A Manifesto against Ageism* by Ashton Applewhite
- *Why Survive: Being Old in America* by Robert N. Butler (coined "ageism" in 1968)
- http://www.huffingtonpost.com/karl-a-pillemer-phd/listening-to-elders_b_4200329.html
- <http://careforyou.us/5-common-nursing-home-issues-and-how-to-deal-with-them/>

Notes from May 3, 2016 Support Group Discussion

- One person expressed wanting to know how long she will have Parkinson's and what it will look like for her down the road. She also wanted to know the statistics around how many people with Parkinson's become dependent, use a wheelchair, and move to nursing homes. We discussed how someone people want to know this information because it helps them to mentally, financially, and organizationally prepare.
- It was also discussed that some people don't want to know their Parkinson's future because whatever is going to happen is going to happen, and talking about it doesn't make it happen any earlier or necessarily change the outcome.
- We live in a society that denies and fears aging and death.
- It is important to get your children and other family members involved so that they are aware of your beliefs and so that they won't have to "fight" over decisions around your end of life care wishes or who inherits what from you.
 - When is a good time to do this and how? -> Host a family meeting specifically to discuss this; bring it up when you're all together for a different, fun reason, like a holiday; write them a letter/email/"prospectus" instead of having an in-person discussion
 - Just because you want may want to talk about it or start to plan for it, doesn't mean your kids want to.
- What questions do you wish you had asked your parents or grandparents while they were alive? Ask your kids what they want to know about you. Write the answers down for them. (You can use Cynthia's handout with questions as a guide)
- Are there sentimental items that can you pass on to future generations so that you can be remembered through them? Now is a good time to prepare them. For example, your favorite recipes and labeling family pictures (e.g., who is in them, the year, the location).
- You do not die *from* Parkinson's, you die *with* Parkinson's or from complications of PD (which can often be prevented)
- It is crucial to have tough conversations, like many of these mentioned here, early and way beforehand, because there is no time like the present and none of us know what is around the corner.
- Participant answers to the question "What would you like to see change in the world?"
 - Not as much dependence on cars
 - More choice and control over death with dignity, like legal physicians assisted suicide
 - An improved election system
 - Repeal HB2
- Life review can be a cathartic and enlightening therapy to do during the normal aging process: Tell your story (write a memoir?), what have you learned over your life, what were your most significant events, what messages do you want to pass on