

LEGACY LEAVING

*From the Massachusetts General Hospital
ALS Parenting At a Challenging Time (ALS PACT Program)*



Parenting with ALS: Guidance for Supporting your Children

From the Massachusetts General Hospital ALS Parenting at a Challenging Time (PACT) Program

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Legacy Leaving

People cope with life-threatening illnesses in many ways. Some people reflect on how they hope others will remember them someday, including their children and grandchildren. When children are not yet adults themselves it can be especially difficult to have any idea about what parts of a relationship they will carry forward.

In this handout, we offer ideas about “legacy leaving” collected over the years from parents with serious medical illness, and from interviews with young adults who lost a parent as a child (Muriel et al., 2019). Planning this kind of legacy is not for everyone, but it is meaningful to some parents and to their children.

The Legacy Leaving handout:

- Describes what is meant by legacy and why a legacy can be valuable to children
- Offers examples of several types of legacies (e.g., writing, photos, important belongings)
- Notes ways that particular types of legacies may cause unintended distress

What Is a 'Legacy'?

Here, we use the word legacy to mean a gift passed to a new generation. There are many kinds of legacies (Hunter & Rowles, 2005), including:

- Material legacies (like personal belongings)
- Historical legacies (family rituals and stories)
- Symbolic legacies (attaching one's name to something that will continue to exist)
- Values legacies (sharing one's values and beliefs)

Why are Legacies Valuable?

Different kinds of legacies serve different purposes. Benefits that might be particularly meaningful to children include:

- Feeling closer to the parent, being reminded of important memories they have of a parent
- Knowing about the parent's memories of the child, and what made the child special in the parent's eyes
- Feeling assured of the adult's love and pride
- Feeling encouraged or guided through difficult times
- Learning more about the parent, giving a child a richer, fuller picture of the parent as person

The person leaving the legacy might also find that the process creates an opportunity to reflect on what they want children to know about them and their relationship, review memories and family stories, and think about how being a parent and/or grandparent changed their life.

What Might a Legacy Look Like?

There is no limit to the creativity that people can bring to legacy leaving. But, a few kinds of legacies are very common and don't require enormous amounts of time or energy.

Gifts

Material possessions can be an enduring symbol of love and can also symbolize family values and history. Some examples are:

- Jewelry (sometimes engraved for the child, or with the story of its meaning and significance attached to it)
- Favorite cookbooks, family recipes (sometimes handwritten) especially for foods served at holidays
- Items that were used in shared activities or often used by the parent (a lucky fishing rod, baseball glove, sewing machine, tools, special kitchen implements)
- Clothing
- Favorite books (religious, inspirational, books enjoyed many times)

Written Materials

Letters to individual children (or to a group of children)

Letters can allow children to see themselves through the parent's eyes as well as learn more about the parent as a person- for example, the parent's values and victories, how they saw the world, and dealt with challenges. Reading and re-reading letters as children move through new developmental stages may help them see parents in a new light. For example, grown children may appreciate very different things about their parent after they have children of their own.

Because it is likely that letters will be saved and read many times, it is worth thinking about how what you want to share will be understood and appreciated by your child, at whatever age they receive the letter. Some parents create letters to be given to the child in the future at challenging times, life decision points, or developmental milestones, such as getting a driver's license, graduations, marriage, or times of hardship. These are times when a reminder of the ongoing connection to a parent might feel especially valuable.

Some parents write multiple cards, for a number of future birthdays, for example. There are upsides and downsides to this kind of writing for the future- it may be very meaningful to a child to know that you were thinking about their future and wanted to continue to express your love. On the other hand, advice or reflections that really miss the mark of your child's needs at the time might feel uncomfortable to the child. And it is impossible to write out in advance the kind of advice you might in person, without knowing the specifics of any challenge.

Some young adults who received letters like these reflected on what they appreciated, and also would not want, in a letter. They valued reading about:

- A description of the child's strengths
- The parent's special (or everyday) memories with the child
- The parent's hopes for the child. However, it is important to be careful that hopes aren't so specific that a child could feel they'd let a parent down if the hopes weren't realized. Parents might think about sharing general hopes and encouragement that don't sound like expectations to the child.

Put most simply, letters can affirm that your child was seen as an individual, understood, valued, and loved. At heart, what adult children said they wanted was "words that were from him, for me in particular."

Journals to individual children (or to a group of children)

Sometimes parents wonder about intentionally leaving journals for children to read later. Certain kinds of journals lend themselves to having children read them:

- Journals that include prompts meant to help the writer record details of their life history (books like these can be found online by searching "guided journal" and father, mother, grandfather, etc.)
- There is an online subscription service that emails a prompt every week, saves each story written by the adult, and then after a year creates a hard copy book. Photos can also be uploaded and included in the book (www.storyworth.com)

- Some parents keep journals during their children’s early years that function as a record of their child’s development.
- Some journals can help a child know how their parent saw the world or saw them.

However, some journals may cause unintended pain:

- A personal journal used during difficult times (such as going through a divorce, or an episode of depression, or a particularly conflictual time with the child), used to vent about anyone, express opinions or disclose secrets that could be upsetting (such as an extramarital affair, or family history that has not been shared with children).
- People often record strongly felt, but temporary emotions in a journal. While the writer may look back and understand that an entry really captured just one moment in time, a child reading the same entry may end up with the impression that these feelings were long lasting.
- Something that might not be very upsetting if you talked about it face to face, could feel very different to a child reading it who has no opportunity to ask questions and process emotions together.

Recordings

Audio recordings of favorite children’s books, songs, family stories, jokes, or simply messages of love may be possible even when writing is difficult. Audio or video recordings may also be meaningful reminders of shared activities (such as sports, music, cooking, or crafts), holiday and other family traditions, and family milestones. Some people create “video journals,” that can be shared as they are recorded, or in the future. This could be something as simple or brief as “a day in my life.”

It is worth considering that some children might feel reluctant to spend much time looking at pictures or videos in which a parent appears seriously ill. Generally, it may be best to focus more on a parent’s resilience rather than the illness itself.

Photo Albums

Photos of the parent and child together, of extended family, of important family moments, may be particularly meaningful when there are added notes about who is there and what is happening. Many people are able to have immediate access to favorite photos on their phones or computers. Photo albums can be organized online and printed as an entire book, or saved in one place as digital files. As noted earlier, some children might feel reluctant to spend much time looking at pictures or videos in which a parent appears seriously ill.

Connections to others who knew you well

One other kind of legacy to consider has been called a “living legacy,” (Swick&Rauch, 2006) reflecting the idea that important people in your life who know you well can share memories of you that respond to a child’s needs in the moment, at whatever developmental stage they have reached. You might create a list of people (with contact information) who have known you at different stages of your life. Think about who has stories that might feel relevant to your children at different times in their lives, or whose advice would best reflect your own values. You might also be able to talk directly with these people to let them know that you hope you can share their names with your children so that they have another way to learn about you as they mature.

What if I can’t do this?

For all kinds of understandable reasons, this kind of work isn’t possible, or of interest, to everyone. While potentially valuable to children, it is important that no one be made to feel guilty or that they have let their children down, because of not creating something.

Resource

Storyworth (subscription online journaling service that emails weekly prompts):
www.storyworth.com

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