



Considerations for Legacy Activities

About

Legacy activities have been shown to be effective across age groups^{1 2 3} to positively impact the emotional and social health of the patient and to strengthen bonds and relationships.^{1, 2} The products of legacy activities, whether memories or physical objects, become totems that can be helpful to support coping throughout illness, grief and bereavement.⁴ Legacy activities have also been shown to positively impact a patient's sense of personal integrity (ego-integrity), sense of dignity, and reduced depression.^{3 5} Patients and families report wishing they had done legacy activities sooner to take advantage of the patient's ability to most fully participate in the activity(s).²

When end of life is quickly approaching, some patients and families have reported feeling mentally unprepared, and being ill-equipped with supplies to engage in activities that create legacy. Discussions about legacy activities, prompted by healthcare team members, can help patients and families begin to consider them, and/ or to participate in legacy activities that will be meaningful to them through their grief and bereavement.⁴

The information that follows aims to enhance your comfort and ability to support others to complete legacy activities.

Inquire

Points to consider:

- Ask the patient or family if they have heard of legacy activities.
- Be sensitive that discussing legacy activities, may sound like you are informally telling the patient/ family that there has been a decline in condition.
 - *"Your relationship with [name] seems very important to you, and any time is good to think about, and to create, memories and keepsakes."*
- Highlight that this is a discussion had with all patients and families.^{2 4}
- Share that we know with other patients and their families, legacy activities have been very meaningful and helpful to do.
- Provide the patient and/or family with as much information, as they wish, regarding the benefit of legacy activities.² Check understanding. Some patients and/or families may have already done activities that create legacy – highlight this to the patient and/or family.

¹ Allen, R., Hilgeman, M., Ege, M., Shuster, J., Burgio, L. (2008). Legacy Activities as Interventions Approaching the End of Life. *Journal of Palliative Medicine*, 11(7), p1029-1038.

² Foster, T., Dietrich, M., Friedman, D., Gordon, J., Gilmer, M. (2012). National Survey of Children's Hospitals on Legacy-Making Activities. *Journal of Palliative Medicine*, 15 (5), 573-578.

³ Hesse, M., Forstmeier, S., Ates, G., Radbruc, L. (2019). Patients' priorities in a reminiscence and legacy intervention in palliative care. *Palliative Care & Social Practice*, 13, 1-8.

⁴ Akard, T., Duffy, M., Hord, A., Randall, A., Sanders, A., Adelstein, K., Anani, U., Gilmer, M. (2018). Bereaved mothers' and fathers' perceptions of a legacy intervention for parents of infants in the NICU. *Journal of Neonatal-Perinatal Medicine*, 11, 21-28.

⁵ Akard, T., Dietrich, M., Friedman, D., Hinds, P., Given, B., Wray, S., Gilmer, M. (2015). Digital Storytelling: An Innovative Legacy-Making Intervention for Children with Cancer. *Pediatric Blood & Cancer*, 62(4): 658-665.

- If the patient and/or family is interested, and would like ideas about legacy, share with them the list of legacy activity suggestions, as well as information about required supplies. Remind them that these suggested activities are a “springboard”, and to use their creativity.
- Document & share with the patient’s healthcare team.

Sample Legacy Activities (Click activity to view instructions).

Capturing Heartbeats	Family Bracelet	Family Collage	Family Handprint Tree
Family Stars	Favourite Memories	Fingerprint Tree	Handprint Painting
Hug Scarf	Lip Print Momento	Stained Glass Star	Making Memories Activity Sheets

Prepare

Points to consider:

- Gather supplies (if able).
- Provide the patient and/or family with legacy activity ideas, and supplies (if able). Patients and families may also need information or assistance on how to take part in legacy activities together virtually, using online video-conferencing platforms on their phone, tablet or computer.
- Some patients or families will require your support to do the activity(s). Others will wish to do them on their own.
- Many types of emotions may arise while doing the legacy activity, and after it is completed; this is normal. Patients and families should be prepared for this and should be supported in follow-up.^{1 2 4}
- Document & share with the patient’s healthcare team.

Follow-Up

Points to consider:

- If you are aware that a patient or family has been given a legacy activity kit or completed legacy activities, please follow-up with them about the experience, and provide support as necessary.
- Document & share with the patient’s healthcare team.