

Lewy Line: 800.539.9767

Preparing Families with LBD for End of Life

Considerations for Planning:

- **Do advance care planning early**. The person with LBD and their family should discuss wishes surrounding the appropriate health care surrogate(s) and living wills. These discussions can be assisted by clinicians, social workers, and elder law attorneys.
- **Think ahead**. In interviews after the survey, care partners reported that the end of life went more smoothly if they had details even things like funeral arrangements planned out in advance. This can be helpful for anyone, not just for people with diseases like LBD.
- **Talk to your doctor**. The survey found that physicians often don't raise topics relating to end of life. If you have questions about this, make sure to ask.
- Consider palliative care. While hospice services in the United States are intended to support the last 6 months of life, palliative care is appropriate at any stage of LBD. Palliative care is specialized medical care that focuses on quality of life for people with serious illnesses and their families. Availability of palliative care can vary by where you live.
- **Create meaning**. In follow up interviews, care partners of people who died with LBD described activities that helped them during the end of life period, such as intentionally creating special memories with the person with LBD, making art (e.g. songs) for the person with LBD, documenting their experiences, and finding value in helping others.