



Aging Caregiver Checklist

This checklist can help you organize your thoughts as you prepare for a healthy and smooth future while ensuring your loved ones have everything they need to thrive. This list will help you get organized but should not be considered as a substitute for legal and financial planning advice. **Your first step on this checklist is to investigate an agency/consultant to work with for any formal paperwork.**

Recommended steps to life and future planning

1. Determine the needs of the individual with a disability in the following areas, being sure to think of both present and future needs.
 - a. Vocation and education
 - b. Housing
 - c. Medical care
 - d. Recreation, leisure, and hobbies
 - e. Legal needs
 - f. Daily living assistance
 - g. Emotional needs
 - h. Other areas

TIP: Consider, realistically, how much family, friends, and others are willing and/or able to assist an individual now and in the future. Paid life planning professionals can help with these steps. To the maximum extent possible, involve the individual with TSC in developing and implementing each of the life planning steps.
2. Write a "Future Care Plan" (also called a "letter of intent"). This describes your hopes and expectations in writing and provides guidance for future care providers.
3. Recommend future advocates or guardians – people who will visit (as appropriate) and ensure your wishes are carried out.
4. Create a family financial plan that addresses the needs of the individual with TSC, while also providing for the financial objectives of other family members/caregivers.
5. Select a combination of resources that will provide adequate funds for that person's lifetime. This will include government benefits, family assistance, settlements, inheritances, savings, investments, and life insurance.
6. Work with an attorney who specializes in special needs estate planning. Have the proper wills and special needs trust established so resources now, and in the future, protect government benefits and provide supplemental income.
7. Choose a number of successor trustees from relatives and friends or select a corporate trustee to manage the trust funds in the future.
8. Meet with all persons involved to review the plan.
9. Store the life plan, financial plan, and legal documents in a safe place.

10. Review the plan at least once a year. Update the future care plan (from step 2), financial plan, and legal documents as necessary.

Estate and financial planning: quick guide

The topics mentioned in this section are discussed at greater length in the [Adult Guide of the Life Stages Program](#). Develop a solid working relationship with a long-term care provider (i.e., an internist or gerontologist) who can provide insight and support while making these decisions.

- Special needs trust or living trust
- Living will (conservatorship)
- Advanced medical directive
- Healthcare coverage (including Medicaid coverage)
 - Resource: The Arc [Center for Future Planning](#)[®]
- Housing arrangement options, including a transition plan
 - At home with or without assistance
 - Group home with constant (24/7 × 365) supervision
 - Independent living or semi-independent living (e.g., inter-generational communities)
 - Institutional residency

Emergency network: quick list

These are some topics to consider when putting together an emergency network or action plan should anything happen before future plans are firmly in place.

- Contact information for key medical team members:
 - Primary care provider
 - Key specialist(s)
 - Pharmacy
 - Social worker/coordinator if applicable
- Medication list
- “Go bag” that contains emergency supplies for a 24-hour stay at away from home
- Non-medical “who to contact” list
 - Family, friends, or others who may be able to provide support during an emergency (and contact information)