

Long-Term Planning Checklist for Families Caring for a Dependent with a Rare Disease

This checklist is designed for parents and caregivers responsible for someone who is fully dependent due to a rare disease with an uncertain lifespan. It is structured to guide you through key care, legal, and financial planning steps, applicable internationally. Local legal and healthcare systems vary—so use this as a starting framework.

✓ = Start here. ⚠ = Consult professionals. 📁 = Gather or create documents.

1. Immediate & Daily Care Planning

- ✓ List daily care needs and routines.
- 📁 Maintain updated medical history and medication list.
- 📁 Prepare an emergency care plan and post it visibly.
- ⚠ Identify and document seizure protocols, allergies, feeding support, or respiratory interventions.

2. Medical & Therapeutic Planning

- ✓ Maintain regular communication with all specialists.
- 📁 Organize medical records and keep digital backups.
- ✓ Create a medication administration schedule.
- ⚠ Explore clinical trials or rare disease registries (if applicable).

3. Legal Planning

- ⚠ Draft a will, designating guardianship for minor or adult dependent.
- ⚠ Create a power of attorney for medical and financial matters.
- ⚠ Consider establishing a special needs trust or disability trust (varies by country).
- 📁 Store copies of all legal documents in a known location.

4. Financial Planning

- ✓ List all current and future care-related costs (equipment, therapies, caregiving).
- ⚠ Meet with a financial planner experienced in disability care.

- ⚠ Explore life insurance options with the dependent's future care in mind.
- ⚠ Research available government support or disability grants in your country.

5. Education & Transition to Adulthood (if applicable)

- ✓ Understand local special education rights and services.
- ⚠ Plan for vocational training, supported employment, or lifelong learning options.
- ⚠ Prepare documentation needed to establish adult legal guardianship or supported decision-making.

6. Housing & Long-Term Care Planning

- ✓ Consider long-term housing options: home modifications, group homes, assisted living.
- ⚠ Research housing benefits or subsidies for disability care in your country.
- ⚠ Document your preferences for future care and housing in your will or trust.

7. Social, Emotional & Community Support

- ✓ Build a support network (family, friends, respite care providers).
- ✓ Connect with rare disease advocacy groups or online communities.
- ✓ Seek mental health support for family caregivers.

8. Cross-Border Considerations (if relocating or citizen of multiple countries)

- ⚠ Understand residency, health coverage, and disability entitlements in each relevant country.
- ⚠ Ensure all legal documents (e.g. POA, trust, guardianship) are valid in each jurisdiction.
- ⚠ Consult international planning experts or lawyers when needed.