



Life Care Guide

(Special Needs Child)



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IMPORTANT NOTE TO USER:

As a reminder, this binder should be kept confidential because the information contained in here is highly personal to you and the special needs individual you care for. This should be made available only to those people who need to know to provide proper care for your special needs individual. If you have been directed by your attorney to complete the information in this binder, it may also be protected by the attorney client privilege and special care should be taken so as to avoid the inadvertent disclosure of this information to adverse parties or make any other disclosure which would destroy the privilege. If this applies to you, you should consult with your attorney about the proper maintenance of these records. [This generally applies in cases where the special needs individual has been involved in a lawsuit, but there are other situations which apply also, if you are uncertain, you are encouraged to consult with your attorney.]



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It is our desire that this guide be useful to families with special needs, we welcome your comments and suggestions.

You may make as many copies of the pages you need for your personal use.



CONFIDENTIAL

Life Care Guide For

Maintained by:

Name: _____ Relationship: _____

Name: _____ Relationship: _____

Name: _____ Relationship: _____

Name: _____ Relationship: _____

Introduction

The goal of this guide is to serve as an essential tool in the event that the primary care giver of your child is unable to provide care for him or her. This is a place for you to organize important information regarding the care of your child. In the unlikely event that a complete stranger must step in and provide proper care for your child, this binder can be the primary source of information that person needs to know.

In the following pages, you can fill in detailed information concerning your child, including his or her medical, social, emotional, and spiritual needs as best you can describe them. This information should be kept confidential, but it is important that it is available when it is needed. This can be accomplished by keeping it up to date. Depending on the needs of your child, a yearly review and revision may be sufficient, others may require a monthly or even a weekly review.

Please be aware that this guide, standing alone, is not legally enforceable for any purpose.



Life Care Guide

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1. Quick Reference

This section contains a quick overview of critical information that would be needed in the event that the primary caregivers were unavailable.



General Information

Full legal name of individual with special needs _____

Prefers to be called: _____

Home Address: _____

City, State, Zip: _____

Phone: _____

Is currently living at (name of facility): _____

Address: _____

City, State, Zip: _____

Names of individuals living with child:

Relation to child

Does child require Home Health Aides/Nurses? Yes No (Circle one)

Name of person usually providing such care: _____

Name of agency providing such care? _____



Specific Information

Child's Name: _____

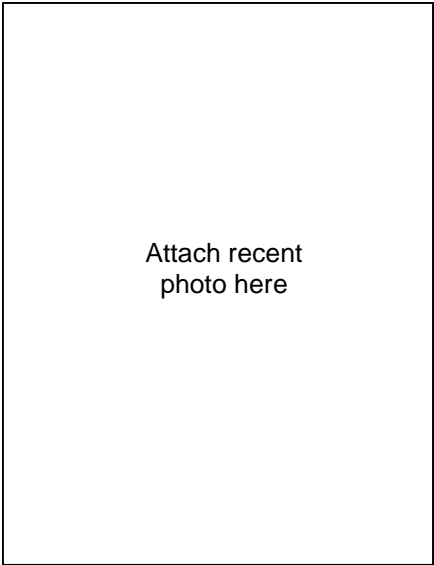
Birth Date: _____

Social Security Number: _____

Medicaid Number: _____

Insurance (Health) Number: _____

Dental Insurance Number _____



General Description of Child (attach photo if one is available)

Height _____ Weight _____ Hair Color _____ Eye Color _____

Please identify disabling condition if known/diagnosed (medical or developmental):

General description of disabling condition: _____

Prognosis: _____

Please attach a copy or reference to a source of information you found helpful in learning about your child's disability. Information that you consider important for someone caring for your child.



Is your child able to communicate in spoken English? Yes No

Is your child able to communicate in a spoken language other than English? Yes No

If yes, What language(s)? _____

Is your child able to communicate with a non-verbal language such as sign-language?

Yes No

If yes, what non-verbal language(s)? _____

Is your child able to communicate his/her needs or desires to others? Yes No

How does your child communicate his or her needs or desires to others?

Does your child understand when new people speak with him or her? Yes No

If someone had to explain bad news to your child, would your child understand? Yes No

Who would you want to explain bad news to your child if it were possible or practicable?

Name: _____ Phone: _____ Cell: _____

Relation to Child: _____

Please describe child's current awareness of disability and self-advocacy skills:



This section contains important information about the medications your special needs individual takes. It is critically important that this information be kept up to date. As you are aware, changes in medication routine can have troubling effects that can take a long time to correct. It is suggested that you maintain a record of all previous medications and reason for discontinuing so that important medical history is not lost.

If there have been adverse reactions to over the counter meds please add a sheet on that medication as well. Also, if some over the counter medications have been particularly useful, add them to this binder as well.



Cut this corner
off when this
medication is
no longer used

Medications

Name of Medication: _____

Description: Tablet Capsule Oral Liquid Injection other: _____

Prescribing Physician: _____ Phone: _____

Pharmacy: _____ Phone: _____

Dosage: _____ Frequency: _____ When Given? (Circle) AM PM With Food

How is medication administered: _____

Who administers medication: _____ At school/work? _____

Purpose of medication: _____

Location medication is stored: _____

Side effects:

Date Started Med: _____ Date Stopped Med: _____

Reason for stopping medication:

Doctor Directed Allergy Side effects too severe

Please describe: _____



3. Doctors/Professionals

This section contains important information about the doctors, therapists, social workers, and other professionals involved in the care of your special needs individual. This will help provided critical continuity of care as well as identify where important medical information can be located.

It is suggested to maintain a record of doctors and professionals who have been used in the past and for what reason, in case a similar need arises in the future, then your special needs individual can have the same care as before. Or, in the alternative, if a professional was discontinued and you do not want that professional used again in the future, you can indicate the reason and your desire that they not be consulted. Please understand however that this does not put a legal obligation on a future caregiver to follow, rather it provides them with information about what may be in the special needs individual's best interest.



Physicians

Physician's Name: _____ Primary Care? Y N

Practice Name: _____

Phone: _____ Fax: _____ Pager: _____ Cell: _____

Address: _____

City: _____ State: _____ Zip: _____

Affiliated Hospital: _____

Practice Area/ Specialty: _____

Reason my child sees this doctor: _____

How often? Daily Bi-Weekly Weekly 2-weeks Monthly
 3 months 4 months 6 months yearly other _____

Who usually takes your child to see this doctor? _____

How does your child react to having to go to doctor? _____

Tips or suggestions to help your child with visiting this doctor: _____

Date Started seeing Doctor: _____ Date Stopped seeing Doctor: _____

Reason no longer seeing this doctor? _____



Therapists

Therapist's Name: _____

Practice Name: _____

Phone: _____ Fax: _____ Pager: _____ Cell: _____

Address: _____

City: _____ State: _____ Zip: _____

Affiliated Hospital: _____

Practice Area/ Specialty: _____

Reason my child sees this therapist: _____

How often? Daily Bi-Weekly Weekly 2-weeks Monthly
 3 months 4 months 6 months yearly other _____

Who usually takes your child to see this therapist? _____

How does your child react to having to go to therapy? _____

Tips or suggestions to help your child with visiting this therapist: _____

Date Started seeing therapist: _____ Date Stopped seeing therapist: _____

Reason no longer seeing this therapist? _____



Psychologists

Psychologist's Name: _____

Practice Name: _____

Phone: _____ Fax: _____ Pager: _____ Cell: _____

Address: _____

City: _____ State: _____ Zip: _____

Affiliated hospital or treatment facility: _____

Practice Area/ Specialty: _____

Reason my child sees this psychologist: _____

How often? Daily Bi-Weekly Weekly 2-weeks Monthly
 3 months 4 months 6 months yearly other

Who usually takes your child to see this psychologist? _____

How does your child react to having to go to psychologist? _____

Tips or suggestions to help your child with visiting this psychologist: _____

Date Started seeing psychologist: _____ Date Stopped seeing psychologist: _____

Reason no longer seeing this psychologist? _____



Other Professionals

Name: _____

Practice Name: _____

Phone: _____ Fax: _____ Pager: _____ Cell: _____

Address: _____

City: _____ State: _____ Zip: _____

Affiliated hospital or treatment facility: _____

Practice Area/Specialty: _____

Reason my child sees this person: _____

How often? Daily Bi-Weekly Weekly 2-weeks Monthly
 3 months 4 months 6 months yearly other

Who usually takes your child to see this person? _____

How does your child react to having to go here? _____

Tips or suggestions to help your child with visiting this person: _____

Date Started seeing person: _____ Date Stopped seeing person: _____

Reason no longer seeing this person? _____



4. Equipment

This section contains information about any special equipment that your special needs individual may require. Please include information about durable medical equipment as well as anything else that contributes to your special needs individual's ability to do things for themselves, brings them enjoyment, or has been simply helpful in his/her care.

By providing information about vendors and maintenance you make it easier for a future care giver to keep equipment in proper, safe working order.



Special Equipment

Equipment Name: _____ How does your child refer to it: _____

Purpose: _____

Can your child use it independently? Yes No Eyes on Supervised Hands on Supervised

Who knows how to use it? _____ Phone: _____

Where is it kept? _____

Who supplied it (see provider list for contact information)? _____

Who maintains it? _____

Who paid for it? Medicaid Medicare Private Insurance Private pay

Is it rented or owned? _____

How often is it needed?

Daily Bi-Weekly Weekly 2-weeks Monthly

3 months 4 months 6 months yearly other

Please describe how your child uses it: _____



5. Financial Information

This section contains important financial information regarding your special needs individual. Be as complete and thorough as possible. This will assist you or a future caregiver to appropriately provide for your special needs individual as well as assist in securing benefits for your special needs individual.



Government Benefits

Agency: _____

Location: _____

Contact Name: _____ Phone: _____

Case or File Number: _____

Location where ID card is kept (keep a photocopy of front and back of card in this manual):

Amount of monthly benefit: _____

Where does this money go? (Bank, Check sent to home, etc): _____

Account Number: _____

Is there an annual case review? Yes No

If so, When is this annual review usually done? _____

Please indicate where previous copies of annual reviews and correspondence are kept, you may want to keep them in this binder. _____

Any other helpful or useful information?



Current Private Benefits

Source of Private Benefit: _____

Location: _____

Contact Name: _____ Phone: _____

Case or File Number: _____

Location where ID card is kept (keep a photocopy of front and back of card in this manual):

Amount of monthly benefit: _____

Where does this money go? (Bank, Check sent to home, etc)

Account Number: _____

Is there an annual case review? Yes No

If so, When is this annual review usually done? _____

Please indicate where previous copies of annual reviews and correspondence are kept, you may want to keep them in this binder.

What is the source of this benefit? _____

Was this a settlement to a lawsuit? Yes No

If so, please indicate case, location, and attorney representing your child: _____

Are these funds from an inheritance? Yes No

If so, please provide a copy of the instrument creating the funds: (Will, Certificate of Trust)



Current Private Medical Insurance

Source of Private Insurance: _____

Location: _____

Contact Name: _____ Phone: _____

ID Number: _____

Location where ID card is kept (keep a photocopy of front and back of card in this manual):

Is this provided by an employer? Yes No

Name of Employer: _____

Contact Name: _____ Phone: _____

Who is primary card holder? _____ Social Sec No. _____

Is there an annual case review? Yes No

If so, When is this annual review usually done? _____

Please indicate where previous copies of annual reviews and correspondence are kept, you may want to keep them in this binder. If you have a summary of benefits, please include that here as well.

Under what circumstances will this coverage be terminated? _____

Any other helpful or useful information? _____



Assets Belonging to Special Needs Child

Assets include personal property, cars, bank accounts in their name, any real property, any sources of income. Identifying the assets your child has will help identify exempt assets under need based qualifying standards, as well as if your child is in a residential facility this will alert a care giver to secure any personal property and assure that your child has access to their property. Please identify if any of the items have a strong personal or sentimental value.

Does your child own any land, house, building, real estate? Yes No

If yes please complete the following for each asset of this nature:

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

How is this property titled? _____

How was this property acquired? _____ Insured? _____

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

If vehicle or real property (land, house, building) How is this property titled? _____

How was this property acquired? _____ Insured? _____

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

How is this property titled? _____

How was this property acquired? _____ Insured? _____

Does special needs person own any vehicles (cars, trucks, vans, boats)? Yes No

If yes please complete the following:

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

How is this vehicle titled? _____

How was this property acquired? _____ Insured? _____



Assets (continued)

Please identify important personal property:

Item Description	Location	Importance to Child
------------------	----------	---------------------

Bank Accounts:

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

How are accounts titled? _____

How was account acquired/what is source of funds? _____

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

How are accounts titled? _____

How was account acquired/ what is source of funds? _____

Description of Asset	Location	Contact person	Phone
----------------------	----------	----------------	-------

How are accounts titled? _____

How was account acquired/ what is source of funds? _____



6. Life Activities and Routines

This section contains a wealth of information that will assist in maintaining continuity in routine for your special needs individual. This section should be reviewed by anyone who is charged with caring for your individual with special needs. It includes information about home, family, friends, social activities, pets, responsibilities, religious preferences, agencies and support groups, transportation needs, communication needs, eating, drinking, personal care, safety, mobility, sleeping habits, and social behaviors.



Home, Family, & Friends

Please list others who live with your child and their relationships to your child.

_____	_____
_____	_____
_____	_____
_____	_____

Are there any interaction problems that your child has with any family members or friends? If so please describe.

Do you have any special family traditions?

Where does your child like to for vacation? Check all that apply and add in your own.

- Mountains
- Big cities
- Camping
- Hiking
- Lake
- Snowy areas
- Boat
- _____
- _____
- _____
- _____



Recreation, Leisure, & Play activities

What activities or games does your child enjoy most?

_____	_____
_____	_____
_____	_____
_____	_____

With whom does your child usually play?

Name: _____ Phone Number: _____
Address: _____

Name: _____ Phone Number: _____
Address: _____

Are there any relatives who visit your child on a regular basis?

Name: _____ Phone Number: _____
Address: _____

What is your child's favorite thing to do when it is raining?

What does your child enjoy doing outside?



Responsibilities

What responsibilities does your child have at home? (chores, etc.)

Does your child enjoy cleaning? Y N

Explain:

Does your child enjoy cooking? Y N

Explain:

Does your child enjoy yard work? Y N

Explain:

What types of housework does your child enjoy the most?



Pets

Does your child enjoy being around animals?

Do you have any family pets? Y N
If yes, what kind and what are their names?

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Do you have anyone who brings their dog or pet to your child for a visit? Y N
If yes,
How often do they visit? _____

Contact information

Name: _____ Phone Number: _____
Address: _____



Religious Affiliation

Group Name: _____

Location: _____

Contact Name: _____ Phone: _____

Type of Activities my child usually participates in:

- Regular Worship Services
- Special Services
- Sunday School
- Weekday programs
- Music Programs
- Camping trips
- Sporting trips
- Evening programs
- Youth Program

Briefly describe how your child participates and what types of accommodations are necessary:

Are there any groups or activities that you do not want your child participating in?



Agencies and Support Groups

Group Name: _____

Location: _____

Contact Name: _____ Phone: _____

Briefly describe how your child or family participates and what types of support this group provides: _____

Group Name: _____

Location: _____

Contact Name: _____ Phone: _____

Briefly describe how your child or family participates and what types of support this group provides: _____

Group Name: _____

Location: _____

Contact Name: _____ Phone: _____

Briefly describe how your child or family participates and what types of support this group provides: _____



Community

Is your child a member of any religious group? Y N

If yes, name of group: _____

Location of the Group: _____

Contact person: _____ Phone Number: _____

Does your child participate in any community activities? (sports, etc)

Does your child enjoy going shopping? Y N Please Explain: _____

Are there any special affiliations with which your child is associated?



Transportation

Does your child have any transportation needs? (van with a lift, special car or seat, community transportation)

Who maintains special equipment?

Company: _____

Contact: _____ Phone Number: _____

Community Transport: _____

Contact: _____ Phone Number: _____

How does your child usually get to where he or she needs to go?



Communication

How are the needs of your child communicated? (verbal, gestures, pictures, sign language, special equipment)

Does your child communicate:

Easily

With Some Difficulty

With Great Difficulty

Please explain:

On a scale of 1 to 5, how well are basic instructions understood?

1 _____ 2 _____ 3 _____ 4 _____ 5
Not understood at all _____ Understands with little difficulty

Describe what happens when your child becomes frustrated when trying to communicate.



Eating

Is your child able to eat by his or herself? Y N

If no, please describe help needed: _____

Have you created any special eating adaptations to make eating easier for your child?

Does your child have any special feeding equipment? Y N

Please describe: _____

Who maintains and supplies equipment? _____

Contact: _____ Phone Number: _____

What is your child's eating schedule?: _____

List your child's favorite foods:

What types of food does your child dislike?

Does your child have any food restrictions? _____

Food allergies– List food and type of reaction (ex: choking, gagging, hives, etc.)



Drinking

Is your child able to drink by his or herself? Y N

If no, please describe help needed: _____

Have you created any special drinking adaptations to make drinking easier for your child?

What are your child's favorite drinks

Least favorite drinks

Does your child have any beverage restrictions? Y N

If yes, please explain: _____



Personal Care

Is your child potty-trained? Y N

Does your child need any help or special equipment using the toilet? Y N

Explain: _____

How often (and when) do accidents happen?

Does your child need any help bathing?

Describe your child's grooming habits and any help he or she may need.

Describe your child's dressing habits and any help he or she may need.



Safety

On a scale of 1 to 5, describe the level of supervision that your child requires?

1 _____ 2 _____ 3 _____ 4 _____ 5
Needs very little supervision Must always be supervised

Please explain: _____

How would your child react if he or she had a simple cut or minor burn?

What would your child do if there was a fire?

Does your child know how to dial 911? Y N

Are there safety issues you are concerned about in or around your home? Please explain

Are there safety issues you are concerned about when in public? Please explain.



Mobility

How much mobility does your child have?

Does your child need any special equipment for mobility? Y N

If yes, please describe:

Product Information—please list any important information including model numbers and names of equipment needed and where you purchase equipment from

If bed ridden, how often is your child re-positioned?

What steps are taken to reduce or avoid bedsores?



Sleeping Habits

Please describe your child's bedtime routine (include usual bedtime)

How often does your child take a nap? _____

How long does he or she sleep? _____

Describe your child's sleeping habits

How often does your child wake up in the middle of the night? _____

Describe how to best deal with night awakenings. _____

Describe your child's morning routine (include when your child usually wakes up)



Social Behavior

Describe your child's general temperament.

Does your child enjoy being in public places? Y N

What are your child's favorite places to go? _____

Describe how your child responds to unfamiliar situations? _____

Describe any behaviors that you feel are dangerous to your child or to others

Does your child ever intentionally destroy things? Y N

If yes, please explain:

Are there any behaviors that must be dealt with? _____

Describe your current behavior support plan. _____

Does your child have a BIP (Behavior Intervention Plan) at school? Y N

If yes, please include a copy of it here or write where it is located. _____



7. Education and Employment

This section contains important information about the special needs individuals education and employment.

Education – Federal law provides significant safeguards to ensure a free, appropriate public education for individuals with disabilities. This is done in conjunction with the local school district and is usually specified in an Individualized Education Plan (IEP). Many IEPs are very thorough and occupy a separate binder. This section should either contain a copy of the current IEP and indicate where previous IEPs are located, or you should indicate where the IEP is kept so it can be located when needed. [NOTE: If you are unable to locate a copy of the current IEP, the local school district will have a copy on file, generally only a parent or guardian is able to access that information from the school system]

Employment – Many individuals with special needs are able to participate in a wide variety of occupational activities. There are numerous programs offered through the State and private companies. Often, a transition plan is developed in conjunction with the school system which includes work training and placement opportunities. This section will contain contact information if this applies to your special needs individual.



Education

Is your child currently enrolled in school? Y N Where? _____

Does your child go everyday? Y N If not, which days? _____

Is IEP Information included in this Binder? Y N

Please identify where any other IEP information is stored. _____

Does your child enjoy going to school? _____

What is your child's favorite subject in school? _____

What supports does your child need during the school day? See IEP

How does your child get to school? (bus, car, etc)? See IEP



Employment

What is your child's current job placement?

How often does he or she work?

Does your child receive any employment supports? (job coach, employment counselor, transportation)

Y N

If yes, please list contact information

Name: _____ Phone Number: _____

Address: _____

Job title: _____

Briefly describe your child's employment history.



8. Miscellaneous

This section is less structured and is provided so that the caregiver can provide other useful nuggets of information that will aid in providing the best possible care for the individual with special needs. If there is something either important or useful that has not been indicated elsewhere in this binder, this section is provided to record that information. Attach additional pages as needed.



Miscellaneous Information

Please use the space provided to add any additional information that is important for someone to know about your child. Add additional pages if necessary

Likes & Dislikes

Fears



Miscellaneous Information

Please use the space provided to add any additional information that is important for someone to know about your child. Add additional pages if necessary

Special Concerns

Any Other Useful Information



Supervision

Residence



Education

Employment



Social Activities

Behavior Management



Medical Care

Religion



Care Givers

Trustee of Assets

Trustee/Guardian of Person



Care Givers

Direct Care Providers

Advocates



Care Givers

Special Instructions

Are there any family members or other people you
DO NOT want to care for your child or his or her assets?

Other



9. Guardianship

This section contains important information about any legally recognized or court established/supervised guardianships for the special needs individual.

This section should contain copies of the Order creating the guardianship, Letters of Guardianship, any reports filed with the court such as the annual inventory and personal status report.



Guardianship Information

Name of Guardian: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone Number(s): Home: _____

Work: _____

Cell: _____

*Check all that apply, add additional sheets for additional guardians

Guardian of Person Guardian of Property

Identify court where guardianship was first established

Name of Court Probate Superior State

Common Other _____

Of _____ County

_____ State

Address of Court: _____

Judge: _____

Clerk: _____

When is annual filing due: _____ (Anniversary date of original order)

Attorney who represented Guardian: _____

Address of attorney: _____

Phone Number: _____ Fax Number: _____

Was an attorney appointed to represent ward? Y N

If yes, who? Name: _____

Address: _____

Phone Number: _____

**Include copies of all court reports/correspondence



10. Care Giver's Estate Plan Overview

This section contains information about you (the caregiver) and your estate plan. This is important so that your wishes are followed and any future caregiver can assist with making sure those plans become effective.

This section only contains an overview and probably will not contain the actual documents that put the plan into effect. There is a place to indicate where the documents are kept. The information provided here does not have any legal force or effect, only properly drafted and executed documents have the legal binding effect to put your estate planning in place. This means generally the originals of the various documents would be required at such a time as it becomes necessary.



Estate Plan Overview for: _____

Please note that information here has no legal force or effect, only properly drafted and executed documents will have such. If there is a conflict between information here and what is in a properly drafted and executed document, the properly drafted and executed document prevails. Any mistakes are inadvertent and should not be constructed as an amendment or revocation of a previous document

I have a check all that apply:

- Will
- Trust (RLT)
- Durable Power of Attorney
- Durable Healthcare Power of Attorney
- Living Will
- HIPAA Authorization
- ILIT
- Other _____

The documents are located in a:

- Bank safe deposit box
- Safe
- Fire box
- Other _____

Answer any question that pertains to where the documents are located

The key is located: _____

The combination is: _____

The combination can be found at: _____

Persons who have access to them are:

Name: _____

Address: _____

Phone Number: _____

General Durable Power of Attorney

Is this a springing Power of Attorney? Y N

Does it only come into effect upon disability or incapacity? Y N

Name

Address

Phone Number

Agent _____

Joint/

Successor Agent _____



Estate Plan Overview Continued

Durable Medical Power of Attorney

Name	Address	Phone Number
1st Agent _____		
Successor _____		

Trust

Name	Address	Phone Number
1st Agent _____		
Successor _____		
Successor _____		

Guardianship for Self

Determination by: Doctor Panel

Where is this nomination? DPOA Guardianship Nomination
 HCPOA Trust

Nominated Guardian:

Name	Address	Phone Number

If a panel was used to determine incapacity or nominate guardian, who is on the panel?

_____	_____
_____	_____
_____	_____



Estate Plan Overview Continued

Who have you nominated as guardian for minor/dependant children?

Where is this nomination?

- Will
- Trust
- Guardianship Nomination

Named Individuals

Panel to Nominate

Names: _____

Panel members: _____

