

SIB TIPS

HELPFUL TIPS AND A GLOSSARY OF TERMS FOR SIBLINGS -



SIB TIPS

We are both sisters of brothers with special needs. As we each step into the role of caretaker for our brother there is a whole new world of terms and acronyms to learn. We call it the alphabet soup of special needs planning. This glossary of terms is our attempt to share what we have learned over the past many years with other brothers and sisters.

After providing Special Needs Planning for the past 20+ years, we have a few tips to share and have included them as a SibTip with their respective term. We hope you find SIB Tips helpful and welcome any suggestions you may have to make it even better.

If it gets too overwhelming know that we are here to help. Feel free to contact us at 781-365-8586 or online at SpecialNeedsPlanning.com or via SpecialNeeds Financial Planning on Facebook.

Enjoy the journey!

Cindy Haddad, CFP® Ron's Sister

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Vocabulary for Siblings & the Five Factors of Special Needs Financial Planning



FAMILY AND SUPPORT FACTORS

- Adult Family Care
- Advocate
- Individualized Education Plan (IEP)
- Individual Service Plan (ISP)
- Personal Care Assistant (PCA)
- Person Centered planning (PCP)



EMOTIONAL FACTORS

Letter of Intent (LOI)



FINANCIAL FACTORS

- ABLE Account
- · Financial Planner
- Life Insurance
- · Long Term Care Insurance



GOVERNMENT BENEFITS FACTORS

- · Massachusetts State Agencies:
- Department of Developmental Services (DDS)
- Massachusetts Commission for the Blind (MCB)
- Massachusetts Commission for the Deaf and hard of Earing (MCDHH)
- Massachusetts Department of Mental Health (DMH)
- Massachusetts Rehabilitation Commission (MRC)
- Medicaid
- Medicare
- · Section 8 Housing Assistance
- Social Security disability Income (SSDI)
- Supplemental Security Income (SSI)

LEGAL FACTORS

- Conservator
- Executor/Executrix
- Guardian
- Durable Power of Attorney
- Health Care Proxy
- · Legal documents
- · Representative Payee
- Special Needs Trust
- Third party
- OBRA-First party
- Pooled Trust
- Trust
- Trust Advisor
- Trustee
- · Will



ADULT FAMILY CARE (AFC)

A program for frail elderly adults and adults with disabilities who cannot live alone safely. There are two different levels of AFC. AFC adults live with trained paid caregivers who provide daily care. This program is for adults who need help with personal care but want to live in a family setting rather than with a family.

SibTip: If you live with your sibling and they require assistance with their personal care you may be eligible for AFC. You cannot be your sibling's guardian and receive AFC. Caregivers can be family members (except legally responsible relatives), or non-family members. This program is funded through MassHealth.



ADVOCATE

An Advocate is someone who focuses on ensuring that the rights of a person with disabilities are met and not violated. Sometimes these services include special education, housing discrimination, abuse and neglect. They may be a paid advocate or a family member or friend who has the best interest of the individual at heart.

SibTip: In the absence of a formal guardianship for your sib, you may want to become his or her advocate informally or formally with a Power of Advocacy. This will allow you to participate in the decision making aspects of their life particularly with residential, employment, and provider agencies. You won't have any legal authorization, but you may already be acting as their "advocate" by standing by them as a sib.



CONSERVATOR

A person appointed by a court or regulatory authority to supervise a person or entity's financial affairs. While guardianship can encompass all personalaffairs of an individual, a conservatorship is limited to the management of the property and financial affairs. It is similar to guardianship in that conservatorship may be full, limited,

temporary or joint.

SibTip: Similar with guardianship you may want to suggest that you become co-conservator to help you transition into the role.



EXECUTOR/EXECUTRIX

The executor/executrix are the individuals or corporations that are appointed in a will who will have the legal responsibility for carrying out the provisions of the will, to the best of their ability according to the current federal and state laws. The executor may seek the assistance of an attorney to complete the process of settling an estate.

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FINANCIAL PLANNER

Financial planners offer different services depending on a number of factors, including credentials, licenses and areas of expertise. They also have different approaches. Some planners work as part of a team of advisors, and others work primarily on their own. Your financial planner should be a trusted partner whom you feel comfortable with and who understands your needs – particularly when it comes to planning for an individual with special needs. They should be competent in The Five Factors of Special Needs Planning $^{\text{TM}}$ to include; Family & Support, Emotional, Financial, Legal, and Government benefits.

Financial planning is the long-term process of wisely managing your finances so you can achieve your goals and dreams, while at the same time negotiating the financial barriers that inevitably arise in every stage of life. Remember, financial planning is a process, not a product.

Most people think all financial planners are "certified," but this isn't true. Anyone can use the title "financial planner." Only those who have fulfilled the certification and renewal requirements of CFP Board can display the CFP® certification trademarks which represent a high level of competency, ethics and professionalism. A CFP® professional is both competent and ethical.

SibTip: Having a family member with special needs makes financial planning more complex since the family must provide for two generations; college for other sibs, their own financial security and the lifetime needs of their child with special needs both during their lifetime and when they die. Working with a qualified financial planner (preferably a Certified Financial Planner ™ practitioner) who can provide comprehensive special needs financial planning for a fee rather than for selling a financial product is most important for unbiased advice and guidance. For a Checklist for Interviewing a Financial Planner see SpecialNeedsPlanning.com.



GUARDIAN

A Guardian is a person appointed by the Probate Court to assume some decision-making responsibilities for an individual who is unable to make decisions for him- or herself. The guardian has the legal authority and responsibility to care for the person and property of another person. When a child reaches age 18 a parent must apply for guardianship, if appropriate, to be able to make decisions on behalf of the adult child.

SibTip: Parents may become co-guardians together. As they age, you may want to suggest that you become the co-guardian. This will help you to transition into this role.



GUARDIANSHIP ALTERNATIVES

SibTip: If your sibling is fairly competent and able to make decisions on their own, they may not require a legal guardianship. There are alternatives to this full guardianship. Your parents may be first in line, but you may be named as a successor on your parent's documents or your sibling's documents. These are a few options to guardianship.



DURABLE POWER OF ATTORNEY (POA)

The Durable Power of Attorney is a legal document which allows one person (the principal) to authorize another person (the attorney-in-fact or agent) to act on his or her behalf with respect to specified types of property, and which may remain in effect during a subsequent disability or incompetency of the principal.



DURABLE POWER OF ATTORNEY (POA) FOR HEALTH CARE

A legal document which grants decision-making powers related to health care to an agent; generally provides for removal of a physician, the right to have the incompetent patient discharged against medical advice, the right to medical records, and the right to have the patient moved or to engage other treatment.



HEALTH CARE PROXY

A document that contains language that helps an assigned person to make medical decisions if the person is unable to do so.



INDIVIDUALIZED EDUCATION PLANS (IEP)

An Individualized Education Plan, commonly referred to as an IEP. An IEP defines the individualized objectives of a child who has been found with a disability. The IEP is intended to help children reach educational goals more easily than they otherwise would. In all cases the IEP must be tailored to the individual student's needs as identified by the IEP evaluation process, and must especially help teachers and related service providers understand the student's disability and how the disability affects the learning process.

An IEP is meant to ensure that students receive an appropriate placement, not "only" special education classrooms or special schools. It is meant to give the student a chance to participate in "normal" school culture and academics as much as is possible for that individual student. In this way, the student is able to have specialized assistance, and otherwise maintains the freedom to interact with and participate in the activities of his or her more general school peers.



SibTip: Your sibling's IEP is the driver in their education and there will be many IEP meetings throughout their school years (up to age 22) and you may ask to participate.

INDIVIDUAL SERVICE PLANS (ISP)

The ISP is the written details of the supports, activities, and resources required for the individual to achieve personal goals. The Individual Service Plan is developed to articulate decisions and agreements made during a person-centered process of planning and information gathering.

ISP team is responsible for assessing and documenting each person's: Personal choices and preferences, Significant health care, mental health or behavioral needs and related maintenance needs, Safety and financial skills. An ISP meeting needs to take place within three months of an individual turning age 22.

SibTip: As a sibling you can play a major role in the development of your siblings ISP. You can attend your sibling's ISP meetings to help your sibling set defined goals after age 22. At the meetings you are able to introduce yourself to the important people working with your sibling on a daily basis.



LEGAL DOCUMENTS

There are documents, and roles, that need to be legally formalized. These include wills, trusts, powers of attorney or advocate and health care proxies. In addition some roles that need to be legally appointed would be guardianship, conservator, or executor/rix. Legal documents need to be created with a knowledgeable disability law attorney in the state where your parents reside (for their documents). You may be

named as one or all of the roles in your sibling or parent's estate plan so it is important to know what is expected of you before it happens.

SibTip: If your parents do have their estate planning documents prepared, you may want to remind them to review and possibly update them every 5 years or in the event of a change in their family, marital, financial, or health situation. You should also know if you have a role to play and what their expectations are



for you. To find a qualified attorney in your state visit these websites at www.specialneedsalliance.org or www.specialneedsanswers.com.

LETTER OF INTENT

Although not legally binding, the Letter of Intent is a way to communicate your desires and concerns to future caregivers, siblings, trustees and others involved in the care of your child with special needs. It covers all those things that a parent (or current caregiver) knows about the person including vital statistics; details about what works well or not so well for the individual; suggestions about what changes might be needed for the future; a list of the locations of all pertinent documents, financial information and medical records; and of course who's who in the life of the individual. There is a fill in the blank version with the accompanying CD-ROM included with The Special Needs Planning Guide (Brookes Publishing), as well as many on the web. The LOI should be updated at least annually to keep information current.

SibTip: It is helpful for you to know the important aspects of your sibling's life – things that most parents know but fail to share. This includes pertinent information such as their social security number, health insurance information, medical information and doctors, agencies supporting your sib, etc. It is important for you to know who is who in their life and why you would contact that person- and why you would not! Encouraging your parent(s) to complete a LOI will be a big help for you as you step into a more involved role with your sib either before or after your parent(s) dies. Complete one together if you can.



LIFE INSURANCE

Life insurance is an important part of one's financial plan. There are many types of life insurance, but the bottom line is that they pay cash to your family after the death of the person who is insured by the policy. Most parents that have a child with special needs should have some type of life insurance in place – preferably a permanent policy that provides for lifelong protection.

SibTip: Often times parents struggle with planning "fairly" or "equally" for all children. However having a child with special needs may require additional funds earmarked for their inheritance and lifelong needs. Life insurance can provide for your sibs supplemental needs without them becoming a financial burden to you. For more information about life insurance visit the website www.lifehappens.org.



LIFE INSURANCE TYPES

Term Life Insurance

This type of life insurance covers the insured for a certain period of time, or term. The policy pays death benefits only if the insured dies during the term, which can be 1, 5, 10, 20 or even 30 years.

Universal Life Insurance

A type of permanent life insurance that allows you, after your initial payment, to pay premiums at any time, in virtually any amount, subject to certain minimums and maximums.

Whole Life Insurance

Whole life insurance is the most common type of permanent life insurance. With this type of policy, premiums generally remain constant over the life of the policy and must be paid periodically in the amount specified in the policy.

Survivorship Life Insurance (Second to Die)

This type of life insurance covers two individuals and pays the death benefit at the death of the second insured. The premiums are significantly less than two traditional insurance policies because the policies insure two lives for one benefit. For older individuals with some health considerations, this may be a viable option for coverage.

SibTip: Second to Die Life insurance is frequently used in the disability market because it is a cost effective way to fund a special needs trust. It insures both mom and dad and pays a death benefit after the second parent dies. A major concern of parents (and sibs) is having enough money available to support the life of the child with special needs when both parents are gone; a time when money is often needed the most.



LONG TERM CARE INSURANCE

Long Term Care Insurance (LTCI) provides coverage that, under specified conditions, provides skilled nursing care, home-health care, personal or adult day care for individuals with a chronic or disabling condition that needs constant supervision. LTC insurance offers more flexibility and options than many public assistance programs. This coverage is usually on the parent, not the child with special needs.

SibTip: If your parents have purchased long term care insurance it is important that you are aware of it before they require long term care assistance either in their home or in a long term care facility. Proper use of LTCI can help to pay for the cost of their care and preserve the estate for the family.



MASSACHUSETTS STATE AGENCIES

SibTip: It is important to identify and connect with the State Agency who serves the needs of your brother or sister's disability. This is often the gateway to access services and supports. Since funding is based upon state budget appropriations, even if the individual qualifies for services based upon eligibility, there may not be sufficient funds to fully serve their lifetime needs. The following is a list of the primary agencies in Massachusetts and their website link.



DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS)

Formerly known as Department of Mental Retardation, DMR) Massachusetts has a comprehensive system of specialized services and supports to give individuals with intellectual disabilities the opportunities to live the way they choose. The Department is the state agency that manages and oversees this service system. Every day, they provide these specialized services and supports to approximately 32,000 adults with intellectual disabilities and children with developmental disabilities. The types of specialized services and supports include day supports, employment supports, residential supports, family supports, respite, and transportation. DDS provides these services through facilities and community-based state operated programs and by contracting with 235 private provider agencies.

SibTip: Find the area office that serves your sibling. http://www.mass.gov/eohhs/gov/departments/dds/



MASSACHUSETTS COMMISSION FOR THE BLIND (MCB)

The Massachusetts Commission for the Blind is a state agency, established in 1906, to provide a wide range of social and rehabilitation services to legally blind Massachusetts residents of all ages. Agency services may address a number of varied needs of individual blind persons. The Massachusetts Commission for the Blind (MCB) provides the highest quality rehabilitation and social services to blind individuals.

leading to independence and full community participation. MCB accomplishes this critical mission by working in partnership with legally blind consumers, families, community agencies, health care providers, and employers.

SibTip: Check out their website to find a list of the services they provide. http://www.mass.gov/eohhs/gov/departments/mcb/



MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING (MCDHH)

The Mission of MCDHH is to provide accessible communication, education and advocacy to consumers and private and public entities so that programs, services and opportunities throughout Massachusetts are fully accessible to persons who are deaf and hard of hearing.

SibTip: check out their website to find a list of the services they provide. http://www.mass.gov/eohhs/gov/departments/mcdhh/



MASSACHUSETTS DEPARTMENT OF MENTAL HEALTH (DMH)

In Massachusetts, responsibility for providing public mental health services falls under the umbrella of the Executive Office of Health and Human Services (EOHHS). DMH is one of 14 EOHHS agencies. DMH is organized into three geographic Areas, each of which is managed by an Area Director. Each Area is divided into local Service Sites. Each Site provides case management and oversees an integrated system of state and

provider-operated adult and child/adolescent mental health services.

SibTip: Find the area office that serves your sibling. http://www.mass.gov/eohhs/gov/departments/dmh/



MASSACHUSETTS REHABILITATION COMMISSION (MRC)

The Massachusetts Rehabilitation Commission (MRC) promotes equality, empowerment and independence of individuals with disabilities. These goals are achieved through enhancing and encouraging personal choice and the right to succeed or fail in the pursuit of independence and employment in the community.

The MRC provides comprehensive services to people with disabilities that maximize their quality of life and economic self-sufficiency in the community.

MRC is responsible for Vocational Rehabilitation Services, Community Services, and eligibility determination for the Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) federal benefits programs.

SibTip: Find the area office that serves your sibling. http://www.mass.gov/eohhs/gov/departments/mrc/



MEDICAID

Medicaid is a joint federal and state program that helps with medical costs for people with low incomes and limited resources. Medicaid programs vary from state to state, but most health care costs are covered if an individual qualifies for both Medicare and Medicaid. People with Medicaid may get coverage for things like food stamps, nursing home care and outpatient prescription drugs that are not covered by Medicare.



MEDICARE

Medicare is the federal health insurance program for people 65 years of age or older and also for certain younger people with disabilities.

SibTip: Since eligibility for Medicaid is based on your sibs disability AND financial need, they should never have more than \$2,000 of assets in their name (this includes bank accounts, savings bonds and accounts, retirement accounts, life insurance or annuities). If this asset limit is exceeded, you should contact a financial planner or attorney who is knowledgeable in disability law and special needs planning. There are qualifying ways to protect eligibility for your sibs Medicaid benefits.



PERSONAL CARE ASSISTANT (PCA)

A MassHealth Program that helps people with long-term disabilities live independently at home. Gives eligible member funds to hire a PCA to help with activities of daily living.

SibTip: Check out the MassHealth PCA Program Consumer Handbook for eligibility requirements, application process and PCA Program Rules. You may be eligible to be your siblings PCA!



PERSON CENTERED PLANNING (PCP)

Person-centered planning is a process-oriented approach to empowering individuals with disabilities. It focuses on the individual and their needs by putting themselves, caregivers and loved ones in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately leads to greater inclusion as valued members of both community and society. Person-centered planning involves the development of a "toolbox" of methods and resources that enable individuals with disabilities, their caregivers and loved ones to choose their pathways to success; the planners simply help them to figure out where they want to go and how best to get there.

SibTip: Person Centered Planning is an effective tool to help identify and create a full and rich life for your sibling. Include everyone that has any type involvement in your sibling's life to share everyone's vision for your sibling's future.



REPRESENTATIVE PAYEE

In cases in which an individual is not capable of managing his or her own Social Security income benefits and after careful investigation, a person appointed by Social Security, who may be a relative, friend, or another concerned party to handle that individual's Social Security matters. The Rep Payee is then required to provide detailed records of the distribution of these funds. Note that a person having power of attorney over an individual does not automatically qualify that person to be a representative payee.

SibTip: Often times a parent assumes the role of the Rep Payee. This is commonly used to establish a bank account for deposit, proper use, record keeping and reporting of the individual's social security checks. In many cases, the agency providing residential services to the individual becomes the Rep Payee and assumes these duties.



SECTION 8 HOUSING ASSISTANCE

The Section 8 Housing Choice Voucher Program is the federal government's major program for assisting very low income families, the elderly, and the disabled to rent decent, safe, and sanitary housing in the private market. Since the housing assistance is provided on behalf of the family or individual, participants are able to find and rent privately owned housing, including single-family homes, townhouses, and apartments. The participant is free to choose any housing that meets the requirements of the program and is not limited to units located in subsidized housing projects.

SibTip: If your sib is living independently you may want to reach out to the local HUD office to inquire about housing assistance including Section 8 Housing subsidy and Fuel Assistance. These programs can help them to financially live in their home.



SOCIAL SECURITY DISABILITY INCOME (SSDI)

SSDI is a program financed with Social Security taxes paid by workers, employers, and self-employed persons. In order to be eligible for a Social Security benefit, the worker must earn sufficient credits based on taxable work. Disability benefits are payable to workers with disabilities, disabled widows or widowers, or adults disabled since childhood who are otherwise eligible. Auxiliary benefits may be payable to a worker's dependents as well. The monthly disability benefit payment is based on the Social Security earnings record of the insured worker on whose Social Security number the disability claim is filed.

SibTip: When a parent dies, becomes disabled, or retires and collects their own social security benefit a disabled adult child may also be eligible for SSDI based upon the parent's earnings record. When a parent dies you should contact the local Social Security office to inform them that you have a sibling with a disability to inquire of their eligibility for income benefits. For more information visit their website at www. ssa.gov.



SUPPLEMENTAL SECURITY INCOME (SSI)

The SSI program provides monthly income to people who are age 65 or older, or are blind or disabled, and have limited income and financial resources. The individual's financial resources (savings and assets owned) cannot exceed \$2,000 (\$3,000 if married). Individuals can be eligible for SSI even if they have never worked in employment covered under Social Security. SSI is to be used to pay for the individuals food, clothing and shelter.

SibTip: Eligibility for SSI also qualifies an individual for Medicaid. In turn, this qualifies them for important supports and services that are paid for by Medicaid funds. Proper financial and estate planning is focused on protecting your siblings eligibility for SSI either now or in the future. This is important to protect the funding source for their residential and day programs.



SPECIAL NEEDS TRUST (THIRD-PARTY)

A special needs trust is designed so that the principal (the amount put into the trust account) and its earnings (from interest or investments) supplement the beneficiary's basic care and do not replace, but supplement, the public funds required to pay for his or her basic care. In other words the use of a properly drafted special needs trust allows parents, grandparents, siblings and others to leave an inheritance to the individual with special needs (the beneficiary) without jeopardizing their eligibility for government benefits including SSI and Medicaid benefits. These are also known as third-party trusts.

SibTip: The typical trust used in special needs planning is the Special Needs (or the Supplemental Needs) Trust. This is the trust your parents would establish for the benefit of your sib to receive his/her share of their estate. It is important that the trust is properly drafted, but it is more important that the trust is adequately funded when they die since that is when you will need the money for your sib the most. Make sure their financial planning and legal documents are properly coordinated.



SPECIAL NEEDS TRUST - OBRA 1993 - PAYBACK: (FIRST-PARTY)

A section in the federal statute governing Medicaid known as (d)(4)(A)) provides that a person can maintain eligibility if he or she places excess funds in an eligible trust. These are called payback trusts, self-settled or first-party trusts. Payback trusts are created with the assets of a disabled individual under age 65 and are established by his or her parent, grandparent or legal guardian or by a court. They also must provide that at the beneficiary's death any remaining trust funds will first be used to reimburse the state for Medicaid paid on the beneficiary's behalf. Source: www.elderlawanswers.com.

SibTip: In the event that your sibling is about to receive an inheritance, legal settlement, or windfall directly in their name, you should consult with a qualified disability law attorney and financial planner. The use of a first-party Special Needs Trust can be the recipient of these funds while protecting eligibility for their SSI, Medicaid and other government benefits that have asset limits (over \$2,000).



SPECIAL NEEDS TRUST - POOLED TRUST

Medicaid and federal law known as (d)(4)(C) also permits trusts that pool the resources of many beneficiaries with disabilities, and those resources are managed by a nonprofit association. Unlike individual disability trusts, which may be created only for those under age 65, pooled trusts may be for beneficiaries of any age, and may be created by the beneficiary. In addition, at the beneficiary's death, the state does not

have to be repaid for its Medicaid expenses on the beneficiary's behalf as long as the funds are retained in the trust for the benefit of the other beneficiaries.

SibTip: There are various Pooled Trusts throughout the country. To find one in the state where your sib resides a Google search will help. In many states they are known as Planned Lifetime Assistance Networks (PLAN).



TRUST

A trust is a legal document under which an individual (grantor) gives fiduciary control of property to a person or institution (trustee) for the benefit of a beneficiary. There are various types of trusts including, Revocable or Irrevocable. Certain trusts are to be funded during the lifetime of the grantor, often referred to as Living Trust and other trusts to be funded upon the death of the grantor, often referred to as a Testamentary Trust.



TRUST ADVISOR

A Trust Advisor is an individual, often a family member or friend, who will provide input on behalf of the beneficiary to the trustee which may be a professional trustee but not a personal trustee. This role removes the fiduciary responsibility of the individual but allows them to be involved in the activity of the Trust. They bring a personal side to the trust administration duties.

SibTip: You may not want, or may not be able to, assume the fiduciary role of the Trustee of your brother or sister's Special Needs Trust. Serving as the Trust Advisor may allow you to still be involved in making sure that your family values are transferred to a corporate or professional trustee when decisions about spending the trust money is concerned.



TRUSTEE

A trustee is a trusted person who manages a trust. They assume the fiduciary responsibility for seeing that the trust funds are properly invested and disbursed according to the wishes of the individual(s) who created the trust (the grantor) for the benefit of the person intended to benefit from the trust (the beneficiary). The trustee can be an individual, a corporation or a professional trustee.

SibTip: You may be named as the Trustee of your sibs Special Needs Trust. If so, you should seek the advice and guidance of knowledgeable professionals in the financial and legal fields. You should try to understand what your parent's expectations and intentions of the trust are for you in this role.



A Will is a legal document which defines how a person wishes his or her estate or property to be dispersed after his or her death. The document must be signed by the testator or testatrix (the person making the will) in the presence of two witnesses who must also sign. An executor (female form executrix) or executors are appointed by the testator to ensure that his or her wishes are carried out.



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COMPREHENSIVE SPECIAL NEEDS PLANNING & WEALTH MANAGEMENT FOR TWO GENERATIONS

We share a common bond with you. We are parents and siblings of people with special needs.

As Certified Financial Planning Professionals,™ we understand the importance of setting and achieving financial goals. We also know, having worked with families for more than 20 years, that planning is about more than the money; it's about creating a full life.



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