

Special Report:

Be Prepared for Unexpected Health Lifequake, Caregiving, and Aging Events

By

**Anne Llewellyn MS, BHSA, RN, CMGT-BC, CRRN, BCPA, FCM
Nurse Advocate**



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How to use this report.

First, read it yourself – then read it again with pen and paper to make a list of things you need to do, so you are prepared before you are faced with life-changing events.

Next, share the report with your family and friends so they can do the work they need to be prepared for their own life event.

Put a date on your calendar to update your documents, as life can change your plans. Maybe when you do your taxes, on your birthday, or the first day of the new year? Just make a note to check your planning documents and update them as needed.

Enjoy your life. Take the trip, eat the cake, and buy the shoes. Hug your kids, kiss your husband, and be in touch with your extended family and friends. Work on healing old wounds, and remember that life is short and that we all need to prepare!

Welcome

If I have learned anything in my career as a critical care registered nurse, it is that life can change on a dime. Our lives can go from healthy and carefree to being diagnosed with a life-changing condition in the blink of an eye.

In the United States, the healthcare system provides professionals, resources, and innovative technologies and drugs to address almost any illness or injury. We have centers of excellence, world-renowned physicians, and healthcare teams that care for people from every walk of life in every setting across the broad healthcare continuum.

What we do not do is teach people how to prepare for life changes before they happen, so they and their families are prepared.

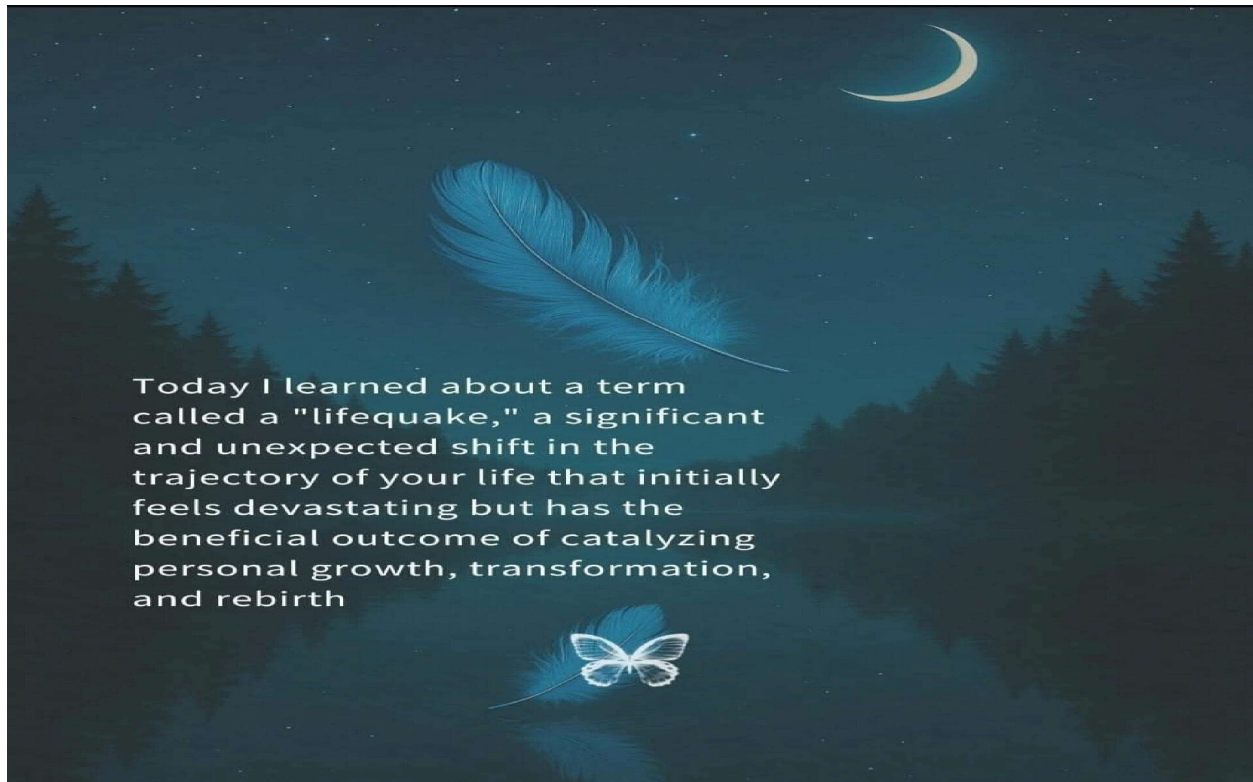
I created this special report to help people (patients and caregivers) learn how to prepare for a life event that can upend their lives and the lives of their families in seconds.

I share the report to help people prepare for unexpected life events, including death. I hope you will read it, reflect on it, and incorporate the suggested tips so you are prepared.

I look forward to your comments and questions. Feel free to email me at allewellyn48@gmail.com

A handwritten signature in black ink, reading "Anne L. Llewellyn". The signature is written in a cursive style with a large, prominent initial "A".

Chapter 1: Preparing for a LifeQuake: Navigating Care in a Complicated System



Today I learned about a term called a "lifequake," a significant and unexpected shift in the trajectory of your life that initially feels devastating but has the beneficial outcome of catalyzing personal growth, transformation, and rebirth

While scrolling through Facebook one day, I came across this image about a LifeQuake and thought it described the feeling I had when I was diagnosed with a Brain Tumor in 2014. In the blink of an eye, I learned I was critically ill, would have to give up my job, and was thrust into the complex world of healthcare.

My husband became my advocate and was there for me at every step. It was a scary time for us both. My husband was supported by colleagues I worked with as a catastrophic nurse case manager. They gave him good suggestions: get a notebook, take notes, get the names and titles of everyone you meet, find out their roles, and, most of all, don't be afraid to ask questions. They helped us find a neurosurgeon at a large cancer center so I could have a biopsy to learn the type of tumor I had. Once diagnosed, I was referred to a hematologist/oncologist who specialized in my tumor type, who saved my life. They provided my husband with guidance on communicating with physicians and other team members, as well as the importance of moving to an academic cancer center.

Healthcare today is complex, costly, and often impersonal. Many contend it has evolved into a system driven more by profit than compassion. As a result, it is easy to lose sight of humanity that should lie at the center of it all and get lost in the system.

But amidst the chaos, many healthcare professionals bring empathy, connection, and healing to the lives of those they serve. Let us look at some of the *Helping Professionals* who are in place to help people navigate the complex healthcare system.

I coined the phrase “helping professionals” because many professionals are available to assist people (patients and their family members). They all perform the same services but have different titles and work in various areas across the healthcare system. Titles include case/care managers, patient/health advocates, insurance advocates, social advocates, care coordinators, and nurse navigators, who help individuals with complex conditions navigate the healthcare system. Here is a description of each and how to reach them.

Independent Professional Patient/Health Advocates: These professionals usually hold Board Certification, a professional license in the health and human services areas, and have expertise gained through life experiences caring for their loved ones. They all choose to make a career out of this work because they want people (patients and caregivers) to have a voice and to receive the care and resources they need to heal.

These professionals are available to assist individuals in navigating the healthcare system. Professional Patient/health advocates work directly for the individual and are paid directly by the patient, the family, or other entity. As a result, their allegiance is to the patient and the family they serve.

Independent patient/health advocates can be found through various search engines. Costs of their services vary by region, the advocate's discipline, the required scope of work, and the experience they bring. They work with the individual and the patient's family, helping to coordinate care, identify necessary resources, provide education about the patient's condition, improve communication among providers, payers, and the patient/family to ensure the patient's voice is heard and respected. They can also address billing issues and help patients and their families resolve concerns with the healthcare team and the insurance company.

They do not provide hands-on care; instead, they connect individuals with resources to help manage their needs. They can be a valuable resource, taking some of the burden off patients and caregivers by helping them safely navigate the healthcare system.

The key is to find an advocate before a “LifeQuake” occurs. If you are a patient with a complex condition or have a family member who could use an advocate, do your research NOW so you are prepared and have someone to rely on when challenges arise.

Ways to find a patient/health advocate.

Word of Mouth: If a family member or friend has worked with one of the helping professionals, they can provide insight into how they helped you or a loved one navigate the healthcare system. Follow their advice as they can point you in the right direction!

Professional Organizations:

National Association of Healthcare Advocacy (NAHAC) <https://nahac.com/directory-of-advocates#!directory>. NAHAC is a professional organization for patient and health advocates nationwide. Members of NAHAC are listed in their online directory. You can find an advocate by entering your zip code into a search engine. Many advocates work virtually, so they might not be in your neighborhood, but they can still help meet your needs.

Greater National Advocates (GMA – NOW) <https://gnanow.org> is an online system that connects people with independent patient/health advocates. You are matched with an advocate who can meet your needs based on your zip code.

Health Advocate X (<https://healthadvocatex.org>) is a professional organization based in Seattle, WA, with advocates across the country. They have a search engine for members to find an advocate.

Aging Life Care Specialists are professionals who specialize in serving elderly patients or those with long-term care needs. The organization maintains a public search engine to help people find an advocate within the organization.

https://www.aginglifecare.org/Shared_Content/ALCA_Directory/ALCA_Find_an_Expert.aspx?hkey=6c3ced7c-b5f0-4d27-9d30-37734ab6cf49

The Patient Advocate Certification Board (PACB) is the Certification Body that certifies independent patient advocates who meet specific eligibility criteria to sit for the Patient Advocate Certification Exam. They have a list of all those who have passed the exam on their website, which can help you find an advocate. If you want to verify a person listed on the platform has maintained their certification, you can contact the PAC Board via this website. <https://www.pacboard.org/bcpa-certificant-list/>

NEW: Medicare now covers patient advocacy. Medicare Beneficiaries can obtain an advocate through traditional Medicare and some Medicare Advantage Plans. Here are a few of the companies I know of at the time of writing this report that you can consult. These companies bill Medicare directly and pay the advocate for their services, so there is no cost to the beneficiary.

Solace Health has been a leader in this area and has one of the largest platforms for connecting Medicare Beneficiaries with patient and health advocates. You can learn more here <https://www.solace.health>

UMBRA: UMBRA is the Consumer Facing Platform of the Alliance of Professional Health Advocates. UMBRA connects individuals with patients and health advocates. To learn more, visit: <https://umbrahealthadvocacy.com>

Partu: handle everything from scheduling to insurance to navigating your diagnosis — making sure you get the best care you need <https://www.pairtu.com/en/myadvocate>

Belle Cares: Belle brings gentle, preventive care right to your home, helping you stay comfortable and independent, move with confidence, and support your overall health. Here is a link to learn more: <https://www.bellecares.com>

Institutional Helping Professionals

Hospital Case Managers/Social Workers, Patient Advocates, Patient Experience Officers, and Nurse Navigators are among the titles used by Hospitals, Rehabilitation Hospitals, Cancer Centers, Nursing Homes, and other inpatient settings that employ helping professionals. These professionals, along with the nursing staff, are available to assist patients and families with any questions or challenges they may face upon admission and throughout their stay. It is important to remember that these professionals work for the hospital, so their allegiance is first and foremost to the hospital. Still, they can be helpful when someone has a question about their care or the care plan. They will usually also provide discharge services and help people arrange home care to meet their needs. This can include durable medical equipment companies, home care companies, rehabilitation professionals, and pharmacies to obtain needed medications and equipment for the patient/family. They are episodic, meaning they provide services when an event happens, and the patient is in the hospital. Once the patient is discharged, the facility is no longer available or responsible for the patient.

Health Insurance Companies: The Patient's health insurance company also has a case manager or on-call nurses who assist the member after hospital discharge. Again, they work for the insurance company and cannot deviate from the insurance guidelines, which can lead to gaps in care.

In closing, knowing there is help is important. Finding help can be challenging, so it is important to be proactive and search for an advocate before an emergency occurs.

Chapter 2: Processing a 'LifeQuake' – Learning Through Our Stories



Receiving bad news from a doctor can be a nightmare. The doctor tells you that you or a loved one has a life-altering condition — causing you to immediately switch focus to an area where you or your family may have little to no experience. A diagnosis can land like a bomb, frightening and disorienting you in a way that little else can.

In this article, I share practical strategies to help you take the next steps and restore balance as you navigate your own LifeQuake. Let us look at them:

Know that your fears will calm down as you learn more about your condition. In the immediate aftermath of a diagnosis, anxiety and fear can feel destabilizing and permanent. But these emotions are important reminders that your body and mind are mobilizing to protect you. The intensity will subside over time. You will still face plenty of challenges, but the intensity, anxiety, and fear will naturally lessen with time.

Slow down. Fight the urge to make major decisions right away; take time to do some research, talk to your primary care doctor, and trusted friends. Get a second opinion. Research the doctors who specialize in your condition. Having an experienced medical team can make all the difference. Look for Centers of Excellence in your area and schedule an exam appointment. Call organizations that specialize in your diagnosis to find a doctor to evaluate you, review the diagnosis, and recommend a treatment plan with you.

Seek comfort, new and old. Accept help from family members and friends. Let them know what you need. Making healthy lifestyle changes and exploring new self-care practices can provide comfort and support, helping you regain some control over your life. Do not abandon your old routines either. If nature walks have always lifted your spirits, go for a walk. If you like to get lost in a book, read. If praying helps, pray.

Choose whom to tell. Support from friends is absolutely essential. But you get to decide with whom to share your news. Those you choose can help you cope, be your second set of eyes and ears, and help you remember things that were said at a doctor or therapy visit – so choose those who you want to accompany you to your appointments or be present when doctors or other healthcare professionals visit you while you are in the hospital. Today, with technology, these people do not have to be in the same area; you can use Zoom or another video call service to bring them into your team. Many doctors allow your visits to be shared with a family member via FaceTime or recorded so you can share the information with your family and friends.

Use the Web and ChatGPT with caution. It is important to remember that the Web and ChatGPT can deliver inaccurate information, so be cautious in your searches, especially at the beginning, as indiscriminate web surfing can increase fears more than it helps you. Talking with trusted health professionals and friends may be more helpful. Asking your treatment team for resources can also be helpful, as they can point you to credible sources.

Write things down. If you are worried, write down your thoughts. Journaling can be therapeutic as you process information. People think of many things when they get bad news. Writing down your thoughts and questions as they come to mind helps you be better prepared for doctor's visits and gain some control over your situation. Do not be afraid to ask any questions – no questions are silly. Your doctor wants you and your family to be active participants in your care, as your input will help you all work together. As mentioned above, many doctors allow you to record visits with your phone, so other members of your family can hear the doctor's thoughts and care plan. Having a recording allows you to share it with your friends and family so they are updated each time you visit the doctor. Another resource I used when I was sick to keep family and friends updated is CaringBridge, a free, secure website where you can communicate with family and friends after appointments or during hospital stays. Here is the link to, to check it out <https://www.caringbridge.org>

Do not worry or feel guilty about telling your boss or manager about changes in your health. Your human resources department might also be helpful in explaining how to take time off to process the information. Also, before a LifeQuake occurs, it is a good idea to review your finances and benefits. Do you have a backup income fund in case you cannot work? Check to see if your employer offers a disability policy, so if you cannot work due to an illness or injury,

you can tap into your disability insurance. Having a disability policy can be a lifesaver to help you pay your bills if you cannot work. A good company to learn about disability and the disability filing process is Allsup. Here is a link to learn more: <https://www.allsup.com>

Find an advocate who can help you address the challenges you face. Review Chapter One to learn how to find a helping professional. Know you do not need to go on the journey alone!

A LifeQuake is difficult. It is difficult for the person receiving the news and for family members. Keep in mind that each person deals with bad news in their own way. Thinking about these things early and preparing in advance is key to surviving a LifeQuake.

PS. I wrote a special report a few years ago titled " Stories from a Nurse Advocate, " where I share stories about my own LifeQuake and a few of the people I helped as a nurse advocate. Take a few minutes to read the stories, as they will offer you some insight into how to deal with your own LifeQuake. Here is a link to download the report. <https://anne-llewellyn.s3.amazonaws.com/Anne+Personal/Storytelling+From+a+Nurse+Advocate/PDF+-+Storytelling+from+a+Nurse+Advocate.pdf>

Chapter 3: Preparing for End-of-Life Duties



We prepare for vacations, meetings for our jobs, and other areas in our lives, so why don't we prepare for our death? We are all going to die – that is a fact. We do not know the day or the hour, but we all know that someday, our lives will end.

Look around your home. Who is going to clean out your closet, go through your most personal items, your medicine cabinet, your jewelry box, and your junk drawer? What will they do with the contents once they find them? What will they do with the high school ring that you never wear but loved to look at because it brings back good memories? Who are you going to ask to close your bank accounts, 401 (k), and social media sites? Who will notify the companies where you have loans/bills with - to let them know that you have passed away? Who is going to sell your home, sell your car, and the other valuables that you have collected and cherished over the years?

We might consider these questions from time to time, but most of us do not take the time to think them through. If we did, we would probably do things a little differently when it is time for us to leave this world.

In this chapter, I wanted to share an inside look at a few of the challenges a friend of mine, whom I will call Diane, encountered as a Trustee for her sister, who passed away. During one of our many calls with Diane, I asked her to share some of the challenges she faced in handling her

sister's affairs. She thought she was prepared, but she quickly learned she was not and wished she had asked more questions before her sister passed.

I hope the information Diane shares spurs you into action so that you will be ready for your death, so that the Trustee/Executor of your estate is prepared as can be.

Diane's sister, Anne, had a beautiful home filled with high-quality furniture, art, and jewelry that were special to her. When she passed away, it became Diane's responsibility to "take care of things." It was a huge responsibility. During one of my calls with Diane, she shared with me how challenging things were. At a time when she was mourning her sister's death, she had lists and lists of things to do to close out the estate. She was exhausted.

As I listened, I realized how hard this was for her. She was grieving the loss of a loved sister, yet she had this huge responsibility that weighed her down. She did have help from good friends, but the burden was definitely on her.

One of the friends was a real estate agent who helped her sell the house. She knew a great deal about what needed to be done, having assisted others in closing out estates throughout her career. She offered several suggestions, but numerous unforeseen obstacles arose along the way because the information that many people needed was unavailable.

Let's hear from Diane about some of the challenges she found as she worked to close her sister's estate:

In early 2025, I was designated as the Trustee of my sister's estate. I had no idea of the work involved in assuming this role. The following are recommendations to make a Trustee's job easier.

Bank Accounts:

As I was **not** on my sister's bank account(s), the attorney handling the Trust assigned me an EIN (Employer Identification Number). This was done to establish a Trust account at a bank to pay bills and related expenses. **This may NOT be necessary in all instances.**

It is imperative that whoever is chosen as a trustee has the name(s) on **all** bank accounts. Additionally, you will need the name of the banking institution, account number(s), user ID, and password for online banking access.

Recurring Payments: Usually Payments made monthly or quarterly, so knowing that information is helpful to know when payments are due.

The Trustee must know how bills are paid: (*very important*)

- Written check
- Auto pay via credit card or bank account

The Trustee should be aware of the user ID and password for **all** payment accounts. It is also good to have a contact telephone number for each. This makes things much easier. Things like:

- monthly utilities
- lawn care
- any loan payments; mortgage, vehicle, etc.
- any insurance policy payments
- Provider(s) for: cell, internet, cable provider, social media, and other accounts, including account numbers, usernames, and passwords if established.

Credit Cards

Trustees should know the type of cards: AMEX, VISA, etc.

Customer Service numbers are on the back of the card.

Trustees should know:

- Credit card numbers, expiration date, security code (all on card)
- user ID and password for online access for **each** credit card, if established

NOTE: If online access is established, the account will indicate how recurring bills are paid.

Health Care Coverage

Note the type of policy the person has and list the member number, the user ID, and the password, if established

If Supplemental policies are in place, provide the number, any user ID, and password if established.

Do not pay any medical bills before confirming that they have been sent to the health insurance company, as they should pay first. If there are balances and the person has a secondary policy, ensure the bills are sent to the secondary policy. Let the various policies know the member is deceased.

Social Security

- Provide SS# and any user ID and password if established.
- If the body is cremated, the company providing the service will notify SSA and also offer a Certificate of Cremation.

Any investment account

Trustees should know:

- Investment company name
- Account number(s)
- Customer Service contact number
- User ID and password, if established

Added note: For investment, bank, and other similar accounts, if beneficiaries are established and reflected on the accounts, the funds will be distributed **directly** to the designated beneficiaries. This will **NOT** be part of the Trust.

This is referred to as **TOD**:

Transfer-on-Death (TOD): A legal term used in estate planning to transfer assets (such as brokerage accounts, bank accounts, or real estate) to named beneficiaries without the need for probate. TOD designations are a way to ensure that assets are passed directly to your heirs upon your death, thereby avoiding the probate court.

I cannot emphasize this enough. It is always best to sit down with the beneficiaries and go over various aspects of your estate.

Establishing the Power of Attorney

The power of attorney gives one or more people the power to act on your behalf as your agent. The power may be limited to a specific activity, such as selling your home, or be generated in its application. The power may give temporary or permanent authority to act on your behalf. (States may have different decision-making powers)

Let your beneficiary know how you would like any jewelry or other valuables handled.

If there is a particular charity you wish to donate to, your furniture and other items, too, please let them know.

If you have lived in your home for many years, it is best to start by clearing out the accumulated items you have had over the years. **This can be a daunting task for family members/beneficiaries.**

I hope this information helps you put into place measures that will assist you and the person you have asked to be your executor or trustee if you are incapacitated or have passed away. Discuss these things while you are here... so everyone is prepared!

Chapter 4: Important Documents



Continuing the series on Being Prepared, I wanted to share documents you should collect and store in a safe place for easy retrieval when needed.

In Chapter Three, I addressed some of the financial information you should gather before your loved one passes.

In this chapter, I would like to share some important documents you should keep close and readily available in case of an emergency.

Review each item and identify any additions needed to ensure they are up to date. Contact the various companies to find out what they require to close your account upon your passing. Your Executor or Trustee will need this information.

Depending on what they say, add that documentation to the list. Ensure the paperwork required for each company is up to date, as you, your executor, or trustee will need to access your accounts. Remember, you might not be around to ask or answer questions, so preparing now will help those you have named close out your estate. They include:

- Funeral Home documentation, if you have pre-made plans for how you want things handled after you die, make sure this information is in your important papers. Many

people are pre-planning their funerals and end-of-life celebrations, so make sure all the paperwork is in place and easily accessible when the time comes.

- Current estate documents: Will, Living Trust, Power of Attorney, Healthcare Surrogate, Living Will. If you make changes to these documents, ensure that you replace them with the updated versions you want to retain.
- Birth certificates
- Marriage license
- Divorce Decree
- Life insurance policies, account numbers, and the name of the company, along with their contact information.
- Bank accounts: Include the name of the bank and account numbers. If you do online banking, add your username and passwords. You can keep a copy of the Trust or Estate Agreement with this information, so your bank knows you have designated this specific person to handle your affairs if you are not able or die.
- Investment accounts: Name of your Investments, the company(s) managing them, and the contact information so your Trustee or Estate Managers can reach them.
- Credit Card Accounts. Account numbers and contact information for the file.
- Loan documents: Name of the lender, contact information, and any account numbers needed. This will enable your Trustee or Estate Managers to access the information and make changes or pay off accounts as required.
- Automobile titles: If you have the actual title, add it to the saved document. If the vehicle is financed, include the lender, account numbers, and the loan payment frequency.
- Property deeds are essential to keep if you own property. Again, any additional information related to this is necessary to keep on hand.
- Keys to automobiles, safe deposit boxes, and other relevant items.
- Account and device passwords. Be cautious with this list. Keep a paper copy of your important papers.

In the next chapter, we will look at some of the technologies being developed to help patients and families communicate more effectively and securely store documents.

Chapter Five: Technologies Keeping Your Documents, Information, and Wishes Safe by Mim Senft, GBA AAI CWWS, Managing Director, Motivity Care



In the next two chapters, we will examine how technology is changing how we develop and secure information for our health and healthcare. Learning about these systems is part of how people can prepare for a 'LifeQuake' as well as end of life. Having these systems in place helps ensure that those we ask to help us can communicate effectively and have the necessary documentation to ensure our wishes are followed.

To help me with this chapter, I contacted a colleague and friend, Mim Senft, GBA AAI CWWS, Managing Director, Motivity Care, to share some things we need to look for when looking for systems to help us as we prepare our affairs, as well as to have people assist us in case we are not able to carry out our own affairs. Mim and her team at Motivity Care have worked tirelessly to develop a system that is safe and secure, allowing those designated to access information as needed.

There are lists to follow of the information and documentation we should have in place, not only to age well but also to help those who might settle our estate one day. But simply organizing them into folders is not the same as ensuring they are secure and accessible only to the people you designate.

Information in a Google Doc or on Dropbox may not provide the security you need. Having information on a spreadsheet may keep you organized, but it is not helpful if it is hacked because it was shared via email. These options also do not allow you to securely share specific pieces of information and not others, or track who is accessing them and when. It isn't helpful if the right people do not have access to what they need to carry out your wishes. It is not secure if the only option is to share all information.

There are now technological options that can be a great tool for caregivers and for estate planning and settlement. However, it is important to understand the level of security they provide. Some storage, information, and communications platforms are not as secure as they should be.

There are some best-in-class security questions you can ask when looking at options for organizing, storing, and sharing care and estate information.

Can you upload and download key documents, like power-of-attorney documents, in case of an emergency?

Yes, the platform you choose should make it easy to upload and download important documents, no matter where you are.

Does the storage platform you use have an up-to-date SOC 2 Type II report?

SOC 2 Type II is not a certification. It is the gold standard verification process that produces a report demonstrating that a service organization's controls for security, availability, processing integrity, confidentiality, and privacy are operating effectively over a period of time (typically 6-12 months). It's a more rigorous assessment than SOC 2 Type I, as it evaluates the operating effectiveness of controls, rather than just their design.

Does the platform you are using not only allow you to share just a piece of information vs. everything on the platform, but also does it require everyone that accesses the platform to double authenticate?

Some of the information and documentation you may be storing can contain sensitive information. You probably don't want everyone to see everything. You also want everyone to have to double authenticate so there is a record of when people accessed information and what they did, as a security feature.

Can I put live URL links to My Charts accounts, insurance portals, a specialist’s medical portal, or home health aide portal?

Yes. This means all the sites you may need are in one place and the live link allows you to quickly get to the information you need wherever you are.

Does the platform date stamp in real time everything that gets added, edited or deleted?

Yes. This can help with legal issues. An example would be a will. The platform should be able to store the will but ensure no one can access it until the designated time. That way, everyone knows there is a will and when it was uploaded.

Does the platform provider help you keep information up to date?

To keep information up to date, the platform provider should provide regular reminders.

If you are traveling across the country or overseas, is the information accessible?

If you are traveling for work or on vacation, you should have peace of mind to have your and/or your loved one’s information easily accessible and secure.

Is information available on a desktop and an app for my phone?

Any quality platform should provide both options. Ensuring all required medical, legal, financial, and personal information is securely digitized can provide greater protection, ensure your wishes are carried out, and prevent delays in accessing information, even during a weather event, an accident, while traveling, or at dinner. But everyone should ensure the platform they use has the appropriate security features.

Is there initial training to get the most out of the platform?

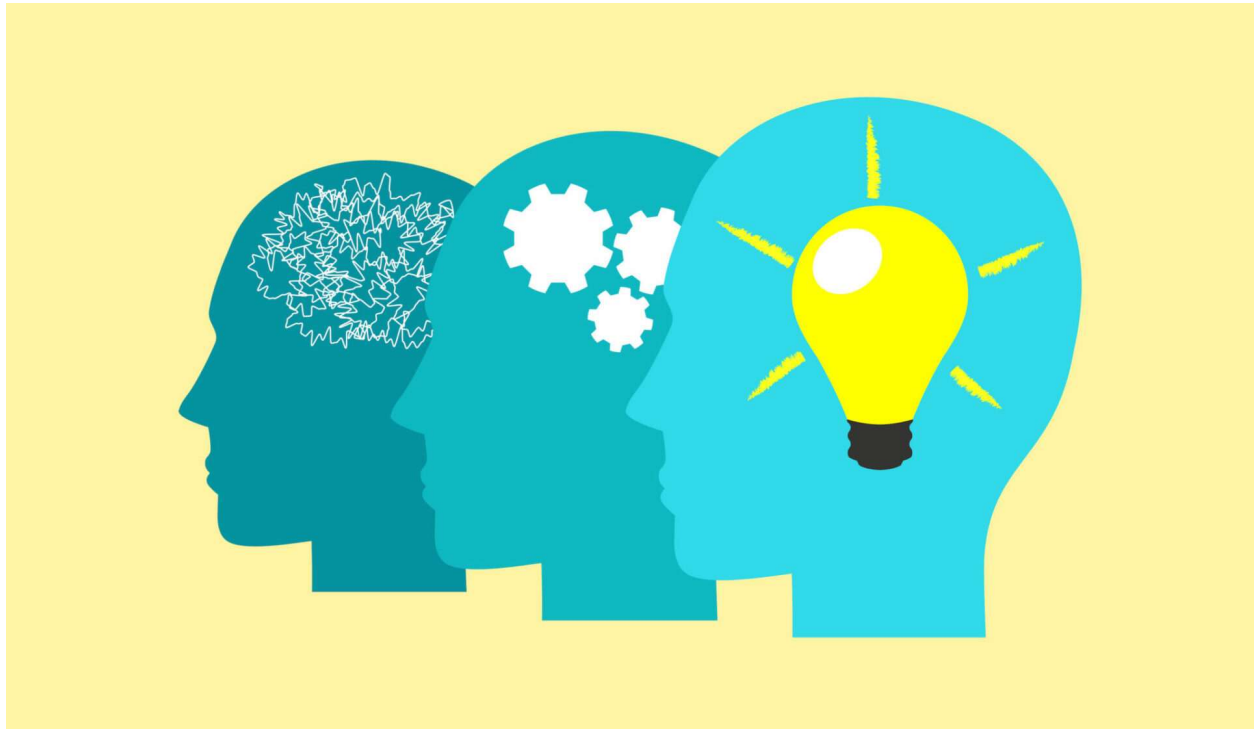
Either group training, easy-to-understand videos, or personalized training should be available.

Is the platform available in English and Spanish? Yes.

Caregiving is challenging, and we are all busy. Living in different cities, states or even countries provides challenges in caring for those you love. Having a secure technology platform that streamlines communication, keeps everyone in the care ecosystem informed, and provides information to support decision-making is vital to easing the burden of caregiving and gives you peace of mind. Start today to get your vital information and documentation in order so you and your family are prepared!

The key is to make sure the program is easy to use, customizable to you and your family’s care journey, secure, and affordable. To learn more about Motivity System, please visit the Motivity Website at <https://motivitycare.com>. For a free consultation: info@motivitycare.com

Technologies Helping Patients and Caregivers Understand Their Health Journey by Jean Ross, RN, Founder of Primary Record



In earlier chapters, this guide emphasized the importance of gathering and organizing important documents. That work is *essential*. Having your legal papers, insurance information, and medical records collected in one place is an act of love for your family.

But in today's healthcare system, preparation requires more than storage.

It requires **understanding**.

Many patients and caregivers believe they are prepared because they have a binder, a file cabinet, or access to an online portal. Yet when a hospitalization or emergency occurs, they quickly discover something unsettling: their carefully organized system sits outside the digital systems their care team uses.

They are asked to complete the same forms again. They repeat the same medical history. They try to remember when the medication was changed. They feel responsible but not included.

A binder cannot update itself when a prescription changes. A spreadsheet cannot reconcile multiple specialists. A stack of discharge papers cannot show how a diagnosis has evolved over time. Information may be stored, but it is not integrated into a living story.

Across the country, there is growing recognition that patients deserve better access to their own information. Organizations such as the [CARIN Alliance](#) advocate for secure digital access to health data to enable individuals to retrieve and use their information more easily. Federal efforts like [Kill the Clipboard](#) encourage healthcare systems to reduce repetitive paperwork and make health information more portable and patient-directed. As a pledge supporter of this movement, **I believe families should no longer feel invisible in the system designed to care for them.**

Innovative technologies are moving beyond document storage toward connected, living health records. These systems securely aggregate information from multiple providers, maintain up-to-date medication and diagnosis lists, and allow patients to share selected information with trusted family members or advocates.

But the most meaningful shift is not just connection, ***it is comprehension and usability.***

Usability means your information does more than sit in a binder. It works for you. It allows you to see what has changed since your last appointment. It consolidates and reconciles medications into a single, accurate list and provides a simple way, such as a QR code or share button, to generate and share it with your care team. It allows lab results to be viewed as trends across systems and time rather than as isolated reports. It places the notes you took during a visit alongside the clinical documentation, rather than scattered across notebooks and email threads.

Some modern platforms now include secure chat assistants that operate within your health information. Instead of searching the internet and receiving general answers, families can ask questions grounded in their actual records, personal notes, uploaded documents, and shared messages.

A caregiver might ask, “What should I update the cardiologist about from the past three months?” or “Have there been medication changes since the last hospitalization?” Because the assistant works within the individual’s own record, the responses are contextual rather than generic. They reflect your history.

These tools do not replace physicians or provide medical advice. They help families organize their thoughts, recognize patterns, and prepare for meaningful conversations. They reduce the mental burden that often falls on one spouse or adult child who feels responsible for remembering everything.

Families already manage health information every day. That work is real and essential. Technology is finally beginning to honor it.

Being prepared today means more than storing documents safely. It means ensuring your information is accurate, connected, secure, accessible to the right people, and understandable.

Technology cannot prevent a “LifeQuake.” But when patients and caregivers can see their full story and use it confidently, they move from scrambling in crisis to participating in care with clarity.

And that changes everything.

If you have questions or want to try Primary Records free for a month, follow this link <https://www.primaryrecord.app/welcome?regcode=BEPREPARED>. You can also reach out to Jean Ross, the founder of Primary Records, via email at jean@primaryrecord.com

A handwritten message in red cursive script that reads "Thank you". The letters are fluid and connected, with a large loop on the 'y'.

Thank YOU for Reading

Thank you for reading this Special Report on Being Prepared. I hope you are taking away useful tips to help you, your family, and your friends navigate a life event and your own end-of-life experience. Doing so will help you give yourself, your family, and your friends a gift that supports them through a life event and, eventually, their own end-of-life.

I look forward to your comments and questions. Feel free to email me at Anne Llewellyn at allewellyn48@gmail.com.

If you receive my weekly Blog, Nurse Advocate, thank you for subscribing. If not, please subscribe now at <https://nursesadvocates.com/blog>. You can see past blog posts and start receiving new ones in your inbox each week.

Stay well!