

The Caregiver's Notebook

An Organizational Tool and Support
TO HELP YOU CARE FOR OTHERS





Feeding the Soul with the Word of God





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How to Use

The Caregiver's Notebook

ne of the most constant roles of my life has been that of a caregiver. In 1959 my father was diagnosed with multiple sclerosis when he was twenty-nine. Mom, assisted by my sister, brother, and me, cared for Dad in our home for more than two decades.

In 1982, the year before Dad developed diabetes and went to a nursing home, my husband and I had our first child, Allen. Hours after his birth, he was diagnosed with a life-threatening birth defect that required immediate surgery at a university hospital far from where he was born. Though he was released from the neonatal intensive care unit three and a half weeks after surgery, our son's medical saga was just beginning. Over the next five years, Allen endured countless hospital procedures and tests, along with seven more corrective surgeries.

We'd barely recovered from that bumpy ride when our daughter, Anne, was born in 1988, and we marveled at how easy it was to care for our typically developing child. Still, the sleep deprivation, well-baby checkups, immunization schedules, and bouts of childhood illnesses were strikingly similar to what we experienced while raising her brother with special needs.

Anne entered middle childhood about the same time Allen required a final corrective surgery when he was fifteen. Then as a young adult, he was diagnosed with post-traumatic stress disorder (PTSD) caused by the early invasive medical treatments he'd endured.

A few months before Allen's successful treatment for PTSD in 2008, my mother was diagnosed with early stage Alzheimer's. Mom sold her house and moved in with my brother and his family, about an hour from where I live. They continue to oversee her daily care. Weekly I run errands with her, take her to appointments, and manage her finances.







Though caregiving has been a nearly constant role in my life, I've not always been an organized caregiver. But as my siblings and I began to coordinate different and increasingly complex components of Mom's care—finances, medical treatments, insurance matters, legal concerns, and day-to-day assistance—I had to become more organized. Eventually it happened, accompanied by a fair amount of blood, sweat, and tears.

The Caregiver's Notebook is designed to jump-start your organizational skills—minus the blood, sweat, and tears. It can be tailored to meet your personal situation, whether you're caring for a typical newborn, a child or adult with special needs, or an elderly parent.

The notebook is designed to be small enough to fit in a diaper bag or briefcase, yet big enough to hold the important documents and information you want at your fingertips at all times. Each section contains directions for use, forms for recording pertinent information, and extra pages for notes. The three-year calendar is blank, waiting to be customized to match your time frame. Pockets in the back of the notebook allow you to carry insurance cards, legal documents, test results, and other important papers. Most sections offer management tips to relieve the stress that can develop as you try to become more organized.

However, *The Caregiver's Notebook* is designed to do more than meet your organizational needs. It's designed to meet your spiritual need for encouragement, too. You already know caregiving is hard work. It can also be discouraging work unless your eyes are fixed upon our caregiver and advocate, Jesus Christ. Therefore, each section begins with an excerpt from books written by caregivers about caregiving. Encouraging quotes and Bible verses are sprinkled throughout the notebook. Toward the back of the book, you'll find

-STRESS RELIEVER-

If you've been entrusted with the care of more than one person, complete a separate notebook to accompany each person to doctor visits, hospital stays, or out-of-town visits. To maintain your own sanity and to avoid double-booking, you can designate one notebook as the "master calendar" to house all appointments and activities.



a Bible reading plan simple enough to use when you're waiting at the doctor's office, sitting with a hospitalized loved one, or caring for a family member at home. Another section offers monthly prayer guides to show caregivers how to pray through Scripture.

So find a pencil and start to make this notebook into the tool you need. Write in the margins. Jot down your own caregiving strategies on the blank, lined pages. Plaster the pages with sticky notes. Do whatever's necessary to make this book a valuable organizational tool—one that will also encourage you to fix your eyes upon Jesus Christ, the ever-present caregiver of our hearts.

If God didn't hesitate to put everything on the line for us, embracing our condition and exposing himself to the worst by sending his own Son, is there anything else he wouldn't gladly and freely do for us?

ROMANS 8:32









od asks two things of us. First, He asks that we recognize our brokenness and bring it to Him to be healed. In Psalm 51:17, David states, "The sacrifices of God are a broken spirit; a broken and contrite heart, O God, you will not despise." Why would God want us to have a broken spirit? Because He understands how prideful and selfish we are when we believe that we arrange the universe and make good things happen. We must be broken in order to rely upon His grace for our needs. When we trust, we can know Him better and love Him more fully. We must accept this idea expressed by Eugene Peterson: "We can't save ourselves by pulling on our bootstraps, even when the bootstraps are made of the finest religious leather."

Second, He asks us to give Him our praise at all times. When we understand God's grace we naturally want to praise Him for all of His gifts, including the gift of being able to rely on Him. The writer of Hebrews puts it thus: "let us continually offer to God a sacrifice of praise—the fruit of lips that confess his name" (Hebrews 13:15 NIV). Praising God has a dual purpose in our lives. First, praising Him for His goodness and love reinforces our belief. Second, we teach others about Him when we praise Him.

Learning to trust and praise God is not a once-and-for-all happening, although it becomes more second nature as we practice it.

—from Doing Well at Being Sick by Wendy Wallace

Although the world is full of suffering, it is full also of the overcoming it.

Helen Keller

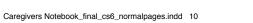




If you don't know what you're doing, pray to the Father. He loves to help. You'll get his help, and won't be condescended to when you ask for it. Ask boldly, believingly, without a second thought.

JAMES 1:5-6







Emergency Information

This section of the notebook is a place to compile your loved one's personal information and emergency contacts for easy reference. Once the information is compiled, the challenge will be to keep it up-to-date. These two tips can make that process easier:

- Use a pencil instead of pen so you can erase and replace outdated information.
- In the calendar section of this notebook, on the third day of every third month, write: *Review and update patient and emergency information*.

STRESS RELIEVER

To avoid identity theft, do not write a Social Security number in this book. Instead, memorize the number, keep it on a card in your wallet, or record it in your cell phone.







PATIENT INFORMATION				
NAME				
ADDRESS				
EMAIL				
PHONE (H)	(W)	(C)		
DATE OF BIRTH	SEX	BLOOD TYPE		
HEIGHT	WEIGHT	EYE COLOR		
ORGAN DONOR YES NO	STATE WHERE DONATION IS REGI	STERED		
ALLERGIES				
DIETARY RESTRICTIONS				
DIAGNOSIS				
PRIMARY LANGUAGE				
CAREGIVER #1				
NAME				
RELATIONSHIP TO PATIENT				
PHONE (H)	(W)	(C)		
CAREGIVER #2				
NAME				
RELATIONSHIP TO PATIENT				
PHONE (H)	(W)	(C)		
CAREGIVER #3				
NAME				
RELATIONSHIP TO PATIENT				
PHONE (H)	(W)	(C)		









EMERGENCY CONTACT INFORMATION PRIMARY EMERGENCY CONTACT NAME RELATIONSHIP TO PATIENT **ADDRESS EMAIL** PHONE (H) (W) (C) **SECOND EMERGENCY CONTACT** NAME **RELATIONSHIP TO PATIENT ADDRESS EMAIL** PHONE (H) (W) (C) THIRD EMERGENCY CONTACT NAME RELATIONSHIP TO PATIENT **ADDRESS EMAIL** PHONE (H) (W) (C) **ATTORNEY'S NAME** PHONE TRUST LIVING WILL DO NOT RESUSCITATE (DNR) DO NOT INTUBATE (DNI) DURABLE POWER OF ATTORNEY (DPOA) **DURABLE POWER OF ATTORNEY (DPOA) NAME RELATIONSHIP TO PATIENT** PHONE (H) (W) (C) **FINANCIAL MANAGER RELATIONSHIP TO PATIENT** (W) PHONE (H) (C) **MEDICAL INSURANCE** PHONE **POLICY NUMBER DENTAL INSURANCE PHONE POLICY NUMBER**







Notes	

He won't brush aside the bruised and the hurt and he won't disregard the small and insignificant, but he'll steadily and firmly set things right.

ISAIAH 42:3





When doctors released me from the hospital in 1999 to return home and recover from my brain lesion, they cautioned me: "Your health is fragile, Shelly. Over the next few years, it will be important to rest and guard against stress."

Rest? Guard against stress? Fast-forward a year, and stress was sweeping through my life. Dan and I returned to Michigan, bringing his father, Norman, with us. We soon moved Norman to the veterans' home four miles from us and moved my mother with Alzheimer's and father into our home. I was caring for three parents and managing their medical appointments. In light of what the doctors had told me, my life just didn't seem . . . fair.

As our parents' conditions deteriorated, my stress increased. At least twice a year, I was scurried to the emergency room with symptoms eerily similar to those that nearly took my life in 1999. But what could I do? Where was I supposed to find the time to care for myself? Often the most difficult thing I did was step over the threshold of my own home as I struggled to hold back my tide of frustrations. And some days, those frustrations boiled over into anger.

I'd always thought that anger was a sin. But a counselor shared with me that anger is a natural, God-given emotion. Psalm 79 teaches key principles of constructive anger management. In our anger, we should strive to:

- Direct our anger at the right source. We must remember that God is not the source of evil in our lives (vv. 1-3). He's the source of all comfort, righteousness, and healing.
- Acknowledge God as righteous and holy. God is merciful and loving, but He directs His anger at those who refuse to acknowledge His sovereignty in His world (vv. 4-7).
- Throw ourselves on the mercy of God and glorify His name.
 When we acknowledge God in the most desperate moments of our lives, we worship and glorify His name (vv. 9-10).









- Freely express our "groans" to God. God listens to our cries of suffering (v. 11). His heart is moved because of His great love for us.
- Acknowledge God as good, in even our most painful moments.
 Even as we groan in our suffering, we can still express God's goodness (v. 13). His strength preserves us, and He battles on our behalf.

During my caregiving years, I learned to explore the reasons and sources of my anger and submit them to God. As I prayed for wisdom for the most appropriate ways to deal with my frustrations, God often showed me just what needed tweaking in my heart and my attitude. In the process, I learned that my anger could become a path to forgiveness and growth.

-from It Is Well with My Soul by Shelly Beach

Be determined to handle any challenge in a way that will make you grow.

LES BROWN









Calendar

This calendar is meant to relieve stress rather than add to it. Each page is blank so you can fill in the months, beginning with the month you start using the notebook. The calendar contains pages to last thirty-six months so you don't need to copy the information from other sections into a new notebook every year.

This calendar can help you coordinate numerous aspects of your loved one's care. Use it to track doctor and therapy appointments, in-home health

care provider visits, when to order supplies and medications, special events, and respite care. In this way, the calendar will become more than the designated location for housing your schedule. Consistent use will make it a resource to consult when a new provider inquires about your loved one's medical history, when insurance companies make inquiries about specific

-STRESS RELIEVER-

Self-care is an essential part of caregiving that is often neglected. Each month, schedule respite days for yourself. Ask family members and friends to sign up for days and times to care for your loved one while you take a much-needed break.

dates for services rendered, or when verification is needed for tax purposes. On occasion, you may want to photocopy and submit calendar pages as documentation.

Pile your troubles on God's shoulders he'll carry your load, he'll help you out. He'll never let good people topple into ruin. PSALM 55:22







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







	SATURDAY	FRIDAY	THURSDAY
Caregiving is the			
hardest work we			
will ever do because			
it demands that			
we love as Christ			
loved, sacrificing			
our time, our jobs,			
our commitments,			
our friendships, and our health, while			
standing against			
the tide of culture.			
SHELLY BEACH			
Notes			
			
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SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Therefore, my
			beloved brethren,
			be steadfast, immovable, always
			abounding in the
			work of the Lord, knowing that your
			toil is not in vain
			in the Lord. 1 Corinthians
			15:58 (NASB)
			Notes
			Notes
			









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Try asking God to
			bring balance to your
			new, crazy life. Then
			be prepared for Him to answer in creative
			and surprising ways.
			JOLENE PHILO
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			If he works severely, he also works tenderly. His stockpiles of loyal love are immense. LAMENTATIONS 3:32
			Notes
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			I did not expect
			caregiving to be a path of restoration for
			my own heart and a
			journey of redemption in my relationships
			with others.
			SHELLY BEACH
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY





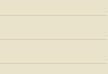


THURSDAY	FRIDAY	SATURDAY



He told me, My grace is enough; it's all you need. My strength comes into its own in your weakness. Once I heard that, I was glad to let it happen. I quit focusing on the handicap and began appreciating the gift. It was a case of Christ's strength moving in on my weakness. 2 CORINTHIANS 12:9

Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			I urge you, as you confront your illness or that of a loved one, to accept pain as a part of your life. Make it your teacher. WENDY WALLACE
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







	SATURDAY	FRIDAY	THURSDAY
People with their mi			
set on you, you ke completely wh			
Isaiah 2			
Not			







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







You rencouragers reach out to church fam you have one, ask them to I JOLENE I	s. So your ily, if and nelp. P _{HILO}
reach out to church fam you have one, ask them to I	your ily, if and nelp. P _{HILO}
church fam you have one, ask them to I JOLENE	ily, if and nelp. P _{HILO}
you have one, ask them to I JOLENE I	and nelp. P _{HILO}
JOLENE I	PHILO
No	tes
No	tes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			May the Master take you by the hand and lead you along the path of God's love and Christ's endurance. 2 THESSALONIANS 3:5
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			In caregiving we reflect Christ's love:
			unconditional love,
			unequivocal love, unreserved love. We
			are called to love in
			ways that will either change us or break us.
			Shelly Beach
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Don't panic. I'm with you. There's no need to fear for I'm your God. I'll give you strength. I'll help you. I'll hold you steady, keep a firm grip on you.
			Isaiah 41:10
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







	You need to give
	yourself permission to
	have bad moments— even bad days. They
	happen. But never
	assume they will
	become your norm. WENDY WALLACE
	Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Is anyone crying
			for help? God is listening, ready to
			rescue you. If your heart is broken, you'll
			find God right there;
			if you're kicked in the gut, he'll help you
			catch your breath. Psalm 34:17—18
			PSALM 34:17-18
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			God created us
			as linear human
			beings, designed
			to do one thing at a
			time. That's how He
			wants resourceful
			caregivers to
			operate. One breath
			at a time. One prayer
			at a time. One
			challenge at a time. Јосеме Рнісо
			JULENE FHILU
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			This I recall to my
			mind, therefore I have hope. The Lord's
			lovingkindnesses
			indeed never cease, for His compassions
			never fail. They
			are new every morning; great is
			Your faithfulness. Lamentations
			3:21–23 (NASB)
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Caregiving is simply the road beneath our feet as we journey beside one another. It is not the journey itself. But it is on that path, as our
			lives converge, that intimacy, empathy, and compassion can take root, and we can grow together. SHELLY BEACH
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Meanwhile, the
			moment we get tired in the waiting,
			God's Spirit is right
			alongside helping
			us along. If we don't know how or what
			to pray, it doesn't
			matter. He does our
			praying in and for us, making prayer out of
			our wordless sighs,
			our aching groans.
			Romans 8:26
			Notes
			Wotes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Fun should never be reserved for someday.
			WENDY WALLACE
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			So speak
			encouraging words
			to one another. Build
			up hope so you'll all be together in this,
			no one left out, no
			one left behind. I
			know you're already
			doing this; just
			keep on doing it. 1 Thessalonians 5:11
			T THESSALUNIANS 3.TT
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Caregiving reveals our
			motives, our agendas,
			our insecurities, our
			fears, our passions,
			and our self-will
			because it strips us down and asks us to
			place the welfare of
			others before our own.
			SHELLY BEACH
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







Are you hurting Pray. Do you fee great? Sing JAMES 5:1
great? Sing JAMES 5:1
JAMES 5:1
Notes
Notes
Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			When you're sleep-deprived and stressed, scared and lonely, close
			your eyes. Picture yourself being carried in God's
			arms, dandled on His knees. Jolene Philo
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			God is good, a
			hiding place in
			tough times. He recognizes and
			welcomes anyone
			looking for help.
			Nahum 1:7
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			In all of life's difficult situations, God often allows us to stew until we are ready to accept the fact that He has been in control all of the time. WENDY WALLACE
			Notes

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SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			God is always on the alert, constantly on the lookout for people who are totally committed to him.
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







	SATURDAY	FRIDAY	THURSDAY
Tell God you expect Him to reveal himsel Shout to Him at the top of your lungs Ask Him to draw nead to you, to open you			
to calm your spiri and to encourag your heart. Wa for Him patiently expectantly Jolene Phil			
Notes			



ect elf. he gs. ar ur ce, rit, ge ait ly, ly. IL0

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SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			I will always show you where to go. I'll give you a full life in the emptiest of places—firm muscles, strong bones. You'll be like a well-watered garden, a gurgling spring that never runs dry. ISAIAH 58:11
			Notes





SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Caregiving is a gift
			that comes wrapped
			with the price tag still
			dangling, a tag that reads <i>Inestimable</i>
			Cost, Eternal Value.
			SHELLY BEACH
			Notes
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Anyone who meets
			a testing challenge
			head-on and manages to stick it out is mighty
			fortunate. For such
			persons loyally in love
			with God, the reward is life and more life.
			JAMES 1:12
			Notes





SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			Ask the God who created laughter to inject some into your life today. When He answers your prayer, accept His prescription with
			a smile. Be silly for a few minutes. Go ahead and laugh. Јосене Рнісо
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			I'm sure now I'll see
			God's goodness in the exuberant earth. Stay
			with God! Take heart.
			Don't quit. I'll say it again: Stay with God.
			PSALM 27:13-14
			Notes

(









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			l have learned
			not to be angry
			at people's
			inability to handle my reality.
			WENDY WALLACE
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			We're not quitters who lose out. Oh, no! We'll stay with it and survive, trusting all the way. HEBREWS 10:39
			Notes







SUNDAY	MONDAY	TUESDAY	WEDNESDAY







THURSDAY	FRIDAY	SATURDAY	
			God will use your travels and the people you meet along the way to show you more of who He is. You'll discover He is in
			control of both your journey and its purpose. JOLENE PHILO
			Notes









SUNDAY	MONDAY	TUESDAY	WEDNESDAY







	SATURDAY	FRIDAY	THURSDAY
For who has			
despised the day			
of small things? Zechariah 4:10			
(NASB)			
Notes			
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Some days there won't be a song in your heart. Sing anyway.

Emory Austin







y trust in God's control was repeatedly tested in the early years of my son's life. At first, I did more hand-wringing and pacing than praying and trusting. Gradually, God taught me to recognize His hand at work in Allen's life, both at home and in the hospital. Slowly, faith replaced my fear.

Each of my son's trips to the hospital honed my ability to recognize God's voice. He first spoke through Allen's primary NICU nurse, who lavished love on our baby when my husband and I couldn't be with him. Eight weeks later, our son quit breathing while I nursed him. After my husband revived him and we rode to the hospital by ambulance, God spoke through a nurse on the pediatric floor. She just happened to be from my hometown. When Allen was a toddler, God spoke with the gentle voice and kind eyes of the gastrointestinal physician Allen dubbed his "buddy doctor."

Between hospital stays, God continued to equip me. The Holy Spirit brought friends into our lives who listened to our questions: What kind of God allows babies to suffer? Why doesn't He heal our son? What purpose could He have in all this?

Our friends answered the questions when they could. When they didn't have answers, they prayed for our family. They encouraged us to search the Bible for more answers. Because of their care, concern, and fellowship, our faith solidified. We gradually became the confident, prayerful parents our son needed.

Maybe some of you developed those habits before you became a caregiver. Or maybe you're more like I was, in need of on-the-job training—or should we call it in-the-hospital training? If the latter is the case, don't lose hope. Be realistic and expect the training to test your patience and stamina. Expect God to honor your efforts to seek Him. Expect His presence to mature and strengthen you, not overnight, but bit by bit.

-from Different Dream Parenting: A Practical Guide to Raising a Child with Special Needs by Jolene Philo





Life's challenges are not supposed to paralyze you; they're supposed to help you discover who you are.

BERNICE JOHNSON REAGON







Contacts

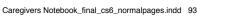
se this notebook section to record pertinent information about the people who provide services for your loved one: physicians, therapists, in-home care companies and workers, schools and school nurses, pharmacies, medical and mental health facilities, and departments within those facilities such as the blood work lab or radiology department. Be sure to include primary physicians as well as all specialists who are part of the medical team. And don't overlook massage therapists, acupuncturists, chiropractors, dietitians, and other providers who work with your loved one.

These suggestions will make the contact information you enter more complete and accessible when you need it in the future:

- Under "Name," record a person's first and last name or the full names of a lab, facility, hospital, or pharmacy.
- Under "Specialty," note an individual's title or the kind of test or procedure performed at a facility.
- In the address slot, note the correct suite number and/or floor when applicable.
- Use the space for "Contact Name" to write the name of a nurse or physician's assistant (PA) who is your first point of contact in a physician's office. For each lab, imaging facility, or pharmacy listed, write the name of the person with whom you frequently interact. You can also write the name of the tech you want to request for your loved one's procedures.
- Write your contact's direct phone number under "Phone." You can save a lot of time by dialing directly rather than going through the receptionist.

The contacts mentioned above are just a starting point. Depending on your situation, other people or organizations should be recorded, too. Use these three questions to come up with a complete listing:

• Who else would I call in the event of an unexpected hospital stay?







- Who will want to pray for us in crisis situations?
- Who will be willing to take care of loose ends at home?

Add to your contact list the people, support groups, and organizations that spring to mind. You'll do a better job of caregiving when you know friends are thinking about you and praying for you. And you'll know how to contact people who can bring you clean clothes, mail your computer cord, or take care of the pet in your absence.

-STRESS RELIEVER-

On your first visit with a provider, ask for a business card or a sheet of letterhead that contains contact information. Look it over and ask for any information you still need. Write down the additions, tuck the paper into a pocket in the back of the notebook, and transfer the information to the contact section once you get home.

SAMPLE CONTACT FORM

NAME Dr. Jane Smith		
SPECIALTY Director of Pediatric Neurosurgery		
PHONE 100-000-4343	EMERGENCY PHONE 101-000-4346	
FAX 101-000-4345	EMAIL jsmith@docmail.com	
ADDRESS Medical Arts Building Suite #406 1414 Union Street Any City, IA 00000		
CONTACT NAME Jason McDougall		
POSITION Dr. Smith's nurse		
PHONE 101-000-4350	EMAIL jmcdougall@docmail.com	



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I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.

Maya Angelou





uring Allen's first hospitalization, my emotions were raw. Hormonal mood swings whacked me every time I turned around. My idea of self-restraint was to let the doctor introduce himself before I launched a volley of questions. The most I could do to control my emotions was to wipe my perpetually tear-stained face and runny nose with tissues instead of my shirtsleeve.

If only I had known Naomi way back then. She's the mother of five children. Two are autistic, one is hyperactive, one has a cleft palate along with major language and speech delays, and one died of a brain tumor as a toddler.

The most important thing to control, she feels, is overly emotional responses when you're under stress. "Always be kind and gracious to the doctors, unless they mess up with your child or do something serious. They, next to you, are going to give the child the best care." With that reality in mind, Naomi says sometimes you need to bite your tongue: "'Cause you're emotionally charged anyway, so you may be responding in a way that is inappropriate under normal circumstances."

She issues a caution, too. "Don't change your personality because you're in pain. Don't mistreat people because you're overwhelmed with grief. If you do that, you isolate yourself. And you don't have a support group if you isolate yourself."

But how do you keep from using your circumstances to justify wrong behavior? How do you keep from pushing people away and isolating yourself? In my case God provided someone to mentor me. That someone was my husband, who, even under stress, is a kind and gracious man. When the doctors talked to us after Allen's surgeries, Hiram pondered their words before asking questions. When a nurse came after we turned on Allen's call button, Hiram thanked her before making a request. He thought before speaking and considered alternatives before acting. Thankfully, under his patient tutelage, I started to do the same.

Perhaps you know how to respond with grace and kindness in times of great stress. But if you don't, look for a mentor to teach you.





In the end, your gracious words and kindness will yield two precious gifts. The first, as Naomi mentioned, is immediate: the gift of better care for your loved one in the hospital. The second gift is your example of how to speak and respond rightly under pressure.

Your example has power. Your words have power. So wrap them in kindness and grace. Make your words, even in the hospital, a precious gift to your loved one.

-from A Different Dream for My Child: Meditations for Parents of Critically or Chronically III Children by Jolene Philo

Love and kindness are never wasted. They always make a difference. They bless the one who receives them, and they bless you, the giver.

BARBARA DE ANGELIS



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he blank pages in this section can be used for a variety of purposes. Some possible ideas are listed below. Feel free to customize them to fit your needs or come up with your own unique ways to fill the pages.

- Before appointments, jot down questions to ask the doctor or therapist, leaving space to record his or her answers. Add new questions that come to mind during the checkup or therapy session.
- If you care for a child with special needs, record questions to ask at parent-teacher conferences, IEP (Individualized Education Program) meetings, or annual reviews. Again, jot down new questions that arise during the meetings.
- Log observations about side effects whenever a new medicine is administered.
- Log observations about physical or behavioral changes when a new therapy begins.
- Play tic-tac-toe or hangman while in a waiting room.

·STRESS RELIEVER—

Record the day, month, and year when you asked medical or school personnel your questions. Also, record and date their responses. Do the same for any observations recorded on these pages. Dated entries create a history that can be used to inform insurance companies, track the effectiveness of medications and therapies, and influence future treatment.

Trust God from the bottom of your heart; don't try to figure out everything on your own. Listen for God's voice in everything you do, everywhere you go; he's the one who will keep you on track. Don't assume that you know it all. Run to God! Run from evil!

Proverbs 3:5-7





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God will never walk away from his people, never desert his precious people.

PSALM 94:14













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WILLA CATHER

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no eye seen, a God like you who works for those who wait for him.

ISAIAH **64:4**







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We make a living by what we get, but we make a life by what we give.

SIR WINSTON CHURCHILL

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When all is stripped away, God longs for us to love Him for who He is, apart from what He gives us, apart from what He provides for us, apart from anything we can see or measure for ourselves.

Even when the world doesn't make sense.

Even in the midst of pain.

Even when we're suffering, or those we love most are suffering.

Why? Because we can trust in the character of a sovereign God who wove together the fabric of eternity, the timelines of history, and the love of a Father just to redeem us. This is the wellspring that runs deep beneath the circumstances of life and enables us to serve, to love, to care, to forgive, and to hope in the midst of suffering and pain.

When Jesus encapsulated the passion and purpose of His life in response to the Pharisees—to those who despised Him and sought to pervert His every good intent for the world—He couldn't have been any clearer.

Let love for God overwhelm your heart. Let it engulf the center of your being. Let it so captivate you that it possesses your emotions, your mind, and your actions. And when you do, your life will pour out in service to others as you take on the nature of Christ through the power of the Holy Spirit.

And will your efforts ever fall short? For many of us, much of the time.

Will we struggle against the temptation to pour out our caregiving from the muddied waters of our emotional reserves? Yes.

Will we attempt to squeeze out a few more drops of our own wisdom for the tough questions? Sometimes.

Will we muster up our own sheer determination to simply get through the next task, through the next day? Perhaps. But when we seek to love others and meet their needs from our limited resources or when we seek to love God first with our limited emotions or intellect, we will always fall short. It is only when we root our understanding and worship deeply in His character that loving Him with our soul and







mind and loving others can be possible. To do it in reverse order is a matter of the will and will collapse in failure.

-from Ambushed by Grace by Shelly Beach

We can do no great things—
only small things with great love.

Mother Teresa









Medications

edication management is an important element of caregiving for many reasons. Physicians, nurses, dentists, and other professionals frequently ask for a list of current medications. Caregivers need to know when to administer medications and in what dosage. Prescriptions need to be renewed. Refills must be ordered and picked up before the current supply runs out. Medication changes occur. Copays need to be recorded. All of these tasks create a complex and confusing situation. The three forms in this section—a medication list, medication notes, and a medication pickup form—are designed to organize medication management.

Prescriptions and Over-the-Counter Medications List: Think of this form as a medication quick reference guide. For each medication, list information from the label such as name of the medication, dosage, when it is administered, and reason it's given. Include over-the-counter medications, vitamin and mineral supplements, and holistic and herbal remedies. Health care professionals need to know about all of them.

Medication Notes: These pages provide space for more detailed information about medications and supplements your loved one uses. Complete one box per medication or supplement. Record the start date and end date, when applicable, for each medication. Write the name of the medication found on the prescription or supplement label. Check the small box if the generic form of a prescription drug is being used. Use the label to fill in the dosage, frequency of administration, the prescribing doctor, the purpose of the medication, and possible side effects. For prescription drugs also record the pharmacy where it is filled and the Rx number found on the prescription label.

The sample on the next page shows what the medication note form might look like once it's filled in.





SAMPLE MEDICATION NOTE FORM

START DATE 06/26/15	END DATE NA	MEDICATION Zolpidem	✓ GENERIC
DOSAGE 10 MG	FREQUENCY 1 tablet at bedtime	PHARMACY Hometown Drugstore	RX 999999-00000
DESCRIPTION Small, round, white capsules—74 stamped on one side, TEVA on the other		PRESCRIBING DOCTOR Dr. John Smith	
PURPOSE initiate Sleep at bedtime		SIDE EFFECTS on rare occasions can aggressiveness; agitation hallucinations; amnessineartbeat; and chest	on; ia; rapid, racing
NUMBER OF REFILLS 2 before 11/26/15		QUANTITY TO ORDER 30	

Medication Pickup and Payment Record: This form allows multiple caregivers to coordinate the pickup and payment of medications. Complete one line for each medication purchased. Fill in the date, medication, person who picked it up, payment method, and amount paid. When more than one prescription is picked up at the same time, use one line per item. If special circumstances apply (e.g., perhaps the pharmacy could only fill half the order, but you paid for the whole thing), jot that on the next line, along with the new pickup date.

-STRESS RELIEVER-

Recording the payment method and amount paid for each medication is a big help at tax time. If a receipt is missing, the "payment method" column tells where to look for it. Add up the numbers in the last column for the current tax year, and voila, you have the year's deduction amount!





PRESCRIPTION AND OVER-THE-COUNTER MEDICATIONS LIST

PRESCRIPTION AND OVER-THE-COUNTER MEDICATIONS LIST			
Medication Name	Dosage	Times Per Day/ Times Of Day	Reason For Medication







PRESCRIPTION AND OVER-THE-COUNTER MEDICATIONS LIST

PRESCRIPTION AND OVER-THE-COUNTER MEDICATIONS LIST			
Medication Name	Dosage	Times Per Day/ Times Of Day	Reason For Medication







MEDICATION NOTES				
START DATE	END DATE	MEDICATION	GENERIC GENERIC	
DOSAGE	FREQUENCY	PHARMACY	RX	
DESCRIPTION		PRESCRIBING DOCTOR		
PURPOSE		SIDE EFFECTS		
NUMBER OF REFILLS		QUANTITY TO ORDER		

START DATE	END DATE	MEDICATION	GENERIC GENERIC
DOSAGE	FREQUENCY	PHARMACY	RX
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DOSAGE	FREQUENCY	PHARMACY	RX
DESCRIPTION		PRESCRIBING DOCTOR	
PURPOSE		SIDE EFFECTS	
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MEDICATION PICKUP AND PAYMENT RECORD Date Medication Pickup **Pharmacy** Payment Method Amount Paid Person







MEDICATION PICKUP AND PAYMENT RECORD Date Medication Pickup **Pharmacy** Payment Method Amount Paid Person







MEDICATION PICKUP AND PAYMENT RECORD Date Medication Pickup **Pharmacy** Payment Method Amount Paid Person







MEDICATION PICKUP AND PAYMENT RECORD Date Medication Pickup **Pharmacy** Payment Method Amount Paid Person







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Every desirable and beneficial gift comes out of heaven. The gifts are rivers of light cascading down from the Father of Light. There is nothing deceitful in God, nothing two-faced, nothing fickle.

James 1:17





t's impossible to think about the character of God without thinking about grace. And it needs to be that way with us, too. Grace should be woven through the very fabric of our lives. Forgiveness, blessing, hope, affirmation, encouragement, woven through the words that we speak, the tone that we choose, the expression that we reflect, the actions that we portray. Even in the most mundane of moments, the moments that measure the character of who we really are.

When we discover that two prescriptions have run out, and the caregiver is late, and Dad is refusing to take the meds we do have.

When Mom is sick in the middle of the night, and we know we're heading out to the ER again.

When the doctor isn't returning our calls, we haven't slept through the night in four months, and there's no hope for respite.

When our spouse informs us that the alternator is going out on the van and we won't be able to use it to drive our parents to the doctor, and we don't know how we'll load a wheelchair into the trunk of our Mazda.

When we haven't heard from our kids in seven weeks and from anyone at church forever, and we're pretty sure that the mailman and our sick husband are the only people who know we're alive anymore.

When we've been put on hold for the sixth time by the mail order prescription company, after having our call transferred three times and disconnected twice.

It's in those moments that we're asked to measure our maturity—to look in the mirror and to see how much we resemble our Father.

Do we speak words of grace?

Do our eyes and tone reflect a spirit of grace?

Do we forgive with grace?

Do we see others with the eyes of grace?

Do we lavish grace or measure it in thimbles?

In the jostle and tumble of life, when I am insulted and affronted, I will stand unflinchingly in the knowledge of who I am and offer life and redemption. That the face of grace I portray to the world would be the face of my Father reflected in my own.

-from Ambushed by Grace by Shelly Beach







A difficult time can be more readily endured if we retain the conviction that our existence holds a purpose—a cause to pursue, a person to love, a goal to achieve.

JOHN MAXWELL







Medical Information

Think of the medical information section as a medical history in progress. Use it to record pertinent information about your loved one's health. As medical situations unfold, add new information where it best fits. As always, date each entry to create an accurate log to share with health care providers and insurance companies. The following instructions explain how to use each of the forms contained in this section.

Current Diagnosis: Use this form as a quick reference document. When you begin using the notebook, list all pertinent diagnoses, one per line. Then record each new diagnosis when it is made, along with the date of diagnosis and the diagnosing physician.

-STRESS RELIEVER-

If your loved one has several diagnoses, deciding which ones are "current" may be a puzzle. To solve the puzzle, answer these questions:

- Does this diagnosis still impact my loved one's health?
- · Is the condition still being treated?
- Is the diagnosis pertinent even though the condition has been successfully treated or resolved?

If the answer to any of those questions is yes, include it on the "current diagnosis" form.

Allergies and Sensory Sensitivities: Use this page to list airborne, chemical, food, and drug allergies, along with an accurate description of each allergic reaction and how to treat it.

Immunizations: For children ages birth to eighteen, record the dates recommended childhood vaccines are administered. For adults, record booster shots, as well as doctor-recommended vaccines for adult-onset conditions such as shingles, hepatitis, and influenza.







Dental and Vision Care: Fill out one box per appointment.

Tests/Procedures: Record diagnostic tests and procedures on these forms. Think about previous tests or procedures that led to the current diagnosis and write them down, too. Each box has spaces to note the date, the type of test (blood work, scans, x-rays, stress tests, swallows, etc.), the body region, the name of the requesting physician, the facility where it was administered, the reason it was requested, and the results.

Treatments/Therapies: On this form, you can record treatments and therapies prescribed by physicians or other health care professionals. Record each new course of treatment or therapy in a new box, noting start and end dates, the requesting physician, the facility where it takes place, a description of the treatment or therapy, and the frequency of visits (every other day, weekly, monthly, etc.). The large space in the bottom right corner of each form can be used to record special instructions or observations such as side effects, complications, or improvements.

Hospitalizations: Use this form to log hospital stays and surgeries. For each inpatient hospitalization, write the date of admission, the reason for the stay, the facility name and location, and the discharge date.

-STRESS RELIEVER-

Whenever a hospitalization, test, procedure, treatment, or therapy occurs in a facility new to you, flip back to the contact section and create a new entry. Be sure to note the name of the person administering the test.







CURRENT DIAGNOSIS		
Diagnosis/Description	Date of Diagnosis	Physician/Specialist







CURRENT DIAGNOSIS						
Diagnosis/Description	Diagnosis/Description Date of Diagnosis Physician/Specialist					







ALLERGIES AND SENSORY SENSITIVITIES		
Reaction	Treatment	









ALLERGIES AND SENSORY SENSITIVITIES Allergy/Sensory Sensitivity Reaction Treatment







IMMUNIZATIONS		
Vaccine	Date	Who/Where Administered





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HOSPITALIZATIONS			
Admit Date	Reason	Hospital/Location	Discharge Date







HOSPITALIZATIONS			
Admit Date	Reason	Hospital/Location	Discharge Date







HOSPITALIZATIONS			
Admit Date	Reason	Hospital/Location	Discharge Date







Notes	

I look up to the mountains; does my strength come from mountains? No, my strength comes from God, who made heaven, and earth, and mountains.

PSALM 121:1-2





The moment the doctor diagnosed our newborn son's condition and described the surgery required to save his life, a torrent of questions flooded my brain. Most of them were what I thought a concerned, loving parent should ask. Will he live? Will the separation from us traumatize him? How much pain will he have? Will he remember it?

Some of the questions were practical. What if our insurance doesn't cover the bills? How will we pay for gas for the long trip? How will we pay for meals? Where will we stay when we arrive? How will we keep friends and family updated?

To be honest, my preoccupation with logistical questions shocked me. My baby was fighting for his life and being flown to a hospital 750 miles away for surgery, and I was worrying about insurance and logistics. What kind of parent was I?

Why wasn't I wringing my hands, ridden with angst? Why wasn't I being holy, praying and reading the Bible? Why wasn't I crying? Surely crying would have been a better demonstration of love than sitting there dry-eyed and numb, trying to remember if the checking account had enough money in it to pay for a cross-country trip.

Racked with guilt, alone in the hospital while my husband drove ninety miles home to pack our suitcases, I felt completely useless. I couldn't hold our baby. I couldn't help my husband. I couldn't do a thing.

Then again, maybe I could.

I picked up the phone and dialed the business manager at my workplace to ask about our insurance coverage.

Was our son covered even though he'd been born before he officially went on our policy?

Yes.

Did the policy pay for treatment in another state?

Yes

Did we need to sign anything before we left to join our son? No.









With each answer, my guilt eased and my confidence grew. My questions were necessary. The answers provided information for our upcoming journey. By asking them, I learned another lesson. I wasn't helpless. I was a resourceful caregiver, and gathering information was a way to advocate for my son.

-from Different Dream Parenting by Jolene Philo

The beginning of anxiety is the end of faith, and the beginning of true faith is the end of anxiety.

GEORGE E. MUELLER









Insurance Information

This section is your personal, one-stop insurance policy shop. Upon completion, it will provide quick access to the details of your loved one's medical, drug, dental, and vision insurance policies.

Before completing this section, list all of your loved one's medical insurance policies on a sheet of paper. In addition to insurance provided through the Affordable Care Act's Health Insurance Marketplace, employers, and private insurance plans, include programs such as disability, Medicare, Medicaid, long-term care, Medicaid waiver programs for children, and state children's health insurance programs (CHIP). Record the information for each type of insurance plan in one of the boxes designated for medical insurance. Record all other insurance information in the specifically labeled boxes. Again, use a pencil so the details can be changed easily if your insurance company or coverage changes.

Forms for recording insurance company phone calls are located at the end of this section. Fill in one form per contact. Before ending any call, ask for the first and last name of the person you spoke to and that person's extension number. Always jot down the purpose of the call and the answers given. If you aren't satisfied with the results of the call, ask to speak to the supervisor or manager. When you are transferred, use a new contact form to log the conversation with the new person.

-STRESS RELIEVER-

Is the thought of trying to locate information for this section making you hyperventilate? Then grab a paper bag with one hand and your loved one's wallet (or your own if you're caring for a child) with the other. Those handy wallet-size insurance cards contain most of the information you need. Whatever's missing can be found by calling the number on the insurance card and asking for assistance.





HEALTH INSURANCE POLICIES			
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PHONE NUMBER		AFTER-HOURS NUMBER	
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COMPANY NAME			
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Notes	

Friends love through all kinds of weather, and families stick together in all kinds of trouble.

Proverbs 17:17







The night air is sharp, the cold burning my fingertips with hot pinpricks as I pull out of the hospital parking lot and head through the darkened streets of the city. I reach for the controls of the heater and adjust the knobs, knowing that there will be no warmth until I pass the pizzeria near Division Street. On milder nights I have felt the first breaths of comfort within a few blocks of the hospital, but not tonight. I slide my right hand beneath my thigh to keep it warm.

Earlier today we gathered around my father-in-law's bed and asked him to sign a Do Not Resuscitate order. The doctor told us that Norman's frail body would not survive CPR, that the chest compressions would most likely break his fragile bones. He described in vivid detail the trauma of resuscitation to prolong Norman's life. Norman does not want a ventilator—he has expressed that desire clearly—and it has become our task to make him now see the futility of CPR.

The silence, like so many silences in Norman's life, has been loud and prolonged as his family gathers around the bed. My husband sits in a chair at Norman's side, his hand resting lightly on his father's leg. I stand at the foot of the bed.

The conversation is halted, awkward. It seems as though we are asking the man we love to simply give up and die. Perhaps that is what we are asking him to do. He has always sought, above all things, to do what is right. Even in this moment, he is searching to know what is right.

His eyes flutter closed briefly, and he finds his answer. "Tell them not to do CPR."

I turn onto the interstate and head north toward home.

The heater is puffing its first feeble breaths of warmth. I reach my hand toward the vent and rotate my fingers in the tepid stream of air as I glance toward home. A pale amber glow burns in the northwest sky. I scan the horizon and spot a second pillar of light, then a third as I make my way north.

By the time I reach my exit, I'm fascinated. I turn west, then north again and drive slowly through a crystalline fog that has enveloped my





car. Every light in my path has become an amber beacon, reflecting into the night sky with a surreal radiance.

A porch light glows with haloed rings of white.

Headlights from an approaching car nearly blind me with their intensity.

Circling spotlights from the nearby airport shimmer in a psychedelic light show.

The intense cold has transformed invisible crystals into tiny refractors that cast light upward in a heavenly dance.

I suddenly realize the truth.

Norman is giving up nothing and gaining everything. We are inviting him to join in the heavenly dance, to allow himself to be blinded with the intensity of the nearness of glory, and to gain comfort from the lights approaching on the horizon. We are asking him to let go of the dimness of this world for the brilliance of the next. And that is the best thing we could ever ask of him. The heavenly lights are his invitation and our assurance.

-from Precious Lord, Take My Hand by Shelly Beach

God will not permit any troubles to come upon us, unless He has a specific plan by which great blessing can come out of the difficulty.

PETER MARSHALL









amily caregivers are responsible for more than their loved one's medical care. They also need to know the whereabouts of legal documents and be prepared to carry out the wishes stated in them. Adults should have the following completed documents in place: a last will and testament, a living will

or advance directive, a medical or health care power of attorney, and a durable power of attorney. Optional legal documents for adults are a trust, a do-not-resuscitate order, and a do-not-intubate order.

The forms on the next pages can help you locate legal papers and quickly contact designated decision-makers. Use one form per legal document, recording the name of the decision-maker, that person's contact information, and the location

-STRESS RELIEVER-

Copy pertinent legal documents for your loved one to take in case of an emergency while on extended visits with other family members. Include copies of the living will, durable power of attorney, and health care power of attorney. Tuck an extra set of the documents into a pocket of this notebook to take along whenever your loved one is hospitalized.

of the original document. The "other" boxes can be used for a variety of legal information such as guardianship details for a child or an adult with special needs.

If your adult loved one hasn't prepared these documents, consult with a lawyer about how to proceed, as laws vary from state to state. Parents caring for a child with special needs should meet with a lawyer about creating a special-needs trust to have in place when their child turns eighteen.

-STRESS RELIEVER-

Is all this legal speak giving you a headache? Then flip to the glossary near the back of the notebook. It contains definitions for terms found in this section, as well as for the medical and insurance terms used throughout *The Caregiver's Notebook*.







For God, who said, "Let light shine out of darkness," made his light shine in our hearts to give us the light of the knowledge of the glory of God in the face of Christ.

2 Corinthians 4:6 (NIV)



No test or temptation that comes your way is beyond the course of what others have had to face. All you need to remember is that God will never let you down; he'll never let you be pushed past your limit; he'll always be there to help you come through it.

1 Corinthians 10:13







	LAST WI	LL AND TESTAM	IENT	
DESIGNATED DECISION-MAKER				
ADDRESS				
PHONE NUMBERS	(H)	(W)	(C)	
DOCUMENT LOCATION			·	
(Also kn		LIVING WILL Care Declaration or Hea	Ith Care Directive)	
DESIGNATED DECISION-MAKER				
ADDRESS				
PHONE NUMBERS	(H)	(W)	(C)	
DOCUMENT LOCATION				
		POWER OF ATTO s Health Care Power of		
DESIGNATED DECISION-MAKER				
ADDRESS				
PHONE NUMBERS	(H)	(W)	(C)	
DOCUMENT LOCATION		l l	l	





	DO NOT RESU	SCITATE (DNR)	
DESIGNATED DECISION-MAKER			
ADDRESS			
		I	I
PHONE NUMBERS	(H)	(W)	(C)
DOCUMENT LOCATION			
	DO NOT INT	UBATE (DNI)	
DESIGNATED DECISION-MAKER			
ADDRESS			
PHONE NUMBERS	(H)	(W)	(C)
DOCUMENT LOCATION			
	DURABLE POWE	R OF ATTORNE	Υ
DESIGNATED DECISION-MAKER			
ADDRESS			
PHONE NUMBERS	(H)	(W)	(C)
DOCUMENT LOCATION		1	1







SPECIAL NEEDS TRUST			
DESIGNATED DECISION-MAKER			
ADDRESS			
PHONE NUMBERS	(H)	(W)	(C)
DOCUMENT LOCATION			
	ОТІ	HER	
TITLE OF LEGAL DOCUME	ENT:		
DESIGNATED DECISION-MAKER			
ADDRESS			
PHONE NUMBERS	(H)	(W)	(C)
DOCUMENT LOCATION			
TITLE OF LEGAL DOCUME	ENT:		
DESIGNATED DECISION-MAKER			
ADDRESS			
PHONE NUMBERS	(H)	(W)	(C)
DOCUMENT LOCATION			







Notes	

You, O God, are both tender and kind, not easily angered, immense in love, and you never, never quit.

PSALM **86:15**





am learning something new tonight—how to bask in the beauty of the present. The gift of the now has often eluded me. Too often the next destination has obscured the blessing of the present.

Mom stands beside me at the kitchen sink, meticulously stripping away the shell of a hard-boiled egg. She focuses on the task, occasionally rinsing off the tenacious bits beneath a gentle stream of water flowing from the faucet. It takes her ten minutes to pick one clean before she nestles it gently in the yellow stoneware bowl where I've placed the dozen I've already peeled.

I hand her the chopper I've rescued from her kitchen and conscripted into my meager artillery of kitchen supplies. The metal has been worn smooth by her hand, and I wonder if the grip feels familiar to her, if perhaps her fingers remember what her mind cannot. She eyes it for a moment, then raises and lowers her forearm slowly in a delicate motion that barely grazes the tissue of the eggs. She works without distraction as a CD of hymns plays softly in the background. Three-and-a-half hymns mark the time between us before she speaks.

"Am I doing this right?"

It couldn't be any more right, I assure her.

I ladle in the remaining ingredients for egg salad and place a wooden spoon in her hand. She works the mixture in wispy strokes in the center of the bowl.

"What's this?" she asks.

"Egg salad-just like you like it—with a bit of mustard, relish, and Miracle Whip."

"I didn't know I liked egg salad."

"You do."

I watch silently for a few more moments as she stirs. "What's this?"

"It's egg salad, Mom."

She reaches into the sink where the broken shells lay. "Do you want these in there?"

"Not today, Mom."

Ten minutes later, the egg salad is finished. It is the crowning







achievement of the day, the week, the month. It is a moment of shared delight that will never again be duplicated. It is the gift of the now that even in the making has become a gift for forever. I am storing up the egg salad moments—hoarding them like sweets in the hand of a child. Each day is a scavenger hunt. Each sight, sound, memory—a treasure.

The scent of Oil of Olay as I work its silky texture into my mother's arms and legs.

The gentle arch of her shoulders as I massage her back after a bath.

Her raised eyebrows and smile when I offer her ice cream.

They are all daily lessons in basking in the moment—small gifts of the present that will sustain me in the future. Gifts of constant, daily provision to sustain and strengthen my heart. Gifts from God. Good things in the midst of the hard things. Glorious things disguised as the mundane and the incidental.

I only wish that the basking lessons had begun sooner, that I had learned in my younger years to recognize that what appears to be mundane and insignificant always nestles in the palm of the eternal. It is a truth that makes even the scent of egg salad a reason for thanks.

-from Precious Lord, Take My Hand by Shelly Beach

An inconvenience is only an adventure wrongly considered.

G. K. CHESTERTON









Routines and Schedules

outines make life easier. But as the number of people caring for a person increases, it becomes harder to maintain a consistent routine. This section is a place to record the schedules, habits, likes, and dislikes that define your loved one's daily routine. Once recorded, designated caregivers—paid in-home workers, teachers and para-professionals, adult day care staff, respite providers, the neighbor who comes on Tuesday mornings, family members who rotate responsibilities—can consult these forms and follow the routines described.

This section begins with forms for recording routines and preferences for communication, environment, administering medications, use of medical equipment, personal care, mobility, eating, and sleeping. Write down the routine as well as where to find necessary supplies and specific details that make the process easier or are comforting for your loved one. The goal is to maintain consistency, so any hints that aid in achieving that goal should be noted. Forms for describing likes, dislikes, and favorite activities are located

in the middle of this section. No detail is too trivial to include. Personal preferences that increase your loved one's ability to function and enjoy life should be noted, along with dislikes that decrease those abilities. Use the spaces labeled "other" to note anything that doesn't seem to fit anywhere else but is crucial to your loved one's well-being.

Weekday, weekend/holiday, and weekly schedules comprise the remainder of the section. The weekday and weekend/holiday schedules allow for differences in the daily routines of children who attend school and older people who attend adult

-STRESS RELIEVER-

A person's likes, dislikes, and favorite things change over time, especially in young children. Therefore, consider using a pencil to complete this section, even though that appears contrary to the goal of creating consistency. When your charge decides that grilled cheese has replaced peanut butter and jelly sandwiches as the only food fit to eat, the change will be easily made in the notebook . . . right after you run to the grocery store to stock up on bread and cheese.









day care. The weekly schedule can be used to record a quick overview of standing appointments, club events, after-school lessons, or playdates that occur on either a weekly or monthly basis.

-STRESS RELIEVER-

Are you wondering how to create a daily schedule for the time your child is at school or your parent is at adult day care? Arrange to observe at school or adult day care and complete the schedule while you're there. Or enlist the help of whoever works most closely with your loved one at school or adult day care. Ask that person to complete the schedule when time permits.









DAILY ROUTINES	
COMMUNICATION	
SPEECH/LISTENING Verbal Nonverbal Understands verbal language Does not understand verbal language Uses sign language	
ASSISTIVE DEVICES Alphabet board Notepad & pen Picture board Electronic tablet Other:	OPERATING INSTRUCTIONS
LANGUAGE SPOKEN	

ENVIRONMENT		
ROOM TEMPERATURE PREFERENCE		
LIGHTING PREFERENCES AND TRIGGERS		
SOUND PREFERENCES AND TRIGGERS		
SMELL PREFERENCES AND TRIGGERS		









DAILY ROUTINES MEDICATIONS AND MEDICAL APPARATUS NOTE: More details about medications are located in the Medication section **ORAL MEDICATIONS** $\ \square$ Self-administers ☐ Needs reminder □ Needs supervision $\hfill\square$ Needs to be administered SHOTS, INFUSIONS, **GLUCOSE CHECKS** \square Self-administers ☐ Needs reminder ☐ Needs supervision \square Needs to be administered **MEDICAL APPARATUS** (Oxygen, pain pump, feeding tube, etc.) □ Operates independently ☐ Needs reminder ☐ Needs supervision $\hfill\square$ Needs to be operated by others OTHER:







DAILY ROUTINES		
PERSONAL CARE		
DRESSING ☐ Independent ☐ Needs assistance		
CLOTHING PREFERENCES AND TRIGGERS		
GROOMING ☐ Independent ☐ Needs assistance		
BATHING/SHOWER Independent Needs assistance		
TOILETING ☐ Independent ☐ Needs assistance		







DAILY ROUTINES			
	MOBILITY/TRAVEL		
WALKING □ Independent □ Needs assistance			
STAIRS ☐ Independent ☐ Needs assistance			
ASSISTIVE DEVICES Wheelchair Walker Cane Crutches Stroller			
TRAVEL CONSIDERATIONS			







DAILY ROUTINES			
	EATING		
FOOD ALLERGIES OR SENSITIVITIES			
DIET REQUIREMENTS Chopped Puree Liquid No salt Diabetic Other:			
NORMAL MEAL AND SNACK TIMES			
MEAL AND SNACK LOCATIONS			
TABLE SETTING Feeds self Needs some assistance Must be fed			
POTENTIAL PROBLEMS Choking Difficulty swallowing Vomiting			







DAILY ROUTINES	
	SLEEPING
MORNING WAKE-UP	
EVENING BEDTIME	
NAPTIMES	
ASSISTIVE DEVICES □ Earplugs □ Eyeshades □ White noise □	
FAVORITE SLEEPWEAR	
	LIKES AND DISLIKES
UNUSUAL LIKES AND/OR OBSESSIONS	
STRONG DISLIKES	







DAILY ROUTINES		
FAVORITES		
READING □ Read to □ Read together □ Reads alone	FAVORITE READING MATERIAL:	
EXERCISE		
TELEVISION SHOWS/ CHANNELS		
RADIO SHOWS/CHANNELS		
MUSIC		
GAMES		
COMPUTER PROGRAMS/ APPS		
HOBBIES		
CONVERSATION TOPICS		
FOODS		
CLOTHES		
OTHER		
OTHER		







	SCHEDULES
	WEEKDAY SCHEDULE
5:00 AM	
6:00 AM	
7:00 AM	
8:00 AM	
9:00 AM	
10:00 AM	
11:00 AM	
12:00 PM	
1:00 PM	
2:00 PM	
3:00 PM	
4:00 PM	







5:00 PM			
6:00 PM 7:00 PM 8:00 PM 9:00 PM 11:00 PM 11:00 PM 12:00 AM 2:00 AM 3:00 AM		WEEKDAY SCHEDULE	
7:00 PM 8:00 PM 9:00 PM 10:00 PM 11:00 PM 12:00 AM 2:00 AM 3:00 AM 3:00 AM	5:00 PM		
8:00 PM 9:00 PM 10:00 PM 11:00 PM 12:00 AM 2:00 AM 3:00 AM	6:00 PM		
9:00 PM 10:00 PM 11:00 PM 12:00 AM 2:00 AM 3:00 AM	7:00 PM		
10:00 PM 11:00 PM 12:00 AM 2:00 AM 3:00 AM	8:00 PM		
11:00 PM 12:00 AM 1:00 AM 2:00 AM 3:00 AM	9:00 PM		
12:00 AM 1:00 AM 2:00 AM 3:00 AM	10:00 PM		
1:00 AM 2:00 AM 3:00 AM			
2:00 AM 3:00 AM	12:00 AM		
3:00 AM	1:00 AM		
	2:00 AM		
4:00 AM	3:00 AM		
	4:00 AM		







	SCHEDULES
	WEEKEND/HOLIDAY SCHEDULE
5:00 AM	
6:00 AM	
7:00 AM	
8:00 AM	
9:00 AM	
10:00 AM	
11:00 AM	
12:00 PM	
1:00 PM	
2:00 PM	
3:00 PM	
4:00 PM	







WEEKEND/HOLIDAY SCHEDULE		
	WEEKEND/HOLIDAY SCHEDOLE	
5:00 PM		
6:00 PM		
7:00 PM		
8:00 PM		
9:00 PM		
10:00 PM		
11:00 PM		
12:00 AM		
1:00 AM		
2:00 AM		
3:00 AM		
4:00 AM		







SCHEDULES				
	WEEKLY SCHEDULE			
SUNDAY				
MONDAY				
TUESDAY				
WEDNESDAY				
THURSDAY				
FRIDAY				
SATURDAY				

Keep your eyes open for God, watch for his works; be alert for signs of his presence.

PSALM 105:4







lie in bed facing the shadows on the ceiling cast by the night-light and listen for the creaking of the door across the hallway. I whisper the prayer I've prayed each night for more than two years—that my mother will sleep.

Even as my heart voices the words, I know time is running out. In minutes, the skewed circadian rhythms of my mother's body will wake her, and her nightly wandering will begin—the circuit from the kitchen to the living room, down the hall and back to the kitchen.

I squeeze my eyes shut. I will the burning muscles in my calves to relax, but they refuse. Pain rips through my feet and legs, and I jerk to a seated position. This is my nightly dance. Moments after I lie down, peripheral neuropathy shoots searing pain through my toes, feet, and legs. Could life be more ironic? Even my tiniest snippets of rest are stalked by pain.

I hear my mother stir in her room, and I rise and meet her in the hallway. Her frame is thin beneath her pink nightgown, and she is whimpering.

She wants to go home.

I walk beside her and we talk, of her childhood home on the corner of Getty Street, of her mother and sister, Erma, and brothers Eddie and Elwin. I steer her for the umpteenth time away from the dangers of the stairwell. Like the night before and nights before that, I've slept just minutes after a day of writing, laundry, cooking, cleaning, and doctors' appointments. Each day I diverted her from countless perils: quarters and dimes on the counter (who'd have thought they were snack food?), throw rugs (trip-and-fall), and unlocked doors (the Great Escape).

A migraine pounds behind my eyes and a fog clouds my brain, but I will myself to stay awake. I guide my mother to the living room couch where we settle and turn our attention to reruns of *I Love Lucy*. I look at my mother beside me through my migraine fog as pain surges through my leg, and I choose joy. Not happiness, but the living, breathing truth that God's great and glorious plan surpasses all I see or understand.

(







I choose joy for the moment. Joy for the gift of presence. Joy for reassurance of purpose in pain. Joy for the blessings of memory. Joy for the gift of mystery that calls us to God in our suffering. Joy for promised healing beyond the boundaries of earthly time. Joy for the promise that God's bigger picture surpasses our understanding.

And I pray for a relentless joy sustained by the hope of Jesus Christ that will strengthen me for the road ahead.

-from It Is Well with My Soul by Shelly Beach

The unselfish effort to bring cheer to others will be the beginning of a happier life for ourselves.

HELEN KELLER









Resources

This section is a starting place for caregivers who need information and guidance for their loved ones and themselves. Consider it as a compass to point you in the right direction as you begin your search. A visit to a website or phone call to an organization listed here may not result in a definitive answer, but it may set you on the right course. To make the resource section easier to navigate, the entries are divided into the following categories:

- Books
- Medical
- Mental Health
- Financial Assistance and Insurance
- Legal
- Educational
- Caregiver Information, Advocacy, and Support
- Grief, Hospice, Pain and Palliative Care

The items in each category are arranged in three subcategories: general resources of interest to both adults and children, adult listings often but not exclusively geared to the elderly, and listings specific to children and their family members.

-STRESS RELIEVER-

Remember, this is your notebook, and you can write wherever you want on the pages. So if one of the links listed in the resource section quits working, cross it out. If you go to a website and find a phone number, write it beside the listing. If you find resources specific to your situation, note them on the blank pages at the end of this section.









-STRESS RELIEVER-

If a resource leads to a provider or service you access frequently, add more detailed information in the contact section near the beginning of the notebook.

Before they call out, I'll answer. Before they've finished speaking, I'll have heard.

ISAIAH 65:24







BOOKS

- Ambushed by Grace: Help and Hope on the Caregiving Journey by Shelly Beach (Discovery House Publishers, 2008).
- Designated Caregiver: Resource Manual for the Caregiver "On Call 24/7" by Cecelia Salamone (Reach for a Rainbow, March 2012).
- A Different Dream for My Child: Meditations for Parents of Critically or Chronically Ill Children by Jolene Philo (Discovery House Publishers, 2009).
- Different Dream Parenting: A Practical Guide to Raising a Child with Special Needs by Jolene Philo (Discovery House Publishers, 2011).
- Doing Well at Being Sick: Living with Chronic and Acute Illness by Wendy Wallace (Discovery House Publishers, 2010).
- It Is Well with My Soul: Meditations for Those Living with Illness, Pain, and the Challenges of Aging by Shelly Beach (Discovery House Publishers, 2012).
- *Precious Lord, Take My Hand: Meditations for Caregivers* by Shelly Beach (Discovery House Publishers, 2007).

MEDICAL RESOURCES

General

American Academy of Home Care Medicine (AAHCM): www.aahcm.org

American Medical Association (AMA) Doctor Finder:

https://extapps.ama-assn.org/doctorfinder/

Centers for Disease Control and Prevention (CDC): www.cdc.gov

Centers for Disease Control and Prevention (CDC) Immunization Schedules: www.cdc.gov/vaccines/schedules/

Family Doctor Health Information: www.familydoctor.org

Food Allergy Research and Education (FARE): www.foodallergy.org

Health Care Grades Doctor, Dentist, and Hospital Finder:

www.healthgrades.com

Joni and Friends: www.joniandfriends.org

Mayo Clinic Health Information Finder: www.mayoclinic.com

Medline Plus Health Information: www.medlineplus.gov

National Institutes of Health: www.nih.gov

National Patient Safety Foundation (NPSF): www.npsf.org

U.S. Department of Health Information Finder: www.healthfinder.gov

Visiting Nurse Associations of America: www.vnaa.org





For Adults

AARP: www.aarp.org

Administration on Aging (AOA): www.aoa.gov

The American Geriatrics Society (AGS): www.americangeriatrics.org

American Health Care Association and National Center for Assisted

Living Care Conversations: www.careconversations.org

American Pain Foundation: www.painfoundation.org

Eldercare Locator: www.eldercare.gov/Eldercare.NET/Public/Index.aspx

National Adult Day Services Association: www.nadsa.org

National Association of Professional Geriatric Care Managers:

www.caremanager.org

National Institute on Aging: www.nia.nih.gov

Rest Ministries, Inc., Chronic Illness and Pain Support:

www.restministries.com

For Children

Children's Hospital Association: www.childrenshospitals.net

Cleveland Clinic Children's Hospital:

http://my.clevelandclinic.org/childrens-hospital/default.aspx

Phoenix Children's Hospital Emily Center:

www.phoenixchildrens.com/health-information/

Seattle Children's Hospital Center for Children with Special Needs:

http://cshcn.org/diagnosis-information

St. Jude Children's Research Hospital: www.stjude.org

Tufts University Child & Family Web Guide: www.cfw.tufts.edu

MENTAL HEALTH RESOURCES

General

American Association for Marriage and Family Therapy (AAMFT)

Therapist Locator: www.therapistlocator.net/iMIS15/therapistlocator/

American Association of Christian Counselors, Find a Counselor:

http://www.aacc.net/resources/find-a-counselor/

Christian Counseling Resource Directory:

www.christiancounselingresource.com

National Alliance on Mental Illness: www.nami.org

For Children

The National Child Traumatic Stress Network: www.nctsnet.org





FINANCIAL ASSISTANCE AND INSURANCE RESOURCES

General

The ARC: www.thearc.org. Provides support and services for people with intellectual and developmental disabilities.

Centers for Medicare and Medicaid Services: www.cms.gov. A user-friendly government website with information on how to coordinate Medicare and Medicaid. Explains the Children's Health Insurance Program (CHIP).

Easter Seals Disability Services: www.easterseals.com

Friends of Disabled Adults and Children (FODAC): www.fodac.org

Health Insurance Marketplace: www.healthcare.gov

Medicare's official U.S. government site: www.medicare.gov

Medicare Rights Center: www.MedicareRights.org. A nonprofit organization that helps people navigate Medicare.

National Association of Insurance Commissioners State Insurance Commissioner Locator: www.naic.org/state_web_map.htm

Patient Advocate Foundation: www.copays.org. Provides financial support for qualified patients.

Pharmaceutical Research and Manufacturers of America: www.phrma.org. Assists those who have low incomes with drug costs.

Rural Assistance Center: www.raconline.org. Provides U.S. Health and Human Services information for those in rural areas.

U.S. government's benefit eligibility website: www.govbenefits.gov

U.S. Social Security Administration Office Locator: https://secure.ssa.gov/apps6z/FOLO/fo001.jsp

For Adults

American Association of Daily Money Managers: www.aadmm.com Benefits Checkup: www.benefitscheckup.org. Free service of the nonprofit National Council on Aging that assists in finding benefit programs to pay for medications, health care, food, utilities, and more.

Medicare Prescription Drug Plan: http://www.medicare.gov/sign-up-change-plans/get-drug-coverage/get-drug-coverage.html National Council on Aging: www.ncoa.org

For Children

First Hand Foundation: www.shop.firsthandfoundation.org Kiddos' Clubhouse Foundation: www.kiddosclubhousefoundation.org





March of Dimes: www.marchofdimes.com

Medicaid waiver programs by state: www.medicaid.gov/Medicaid

-CHIP-Program-Information/By-Topics/Waivers/Waivers.html

Small Steps in Speech: www.smallstepsinspeech.org

United Health Care Children's Foundation: www.uhccf.org

LEGAL RESOURCES

For Adults

Caring Connections (a program of the National Hospice and Palliative Care Organization) Advance Directives by State: www.caringinfo.org/i4a/pages/index.cfm?pageid=3289

Mayo Clinic Health Information:

www.mayoclinic.com/health/living-wills/HA00014. Offers definitions and explanations of advanced directives, living wills, power of attorney, and more.

National Academy of Elder Law Attorneys, Inc.: www.naela.org

For Caregivers of Children

Different Dream Parenting: A Practical Guide to Raising a Child with Special Needs by Jolene Philo, chapter 24.

Merrill Lynch and *Exceptional Parent* magazine online special needs planning seminar: http://www.wealthmanagement.ml.com/WM/pages/ArticleViewer.aspx?TITLE=exceptional-parent-magazine-online-seminar

Special Needs Alliance: www.specialneedsalliance.com. A nonprofit that connects families of children with special needs to attorneys familiar with disability law.

EDUCATIONAL RESOURCES

Autism Speaks Goodwin Proctor's Guide:

www.autismspeaks.org/what-autism/your-childs-rights. Explains the rights of children with Individualized Education Plans (IEPs).

Council for Exceptional Children: www.cec.sped.org

Early Childhood Technical Assistance Center (ECTAC) Early Childhood Intervention State Directors: www.nectac.org/contact/ptccoord.asp





Understanding Special Education:

www.understandingspecialeducation.com

U.S. Department of Education: http://idea.ed.gov

Wrightslaw: www.wrightslaw.com

CAREGIVER INFORMATION, ADVOCACY, AND SUPPORT

General

AARP Caregiving Resource Center:

www.aarp.org/home-family/caregiving/

CarePages: www.carepages.com

Caregiver Action Network: http://caregiveraction.org

CaringBridge: www.caringbridge.org

Lotsa Helping Hands: www.lotsahelpinghands.com

National Caregiver's Library: www.caregiverslibrary.org

Strength for Caring: www.strengthforcaring.com

Web of Care: www.webofcare.com

Caregivers of Adults

Aging Care: www.agingcare.com

Family Caregiver Alliance (FCA): www.caregiver.org

National Caregivers Library Caregiving Ministries:

www.caregivingministries.org

Seniorlink Online: www.seniorlinkonline.com

Today's Caregiver: www.caregiver.com

Well Spouse Association: www.wellspouse.org

Caregivers of Children

About.com Children with Special Needs: specialchildren.about.com

Baby Home Pages: www.babyhomepages.net

Brave Kids: www.bravekids.org

Different Dream for My Child: www.DifferentDream.com

The Friendship Circle: www.friendshipcircle.org

Mommies of Miracles: www.mommiesofmiracles.com

Not Alone: www.specialneedsparenting.net. A special needs parent

community.

Snappin' Ministries: www.snappin.org





GRIEF, HOSPICE, PAIN AND PALLIATIVE CARE INFORMATION

General

Center for Loss: www.centerforloss.com
Hospice Education Institute: www.hospiceworld.org
Hospice Foundation of America: www.hospicefoundation.org
National Association for Home Care and Hospice: www.nahc.org
National Hospice and Palliative Care Organization: www.nhpco.org

For Children

Children's Hospice and Palliative Care Coalition: www.chpcc.org Children's Hospice International: www.chionline.org The Compassionate Friends: www.compassionatefriends.org The Dougy Center, The National Center for Grieving Children and Families: www.dougy.org

Faith's Lodge: www.faithslodge.org

M.I.S.S. Foundation: www.missfoundation.org

The National Child Traumatic Stress Network (NCTSN): www.nctsn.org/ trauma-types/traumatic-grief

National Hospice and Palliative Care Organization (NHPCO): www.nhpco.org/resources/pediatric-hospice-and-palliative-care







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Don't bargain with God. Be direct.
Ask for what you need.

MATTHEW **7:7**

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A nurse led us past rows of Isolettes, but we saw only the one where she stopped. Cords dangled from the bank of medical instruments on the wall behind the incubator, but our eyes were fixed upon the tiny form lying in the clear plastic box that was our son's bed.

"Get right next to him," the nurse suggested. Unable to move, we stared at the baby clad only in a diaper. Monitor patches dotted his chest. Wires sprouted from the patches and snaked their way to the machines on the wall. The IV in his arm was splinted in place with a tongue depressor and tape. His torso sprouted two drainage tubes below his ribs and a feeding tube in his stomach. When Susan, the nurse, turned him on his side, we saw the angry, horizontal scar that slashed his upper back from spine to armpit. Nothing could have prepared me for my first look at Allen after his surgery.

Susan smiled and asked, "Would you like to hold him?" I frowned at the tubes and wires.

"How?"

"Not a problem." She moved chairs and rearranged poles, pushed wires and cords away, and motioned for us to sit. She lifted the incubator lid and wrapped Allen in a blanket.

"Will this hurt him?" my husband asked. "We can wait."

"No, he needs to feel your touch." She handed the bundle to Hiram. Allen didn't stir.

While he slept, we did what all parents do. We inspected all ten of his fingers and toes. We marveled at his soft black hair, long upper lip, and wide-set eyes.

Susan teased Hiram. "Are you going to let his mama hold him?" She took Allen and set him in my arms. His lids opened and our eyes locked. He studied my face. Then, I turned until he could see his father. Allen uncurled one fist, and Hiram placed his index finger on that tiny, soft palm. And Allen did what all babies do. He wrapped his small hand tightly around the source of his comfort and love.

A parent's first look at a child of any age, after surgery or a major hospital procedure or an accident, can be pretty grim. Your first reaction to the sight might be to freeze with fear or to back away.





But it's vitally important for your child, and for you, to look past the medical paraphernalia and offer the blessing of a loving touch.

Your gentleness speaks safety to your child. Your touch, whether you can wrap your baby in your arms or stroke a toddler's hair or hold a youngster's hand, is the one consistent link between life at home and life in the hospital. Each time you pat your little one and smile into frightened eyes, your touch is a reminder of the comfort and safety of home.

Sometimes while you're at the hospital, you'll be as frightened as your loved one. When that happens, you need the gentle touch of the loving God who cared enough to send His Son to a world tangled by sickness and disease and pain. Through His Son, God touches our hearts with the promise of life beyond the one we see.

His touch will remind you, as it has reminded frightened people for thousands of years, that true safety and an eternal home exists beyond this tangled world of sickness and disease and pain. Once you wrap your hand around the source of your comfort and love, you can share His blessed comfort with your loved one.

-from A Different Dream for My Child by Jolene Philo

To us, family means putting your arms around each other and being there.

BARBARA BUSH









Bible Reading Plan

ne way to draw near to God is by reading His Word. Scripture is the primary way God answers our questions, shares His thoughts, and speaks

consistent truth. However, setting aside time to read and listen what God has to say can be a challenge for busy caregivers. The Bible reading plan included here is intended to take readers through the Bible in a year. But sometimes finding time each day can be difficult for caregivers. So give yourself a break and proceed through the plan at a pace that works for you. God will be pleased with your desire to seek after Him, even if it takes more than a year to read through the Bible.

STRESS RELIEVER-

The devotional *Our Daily Bread* includes a daily Bible reading plan. At odb.org, you can choose to have the print edition of the devotional delivered to your home, sign up for the email version, or download the app to your smartphone or tablet. A daily podcast is also available through iTunes. All products are free of charge.

You've kept track of my every toss and turn through the sleepless nights, each tear entered in your ledger, each ache written in your book.

PSALM 56:8





JANUARY

- 1 Gen. 1-3; Mt. 1
- Gen. 4–6; Mt. 2
- Gen. 7–9; Mt. 3
- 4 Gen. 10-12; Mt. 4
- Gen. 13–15; Mt. 5:1-26
- Gen. 16–17; Mt. 5:27-48
- 7 Gen. 18-19; Mt. 6:1-18
- 8 Gen. 20–22; Mt. 6:19-34
- Gen. 23–24; Mt. 7
- Gen. 25–26; Mt. 8:1-17
- Gen. 27–28; Mt. 8:18-34
- Gen. 29–30; Mt. 9:1-17
- Gen. 31–32; Mt. 9:18-38
- Gen. 33–35; Mt. 10:1-20
- 15 Gen. 36-38; Mt. 10:21-42
- Gen. 39–40; Mt. 11

- Gen. 41–42; Mt. 12:1-23
- Gen. 43–45; Mt. 12:24-50
- Gen. 46–48; Mt. 13:1-30
- 20 Gen. 49-50; Mt. 13:31-58
- Ex. 1–3; Mt. 14:1-21
- Ex. 4–6; Mt. 14:22-36
- 23 Ex. 7-8; Mt. 15:1-20
- Ex. 9–11; Mt. 15:21-39
- Ex. 12–13; Mt. 16
- Ex. 14–15; Mt. 17
- Ex. 16–18; Mt. 18:1-20
- Ex. 19–20; Mt. 18:21-35
- Ex. 21–22; Mt. 19
- Ex. 23–24; Mt. 20:1-16
- Ex. 25–26; Mt. 20:17-34

FEBRUARY

- 1 Ex. 27-28; Mt. 21:1-22
- Ex. 29–30; Mt. 21:23-46
 - Ex. 31–33; Mt. 22:1-22
- 4 Ex. 34-35; Mt. 22:23-46
- Ex. 36–38; Mt. 23:1-22
- Ex. 39–40; Mt. 23:23-39
 - 7 Lev. 1-3; Mt. 24:1-28
- Lev. 4–5; Mt. 24:29-51
- Lev. 6–7; Mt. 25:1-30
- Lev. 8–10; Mt. 25:31-46
- Lev. 11–12; Mt. 26:1-25
- Lev. 13; Mt. 26:26-50
- Lev. 14; Mt. 26:51-75
- Lev. 15–16; Mt. 27:1-26
- Lev. 17–18; Mt. 27:27-50

- Lev. 19–20; Mt. 27:51-66
- 17 Lev. 21–22; Mt. 28
- Lev. 23–24; Mk. 1:1-22
- Lev. 25; Mk. 1:23-45
- Lev. 26–27; Mk. 2
- Num. 1–3; Mk. 3
- 22 Num. 4-6; Mk. 4:1-20
- Num. 7–8; Mk. 4:21-41
- Num. 9–11; Mk. 5:1-20
- Num. 12–14; Mk. 5:21-43
- Num. 15–16; Mk. 6:1-29
- Num. 17–19; Mk. 6:30-56
- Num. 20–22; Mk. 7:1-13

(if a leap year, no reading on 29)



MARCH

- 1 Num. 23–25; Mk. 7:14-37
- Num. 26–27; Mk. 8:1-21
- Num. 28–30; Mk. 8:22-38
- 4 Num. 31–33; Mk. 9:1-29
- Num. 34–36; Mk. 9:30-50
- Dt. 1–2; Mk. 10:1-31
- 7 Dt. 3–4; Mk. 10:32-52
- Dt. 5-7; Mk. 11:1-18
- Dt. 8–10; Mk. 11:19-33
- Dt. 11–13; Mk. 12:1-27
- Dt. 14–16; Mk. 12:28-44
- Dt. 17–19; Mk. 13:1-20
- Dt. 20–22; Mk. 13:21-37
- Dt. 23–25; Mk. 14:1-26
- Dt. 26–27; Mk. 14:27-53
- Dt. 28–29; Mk. 14:54-72

- Dt. 30–31; Mk. 15:1-25
- Dt. 32–34; Mk. 15:26-47
- Josh. 1-3; Mk. 16
- Josh. 4–6; Lk. 1:1-20
- Josh. 7–9; Lk. 1:21-38
- Josh. 10–12; Lk. 1:39-56
- Josh. 13–15; Lk. 1:57-80
- I 1 16 10 I1 21 24
- Josh. 16–18; Lk. 2:1-24
- Josh. 19–21; Lk. 2:25-52
- Josh. 22–24; Lk. 3
- Jud. 1–3; Lk. 4:1-30
- Jud. 4–6; Lk. 4:31-44
- Jud. 7–8; Lk. 5:1-16
- Jud. 9–10; Lk. 5:17-39
- Jud. 11–12; Lk. 6:1-26

APRIL

- Jud. 13–15; Lk. 6:27-49
- Jud. 16–18; Lk. 7:1-30
- Jud. 19–21; Lk. 7:31-50
- 4 Ruth 1–4; Lk. 8:1-25
- 1 Sam. 1–3; Lk. 8:26-56
- 1 Sam. 4–6; Lk. 9:1-17
- 7 1 Sam. 7–9; Lk. 9:18-36
 - 1 Sam. 10–12; Lk. 9:37-62
- 1 Sam. 13–14; Lk. 10:1-24
- 1 C ... 15 1C 11 10 25 42
- 1 Sam. 15–16; Lk. 10:25-42
- 1 Sam. 17–18; Lk. 11:1-28
- 1 Sam. 19–21; Lk. 11:29-54
- 1 Sam. 22–24; Lk. 12:1-31
- 1 Sam. 25–26; Lk. 12:32–59
- 1 Sam. 27–29; Lk. 13:1-22

- 1 Sam. 30–31; Lk. 13:23-35
- 2 Sam. 1–2; Lk. 14:1-24
- 2 Sam. 3–5; Lk. 14:25-35
- 2 Sam. 6–8; Lk. 15:1-10
- 2 Sam. 9–11; Lk. 15:11-32
- 2 Sam. 12–13; Lk. 16
- 2 Sam. 14–15; Lk. 17:1-19
- 2 Sam. 16–18; Lk. 17:20-37
- 2 Sam. 19–20; Lk. 18:1-23
- 2 Sam. 21–22; Lk. 18:24-43
- 2 Sam. 23–24; Lk. 19:1-27
- 1 Ki. 1–2; Lk. 19:28-48
- 1 Ki. 3–5; Lk. 20:1-26
- 1 Ki. 6–7; Lk. 20:27-47
- 1 Ki. 8–9; Lk. 21:1-19



MAY

- 1 Ki. 10–11; Lk. 21:20-38
- 1 Ki. 12–13; Lk. 22:1-20
- 1 Ki. 14–15; Lk. 22:21-46
- 1 Ki. 16–18; Lk. 22:47-71
- 1 Ki. 19–20; Lk. 23:1-25
- 1 Ki. 21–22; Lk. 23:26-56
- 7 2 Ki. 1–3; Lk. 24:1-35
- 2 Ki. 4–6; Lk. 24:36-53
- 2 Ki. 7–9; Jn. 1:1-28
- 2 Ki. 10–12; Jn. 1:29-51
- 2 Ki. 13–14; Jn. 2
- 2 Ki. 15–16; Jn. 3:1-18
- 2 Ki. 17–18; Jn. 3:19-36
- 2 Ki. 19–21; Jn. 4:1-30
- 2 Ki. 22–23; Jn. 4:31-54
- 2 Ki. 24–25; Jn. 5:1-24

- 1 Chr. 1–3; Jn. 5:25-47
- 1 Chr. 4–6; Jn. 6:1-21
- 1 Chr. 7–9; Jn. 6:22-44
- 1 Chr. 10–12; Jn. 6:45-71
- 1 Chr. 13–15; Jn. 7:1-27
- 1 Chr. 16–18; Jn. 7:28-53
- 1 Chr. 19–21; Jn. 8:1-27
- 1 Chr. 22–24; Jn. 8:28-59
- 1 Chr. 25–27; Jn. 9:1-23
- 1 Chr. 28–29; Jn. 9:24-41
- 2 Chr. 1–3; Jn. 10:1-23
- 2 Chr. 4–6; Jn. 10:24-42
- 2 Chr. 7–9; Jn. 11:1-29
- 2 Chr. 10–12; Jn. 11:30-57
- 2 Chr. 13–14; Jn. 12:1-26

JUNE

- 2 Chr. 15–16; Jn. 12:27-50
- 2 Chr. 17–18; Jn. 13:1-20
- 2 Chr. 19–20; Jn. 13:21-38
- 2 Chr. 21–22; Jn. 14
- 2 Chr. 23–24; Jn. 15
- 2 Chr. 25–27; Jn. 16
- 2 Chr. 28–29; Jn. 17
- 2 Chr. 30–31; Jn. 18:1-18
- 2 Chr. 32–33; Jn. 18:19-40
- 2 Chr. 34–36; Jn. 19:1-22
- Ezra 1–2; Jn. 19:23-42
- Ezra 3–5; Jn. 20
- Ezra 6–8; Jn. 21
- Ezra 9-10; Acts 1
- Neh. 1–3; Acts 2:1-21

- Neh. 4–6; Acts 2:22-47
- Neh. 7–9; Acts 3
- Neh. 10–11; Acts 4:1-22
- Neh. 12–13; Acts 4:23-37
- Est. 1–2; Acts 5:1-21
- Est. 3–5; Acts 5:22-42
- Est. 6–8; Acts 6
- Est. 9–10; Acts 7:1-21
- Job 1–2; Acts 7:22-43
- Job 3–4; Acts 7:44-60
- Job 5–7; Acts 8:1-25
- Job 8–10; Acts 8:26-40
- Job 11–13; Acts 9:1-21
- Job 14–16; Acts 9:22-43
- Job 17–19; Acts 10:1-23

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JULY

- Job 20–21; Acts 10:24-48
- Job 22–24; Acts 11
- Job 25–27; Acts 12
- 4 Job 28–29; Acts 13:1-25
- Job 30–31; Acts 13:26-52
- Job 32–33; Acts 14
- 7 Job 34–35; Acts 15:1-21
- Job 36–37; Acts 15:22-41
- Job 38–40; Acts 16:1-21
- Job 41–42; Acts 16:22-40
- Ps. 1–3; Acts 17:1-15
- Ps. 4–6; Acts 17:16-34
- Ps. 7–9; Acts 18
- Ps. 10–12; Acts 19:1-20
- Ps. 13–15; Acts 19:21-41
- Ps. 16–17; Acts 20:1-16

- Ps. 18–19; Acts 20:17-38
 - Ps. 20–22; Acts 21:1-17
 - Ps. 23–25; Acts 21:18-40
 - Ps. 26–28; Acts 22
 - Ps. 29–30; Acts 23:1-15
- Ps. 31–32; Acts 23:16-35
- Ps. 33–34; Acts 24
- Ps. 35–36; Acts 25
- Ps. 37–39; Acts 26
- Ps. 40–42; Acts 27:1-26
- Ps. 43–45; Acts 27:27-44
- Ps. 46–48; Acts 28
- Ps. 49–50; Rom. 1
- Ps. 51–53; Rom. 2
- Ps. 54–56; Rom. 3

AUGUST

- Ps. 57–59; Rom. 4
- Ps. 60–62; Rom. 5
- Ps. 63–65; Rom. 6
- Ps. 66–67; Rom. 7
- Ps. 68–69; Rom. 8:1-21
- Ps. 70–71; Rom. 8:22-39
 - Ps. 72–73; Rom. 9:1-15
- Ps. 74–76; Rom. 9:16-33
- Ps. 77–78; Rom. 10
- Ps. 79–80; Rom. 11:1-18
- Ps. 81–83; Rom. 11:19-36
- Ps. 84–86; Rom. 12
- Ps. 87–88; Rom. 13
- Ps. 89–90; Rom. 14
- Ps. 91–93; Rom. 15:1-13
- Ps. 94–96; Rom. 15:14-33

- Ps. 97–99; Rom. 16
- Ps. 100–102; 1 Cor. 1
- Ps. 103–104; 1 Cor. 2
- Ps. 105–106; 1 Cor. 3
- Ps. 107–109; 1 Cor. 4
- Ps. 110–112; 1 Cor. 5
- Ps. 113–115; 1 Cor. 6
- Ps. 116–118; 1 Cor. 7:1-19
- Ps. 119:1-88; 1 Cor. 7:20-40
- Ps. 119:89-176; 1 Cor. 8
- Ps. 120–122; 1 Cor. 9
- Ps. 123–125; 1 Cor. 10:1-18
- Ps. 126–128; 1 Cor. 10:19-33
- Ps. 129–131; 1 Cor. 11:1-16
- Ps. 132–134; 1 Cor. 11:17-34

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- Ps. 135–136; 1 Cor. 12
- Ps. 137–139; 1 Cor. 13
- Ps. 140–142; 1 Cor. 14:1-20
- Ps. 143–145; 1 Cor. 14:21-40
- Ps. 146–147; 1 Cor. 15:1-28
- Ps. 148–150; 1 Cor. 15:29-58
- Prov. 1–2; 1 Cor. 16
- Prov. 3–5; 2 Cor. 1
- Prov. 6–7; 2 Cor. 2
- Prov. 8–9; 2 Cor. 3
- Prov. 10–12; 2 Cor. 4
- Prov. 13–15; 2 Cor. 5
- Prov. 16–18; 2 Cor. 6
- Prov. 19–21; 2 Cor. 7
- Prov. 22–24; 2 Cor. 8

- Prov. 25–26; 2 Cor. 9
- Prov. 27–29; 2 Cor. 10
- Prov. 30–31; 2 Cor. 11:1-15
- Eccl. 1–3; 2 Cor. 11:16-33
- Eccl. 4–6; 2 Cor. 12
- Eccl. 7–9; 2 Cor. 13
- Eccl. 10–12; Gal. 1
- Song 1–3; Gal. 2
- Song 4–5; Gal. 3
- Song 6-8; Gal. 4
- Isa. 1–2; Gal. 5
- Isa. 3–4; Gal. 6
- Isa. 5–6; Eph. 1
- Isa. 7-8; Eph. 2
- Isa. 9–10; Eph. 3

OCTOBER

- Isa. 11–13; Eph. 4
- Isa. 14–16; Eph. 5:1-16
- Isa. 17–19; Eph. 5:17-33
 - Isa. 20–22; Eph. 6
- Isa. 23–25; Phil. 1
- Isa. 26–27; Phil. 2
- 7 Isa. 28–29; Phil. 3
- Isa. 30–31; Phil 4
- Isa. 32–33; Col. 1
- Isa. 34–36; Col. 2
- Isa. 37–38; Col. 3
- Isa. 39–40; Col. 4
- Isa. 41–42; 1 Th. 1
- Isa. 43–44; 1 Th. 2
- Isa. 45–46; 1 Th. 3
- Isa. 47–49; 1 Th. 4

- Isa. 50–52; 1 Th. 5
- Isa. 53–55; 2 Th. 1
- Isa. 56–58; 2 Th. 2
- Isa. 59–61; 2 Th. 3
- Isa. 62–64; 1 Tim. 1
- Isa. 65–66; 1 Tim. 2
- Jer. 1–2; 1 Tim. 3
- Jer. 3–5; 1 Tim. 4
- Jer. 6–8; 1 Tim. 5
- Jer. 9–11; 1 Tim. 6
- Jer. 12–14; 2 Tim. 1
- Jer. 15–17; 2 Tim. 2
- Jer. 18–19; 2 Tim. 3
- Jer. 20–21; 2 Tim. 4
- Jer. 22–23; Ti. 1

NOVEMBER

- Jer. 24–26; Ti. 2
- Jer. 27–29; Ti. 3
- Jer. 30–31; Philemon
- Jer. 32–33; Heb. 1
- Jer. 34–36; Heb. 2
- Jer. 37–39; Heb. 3
- 7 Jer. 40-42; Heb. 4
- Jer. 43–45; Heb. 5
- Jer. 46-47; Heb. 6
- Jer. 48-49; Heb. 7
- Jer. 50; Heb. 8
- Jer. 51–52; Heb. 9
- Lam. 1–2; Heb. 10:1-18
- Lam. 3–5; Heb. 10:19-39
- Ezek. 1–2; Heb. 11:1-19

- Ezek. 3–4; Heb. 11:20-40
- Ezek. 5-7; Heb. 12
- Ezek. 8–10; Heb. 13
- Ezek. 11–13; Jas. 1
- Ezek. 14–15; Jas. 2
- Ezek. 16–17; Jas. 3
- Ezek. 18–19; Jas. 4
- Ezek. 20–21; Jas. 5
- Ezek. 22–23; 1 Pet. 1
- Ezek. 24-26; 1 Pet. 2
- Ezek. 27–29; 1 Pet. 3
- Ezek. 30–32; 1 Pet. 4
- Ezek. 33–34; 1 Pet. 5
- Ezek. 35–36; 2 Pet. 1
- Ezek. 37–39; 2 Pet. 2

DECEMBER

- Ezek. 40–41; 2 Pet. 3
- Ezek. 42–44; 1 Jn. 1
- Ezek. 45–46; 1 Jn. 2
- Ezek. 47–48; 1 Jn. 3
- Dan. 1–2; 1 Jn. 4
- Dan. 3–4; 1 Jn. 5
- Dan. 5-7; 2 John
- Dan. 8-10; 3 John
- Dan. 11–12; Jude
- Hos. 1–4; Rev. 1
- Hos. 5–8; Rev. 2
- Hos. 9–11; Rev. 3
- Hos. 12–14; Rev. 4
- Joel 1-3; Rev. 5
- Amos 1–3; Rev. 6
- Amos 4–6; Rev. 7

- Amos 7–9; Rev. 8
- Obadiah; Rev. 9
- Jonah 1–4; Rev. 10
- Mic. 1–3; Rev. 11
- Mic. 4–5; Rev. 12
- Mic. 6–7; Rev. 13
- Nahum 1-3; Rev. 14
- Habakkuk 1-3; Rev. 15
- Zephaniah 1–3; Rev. 16
- Haggai 1–2; Rev. 17
- Zech. 1–4; Rev. 18
- Zech. 5–8; Rev. 19
- Zech. 9–12; Rev. 20
- Zech. 13–14; Rev. 21
- Malachi 1–4; Rev. 22



Notes	
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By your words I can see where I'm going; they throw a beam of light on my dark path. PSALM 119:105





was fourteen the day Miss Edith invited me to her home and insisted I pick out a favorite piece of furniture. My favorite Sunday school teacher from the days she let me wiggle flannelgraph camels across a watercolor fabric desert, Miss Edith reminded me of Angela Lansbury: her ash-brown hair upswept in a neat chignon, her fingernails neatly manicured, and her full-figured body decked out in close-fitting, stylish suits.

Among the various fascinations that set Miss Edith apart were her independent singleness and the distinction of being the voice of our local telephone company recordings. Whenever I heard the familiar timbre of her voice telling me a number I'd dialed had been disconnected, a strange thrill washed over me, as though I knew a movie star personally. Her home boasted colorful Princess phones in pastel colors in every room, which placed her in a category, in my book, somewhere next to rock star.

Miss Edith lived in a tidy yellow house on Broadway Boulevard, where she superintended the care of her mother, who lived in a nursing home across the street. I'd known Miss Edith since I was born because she'd taught at our church for about as many years as it had taken the children of Israel to cross the desert.

Like most of the kids at my church, I loved Miss Edith. She knew how to make the Bible come alive, and by the time we were teenagers, we couldn't wait to get into her classes. She made mean homemade pastries and took her students to the beach and art shows and on trips to Bible colleges and the big city, like Chicago. Mostly, she loved us well and showed us that older adults could be cool and wise and quirky and fun and godly all at the same time.

Miss Edith's true secret power lay in her prayer life. On that day when I was fourteen and she invited me to pick out a piece of furniture that would someday be mine, I chose her drop-down desk, stacked high with prayer notebooks. Later I'd learn her desk was her favorite spot to pray for "her kids" and journal prayer requests into a notebook—even after we'd graduated, gone to college, married, and had children.

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Miss Edith was perhaps the most powerful and consistent spiritual force in the lives of generations of young people who passed through my church. She, like countless other prayer warriors across the nation, fought unseen battles of spiritual warfare on behalf of others who never knew the power she wielded on their behalf. While we may never know the measure of her influence here on earth, we will see the results of her prayers in heaven. Her prayers influenced the lives of her spiritual "children" here on earth and into eternity.

Like Miss Edith, we may never see the results of our prayers here on earth. Yet may we all be committed to influencing lives—not only in this generation, but the generations that follow—through commitment to persistent prayer.

-from It Is Well with My Soul by Shelly Beach

Don't pray when you feel like it. Have an appointment with the Lord and keep it. A man is powerful on his knees.

CORRIE TEN BOOM









Prayer Guides

Caregivers often battle with feelings of helplessness. They complete the same tasks day after day without any visible indication of fruit. They can't stop the progression of a loved one's incurable disease. They can't always ease their loved one's pain. They can't fix the root problem. They can't make everything better. Faced with so many things they can't do, caregivers often forget what they can do. They can pray. The resources in this section show caregivers how to incorporate Scripture into their prayers, asking God to fulfill His promises in their lives and the lives of their loved ones.

Prayer Guides: The prayer guides in this section are a powerful tool caregivers can use to combat helplessness. Why? Because God loves to honor prayers when they are consistent with His will. Discerning God's will and praying according to it is hard work. But His Word is a powerful guide. In fact, Scripture can be used to pray in God's will. He makes this promise in Isaiah 55:11: "So will the words that come out of my mouth not come back empty-handed. They'll do the work I sent them to do, they'll complete the assignment I gave them." Therefore, believers can confidently pray Scripture back to Him.

Praying Scripture often feels awkward at first, so use the prayer guides to get started. The first guide contains verses to pray for your family and the loved one in your care. Following each verse is an example of how to pray through it. The second guide focuses on your needs as a caregiver. The prayers in it are a

-STRESS RELIEVER-

You may want to create a list of verses specific to your circumstances and feelings. When you run across a passage that speaks to your heart, use the blank pages at the end of this section to record the date, the Bible reference, and a little about how or why the verse resonated with you. Don't force the process or stress over it. Instead, dig into His Word, expect Him to speak to you, and wait patiently for it to happen.









reminder to remain dependent upon God and to trust His sovereignty in every situation, even though you may feel helpless and alone.

Scriptures to Encourage Your Heart: This list of verses was created by DeAnn. She's the mother of Andrew, a toddler who eventually lost his fight against brain cancer. During his illness, DeAnn searched her Bible for passages that spoke to her fears, doubts, and grief. At first she wrote them on whatever slips of paper she could find. Later she copied the verses into a journal.

When you are discouraged, fearful, or doubting, use the verses that encouraged DeAnn to strengthen your heart, too.

THIRTY WAYS TO PRAY FOR YOUR FAMILY

Day 1: What marvelous love the Father has extended to us! Just look at it—we're called children of God! . . . And that's only the beginning. Who knows how we'll end up! What we know is that when Christ is openly revealed, we'll see him—and in seeing him, become like him. (1 John 3:1–2)

Dear God, thank you for being my Father and for not being finished with me yet. Help my family reflect your relationship with your Son until the day He comes again, and we see Him as He is.

Day 2: Like a shepherd, he will care for his flock, gathering the lambs in his arms, hugging them as he carries them, leading the nursing ewes to good pasture. (Isaiah 40:11)

Good Shepherd, have mercy on my family, your lambs. Hold us close in your arms while you lead us to good pastures filled with what we need.

Day 3: Now we look inside, and what we see is that anyone united with the Messiah gets a fresh start, is created new. The old life is gone; a new life burgeons! Look at it! (2 Corinthians 5:17)

Dear life-giving God, you blessed my loved one with physical life. Bless him with assurance of new life in you. May he know the Messiah more each day. Unite my loved one with your Son.

Day 4: If we go through the hard times with him, then we're certainly going to go through the good times with him! That's why I don't think there's any comparison between the present hard times and the coming good times. (Romans 8:17–18)





Jesus, you went through hard times while you were on earth, and you promised better times ahead. That's why my family is moving forward despite our present health challenges. We believe your promise and look forward to what's to come.

Day 5: Don't be obsessed with getting more material things. Be relaxed with what you have. Since God assured us, "I'll never let you down, never walk off and leave you," we can boldly quote, God is there, ready to help; I'm fearless no matter what. Who or what can get to me? (Hebrews 13:5–6)

Dear Provider, when time is short and money is tight, it's hard to believe you are with us. But you are there. You are protecting us. Please, Lord, meet our needs.

Day 6: But we're not quitters who lose out. Oh, no! We'll stay with it and survive, trusting all the way. (Hebrews 10:39)

Lord God, some days I am tempted to give up. But what kind of example would that be to those I love? Give me faith to persevere so my family will see how to survive by faith.

Day 7: By your words I can see where I'm going; they throw a beam of light on my dark path. (Psalm 119:105)

Word of God, in the Bible you say that your Word is a believer's guiding light. Give me motivation to gather my family to read and study it together often.

Day 8: That clinches it—help's coming, an answer's on the way, everything's going to work out. See those people polishing their chariots, and those others grooming their horses? But we're making garlands for God our God. The chariots will rust, those horses pull up lame—and we'll be on our feet, standing tall. (Psalm 20:6–8)

Strong Deliverer, sometimes the onslaught of caregiving feels like an attack. But you promise to help. Please send help to keep me standing when I feel overwhelmed by the needs of my family.

Day 9: Look at me and help me! I'm all alone and in big trouble. My heart and kidneys are fighting each other; call a truce to this civil war. (Psalm 25:16–17)

Lord, I need your help. I'm being pulled in so many directions. I want to do everything and please everyone. But I can't, so show me your will for my family this day so the war within me will cease.





Day 10: That goes for all of you, no exceptions. No retaliation. No sharp-tongued sarcasm. Instead, bless—that's your job, to bless. You'll be a blessing and also get a blessing. (1 Peter 3:9)

Giver of Breath, the life you breathe into us is a blessing. My loved one is a blessing. Show me how to bless those in my care and to recognize each blessing you settle on my family.

Day 11: The suffering won't last forever. It won't be long before this generous God who has great plans for us in Christ—eternal and glorious plans they are!—will have you put together and on your feet for good. (1 Peter 5:10)

Eternal God, some days it is so hard to look beyond our present challenges to your hope. Sustain us until that day comes. Calm our hearts. Put us on our feet.

Day 12: God's a safe-house for the battered, a sanctuary during bad times. The moment you arrive, you relax; you're never sorry you knocked. (Psalm 9:9–10)

God of sanctuary, I don't know when or if these caregiving obstacles will end, but your Word says you are a safe house for battered people. Walk my family through your doors so we can relax in your arms.

Day 13: Consider it a sheer gift, friends, when tests and challenges come at you from all sides. You know that under pressure, your faith-life is forced into the open and shows its true colors. So don't try to get out of anything prematurely. Let it do its work so you become mature and well-developed, not deficient in any way. (James 1:2–4)

God, you are determined to mature our family, aren't you? The pressures of caregiving force us to live our faith and grow. But we can only continue doing this if you hold us close during the painful maturing process.

Day 14: Make this your common practice: Confess your sins to each other and pray for each other so that you can live together whole and healed. The prayer of a person living right with God is something powerful to be reckoned with. (James 5:16)

Forgiving God, give everyone in my family courage to confess sins so we can forgive one another and be whole. Give us compassion to pray for one another every day.



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Day 15: God is a safe place to hide, ready to help when we need him. (Psalm 46:1)

Dear God, some days I am so tired and scared I want to hide from the demands of caregiving. Show me how to hide in your promised safe place and be present with my family at the same time.

Day 16: The person who wins out over the world's ways is simply the one who believes Jesus is the Son of God. (1 John 5:5)

Defender of the weak, be with my loved one when temptation arises. Strengthen his faith in your Son so he can win the battle against discouragement.

Day 17: Give your entire attention to what God is doing right now, and don't get worked up about what may or may not happen tomorrow. God will help you deal with whatever hard things come up when the time comes. (Matthew 6:34)

Dear God of the present, when I think about how much harder it's going to be to care for my loved one in the future, I am overwhelmed. Teach me to be present with my family today and to trust that you will help me deal with what lies ahead.

Day 18: These hard times are small potatoes compared to the coming good times, the lavish celebration prepared for us. There's far more here than meets the eye. The things we see now are here today, gone tomorrow. But the things we can't see now will last forever. (2 Corinthians 4:17–18)

Lord of all eternity, the challenges facing our family seem huge right now. Give us eyes to see beyond this life. Give us feet to stand on your eternal promises. Give us hope.

Day 19: Don't fret or worry. Instead of worrying, pray. Let petitions and praises shape your worries into prayers, letting God know your concerns. (Philippians 4:6)

Dear God who answers prayer, will you wave a red flag when I begin to worry? Stop me in my tracks, so I can turn my worries into prayers. Nudge me to share all my concerns with you.

Day 20: "I don't think the way you think. The way you work isn't the way I work." God's Decree. "For as the sky soars high above earth, so the way I work





surpasses the way you work, and the way I think is beyond the way you think." (Isaiah 55:8-9)

God of wisdom, I am so thankful that even when I don't understand what's happening to my family, you do. Give me faith in your plan, which is far superior to anything I could devise.

Day 21: Don't panic. I'm with you. There's no need to fear for I'm your God. I'll give you strength. I'll help you. I'll hold you steady, keep a firm grip on you. (Isaiah 41:10)

Dear Lord, you tell me not to panic, but it is so hard to stay calm when I think of my family's needs. Wrap your arms around us, steady us, hold us. Keep me from being fearful so they won't be afraid.

Day 22: Don't bargain with God. Be direct. Ask for what you need. (Matthew 7:7)

Dear Provider, you say not to bargain with you but to ask for what my family needs. I need you to show me how to handle our circumstances or bring someone to help us.

Day 23: God's name is a place of protection—good people can run there and be safe. (Proverbs 18:10)

God of protection, if you are the safe place you say you are, I want to run to you and be safe. Give my family time to spend in your Word, so they will run to you and be safe too.

Day 24: Whatever I have, wherever I am, I can make it through anything in the One who makes me who I am. (Philippians 4:13)

Dear Creator, you made everyone in my family who we are: wives, husbands, sons, daughters. So I claim your promise to lead us through whatever lies ahead, wherever we are.

Day 25: When I get really afraid I come to you in trust. I'm proud to praise God; fearless now, I trust in God. What can mere mortals do? (Psalm 56:3-4)

Dear Lord, train every person in my family to come to you when we are afraid. Show us how much stronger you are than humans, so we become fearless and praise you always.





Day 26: God, the one and only—I'll wait as long as he says. Everything I hope for comes from him, so why not? He's solid rock under my feet, breathing room for my soul, an impregnable castle: I'm set for life. (Psalm 62:5–6)

Dear God, you are using my caregiving experience to teach me patience, aren't you? I will wait, confident that in you we can meet every challenge of life. Please teach my loved one patience too.

Day 27: If God doesn't build the house, the builders only build shacks. If God doesn't guard the city, the night watchman might as well nap. (Psalm 127:1)

Dear Builder of our house, your Word says my family must be built on you, or it won't stand. Work in our hearts so we all claim you as Lord of this house.

Day 28: Friends love through all kinds of weather, and families stick together in all kinds of trouble. (Proverbs 17:17)

Dear God of our family, you created families to stick together. Be the glue that holds us together in good times and bad so we will all trust you as Lord and Savior.

Day 29: Let the peace of Christ keep you in tune with each other, in step with each other. None of this going off and doing your own thing. And cultivate thankfulness. Let the Word of Christ—the Message—have the run of the house. Give it plenty of room in your lives. Instruct and direct one another using good common sense. And sing, sing your hearts out to God! (Colossians 3:15–16)

Dear Christ, fill this house with your peace, your song. Bind us together as a family, thankful and supportive, obedient to your Word. Show me how to live my faith so those in my care learn to trust you.

Day 30: Listen to me, family of Jacob, everyone that's left of the family of Israel. I've been carrying you on my back from the day you were born, and I'll keep on carrying you when you're old. I'll be there, bearing you when you're old and gray. I've done it and will keep on doing it, carrying you on my back, saving you. (Isaiah 46:3–4)

Mighty God, I am too tired to meet my family's needs tonight. Would you carry me, as you have carried me since birth? Will you carry my family too, and save us during this adjustment to life of caregiving?





THIRTY PRAYERS OF DEPENDENCE

Day 1: If God hadn't been there for me, I never would have made it. The minute I said, "I'm slipping, I'm falling," your love, God, took hold and held me fast. (Psalm 94:17–18)

Lord God, these caregiving duties make me feel like I'm falling. Hold me and my loved one fast in your hands.

Day 2: I am God, the only God you've had or ever will have—incomparable, irreplaceable—from the very beginning telling you what the ending will be, all along letting you in on what is going to happen, assuring you, "I'm in this for the long haul, I'll do exactly what I set out to do." (Isaiah 46:9–10)

Father God, I trust your promise to be with us for the long haul because in the beginning you promised to send your Son to save us, and you did. I'll depend on you.

Day 3: For whatever was written in earlier times was written for our instruction, so that through perseverance and the encouragement of the Scriptures we might have hope. (Romans 15:4 NASB)

God in heaven, it's hard to believe a book written thousands of years ago is relevant today, but I need encouragement to persevere. Use your Word to teach me perseverance.

Day 4: God told me, "Don't say, 'I'm only a boy.' I'll tell you where to go and you'll go there. I'll tell you what to say and you'll say it. Don't be afraid of a soul. I'll be right there, looking after you." (Jeremiah 1:7-8)

God, I'm only a weak human being. I can't do this unless you tell me what to say, unless you are with me. Give me faith to trust your promise to be with me always.

Day 5: I would have despaired unless I had believed that I would see the goodness of the Lord in the land of the living. Wait for the Lord; be strong and let your heart take courage; yes, wait for the Lord. (Psalm 27:13–14 NASB)

Dear God, I am in despair about how to meet the needs of the person in my care. Give me strength to believe in your goodness. Give me courage to wait for you to act.







Day 6: God is keeping careful watch over us and the future. The Day is coming when you'll have it all—life healed and whole. I know how great this makes you feel, even though you have to put up with every kind of aggravation in the meantime. (1 Peter 1:5–6)

Father in heaven, is what you're saying true? Will there be a Day when wholeness and health returns to my loved one? Help me hang on to this promise in hard times.

Day 7: Whenever we're sick and in bed, God becomes our nurse, nurses us back to health. (Psalm 41:3)

Lord, my heart is sick about my loved one's condition. Nurse my spirit back to health so I can face the future well and strong.

Day 8: I know what I'm doing. I have it all planned out—plans to take care of you, not abandon you, plans to give you the future you hope for. When you call on me, when you come and pray to me, I'll listen. When you come looking for me, you'll find me. (Jeremiah 29:11–13)

God, it's hard to trust your plans in this situation, to believe you haven't abandoned us. I'm praying to you. I'm looking for you. When will I find you?

Day 9: The LORD is my light and my salvation; whom shall I fear? The LORD is the defense of my life; whom shall I dread? (Psalm 27:1 NASB)

Father of light, without you I am defenseless and fearful. Be with me today. Be my light. Remind me of your great salvation. Take away my dread.

Day 10: I can do all things through Him who strengthens me. (Philippians 4:13 NASB)

Lord God, I feel like I can't do anything to change my loved one's situation. Show me all the things I can do today and give me strength to do them.

Day 11: Pray all the time; thank God no matter what happens. This is the way God wants you who belong to Christ Jesus to live. (1 Thessalonians 5:17–18)

Father God, thank you for showing me what I can do for my loved one. Remind me to pray when I'm stressed. Open my eyes to see your gifts.

Day 12: We continue to shout our praise even when we're hemmed in with troubles, because we know how troubles can develop passionate patience in





us, and how that patience in turn forges the tempered steel of virtue, keeping us alert for whatever God will do next. (Romans 5:3-4)

Lord, you don't ask me to praise you for this trouble but to praise you for how you will use it. So I praise you for teaching me patience, virtue, and whatever lesson comes next.

Day 13: All praise to the God and Father of our Master, Jesus the Messiah! Father of all mercy! God of all healing counsel! He comes alongside us when we go through hard times, and before you know it, he brings us alongside someone else who is going through hard times so that we can be there for that person just as God was there for us. (2 Corinthians 1:3–4)

God, come alongside me today. Make me sure of your presence so I can share your hope with someone who needs to hear about it.

Day 14: The spacious, free life is from God, it's also protected and safe. Godstrengthened, we're delivered from evil—when we run to him, he saves us. (Psalm 37:39–40)

Lord, my loved one is weak and defenseless. I can't picture him having the life of freedom you promise. Give me strength to pick up us up and run to you when despair attacks.

Day 15: So then it does not depend on the man who wills or the man who runs, but on God who has mercy. (Romans 9:16 NASB)

Jesus, what a relief to know that my loved one's life depends on your great mercy, not my frail intellect and actions. Have mercy on us today!

Day 16: Don't quit in hard times; pray all the harder. (Romans 12:12)

God, life is so hard for us right now. I want to give up. I want to quit, but then who would be my loved one's voice? Give me a heart to pray all the harder.

Day 17: God's my island hideaway, keeps danger far from the shore, throws garlands of hosannas around my neck. (Psalm 32:7)

Rock of Ages, I would love to get away and relax for a few days. A tropical island would be nice, but you are better. Be my hiding place today and restore my heart.

Day 18: Keep your eyes on Jesus, who both began and finished this race we're in. Study how he did it. . . . When you find yourselves flagging in your faith,





go over that story again, item by item, that long litany of hostility he plowed through. That will shoot adrenaline into your souls! (Hebrews 12:2-3)

Jesus, when I take my eyes off you, my energy and stamina drain away. Stand before me so I can meditate on what you have done. Be the energy I need.

Day 19: If your revelation hadn't delighted me so, I would have given up when the hard times came. But I'll never forget the advice you gave me; you saved my life with those wise words. (Psalm 119:92–93)

Dear God, hearing the doctor diagnose our loved one's condition was so hard. But your Word has strengthened my heart and saved my life in the past, so I won't give up.

Day 20: He knows us far better than we know ourselves, knows our pregnant condition, and keeps us present before God. That's why we can be so sure that every detail in our lives of love for God is worked into something good. (Romans 8:27–28)

Dear Father, human knowledge is so limited. I would be hopeless if I didn't believe a God exists who can work good in this hard situation. Help me trust you to do good.

Day 21: Examine me, God, from head to foot, order your battery of tests. Make sure I'm fit inside and out so I never lose sight of your love, but keep in step with you, never missing a beat. (Psalm 26:2–3)

Great Physician, examine my battered and wounded heart. Heal me so I'm fit to follow you through this journey.

Day 22: Now I take limitations in stride, and with good cheer, these limitations that cut me down to size—abuse, accidents, opposition, bad breaks. I just let Christ take over! And so the weaker I get, the stronger I become. (2 Corinthians 12:10)

God, if you sent this situation to reveal my weakness, you'll have to take over and show me how to keep moving ahead. I can't do it myself.

Day 23: Is there anyone around who can explain God? Anyone smart enough to tell him what to do? Anyone who has done him such a huge favor that God has to ask his advice? Everything comes from him; everything happens through him; everything ends up in him. Always glory! Always praise! Yes. Yes. (Romans 11:34–36)





Dear Lord of the universe, you are vast and I am small. You know all things, and I know so little. Forgive me for telling you what to do. May I trust you to accomplish all things.

Day 24: I'm sure now I'll see God's goodness in the exuberant earth. Stay with God! Take heart. Don't quit. I'll say it again: Stay with God. (Psalm 27:13–14)

Creator God, it's hard to believe in you when my loved one is suffering. Show me your goodness so I won't give up on you.

Day 25: Friends, when life gets really difficult, don't jump to the conclusion that God isn't on the job. Instead, be glad that you are in the very thick of what Christ experienced. This is a spiritual refining process, with glory just around the corner. (1 Peter 4:12–13)

God of glory, when my loved one's caregiving needs first surfaced, I was sure you'd abandoned us. Keep my mind on your Son's past sufferings and future glory so I can trust you today.

Day 26: Cease striving and know that I am God. (Psalm 46:10 NASB)

Father, I want to make my loved one better. I want to yell at someone. I want to argue with you. Settle my spirit so I can rest and know you are really God.

Day 27: Dear God, my Master, you created earth and sky by your great power—by merely stretching out your arm! There is nothing you can't do. (Jeremiah 32:17)

Creator of all things, you can do anything. I can do nothing. Change my loved one's condition, or work through it to accomplish great good.

Day 28: Every good thing given and every perfect gift is from above, coming down from the Father of lights, with whom there is no variation or shifting shadow. (James 1:17 NASB)

Dear Father of lights, give me eyes to see the good and perfect work you are doing in my dear one's life.

Day 29: I'll say no more, I'll shut my mouth, since you, Lord, are behind all this. But I can't take it much longer. (Psalm 39:9–10)

God, if I open my mouth, I fear what will come out. If you are there, if you are truly in control of this situation, send help. I'm too exhausted and broken to go on alone.





Day 30: Let's keep a firm grip on the promises that keep us going. He always keeps his word. (Hebrews 10:23)

God, I am so weak, I can barely cling to your promises. Use the promise that you keep your word to give me hope today.

SCRIPTURES TO ENCOURAGE YOUR HEART

When you blame yourself: Psalm 26:2-3; 37:18-19; John 9:1-3

When it's hard to persevere: Psalm 27:13; Romans 5:2b-5; 8:18; 15:4; James 1:2-4; 1:12; 1 Peter 1:6-7

When you need a refuge: Psalm 34:4-22; 37:39-40; 46:1

When you need to guard your speech: James 1:19; 1:26; 1 Peter 3:8-9

When you need comfort: Psalm 39:7; 2 Corinthians 1:3-4

When you feel weak: 2 Corinthians 12:10

When you need to know others have suffered great loss and survived: 2 Samuel 12:22–23; Job 17:10–11

When you doubt your faith: Job 19:25–27; Psalm 37:3–4; Hebrews 11:1; 1 Peter 4:12–13; 1 John 5:3–5

When you need confidence: Psalm 19:14; 20:7-8; 1 John 5:14-15

When you are fearful: Psalm 25:14; 1 John 4:15–18

When all is dark: Psalm 27:1; 119:105

When you need a reminder of God's purposes: Psalm 103; 1 Peter 2:9-10

When you need a quiet heart: Psalm 46:10; 51:10-12; 94:18-19









Notes	

There is not in the world a kind of life more sweet and delightful than that of a continual conversation with God.

BROTHER LAWRENCE







When a new baby is born with ten fingers, ten toes, and the outward appearance of a typical infant, we say, "She's perfect!" But when a child is born with a special need, we say, "Something's wrong." Immediately, parents wonder if they caused the imperfection. But since when is the form and function of human bodies our standard of perfection?

In Romans, Paul says we've all sinned and come short of the glory of God. He makes it clear that the true standard of perfection is God, not humanity. According to Scripture, even people with ten fingers, ten toes, flawless complexions, full intellectual capacities, and all their innards in the right places are not perfect. Yet we say the baby with all systems go is perfect, but the child born with a cleft palate, developmental delays, or cerebral palsy is not. We say adults in good health and of sound mind are productive and valued citizens. But we consider those who experience brain injuries, can't walk because of multiple sclerosis, or are diagnosed with Alzheimer's as less valuable and less worthy of respect. How cruel we are. And how wrong.

In *Disability and the Church*, Dr. Jeff McNair explains how to avoid a false standard of perfection: "I can choose a standard of perfection that I will succeed at and then use that as my plumb line, or I can use the plumb line that God provides for success and align myself with that. The notion of perfect and imperfect looks quite different when I align myself with God's notion of success or perfect."

Once we make God the true standard of perfection, we see ourselves and others as imperfect. When you see every person on earth as imperfect, you no longer feel guilty about your loved one's imperfections. They may be different than those of most people. They may be more noticeable or limiting, but they are no less perfect than anyone else. Making God the only standard of perfection will help you combat guilt.

-from Different Dream Parenting by Jolene Philo





One person caring about another represents life's greatest value.

Jim Rohn



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Glossary

edical and legal jargon is often hard to understand and easy to misinterpret. This glossary attempts to clarify terms used in the notebook by providing standard definitions for them. Because the glossary was not compiled by lawyers and physicians and because terminology may vary from state to state, be sure to double-check the definitions with the appropriate professionals.

- **504 plan**—an individual plan created by public school personnel for students with physical conditions such as impairment, illness, injury, communicable disease, or chronic conditions like asthma, allergies, and diabetes. The plan details modifications and accommodations needed so students have an opportunity to perform at the same level as peers. Modifications might include a wheelchair ramp, blood sugar monitoring, large print textbooks, home instruction, or a voice recorder or keyboard for taking notes.
- **adult day care center**—a facility that offers social, recreational, and health-related services in a protective setting to individuals who cannot be left alone during the day because of health care and social needs, confusion or disability.
- advance medical directive—a document that specifies the care a person wishes to receive in case he or she is unable to communicate wishes, such as being in a coma. To be enforceable, the person making the directive must be of sound mind, meaning that he or she is still able to think rationally and communicate wishes in a clear manner. The document must be signed and notarized according to the laws in your state.
- Affordable Health Care Act (ACA)—the United States federal statute signed into law in 2010. The ACA expands public and private insurance coverage using mandates, subsidies, and insurance exchanges.
- caregiver—see designated caregiver
- **Children's Health Insurance Programs (CHIP)**—a program administered at the state level that provides health care to low-income children whose parents do not qualify for Medicaid. CHIP may be known by different names in different states. The CHIP program







may also be known by its former name, the State Children's Health Insurance Program (SCHIP).

conservatorship-see guardianship

- **copay**—the amount the insured person pays for a doctor visit, laboratory work, outpatient treatment, hospital, or pharmacy products; the copay amount is set by the insurance provider. A primary care doctor may require a \$25 copay per visit; a specialist may require a \$50 copay.
- **designated caregiver**—someone, typically over age eighteen, who provides care for another. The designated caregiver is responsible for the direct care, protection, and supervision of another person who may be elderly, disabled, or underage. It is generally one who gives assistance to a person who is no longer able to perform the critical tasks of personal or household care necessary for everyday survival.
- **designated decision-maker**—a person designated by durable power of attorney for health care (also known as durable medical power of attorney) who makes medical decisions when a patient is unable to do so.
- dietary supplement—a product taken by mouth that contains a "dietary ingredient" intended to supplement the diet. Ingredients may include vitamins, minerals, herbs or other botanicals, amino acids, and substances such as enzymes, organ tissues, glandulars, and metabolites.
- **disability insurance**—a monetary compensation plan provided by the government and/or an employer to support employees who are disabled due to illness or injury. The government's disability program, *Social Security Disability Insurance*, pays benefits to disabled workers who meet government qualifications outlined at www.ssa.gov/dibplan/dqualify2.htm. *Individual disability insurance* is an insurance product designed to replace anywhere from 45–60% of gross income on a tax-free basis should a sickness or illness prevent the patient from earning an income in his or her occupation.
- **do not intubate (DNI)**—a request that no breathing tube will be placed in the throat in the event of breathing difficulty or respiratory arrest.
- **do not resuscitate (DNR)**—a request to not have cardiopulmonary resuscitation (CPR) if a person's heart or breathing stops. Advance medical directives do not have to include a DNR order, and an advance directive is not required for a DNR order. A doctor can put a DNR order in your medical chart.







- **Durable Power of Attorney (DPOA)**—a power of attorney that remains or becomes effective when the person known as the principal, who created the document, becomes incompetent or unable to manage his or her affairs.
- **Durable Power of Attorney for Health Care**—a power of attorney where the principal appoints an agent to make health care decisions for the principal, and it remains effective even after the incompetence of the principal. It is often used as a form of advance health care directive. It may also be referred to as medical power of attorney or health care power of attorney.
- **general practitioner**—a physician who does not specialize but has a medical practice (general practice) in which he or she deals with all illnesses. Also referred to as a family doctor or GP.
- **generic drug**—a drug product that is comparable to a brand-name drug product in dosage form, strength, route of administration, quality and performance characteristics, and intended use.
- **guardianship**—a legal relationship created when a person or institution is named in a will or assigned by the court to take care of minor children or incapacitated adults. Sometimes called a conservatorship.
- health care directive—see living will
- **Health Care Power of Attorney**—*see* Durable Power of Attorney for Health Care
- **Health Insurance Marketplace**—organizations set up to aid in the purchase of health insurance in accordance with Patient Protection and Affordable Care Act.
- **Health Insurance Portability and Accountability Act (HIPPA) release**—a signed release form that is required for health care providers to discuss a patient's medical information with anyone who is not directly involved in the patient's care.
- herbal medicines—refers to using a plant's seeds, berries, roots, leaves, bark, or flowers for medicinal purposes. Herbal supplements are classified as dietary supplements by the U.S. Dietary Supplement Health and Education Act (DSHEA) of 1994. That means they can be sold without being tested to prove they are safe and effective. However, herbal supplements must be made according to good manufacturing practices.
- **home care**—any form of care given within the home. It can be provided by a home health aide, home health nurse, companion, or caregiver and can be medical or nonmedical. It can include intermittent care, respite care, and home therapies.







- **hospice care**—care designed to give medical, psychological, and spiritual care to people in the final phase of a terminal illness with a focus on comfort and quality of life, rather than a cure.
- **hospitalist**—a physician who specializes in treating hospitalized patients of other physicians, such as general practitioners or internists, in order to minimize the number of hospital visits by other physicians.
- Individualized Education Plan (IEP)—the legal document that defines a child's special education program. The IEP includes the disability that qualifies the child for special education services. It is created by a team of public school educators, with input from parents, and outlines the services the school will provide, along with yearly goals and accommodations that must be made to assist the student's learning.
- **internist**—a physician who specializes in the diagnosis and treatment of non-surgical diseases.
- **living will**—provides instructions to physicians and family members regarding life-prolonging treatment, medical or surgical procedures, and artificial feeding and fluids when the person has a terminal condition and is incapacitated. May have different names, such as health care directive, in different states.
- long-term care insurance—a type of insurance policy that is designed to cover long-term care expenses in a facility or at home. Long-term care insurance covers care that is generally not covered by health insurance, Medicare, or Medicaid. Most policies provide coverage for three to five years.
- **Medicaid**—a program administered at the state level that provides medical assistance to the needy. Families with dependent children, the aged, blind, and disabled who are in financial need are eligible for Medicaid. It may be known by different names in different states.
- **Medical Power of Attorney**—see Durable Power of Attorney for Health Care
- medical waiver program—this program "waives" the parents' income and considers only a child's income so children are eligible for Medicaid programs that pay for home health aides, respite care, day care, and more. A child's income can be no more than two thousand dollars per year.
- **Medicare**—a federal program that helps pay health care costs for people ages 65 and older and for certain people under age 65 with long-term disabilities.









- **Medicare Prescription Drug Plan**—prescription drug coverage available to everyone with Medicare. To obtain coverage, people must join a plan run by an insurance company or other private company approved by Medicare. Each plan varies in cost and drugs covered.
- **Medigap**—various private supplemental health insurance plans sold to Medicare beneficiaries that provide coverage for medical expenses that are not covered or are partially covered by Medicare.
- **mobility**—the ability to move in one's environment with ease and without restriction.
- **nonverbal**—characteristic of a person who is unable to use words to communicate, though he or she may be able to understand verbal communication.
- **nurse practitioner**—a health care worker with a graduate degree in advanced practice nursing. A nurse practitioner (NP) can perform physical exams, order tests and procedures, diagnose and treat diseases, write prescriptions, coordinate referrals, and perform some procedures.
- **occupational therapy**—treatment that helps people who have physical or mental problems learn to do the activities of daily life.
- **over-the-counter drugs**—drugs that can be purchased by a lay person without a prescription. Over the counter medications are chemically active agents that may interact with prescribed drugs.
- **pain and palliative care**—also known as hospice care, this treatment focuses on comfort and quality of life for patients with lifethreatening conditions. It also offers end-of-life care for patients and grief counseling for families.
- **physical therapy**—treatment of disease, injury, or disability by physical and mechanical means, such as massage, regulated exercise, water, and heat.
- physician's assistant—a medical professional who works as part of a team with a doctor. A physician assistant (PA) can examine patients, diagnose and treat illnesses, order and interpret lab tests, perform procedures, assist in surgery, provide patient education and counseling, and make rounds in hospitals and nursing homes.
- **prescription**—an order for medication, therapy, or a therapeutic device given by a properly authorized person, which ultimately goes to a person properly authorized to dispense or perform the order.
- **prescription drug**—a drug that can be dispensed to the public only with an order given by a properly authorized person. The designation of a medication as a prescription drug is made by the U.S. Food and Drug Administration.







- **primary health insurance**—insurance plan that pays medical claims. If patient is covered by more than one health insurance plan, this insurance pays first and to the limit of its responsibility.
- **private health insurance**—coverage by a health plan provided through an employer or union or purchased by an individual from a private health insurance company.
- **provider**—a term used for health professionals who provide health care services: physicians, nurse practitioners, chiropractors, physical therapists, hospitals, and others offering specialized health care services.
- residential care—long-term care given to adults or children who stay in a residential setting rather than in their own home or family home. Residential care for children could be residential schools, orphanages, disability, psychiatric, or foster care. For adults it could encompass disability, geriatric, hospice, psychiatric, or rehabilitation unit care.
- **respite**—temporary or short-term home or residential care of a patient provided, either for pay or on a voluntary basis, by someone other than the designated caregiver. It provides a break for caregivers and allows them to emotionally recharge.
- **secondary health insurance**—insurance plan that pays, to the limit of its responsibility, the balance left unpaid by primary health insurance when patient is covered by more than one health insurance plan.
- **sensory sensitivity**—a heightened sensitivity to light, sound, smells, and tastes that impairs a person's ability to process information and function.
- **Social Security Income (SSI)**—federal program designed to help the aged, blind, and disabled who have little or no income. It provides cash for basic needs like food, clothing, and shelter.
- special needs trust—a legal arrangement and financial relationship that allows disabled adults to receive income without reducing their eligibility for public assistance disability benefits provided by Social Security, Supplemental Security Income, Medicare, or Medicaid. It covers the percentage of a person's financial needs that are not covered by those public assistance payments. It is sometimes referred to as a supplemental needs trust.
- **speech therapy**—treatment of speech defects and disorders through use of exercises and audio-visual aids that develop new speech habits.







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Notes	

Wise men and women are always learning, always listening for fresh insights.

Proverbs 18:15





We all know people who are constantly unhappy regardless of their circumstances. Some of us are blessed to know those who are always happy regardless of their circumstances. My experience has shown me that the difference between these people is usually a strong faith in God.

In *The Saints among Us*, George Gallup Jr. studied the lives of those he described as saints in today's society. Rather than being specially gifted in terms of wealth, education, or status, Gallup's saints were overwhelmingly poor African-American women with a strong faith in the Lord. They had learned the secret Paul speaks of in Philippians 4. After encouraging his brothers and sisters in Christ to "Rejoice in the Lord always" and think about whatever is true, noble, right, pure, lovely, admirable, excellent, or praiseworthy, he sums up his stance by declaring, "I can do everything through him who gives me strength" (vv. 4, 8, 13 NIV).

The women Gallup studied endured hardships due to their poverty, race, and gender; life in this world was not fair to them. But rather than becoming bitter, they became more faithful. Rather than focusing on their pain, they relied on God for strength and joy and received both.

Chronic illness, disabilities, and special needs are not fair; when you consider carefully, you find that there are many aspects of life that are unfair. But chronic illness can lead to chronic peace if you let God guide you through it. I have seen lives eaten up by the question, "Why did this happen to me?" God has taught me that I might just as well ask Him, "Why was I blessed with such a wonderful family, a good education, a free country in which to live, more food than I should eat, and a saving knowledge of you?" We will not know the answers to these questions until we reach heaven, but we can know the attitude with which we should approach all the days He has given us here on earth until then: an attitude of gratitude.

-from Doing Well at Being Sick by Wendy Wallace





The most wasted of all days is one without laughter.

E. E. CUMMINGS



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Organization Systems

The Caregiver's Notebook is designed to help you become a more organized caregiver. It's small enough to fit in a diaper bag or briefcase, just big enough to hold the important documents and information you want at your fingertips wherever you may be.

However, this notebook can't hold all the paperwork that accompanies caregiving. Depending on the length of the caregiving journey, the constant stream of medical, legal, governmental, insurance-related, and educational documents may require a three-ring binder (or two or three) or possibly a file cabinet.

Creating and maintaining an organizational system for all that paperwork is essential. But, because the task is daunting and time consuming, it's often neglected in favor of urgent or day-to-day duties. If you're overwhelmed by forms and files, the website www.DifferentDream.com can help you begin to tame your paper tiger. At the website, click on "The Caregiver's Notebook" tab. The webpage contains examples of organizational systems, links to online resources, downloadable forms, instructions about how to get started, and tips about how to stay organized over the long haul. You can also leave comments there about organizational books you've discovered, links to web-based tools, or tips you use to make your caregiving journey easier.

At www.DifferentDream.com, caregivers will also find a daily blog that features practical and spiritual resources and products geared toward families of children with special needs.

STRESS RELIEVER-

Rome wasn't built in a day, and your paperwork system doesn't need to be either. To make the process manageable, begin by concentrating on one small area. Start with the preparation of legal documents. Or collect information to complete the medical history. Or track down immunization forms. Or file insurance paperwork. You get the idea. Work on that area until it's under control, and then move on to another.







There has never been the slightest doubt in my mind that the God who started this great work in you would keep at it and bring it to a flourishing finish on the very day Christ Jesus appears.

PHILIPPIANS 1:6



