

The Empowered Patient®

Guide to Hospital Care For Patients and Families



Part V: The Patient Journal

Your
Hospital Diary

Dr. Julia A. Hallisy and Helen W. Haskell
An Empowered Patient® Publication

THE EMPOWERED PATIENT®

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Part V

The Patient Journal – Your Hospital Diary



Dr. Julia A. Hallisy and Helen W. Haskell

Portions excerpted from
*The Empowered Patient: Hundreds of Life-Saving Facts,
Action Steps and Strategies You Need to Know*

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www.TheEmpoweredPatient.com

and

*The Empowered Patient Advocate:
A Guide to Hospital Care for Patients and Families*

by Dr. Julia A. Hallisy and Helen W. Haskell

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To our children

We would like to gratefully acknowledge the many people who have helped make this work possible, especially Teresa Arnold, Doris Gleason, and the entire South Carolina office of AARP; Dr. Bob Schultz; Lisa McGiffert, Suzanne Henry, Betsy Imholz, and the staff at Consumers Union; Patty Skolnik; Jan Vick; Dianne Parker; Linda Morrison Spear; our patient and understanding families, who never lost sight of the larger goal; and above all, Kate and Lewis, who showed us the way.

DISCLAIMER

This guide was written to educate and inform readers about the specific information and skills they need to be active participants in their medical care. It is intended to be a catalyst for patients and their advocates to cultivate mutually respectful relationships with healthcare providers, to learn to ask the right questions, and to communicate effectively about treatment options.

It is informational in nature and is not intended as a substitute for the professional advice of a physician, attorney or other advisor.

*The Empowered Patient[®] Guide to Hospital Care
For Patients and Families*

Part V

The Patient Journal – Your Hospital Diary

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PREFACE

My daughter, Katherine Eileen Hallisy, fought cancer five times before the age of ten. Kate was diagnosed when she was five months old with an aggressive eye cancer called bilateral retinoblastoma. Kate's decade-long plan of treatment included experiences with radiation, chemotherapy, reconstructive surgeries, the removal of her right eye, a hospital-acquired infection that led to toxic shock syndrome, and an above-the-knee amputation. During all those years of interacting with physicians and hospitals, we encountered virtually every problem a patient and their loved ones can face.

My husband and I spent years of our lives in hospital hallways, waiting rooms and emergency rooms. We became savvier and more educated the longer my daughter's illness went on. As we progressed, we slowly came to realize that the quality of healthcare our daughter received, as lacking as it sometimes was, was actually far superior to the care other families around us in the hospital were receiving. They began to notice this discrepancy as well, and they wanted to know why. How did we know the things we did and who had given us such valuable "inside" information? We had to explain that we had come across everything we knew the hard way – by watching our daughter suffer through medical errors, misdiagnoses and inexperienced medical providers. We investigated the mistakes and took steps to ensure they didn't occur again.

While we were customizing our solutions to the problems before us, we soon realized that the general principles we were applying were universal. They would work for anyone, regardless of the diagnosis, or the person's degree of medical knowledge. The reason for this is that many of these problems are the result of flaws in the medical system itself. The system works pretty much the same way no matter which hospital one is in and no matter what medical condition one is contending with. Once you understand what your particular problem areas are likely to be within the system, you can prepare your tool kit ahead of time.

The Empowered Patient Guide to Hospital Care for Patients and Families is intended to help you prepare your toolkit. The guide consists of five parts. **Part I** is a guide to help you prepare for hospitalization and understand some of the fundamentals of how hospitals work. It includes information on selecting an advocate and filling out necessary documents, as well how to navigate the hospital hierarchy, how to provide genuinely informed consent, and how to make your medical record work for and not against you. **Part II** covers your interaction with the hospital from diagnosis through discharge and home care, including ways to recognize and prevent infection and medical error. **Part III** is a special section on communication: how to get to the person or department you need within the hospital, and how to resolve questions and issues that may arise after you have left the hospital. **Part IV**, The Deteriorating Patient, includes signs and symptoms to help you recognize when a patient's condition is seriously declining. It is meant to be used in conjunction with **Part V**, the Patient Journal, which includes forms to help you keep track of the patient's treatment and condition. The Patient Journal is an essential tool that allows you to organize and apply information from the rest of the guide, and to make sure your hospital stay goes as it should.

The five parts of the guide are available separately or as a unit. They are best used as an interactive whole, and we urge you to download or order the entire guide if at all possible. Downloadable files and information on ordering *The Empowered Patient Guide to Hospital Care for Patients and Families* can be found at our website, www.empoweredpatientcoalition.org

The information presented in this guide draws on the experience of my own family, of my co-author Helen Haskell, and of many other patients and advocates. It is backed up by nearly a decade of research into patient safety and quality improvement, on the part of both authors. This information has come at a high price physically, economically and emotionally. But it has also taught us that tragedy does not have to define us. The quest for healthcare safety and quality has become a vehicle to help many advocates channel the pain of loss into actions that honor the memory of Kate, and Helen's son Lewis Blackman, who was lost to preventable medical error, and thousands of others. We want to help other patients reduce their chances of injury and error, to understand the importance of forming good partnerships with their providers and to lessen the instances of personal frustration and miscommunication. We all want this journey to be easier for those coming behind us.

-Julia Hallisy, September 2009

Part V

THE PATIENT JOURNAL – YOUR HOSPITAL DIARY

One of the most important steps you can take toward being an empowered patient is to keep your own record of your hospital care. Hospitals are busy places. Multiple departments and dozens of people may be involved in your treatment. It can be difficult for hospital staff to keep up with everything that goes on with you, but you and your advocate are probably acutely aware of your symptoms, problems, and progress. As members of the public become more involved in their own medical care, healthcare professionals have become increasingly comfortable with the notion that they can trust patients and advocates to act as a second set of eyes and ears.

The following pages are intended to help you do just that. The Patient Journal is made up of a series of forms designed to allow you to organize your medical information and your own observations. We have deliberately kept the number of forms low to make the journal easier to handle. If you have downloaded a copy of the journal, we suggest that you print it and put the forms in a three-ring binder for ease of use while in the hospital. Extra copies of the journal as well as other parts of the *Empowered Patient® Guide to Hospital Care for Patients and Families* can be downloaded or ordered from The Empowered Patient Coalition website, www.empoweredpatientcoalition.org

The forms included in the journal are:

- 1. A MEDICAL HISTORY FORM** for the medical information you need to have on hand for doctors' visits and hospital stays. This information can be filled out beforehand and taken with you to the hospital.
- 2. A HEALTHCARE PROVIDERS CONTACT INFORMATION FORM** so that you will have the information you need to get in touch with your doctors and other providers. We recommend that you ask your doctors for a number at which you can contact them directly. (In South Carolina, the Lewis Blackman Patient Safety Act also requires that your nurse provide you with a means of directly contacting your doctor at all times.)
- 3. A RECORD OF VISITS BY HEALTHCARE PROFESSIONALS** that allows you to keep a record of what doctors and other healthcare professionals have said about the patient's condition and what treatments they have prescribed.
- 4. A RECORD OF TESTS AND STUDIES** that allows you to record what tests have been conducted and alerts you to look for the results.
- 5. A RECORD OF PROCEDURES** that allows you to keep track of surgeries and other treatments that have been conducted.
- 6. AN OBSERVATIONS, COMMENTS, AND QUESTIONS FORM** that allows you to make notes on the patient's condition and to record questions you want to ask the doctor on his or her next visit. This is particularly useful when there is more than one advocate.

- 7. A MEDICATION RECORD.** On this form you can record the name, dose, frequency, duration, and stop/start dates of the patient’s prescription medications. You can also note when the drugs were given and check them against the prescription to be sure dosing is correct. (Note: The patient’s official medical record has a similar medication form [the Medication Administration Record, or MAR] for use by his nurses. Your nurse may be willing to get you copies of the daily MAR to put in your binder. However you do it, it is important to have a record of the patient’s medications.)
- 8.** And last, we have the **RECORD OF VITAL SIGNS.** This allows you to keep a running graph of the patient’s vital signs and other significant measurements. Aberrations in vital signs are often the first sign of a serious problem, and alerting the rapid response team early in the process can allow the problem to be addressed before it spirals out of control. Because these measurements are so critical, it is worth spending some time to explain the Record of Vital Signs.
- Every measurement on the chart is one that is routinely taken by nurses or technicians if a patient is ill or is recently recovering from surgery. **You do not need to measure the patient’s vital signs yourself in order to fill out the chart.** A good nurse or vital signs technician will be happy to share her readings with you, or you can copy them from the patient’s medical record at the nurses’ station.
 - In some hospitals, the electronic medical record prompts nurses to call the rapid response team if a patient’s vital signs are seriously out of kilter. You know your patient best, however. **If the patient is not doing well, we recommend that you keep your own record as a backup and let the nurse know if you see a trend that you find alarming.** If your patient is doing well and vital signs are not being taken frequently, you may have no reason to use the chart.
 - **“Normal” vital sign measurements vary from person to person.** For some people – especially athletes, the elderly, children, and people with chronic medical conditions – normal will consistently lie outside the ranges shown in the vital signs record. **If at all possible, we urge you to establish the baseline measurements for your own “normal” before going to the hospital,** by measuring your own blood pressure, pulse, and respiratory rate at different times over several days.
 - **If the patient has readings outside the normal range that are *unusual for that person* or *rapidly changing*, you should be concerned.** A rule of thumb is that any vital sign that rises or falls more than 20 percent from the patient’s baseline *and stays there* is a cause for concern. If a vital sign stays more than 40 percent above or below baseline, you should seek help immediately.
 - **Be advised that hospital staffers sometimes attribute aberrant vital sign readings to faulty equipment. You should always test this assumption before accepting it.** You can do this by testing the equipment on yourself, or suggesting that the staffer do so.

The following measurements can be recorded in the Record of Vital Signs:

- **Body temperature.** Nurses or technicians usually take a patient’s temperature at regular intervals. The range for a typical healthy adult is fairly narrow, usually hovering between about 98 and 99 degrees Fahrenheit. A sick person may have

somewhat wider temperature fluctuations. If the patient's temperature goes over 101 or under 97, you may have cause for concern.

- **Blood pressure.** Blood pressure is the pressure generated when the heart contracts (**systolic** blood pressure – the upper number) or relaxes (**diastolic** BP – the bottom number). The acceptable range for “normal” blood pressure has narrowed significantly in recent years. Nevertheless, very high or very low blood pressure can be a sign of a serious condition and should be investigated.
- **Respiratory rate.** This is still usually measured by watching the chest rise and fall and using a watch with a second hand to measure the number of respirations per minute. For most people, normal is between about 16 and 20 breaths per minute, though one study shows it as low as 12. Respiratory rate can be calculated by timing the patient's breaths for about 15 seconds, then multiplying by four. A very high or very low respiratory rate can be a sign of a serious problem, even in the absence of other symptoms.
- **Pulse (heart rate).** If the patient has a pulse oximeter (also called a “Pulse Ox”) on his finger, his pulse may be continuously recorded on the attached Pulse Ox monitor. If not, the nurse or technician will probably take the patient's pulse at regular intervals. Many factors can affect the pulse rate temporarily, but a resting pulse that stays over 100 or under 60 beats per minute should be investigated, especially if it occurs in conjunction with other abnormal readings.
- **Oxygen saturation (SpO₂).** There are a number of different measurements of oxygen saturation in the blood, most of which require invasive blood tests. SpO₂, however, is measured by the pulse oximeter and should appear on the monitor if the patient is wearing a pulse oximeter. Again, the normal range is fairly limited. A reading below 90 is cause for concern and below 85 is cause for serious concern.
- **Urine output.** We would like to stress that we are *not* asking advocates to measure a patient's urine. Urine output is usually measured in patients who have a urinary catheter. When the nurse empties the bag attached to the catheter, she will record the amount of urine collected. That number will be accessible for you to record should you so desire. Urine output varies enormously according to fluid intake and body size, among other variables. In general, urine output of less than 500 ml a day is regarded as excessively low, and above 2500 ml as excessively high. Either extreme can be a sign of serious conditions.

Finally, the Patient Journal works best in conjunction with Part IV (The Deteriorating Patient) of this guide, which provides an outline of signs and symptoms of some medical conditions that can arise urgently in hospitals. The Deteriorating Patient is intended to give patients and advocates a very general means of interpreting the Vital Signs Record and other changes in the patient's condition, with the aim of allowing them to seek help in a timely fashion. While it includes some of the more dangerous possibilities that could befall a hospital patient, it is not intended to alarm you, or to suggest that these eventualities are likely to occur in *any* hospitalization. Rather, it is meant to provide a basis for asking questions and consulting closely with your health care providers if something does not seem right to you.

WARNING SIGNS OF A RAPIDLY DECLINING PATIENT

1. High or low body temperature
2. Changes in heart rate (pulse) or respiratory (breathing) rate
3. A drop in the patient's blood pressure (it becomes much lower)
4. Mental confusion or other change in mental state
5. Decrease in amount of urine/urine darker in color, looks "concentrated"
6. The patient states that something is wrong with them
7. The advocate observes that the patient doesn't look right
8. The patient is short of breath or having chest tightness or discomfort
9. Acute pain, especially in the abdomen
10. The patient is very pale or breaking out in cold sweats

NOTE: A rapid and sustained change of more than 20% *above or below* the patient's *normal* pulse or blood pressure rate is cause for concern. A change of more than 40% is reason to seek help immediately.

GETTING HELP

1. Ask for the Rapid Response Team
2. Call your doctor or ask for the Attending Physician
3. Call the nursing supervisor who can ask for the administrator on call
4. Document your concerns in the chart and note that you have asked for help!

Patient's name _____ Marital Status _____ Age _____
 Name of insurance company _____ Spouse's Name _____

Name of Advocate _____ Advocate phone/contact information _____

Is advocate allowed access to medical records? Yes/No

Are doctors allowed to share information with advocate? Yes/No

Does patient have a Medical or Healthcare Power of Attorney? (POA) Yes/No DNR? Yes/No

POA name and phone # _____ Advance Directive? Yes/No

Primary Care Physician Name and Phone # _____

Date of most recent physical exam _____ any significant findings? _____

Other practitioners seen in past year _____

(Include specialists, therapists, chiropractor, acupuncturist, etc.)

Current Medications : (Include all over-the-counter, herbal, natural, vitamins, calcium, etc.)

<u>Name of Med</u>	<u>Reason for use</u>	<u>Form</u>	<u>Dosage</u>	<u>Times taken per day</u>	<u>Date Started</u>
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____

Present and Past Medical Conditions : (List most recent first. Examples: Diabetes, High Blood Pressure, Hay fever)

<u>Name of Condition</u>	<u>Date Diagnosed</u>	<u>Doctor</u>	<u>Treatment</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Prior Emergency Room Visits and Hospitalizations:

<u>Date</u>	<u>Reason</u>	<u>Diagnosis</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Invasive and Surgical Procedures:

<u>Name of Procedure</u>	<u>Date</u>	<u>Why Performed?</u>	<u>Hospital or Center</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Allergies: (Include reactions to meds and other substances including tape, iodine, dyes, food, etc)

What causes an allergic response? _____ What is the reaction? _____

Immunizations and Dates:

Hep A _____ Meningitis _____ Influenza (flu shot) _____
Hep B _____ Tetanus _____ Varicella (chicken pox) _____
Pneumovax(Pneumonia) _____ Tdap _____ Last TB Skin Test _____
(Tetanus and Pertussis)

Most Recent Diagnostic Tests and Dates: (Keep copies for your records)

Blood Count (CBC) _____ Current Blood Pressure _____ Bone Density _____
Cholesterol (lipid) panel _____ Treadmill /cardiac _____ PAP Smear _____
Sigmoidoscopy _____ PSA (prostate) _____ Mammogram _____
Colonoscopy _____ MRI/CT _____ X-Rays _____

Family History: (List significant diseases of parents, siblings, grandparents and children)

Social History:

Do you smoke? Yes/No Have you ever smoked? Yes/No How many years? _____ Packs per day _____
Do you drink alcohol? Yes/No Number of drinks per week? _____
Do you use recreational drugs? Yes/No What type? _____ How often? _____

Other:

Height _____ Current weight _____
Do you do any exercise? Yes/No # of times per week _____
Any eating disorders? Yes/No Type? _____ Any sleep disorders? Yes/No
Psychiatric illness? Yes/No Depression? Yes/No
Any disabilities or physical limitations? Yes/No List _____
Do you need assistance walking, bathing, eating, etc? Explain _____
List any internal implants or external medical devices _____
(Include artificial joints, pacemaker, insulin pump, CPAP machine, etc.)
Vision problems? Yes/No Hearing problems? Yes/No Glasses/contacts? Yes/No Hearing Aids? Yes/No
History of falls? Yes/No Vertigo(dizziness)? Yes/No

* Please note: It is not recommended that you include your date of birth, Social Security number, home address or any other information on this form that could lead to privacy violations or identity theft.

Medical Procedures

Date/Time	Procedure	Who performed the procedure?	Comments/outcome/expected followup



24-Hour Record of Vital Signs*

DATE _____

Body Temperature

	Fahrenheit	93°	94°	95°	96°	97°	98°	99°	100°	101°	102°	103°	104°	105+
	Celsius	33.8°	34.4°	35°	35.5°	36.1°	36.5°	37.2°	37.8°	38.3°	38.9°	39.4°	40°	40.5+
8:00														
12:00														
4:00														
8:00														
12:00														
4:00														

Systolic Blood Pressure (top number)

	mm Hg	40	50	60	70	80	90	100	120	130	140	150	160	170+
8:00														
12:00														
4:00														
8:00														
12:00														
4:00														

Diastolic Blood Pressure (bottom number)

	mm Hg	10	20	30	40	50	60	70	80	90	100	110	120	130+
8:00														
12:00														
4:00														
8:00														
12:00														
4:00														

Respiratory Rate

	Breaths per min.	8	10	12	14	16	18	20	22	24	26	28+
8:00												
12:00												
4:00												
8:00												
12:00												
4:00												

Heart Rate (Pulse)

	Beats per min.	20	30	40	50	60	70	80	90	100	110	120	130	140+
8:00														
12:00														
4:00														
8:00														
12:00														
4:00														

Oxygen Saturation (SpO2)

	Percent	85	87	89	91	93	95	96	97	98	99	100
8:00												
12:00												
4:00												
8:00												
12:00												
4:00												

Urine Output

	Avg CC per 4 hours	0	25	50	100	200	300	400	500	600+
8:00										
12:00										
4:00										
8:00										
12:00										
4:00										

* Shaded areas show typical ranges for healthy adults. Ranges are approximate only. Some individuals, especially athletes, the elderly, and people with chronic conditions, may consistently have readings outside these ranges. Vital signs in children vary according to age and cannot be compared with ranges in this chart.



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	mm Hg	10	20	30	40	50	60	70	80	90	100	110	120	130+
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Notes