

READING AFTER EPILEPSY SURGERY

An Introductory Series for Parents and Educators

Part 1

UNDERSTANDING THE BIG FIVE FOR THE EARLY OR STRUGGLING READER



INTRODUCTION

In today's world, **reading is the key to independence**. Reading entertains you when you're bored, keeps you company when you're lonely, and opens up a world of knowledge when you're curious. Through the teen years and into adulthood, reading connects you to friends and family as you text back and forth, helps you order your favorite meal from a menu, and gets you on the right bus on your way to an appointment. Reading makes it possible to have a job, understand the lease agreement for your new apartment, and follow directions on a bottle of prescription medication.

It's clear that reading touches nearly every aspect of our daily lives and is arguably **the most important skill your child will need in their lifetime**. Children who have reading difficulties have a higher school dropout rate, are at greater risk of unemployment, achieve lower income levels in adulthood, and struggle with feelings of low self-esteem and adjustment.¹ This is why it's so important for a child to learn how to read. Unlike learning how to walk or talk, reading **doesn't come naturally** to children – it must be taught!

Unfortunately, children with epilepsy have a **much higher rate of reading difficulties** when compared to the general population.² If the epilepsy is drug resistant, the seizures interfere with knowledge and skill acquisition.

Epilepsy surgery can also negatively impact a child's reading development in many ways. Because reading involves several different areas of the brain working together, removing or disconnecting parts of the brain can contribute to poor reading development. For example, children who have had the occipital lobe removed or disconnected (such as after hemispherectomy, temporal lobe resection, or posterior quadrant resection also known as "TPO") will have vision challenges that make it difficult to see a whole world. Removing a temporal lobe results in auditory challenges which can make it difficult to figure out the sounds letters make. Intellectual impairments or memory deficits can also making reading difficult.

In this guide, we will review the basics of reading to help you understand what's important. Subsequent guides in this series will discuss how the basics of reading relate to a child who has had epilepsy surgery, the unique obstacles they face on the road to reading, and how to make a plan to overcome them. Starting early, with proper assessment, intervention, and a thorough understanding of the obstacles to reading, most children after epilepsy surgery have a chance to become literate.

¹ Patil M, Saraswathi G, Padakannaya P. Self-esteem and Adjustment among Children with Reading and Writing Difficulties. Stud Home Comm Sci 2009; 3(2): 91-95

² Fastenau PS, Jianzhao S, Dunn DW, Austin JK. Academic underachievement among children with epilepsy: proportion exceeding psychometric criteria for learning disability and associated risk factors. J Learn Disabil 2008;41: 195-207.

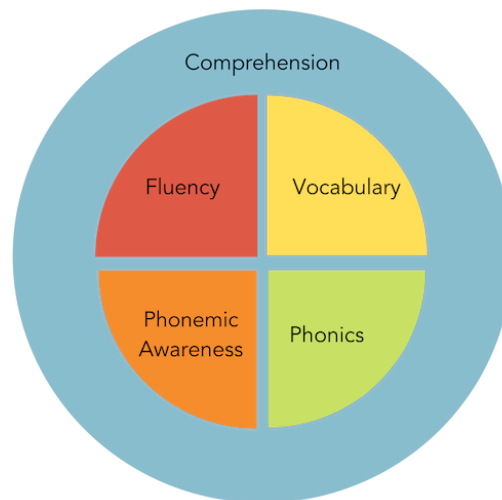
THE BASICS OF READING

While our brains are naturally wired for spoken language, reading is not a natural process like walking or talking. **Reading must be taught explicitly and formally** in order to be acquired.³ This is because reading is a relatively new development in human history – in fact, it is only in the last hundred years that a majority of the world’s population could be called literate.

Reading is a complicated process, involving our vision, hearing, and several areas of our brain working together quickly to make sense of written words. While different regions of the brain do have specialized functions, it’s important to remember that the brain is really a complicated network of pathways involving the eyes, ears, and **both** sides of the brain. If disrupted, these broken pathways can lead to reading challenges.

The Big Five Of Reading

Reading is broken down into five main areas: **phonemic awareness, phonics, fluency, vocabulary,** and **comprehension**. According to the National Reading Panel⁴, it’s important to understand these different parts of reading and how they work together.



Here, we’ll use the word “shop” to explain the five main components of reading.

³ Gabrieli, J., Christodoulou J, O’Loughlin, T, Eddy, M. (2010) "The Reading Brain" In: Mind, Brain, and Education. 1st Ed. Bloomington: Solution Tree Press; p. 113.

⁴ National Reading Panel (U.S.), & National Institute of Child Health and Human Development (U.S.). (2000). *Report of the National Reading Panel: Teaching children to read : an evidence-based assessment of the scientific research literature on reading and its implications for reading instruction : reports of the subgroups*. Washington, D.C.: National Institute of Child Health and Human Development, National Institutes of Health.

Phonemic awareness

While we use our eyes to read, the **true starting point** for reading is **sound**. The child must learn to connect what she **hears** and says to the written letter on the page. This ability to notice, think about, and work with the individual **sounds** in words is called **phonemic awareness**. It's the knowledge that **sounds of spoken language make words**.

Phonemic awareness is **100% auditory**, meaning it is only related to the sounds a letter makes, or the sounds letters make together in a word. Phonemic awareness has nothing to do with written letters or words.

According to the National Reading Panel, teaching phonemic awareness to children significantly improves their reading. For this reason, it's critical that a child learning to read receives **explicit and systematic phonemic awareness instruction**.

Phonemes - The Sounds of Language

A **phoneme** is an **individual sound** in a spoken word. For example, the word "stop" has four phonemes: /s/ /t/ /o/ /p/; "shop" has three phonemes: /sh/ /o/ /p/. While English has 26 letters, it has about 44 phonemes! These are unique, individual sounds we put together to form spoken words.

Children learning how to read may find this chart helpful when learning the different sounds in the English language:

s sat	t tap	p pan	n nose	m mat	a ant	e egg	i ink	o otter
g goat	d dog	ck click	r run	h hat	u up	ai rain	ee knee	igh light
b bus	f farm	l lolly	j jam	v van	oa boat	oo cook	oo boot	ar star
w wish	x axe	y yell	z zap	qu quill	or fork	ur burn	ow now	oi boil
ch chin	sh ship	th think	th the	ng sing	ear near	air stair	ure sure	er writer

There are many activities you can use to help your child learn phonemic awareness. These include:

- matching spoken words by initial sounds ("shop and share both start with /sh/")
- separating the sounds in a word (sh-o-p)
- blending separate sounds into a word ("I say sh-o-p, what word is that?")

- changing the phonemes in a word (“say *stop* without the /s/”)

Note that all of these are about **spoken** language. Parents, therapists and teachers develop children’s phonemic awareness through songs, nursery rhymes, poems, reading aloud and, in general, exposing them to as much spoken language as possible.

The Steps to Phonemic Awareness - Phonological Awareness

Phonological awareness can be described as a series of steps a child takes **before** they reach the ultimate goal of phonemic awareness. These steps often overlap. Here’s an example:

When first learning the sounds of language, a child typically starts by understanding the different sounds in rhymes, word play, and alliteration (when the same sound occurs at the beginning of or in closely connected words). Alliterations like: “She sells seashells by the seashore” or “Peter Piper picked a peck of pickled peppers” and other silly poems or songs help children with this first step.

The child will then start to blend and segment sentences – he may say “put ball in box” and “Mom help” when he means “Mom, help me put the ball in the box.” In kindergarten, the child will start to learn how to blend and segment syllables. Exercises like clapping for each syllable in a word are common kindergarten games. Children will then learn how to blend and segment onsets (the first sound of the word, like “c” in “cat”) and rime (the string of letters that follow the first sound, like “at” after “c” in “cat”).

The last step is blending and segmenting **phonemes - the individual sounds in a word**. This is **phonemic awareness**. Games and exercises like:

- What sound do these words begin with? boy, box, bike;
- What is the middle sound in the word sack?
- What word am I saying - “t” .. “a” .. “p”;
- How many sounds are in the word shop?
- What will I have if I change the “r” in rug to “m”?

Phonics

Phonics is the relationship between, and the explicit instruction of, written letters/letter combinations to spoken sounds. Phonics puts together the sounds you hear (called **phonemes**) with a written symbol (called **graphemes**). In English, letters are graphemes.

Phonics also includes an understanding that there is a **predictable relationship** between the sounds of spoken language, and the letter patterns that represent those sounds in written language (knowing the /sh/ sounds is represented by the two letters -s-h-). This includes **decoding**, commonly known as “**sounding out words**.”

When your child’s teacher talks about phonics you might hear terms like:

- Short and long vowel sounds (‘a’ as in “apple” vs. the long ‘a’ in “ate”)
- Consonant blends (‘st-’ as in “stop”, ‘dr-’ as in “drop”)

- Vowel blends, known as diphthongs (-oi- as in “coin”, -ou- as in “loud”)
- Digraphs (‘sh-’ as in “shop”, ‘-ay’ as in “day”)

Fluency

Fluency is the ability to read text with appropriate **speed, accuracy** and with **expression**. It’s the glue that holds together all the different parts of the Big Five. In order to read well, you must be fluent in phonological skills, recognize letters and words fast, and decode (sound out words) quickly by having fast letter-sound identification skills. Good fluency can start in the very beginning when a child is just learning the letters of sounds and continues throughout the teen years when they are reading novels or textbooks.

Fluency is comprised of three parts:

- **Speed** is how quickly a child can read. To increase speed, children need to recognize and decode words effortlessly. This is done through a combination of decoding (using what you know about phonics to sound out a word) and reading sight words (being able to instantly recognize commonly used words without needing to sound them out).
- **Accuracy** is reading words without mistakes.
- **Expression** (also known as **prosody**) is the ability to change your voice to show feeling when reading.

It’s important to understand that fluency **is not** simply “reading fast.” Fluency often gets confused with reading speed, which it is not! Reading text fast, but pronouncing or identifying the words **wrong** will affect fluency. Similarly, reading the text with a robot voice, without appropriate **inflection**, means that there is a challenge in fluency as well.

A teacher will often assess fluency through a “running record” where they have a child read a passage out loud while the teacher records the errors made and how many words were read correctly in one minute. Terms you might hear a teacher use when talking about your child’s fluency are:

- Fluency rate: how many words per minute (WPM) they read
- Accuracy rate: how many words they read correctly, expressed as a percentage
- Expression (prosody): do they pause at commas? Stop at periods? Change their tone for a question mark or when characters are speaking?

Fluency is important for comprehension. If you can’t read fluently it will be harder to understand what you are reading. For children with memory and processing speed issues, slow, laborious reading means that they are unable to comprehend what they are reading – by the time they get to the end of the line, they may have forgotten what the sentence was about.

Sight Words Or High Frequency Words

To increase a child’s fluency, “sight words” or “high frequency words” are often taught in school. Sight words are words that young readers are encouraged to learn to read by sight or memorization,

rather than sounding them out (**decoding**) or learning the rules of English to read them. They typically have unusual spelling patterns and cannot be sounded out using simple phonics rules. “High frequency words” are words that are commonly used in the English language.

Critics of using sight word lists say that this **prevents children from learning the rules of English**. Proponents say it’s a shortcut to helping build a child’s fluency; because teachers can only teach about 400 new words per year, and children should know 3,000 words by third grade, sight words offer a quick way to reading fluency. Because children with reading difficulties may only memorize 50 new words per year, sight word memorization can be a fluency solution for them.

There are many lists that are used to teach sight or high frequency words. These include:

- Dolch sight words: About 50 - 75% of all words used most books, newspapers, and magazines are on the Dolch sight word list.
- Fry word list: The most commonly used words in English ranked by order of frequency.

Vocabulary

Vocabulary is knowing the meanings and pronunciations of words. For example, the word *shop* can mean: a store, supermarket, boutique, as well as to browse, purchase, buy, look for.

Vocabulary is broken down into two main parts:

- **Expressive** vocabulary: words the child uses to express himself when speaking or writing. This includes **speaking** vocabulary and **writing vocabulary**. **Speaking vocabulary** is the words we use when we speak. Our speaking vocabulary is relatively limited! Most adults use only **5,000 to 10,000 words** for all their conversations and instructions. **Writing** vocabulary are words we use when we write and is largely dependent **spelling ability**.
- **Receptive** vocabulary: All words understood by the child, including spoken, written, or signed words. These include **listening** and **reading** vocabulary. **Listening** vocabulary are words we understand. By the time we reach adulthood, most of us will **recognize and understand close to 50,000 words**. **Reading** vocabulary are words we understand when we read text or sign language.

Vocabulary is usually broken down by tiers when it’s being taught:

- Tier 1: Basic words that commonly appear in spoken language. Examples include clock, baby, happy, and walk.
- Tier 2: High frequency words used by mature language users across several content areas. Examples of Tier 2 words are obvious, complex, establish and verify.
- Tier 3: These are words that are not commonly used, except in certain academic areas or situations. Medical, legal, biology and mathematics terms are all examples of these words.

Some tips for expanding your child’s expressive and receptive vocabulary include:

- Real life experiences: for example, a child is more likely to know words like “produce”, “register”, “grocery,” and “aisle” if they go to the supermarket regularly
- Literature: books can expose kids to unfamiliar experiences, places and people
- Conversation: constantly talking with children, even before they are able to produce speech. By describing what the child or adult is doing, or expanding on what a child has said (“pretty flower”, “yes, it is pretty! The flower is bright red.”) adults expand a child’s vocabulary.

Comprehension

Comprehension is making sense of what you read. *Shop*, depending on how it’s used in a sentence, can mean a retail store or the act of making a purchase. Good comprehension depends on word recognition, fluency, vocabulary and verbal reasoning. Essentially, it is what you get when you weave all the previous skills together.

Reading comprehension requires good phonemic awareness, fluency, vocabulary, and phonics. If a child has mastered these skills, but does not have good reading comprehension, then they are at great risk of being “**functionally illiterate**”. This means that they can read in some capacity, but their reading comprehension level is so low that they cannot manage the everyday aspects of life.

Imagine trying to survive and thrive in a society where you couldn’t comprehend the basic meaning of your cable bill, your lease agreement, or how to follow road signs. Even worse, imagine not being able to read the label on a bottle of medicine or a container of dangerous chemicals. Living safely and productively is only one of the many outcomes of proper reading comprehension skills. Being able to derive meaning from the written word also enables students to develop intellectually, socially, and emotionally – something we all want for our children.

From The Importance of Reading Comprehension, k12reader.com

MORE RESOURCES

For more information on understanding the Big Five:

- Reading Rockets: Research-based strategies to teachers, parents, administrators, librarians, childcare providers, and anyone else involved in helping a young child become a strong, confident reader. <http://www.readingrockets.org/>
- National Reading Panel: A panel of experts convened by the U.S. Congress to evaluate existing research and evidence to find the best ways of teaching children to read. <https://www.nichd.nih.gov/research/supported/nrp>
- Center on Teaching and Learning, University of Oregon: Dedicated website to provide information on the Big Five to teachers and parents across the nation. http://reading.uoregon.edu/big_ideas/
- Scholastic: Partnering With Parents: Literacy Activities and Resources <https://www.scholastic.com/teachers/blog-posts/amanda-nehring/partnering-parents-literacy-activities-and-resources/>

- Reading Tips for Parents - U.S. Department of Education
<https://www2.ed.gov/parents/read/resources/readingtips/readingtips.pdf>
- The Research Building Blocks for Teaching Children to Read: Put Reading First – Kindergarten Through Grade 3 <https://lincs.ed.gov/publications/pdf/PRFbooklet.pdf>
- Put Reading First Helping Your Child Learn How To Read: A Parent Guide
<https://www.nichd.nih.gov/sites/default/files/publications/pubs/Documents/PRFbrochure.pdf>



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