Combating an Elusive Enemy: Understanding Autism

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SENIOR THESIS APPROVAL

This Honors thesis entitled

"Combating an Elusive Enemy: Understanding Autism"

written by

Brandy Ussery

and submitted in partial fulfillment of the requirements for completion of the Carl Goodson Honors Program meets the criteria for acceptance and has been approved by the undersigned readers.

thesis director

second reader

third reader

honors program director

April 15, 2001
"I believe that autism results when some sort of mechanism that controls emotions does not function properly, leaving an otherwise relatively normal body and mind unable to express themselves with the depth that they would otherwise be capable of."¹

--Donna Williams, person with autism, author

Autism is a disorder that affects one out of every one thousand children. It occurs more frequently in boys than in girls and brings with it complications that deprive those affected of a normal life. One such individual is a boy named Tyler Kubinski. Tyler is a twelve-year-old severely autistic child from Paragould, Arkansas. Tyler's world is limited by his inability to speak or communicate further than a scream or contorted laugh. He does not frighten or agitate easily but will strike out fiercely with his muscular legs or well-aimed spit to anyone nearby. Tyler does not interact with his brother or classmates in a personal way but spends hours every day running from room to room tearing up cardboard into pieces. I was given the opportunity to work as Tyler's personal care aide last summer as he could not be cared for well in normal childcare. While working with Tyler I was able to make observations concerning his autism and use my knowledge about the disorder to offer suggestions to his family about treatments for him.

The complications that arose during Tyler's birth, along with his early infections parallel some hypotheses concerning the onset of autism. Over the course of the summer, as Tyler's personal care aide, I attempted to wean him off diapers. Tyler was not antagonistic towards potty training.

I used M & M's candy as a reinforcer in a behavior modification setting.² When Tyler progressed a step from his diapers, such as sitting on the commode when he needed to urinate, he was given an M&M as a reward. Progress was made; unfortunately, the mother was not as supportive of the potty training and did not participate when she was caring for him, he therefore remains incontinent. I found Tyler to be open to taking short walks and playing outside which brought him outside of his fascination of shredding and attempting to eat cardboard that usually took up the majority of his days. I also monitored his eating habits and he progressed to eating at one sitting at the kitchen table. Again, his mother was not so enthusiastic about his progress and did not push him to improve. The following discourse attempts to lay a foundation for the understanding of this complex disorder. For specific information regarding my observations of Tyler Kubinski, see the appendix.

The human nervous system is both complex and vulnerable. While it controls millions of processes daily, one small kink can forever alter its ability to function. There are many neurological disorders that are somewhat understood for which we can take preventative measures. Autism, however, remains a biological and a psychological mystery in many respects.

Autism can be defined by its clinical features and course of illness. There are three diagnostic criteria given by the Diagnostic and Statistical Manual³ and the International Classification of Diseases⁴, with the condition that the symptoms appear completely by age five: 1. failure to develop normal social interactions;

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2. no or abnormal development of language used for communication; 3. a restricted range of interests and behaviors.\textsuperscript{5} It is common for an infant to appear normal until around age three.

In many cases, the symptoms seemingly appear over night. The child ceases talking, becomes unresponsive to social cues, and also begins to use unusual objects repetitiously and inappropriately.

**Failure to develop normal social interactions**

Some factors that designate social growth in infants are increased eye contact and increased dependence on physical touch.\textsuperscript{6} Autistic children are content with lying in a familiar setting like their crib and often upset easily if a parent or guardian expresses physical touch. Young autistic children do not appear to have an attachment to their mothers' or guardians' presence; over time they do develop an attachment but rarely do they show interest in developing relationships with other children or siblings. Persons with autism are solitary individuals. This aversion to interacting with others sometimes subsides; however, persons with this disorder remain socially inept. This social awkwardness is often characterized by poor eye contact and a lack of understanding of social encounters. The result of the disability may be rejection and rebuff by peers.

**Faltering in Language Development**

The ability of an autistic person to communicate depends on the severity of the disorder. One-third of children with autism never develop speech beyond a grunting or screeching sound. Dr. Temple Grandin, an autistic person and author of numerous books,
Stated, "I can remember logically thinking to myself that I would have to scream because I had no other way to communicate." Further, these children do not attempt to use other means of communication such as gestures or eye contact.

The remaining two-thirds develop a varying amount of speech. Many autistic individuals exhibit echolalia, which is a form of immature speech that involves repeating what others say. According to Temple Grandin, echolalia is helpful to the autistic individual in order to understand what is being said to them. If the echolalia is delayed, it may be used in a meaningful way. For instance, "a child who has heard 'do you want some juice?' may always use that exact construction when requesting juice."

The most pronounced communication disability within autism lies in the social aspects of language that make our language complete such as eye contact, steady speech, showing an interest in the person to whom one is communicating, and following the flow of conversation. Often many autistics such as Temple Grandin have a natural monotone quality to their speech that hinders giving language clues.

Restricted Range of Interests and Behaviors

A key definition of autism lies in tendencies toward repetitive and ritualistic interests and activities. Rocking movement is very calming to autistics. Excitement may bring movements like the flapping of wrists and some autistics may have to compulsively touch the wall or doorknobs. Many affected by this disorder have overly focused interests such as baseball statistics, computer operating systems, and train

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9 Ibid
10 Ibid
12 Ibid
timetables. Persons with this disorder focus most of their time and energy into these eccentric interests and may seem obsessed with talking about them or learning them. This aspect of autism is particularly intriguing due to the fact that they are often inattentive to other activities and often are hyperactive. The only concentration demonstrated is related to their eccentric interest.

The Autism Spectrum

There exists a spectrum of severity in persons with autism. This spectrum measures from severe mental retardation and absence of speech to high intelligence and normal structurally but not pragmatically language. About ten percent of persons with autism comprise the savant group. According to Folstein, the basis for this spectrum of traits can most likely be attributed to a confluence of several genes acting together. Which and how many genes are inherited determines the phenotype of the person with the disorder.

Due to autism's wide range of effects, there are other common features that are not included in the diagnostic criteria. A person with autism may have one, a few, many, or none of these traits. Seventy-five percent of autistic children have IQs below seventy. IQs below seventy indicate mental retardation. From results of the Wechsler Intelligence Scales, it has been concluded that many autistic individuals have difficulty with narrative logic. They have a cognitive deficit that is the inability to see a construct as a whole rather than focusing on its individual parts or segments. 

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14 Ibid
Many autistic people often find themselves in a state of sensory overload. Sensory abnormalities cause them to dislike being touched by other people and by certain fabrics. Children may react violently when their senses are overwhelmed by the feel of a fabric or a loud noise. “The reactions of an autistic child and a scared, flighty horse are similar. Both will lash out and kick anything that touches them.”\textsuperscript{15} Temple Grandin is a classic case of one with sensory abnormalities. As a child she earnestly desired touch but could not stand the type of pressure given by hugs. As an adult she was able to construct a “squeeze machine” that allows her to lie down between two soft foam-padded panels and control the amount of pressure by pushing an air valve lever that pulls the two panels tight. Various forms of this squeeze machine are currently used in the treatment of autism. Also, Dr. Grandin wears only soft clothes such as cotton due to the scratchy feel of most clothes. Many autistic children prefer to wear no clothes when possible. Another catalyst of sensory overload is loud noise. According to Dr. Grandin, the hearing sensitivity of a person with autism is akin to an animal’s.\textsuperscript{16} Vacuum cleaners, fire alarms, and airplanes can all cause fear and hysteria. Noise causes stress, which can lead to temper tantrums in many children. Other sensitivities include extreme sensitivity to heat and to smell. Many autistics smell any item they are examining.

One understudied idiosyncrasy of autistic individuals is the area of motor abnormalities. When excited in a positive or negative way, some have a characteristic hand flapping that is carried out by extending the wrist bilaterally; it is often done with the elbows flexed and with fingers in front of their eyes.

\textsuperscript{16} Ibid
Children are sometimes very clumsy in both fine and gross motor coordination and may have difficulty holding a pen and learning to play catch. This deficit can be explained by the inability of the child to execute a voluntary motor movement despite being able to demonstrate normal muscle function. This is referred to as apraxia and is not related to a lack of understanding or to any kind of physical paralysis but is caused by a problem in the cortex of the brain.\textsuperscript{17} Autistic children often are unsuccessful in learning new motor patterns. Their walking patterns are affected by these difficulties and may result in a walk similar to foot drop.

Some persons with severe autism often have difficulty recognizing body boundaries; they cannot determine where their body ends and the outside world begins. For example, if they cannot see their legs, they do not know where they are. Often persons with the disorder will slap or bite themselves in order to determine where their body boundaries are.

In addition, some have severe visual processing problems such as lack of depth perception. This problem is not due to anomalies in the eyes but rather processing that occurs in the brain.\textsuperscript{18} These difficulties in processing lead autistics to prefer peripheral vision; many will not look a person in the eye because sensory processing deficits can make another person's eye movements difficult for a person with autism to look at.

Life Expectancy

There have been very few studies of the life expectancy of individuals with autism. The few results have suggested that some die of drowning (many autistics

\textsuperscript{17} Folstein, Susan E. "Autism" \textit{International Review of Psychiatry} 11: 269-281 1999.
love water), epileptic seizures, or from undetected infections. This is due to the fact that “many persons with autism do not communicate that they are in pain or do not notice pain in a normal way.”

Studies performed have revealed a consistency to the development of an autistic person from the point at which symptoms first appear. The following table illustrates the common growth traits.

### Timeline of development of a person with autism

<table>
<thead>
<tr>
<th>Timeframe</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 18 months</td>
<td>Baby often appears normal; some signs are present</td>
</tr>
<tr>
<td>18-24 months</td>
<td>Decreased interest in social interaction and slow development of babble; failure to develop phrase speech</td>
</tr>
<tr>
<td>36 months</td>
<td>Repetitive routines and rituals</td>
</tr>
<tr>
<td>36 months to 5 years</td>
<td>Social isolation and repetitive routines are at their peak; the children who will speak begin to talk, mostly using echolalia</td>
</tr>
<tr>
<td>5 years</td>
<td>Begin to interact more with adults, particularly parents or teachers</td>
</tr>
<tr>
<td>12-18 years</td>
<td>Puberty often brings epileptic seizures and a failure to gain any more new skills. Sexual maturation makes for awkward behavior</td>
</tr>
</tbody>
</table>

### Diagnostic Methods

There are three major methods for determining the extent of severity of autistic symptoms: behavioral observations, verbal reports, and direct interactions.

Behavioral observations are most useful in a classroom context. Specific adult interactions are arranged to facilitate observation of child behaviors of interest with the assistance of an observation protocol such as the Childhood Autism Rating Scale (CARS).

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20 Ibid

CARS encompasses fifteen four-point scales on which a child's behavior is rated on a scale from normal to severely abnormal.

Interviews are a common assessment practice given by school psychologists to parents or teachers. A typical line of questioning would include questions concerning the child's history from age of onset as well as an extensive medical history. The Autism Diagnostic Interview-Revised is a standardized interview protocol.

When interviews or observations are not possible or do not provide the necessary information, direct interaction in the form of student interviews, direct skills assessment, standardized testing, reinforcer assessment, or functional assessment may be implemented. The student interview would exclude children with little or no functional language skills, but for more high functioning children the method is valuable for comparisons in their answers for determining cognitive deficits. Direct skills assessment involves the measurement of a child's performance in a specific targeted skill area without any standardized aptitude or achievement testing. The purpose of direct skills assessment is to provide information concerning skill deficits and strengths while identifying effective instructional strategies.

The Gilliam Autism Rating Scale is a standardized test that has been designed for the screening of people between the ages of three and twenty-two for autism. It is composed of forty-two behaviorally-stated items that are divided into three subtests: communication, social interaction, and stereotypical behavior. The test can only be applied to those that can communicate. Items in the test are based on DSM-IV and Autism Society of America Standards. The raw score obtained from each of the subtests yields an Autism Quotient (AQ). The GARS and AQ assist in determining the severity of
an autistic person’s mental status, emotional status, learning ability, communication ability, and physical ability.  

Etiology

The fact that statistics regarding autism show an increasing prevalence of the syndrome can be attributed to several factors: 1. Diagnoses are being made earlier and the diagnostic criteria are more specific and inclusive; 2. The public has received education concerning the syndrome and, thus, is more aware of the likelihood in their community; 3. Recent surveys have included institutions as well as schools so that the more severely mentally retarded were accounted for as well as the high functioning children.

There have been documented cases of autism from all racial and ethnic groups in which it has been studied. Based upon the studies there have been no conclusions that any racial group is more or less frequently affected.

Etiological studies have led researchers to one main conclusion: autism is a genetic disorder. There is no one single autism gene, but rather duplications and deletions on particular genes have been hypothesized to contribute to autistic symptoms. One cannot rule out environmental risk factors but the strongest evidence suggests a genetic malfunctioning. This evidence is based largely upon twin and family studies, cytogenetic studies, and genetic linkage data. Family studies indicate that when the parents of an autistic individual conceive again, the chance of the new child of acquiring the disorder

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25 Ibid
raises from five to ten per one thousand to three to six per one hundred which is a half to a double increase in chance.

Both monozygotic and dizygotic twin studies have been performed in geographically defined populations, and approximately half the monozygotic twins were found to be concordant while none of the same-sexed dizygotic twins were concordant. Complicating the matter is that scientists suspect that more than one gene may be involved.26

Cytogenetic studies performed have revealed chromosomal abnormalities. Results of linkage studies have shown a variation in potential genes affected. While cytogenetic studies are a common and accepted practice, the interpretation of linkage data results based on multiple data sets like the ones performed is problematic for complex diseases like autism; there is more of variation than replication of results. There is no consistency in one region that shows a marked increased haplotype sharing in affected sibling pairs.27

Results based on numerous tests have shown aberrations in the forms of deletions, insertions, and duplications on chromosomes 13, 7, 15, HOXA1, and HOXB1 to be possible candidates responsible for onset of autism. The major consistent conclusion in chromosome studies is the idea that autism is the result of abnormalities in more than one gene. A study by Joseph Piven28 concluded that examining of individual behaviors thought to be genetically related to autism in relatives that do not have the full syndrome of autism would enable researchers to separate the phenotype of autism into its narrow

genotype components and further linkages studies would provide a complementary approach to identifying component genes causing the disorder.

PET (positron emission tomography) scans and MRIs (magnetic resonance imaging) have revealed very few anomalies. Some abnormalities observed among children with autism include brachycephaly, large temporal, parietal, and occipital lobe size, and abnormalities in the size of the cerebellar vermis. The most consistent findings are the absence of Purkinje cells in the cerebellar hemispheres. The absence of Purkinje cells results in a loss of the neurons that synapse with those cells. The Purkinje cells are involved in a neuropathway in the cerebellum. The cerebellum is usually associated with motor movements but recent studies have determined that neural connections of the cerebellum may influence both motor and nonmotor abilities such as the synthesis of serotonin.

Alterations in the synthesis of serotonin might contribute to sleeplessness and compulsive behaviors. Additional PET scans have revealed a localized dysfunction of the temporal lobes in the form of bilateral hypoperfusion of ¼ of a group studied. However, studies yet remain on how to connect those dysfunctions with the abnormalities of the disorder. Previous testing for brain abnormalities has given only negative results. These recent findings are a result of improvements in the spatial resolution of imaging methods and thus, as the methods are further improved, autism may be more clearly defined.

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Immunological studies on autism are slowly finding their way to the front of probable causes of various symptoms. A study by R.H. Waring in 1999 provided evidence that there is a total deficiency of sulphite oxidase in autistic persons. Sulphite oxidase oxidizes sulphite ions to sulphate. This deficiency can lead to neurological dysfunction as well as deficiencies in the gastrointestinal tract. When the system is unable to metabolize sulphate, proteins like gluten and casein cannot be completely hydrolyzed; according to Waring, peptides of this type can show opioid activity. They can cross the gastrointestinal wall and penetrate the blood-brain barrier, acting on the central nervous system. These actions are proposed to be responsible for social withdrawal, insensitivity to pain, and altered responses to sensory stimuli that are trademarks of autism.32

Treatment

Due to the spectrum nature of autism, types and variations of treatments are widespread. Treatment exists in forms of therapy, medication, and nutritional control, and a combination of these. Many treatments are promising but also include drawbacks. There are many individual medications that can be administered to control specific behaviors. However, consideration must be given to the fact that medications bring their own complications with their usage. Therapy has been found to be very profitable to the small number it is available to.

Many symptoms of persons with autism consist of abnormal behaviors and disturbed emotions. Neurobiology and neuropsychology research within the last thirty years has demonstrated that behaviors and feelings are the result of complex chemical

interactions within the nervous system. Findings such as chemical substances that are responsible for the transmission of signals between synapses, neurotransmitters, mediate emotional states such as fear and anxiety supports the idea that abnormal behavior or emotions are a result of defects in this intricate system. Psychotropic drugs have been developed to mediate the abnormal transmission of these neurotransmitters. In the treatment of autism, therefore, these drugs are commonly prescribed to treat target symptoms only. When used correctly with the right dosage, psychotropic drugs may alleviate many symptoms of autism; however, a caregiver must take several factors into consideration such as the fact that certain drugs given to epileptics can cause grand mal seizures and excessive doses of many of these drugs can cause insomnia, anxiety, agitation, manic psychosis, and excitement. While the proper use of medications is part of a good treatment program for autism it should not be used as a substitute for educational or therapy programs. The following table lists common symptoms and common drugs used to treat them.

<table>
<thead>
<tr>
<th>Behavioral Deficit</th>
<th>Psychotropic Drug(s) suggested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short attention, impulsive behavior, attention deficit/hyperactivity, disturbance of motility</td>
<td>Clonidine, guanfacine, imipramine, naltrexone (low to middle functioning); methylphenidate, dextroamphetamine, propanolol hydrochloride</td>
</tr>
<tr>
<td>Resistance to change, repetitive thoughts, repetitive behaviors, obsessive-compulsive, abnormal attachments</td>
<td>Clomipramine, fluoxetine, sertraline, paroxetine; those with seizure disorders should avoid clomipramine</td>
</tr>
<tr>
<td>Stereotyped movements or behaviors</td>
<td>Haloperidol, pimozide</td>
</tr>
<tr>
<td>Generalized anxiety</td>
<td>Buspirone</td>
</tr>
</tbody>
</table>

Irritability, labile mood, sleep disturbances, depressive disorder   | Norpramine  
---|---  
Delusions, hallucinations, bizarre behaviors  | Haloperidol, thiothixene, risperidone, olanzapine  
Self-injurious,  | Naltrexone, trazodone  
Aggressive behaviors  | Haloperidol, risperidone, trazodone, carbamazine, felbamate  
Unusual sleeping patterns  | Melatonin, imipramine  
Enuresis  | Imipramine  
Social withdrawal  | Naltrexone, fluoxetine

There have been a few studies in which psychotropic drugs have been administered for the purpose of improving speech impediments. The positive results of the drugs occurred in young children. It is proposed that the drugs may improve speech if given at a young age when the brain is most receptive to learning. The results of the studies are not definite, however, and more is being researched in this area.

Controlling autism with diet is a method that only works in cases in which the autism may have been triggered by an allergic reaction. There have been no cures with special diets but there have been recorded improvements. The foods that must be controlled are foods to which the child may possibly have an allergic reaction. Most likely, these are foods that formed a large part of the diet for the very young child. An effective way to determine if certain foods trigger a child's autism is to remove those foods from the diet. Two of the worst sources of allergies come from proteins found in milk and wheat, casein and gluten, respectively. It takes a certain period of time to

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cleanse the body of these proteins, but once started on the diet, improvements are often seen from the beginning.

Applied Behavior Analysis (ABA) is an educational intervention technique that can be used to inculcate children with autism. ABA is a therapy developed by Ivar Lovaas, a clinical psychologist, over thirty years ago. In ABA, skills are simplified and broken down into small components and taught in a systematic form with one skill building upon the next. For example, attention skills are taught, followed by cooperation and imitation. If the therapist is not able to achieve the attention and cooperation of the child, then it will be very unlikely that the therapist can teach the child language. There is a tremendous amount of structure and reinforcement provided at high intensity using precise teaching techniques. ABA involves a great amount of repetition and it is closely monitored to ensure its effectiveness. It is a very intensive therapy, requiring thirty to forty hours a week, mostly on a one-to-one basis with a trained therapist. It has been shown that many children with autism respond very well to intensive therapy, and if started early, some children only show minor evidence of autism later in childhood.36

The therapy involves tasks in which the child is encouraged to perform. A typical interaction might proceed as follows:

Antecedent: a directive or request for the child to perform an action
Behavior: a response from the child including any response from a successful performance, non-compliance, or no response
Consequence: a reaction from the therapist, such as strong positive reinforcement, faint praise, or a negative response

(each trial is separated with a pause)

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The nature of the therapy is that for each positive consequence, the child is likely to respond with that particular behavior and negative consequences will emit no further response. This is referred to as reinforcement. ABA is very flexible in that, depending on the needs of the child, the therapy can take place in a regular classroom, special education classrooms, or at home.

Research and case study evidence indicate that ABA programs produce comprehensive and lasting improvements in many skill areas in which autistic children have disabilities. While ABA has shown to be effective at any age, early intensive instruction is the most effective for children with autism.37

Final Notes

Tyler Kubinski’s case is similar to thousands of others in neighborhoods all over the world; some have more hope and others less. With the plethora of studies and proposed ideas concerning autism, it is imperative that the caregivers of those with autism come to understand the complexity of the disorder so that they may give hope to the one in every two thousand affected. From my “M&M progress” with Tyler, it is obvious that Applied Behavior Analysis would be greatly beneficial for him. Currently, intensive therapy, drugs to treat specific abnormalities, and a nutritional yet allergen free diet all mixed with love and patience offer the greatest amount of hope to persons trapped inside this elusive enemy.

37 Autism Society of America www.asa.org
Bibliography


19. Autism Society of America www.asa.org


Appendix

This case is a paradigm of many cases in which the parent(s) or guardians are not aware of potential treatments and understanding of the disorder and therefore the child remains untreated and his chances of improvement in the future are rapidly declining. At eleven years old, Tyler is incontinent, has a very poor diet, and cannot be controlled by his mother. The following medical information was obtained from copies of Tyler’s medical records and the abnormalities, diet, and current treatment information was obtained from my observations as his personal care aide.

Date of Study: June 2001-August 2001
Name of Person with Disorder: Tyler Kubinski
Date of Birth: 8-1-90
Age officially diagnosed: 9 years
Appearance of Symptoms: from age 2 months to 1 year Tyler suffered from the following: chronic otitis media, pharyngitis, bronchitis, rhinitis, tonsillitis, oral candidiasis (probably from the antibiotics used to treat the above)
History of illness: walked and began speaking at a normal age, no potty training
Development prior to onset: Tyler underwent psychological evaluation at a psychiatric center in Little Rock at age 9. Among the tests performed: Vineland Adaptive Behavior Scales, Slosson Intelligence Test-revised, Devereux Scales of Mental Development, and Childhood Autism Rating Scale. The results indicated severe autism with mild mental retardation.
Methods of diagnosis:
Medication: Tyler was on sleeping medication (Risperodal) along with Ritalin and Topamax, which is an anti-epileptic drug.
Symptoms/Observed abnormalities: Speech cessation occurred at 16 months and there was no further evidence of language development save screaming and babbling; repetitive routines
such as tearing up cardboard and licking it; walks on the front balls of his feet; aversion to fabrics and loud noise; incontinent; aversion to hair cuts and clipping of toe and finger nails; little to no interaction with others; bites, kicks, and spits viciously; will convulse his body and make undecipherable noises when something is wrong; eats with his hands only; has difficulty imitating motor behavior, and oral fixation with both foreign objects and himself.

Current Treatment: Tyler attends special education classes at a junior high school but is receiving no actual treatment.

Diet: Tyler subsists on frozen pizzas, fast foods, sodas, and microwaveable dinners.

Complications during pregnancy: mother has chronic hypertension, and suffered from pre-eclampsia during pregnancy, along with a myocardial infarction; she carried Tyler eleven months; a caesarian was performed. None of these complications (except the hypertension) arose during her second pregnancy and birth.

History of present illness in family: none observed, but the sister of the mother has cerebral palsy.