

Disability Guidebook

Summary descriptions of the most common disabilities in low- and middle-income countries



The logo for Kupenda for the children features a green silhouette of the African continent with a red heart in the center. The text "Kupenda for the children" is written in a serif font to the left of the map.

Kupenda
for the
children

The logo for Kuhenza for the children features a green silhouette of the African continent with a red heart in the center. The text "KUHENZA for the children" is written in a sans-serif font to the left of the map.

KUHENZA
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About this Guide

Authors

Kupenda for the Children is registered in the U.S. and Kuhenza for the Children is registered in Kenya. As our own nonprofit organizations, we report to our respective national governments, manage our own operational funds, and are overseen by our own boards of directors. Each year, Kuhenza and Kupenda collaboratively fundraise to support our joint projects. We have been co-designing and co-implementing disability programs and materials, such as this guidebook, since 2003.

Purpose

The purpose of this guide is to provide caretakers and communities with a basic understanding of common disabilities, including their descriptions, causes, and recommended interventions. This guide is intended to be used by families and caretakers because it is focused on children with disabilities. However, much of the information included is relevant for adults with disabilities as well.

In low- and middle-income countries around the world, many people believe that a person with a disability has been cursed by God or witchcraft and is less than human. These negative beliefs often result in the neglect, abandonment, abuse, rape, or even murder of people with disabilities. However, when communities have a more accurate understanding of disability definitions, causes, and effective interventions, people with disabilities experience increased access to appropriate healthcare, education, and the love of community that all humans desire and deserve.

Unfortunately, many people in low-income countries have difficulty accessing accurate and simple information. This is due to associated costs, language barriers, or because most materials are highly technical and intended to be used by medical or disability professionals. In response, Kupenda and Kuhenza developed this guidebook. The pages that follow provide brief summaries of commonly encountered disabilities using language and graphics that a layperson can understand.

Non-Diagnostic

The text, graphics, and images contained in this guidebook are for informational purposes only. None of the material in this book is intended to be a substitute for professional medical advice or diagnosis.

Selection and Organization

Some of the disabilities highlighted in this guide fall under one or more of the following categories: intellectual, physical, sensory, mental, and emotional. Since some disabilities may be classified in more than one category, the disabilities are listed in alphabetical order, rather than by category.

The disabilities in this guide were chosen because they have a high prevalence in low-income countries. Some disabilities were also included because they are often misdiagnosed or misunderstood.

Variability

Some people have more than one disability. Additionally, the symptoms and severity of each disability can vary significantly from one person to the next. It is important to understand that this guide provides a general overview of each disability and that no two people with the same disability are exactly alike.

Intersectionality

In most cases, the individuals we've included as examples of people living with disabilities are of African descent. This is because the majority of Kupenda and Kuhenza's work takes place in Africa. However, it should be noted that each disability in this guide occurs among people of all races, ethnicities, and genders, unless otherwise specified.

Disability Risk Reduction

The risk of having some of the disabilities listed in this guide can be reduced while others cannot.

For example, the chances of giving birth to a child with a disability can be reduced if the pregnant mother avoids exposure to anything that might cause infection (such as sleeping under a mosquito net to prevent mosquito-borne diseases like malaria).

To avoid complications during birth which may lead to disabilities, it is best for pregnant women to be seen for regular prenatal and postpartum appointments at a hospital or health facility. It is also important that they deliver at a hospital or health facility with medical equipment and trained staff to help deal with problems that may arise during labor and birth.

Immediately treating infections in infants and children can also reduce their chances of developing certain disabilities. In addition, parents and caregivers should make sure that children are regularly visiting their healthcare providers and sleeping under bed nets to prevent mosquito-borne diseases such as malaria. They should also ensure their children receive timely vaccinations as recommended by their doctor.

Disability-Specific Interventions

Each disability described in this guide includes an "Intervention" section which is divided into two parts: Professional and Family / Community.

Professional

Professional interventions include ways of supporting people with disabilities that must be prescribed by a medical professional, such as a doctor, nurse, therapist, or psychiatrist. A person with a disability in need of medical care should always be supported to access appropriate health professionals.

Family / Community

Family / Community interventions describe ways in which the person with a disability can be effectively supported by those who are not medical professionals, such as parents, caregivers, siblings, friends, spouses, teachers, and neighbors. Many of the interventions in the Family / Community sections can also be implemented by the person with the disability themselves.

Interventions Common to All Disabilities

In addition to the interventions for specific disabilities that are described in this guide, there are also general interventions and support strategies relevant to all disabilities.

Family Support

Disability impacts entire families, so it is important to establish support for everyone involved. Families of children with disabilities do better when they are connected to other families of children with disabilities. This allows them to help and learn from one another. Regardless of the type of disability, individuals with disabilities and their families should not go through the journey of disability alone. When looking for existing support groups or others to meet with, families can ask their community leaders, local schools, nonprofits, places of workshop, and medical facilities.

Professional Medical Diagnosis and Care

If a person shows signs of a disability or illness, they should be taken to a medical facility as soon as possible. A diagnosis of disability should always be given by a medical professional. A medical professional can help the patient and his or her family to understand the disability and access related resources and services. It is also important for family members to learn how they can become involved in exercises and activities that help the person with a disability cope and thrive.

Testimonials

Whenever feasible and with the consent of the individuals involved, we shared disability-related testimonials from our program recipients and partners. In instances where this was not possible, including cases assessed as high risk due to concerns about disability-related stigma, we relied on publicly available content.

Impact

We welcome feedback about your experiences with this guide so we may develop a better understanding of its impact and partner in its successful use. Please share your comments and recommendations by emailing us at kupenda@kupenda.org



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ALBINISM

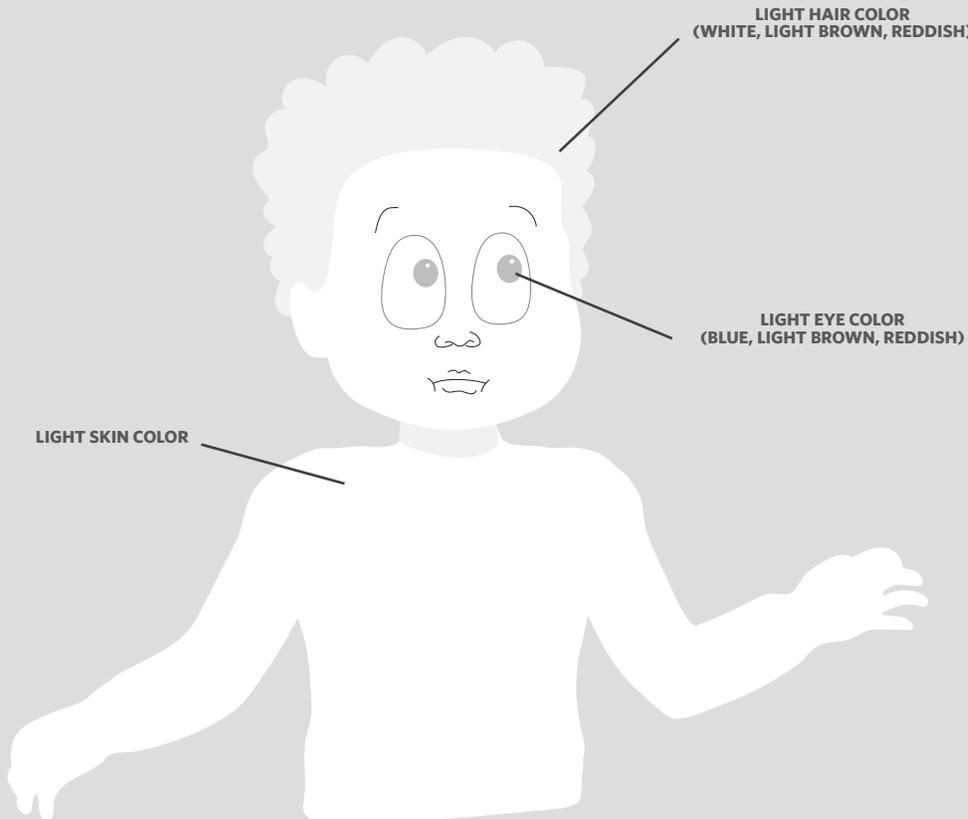


DESCRIPTION ^{4, 5}

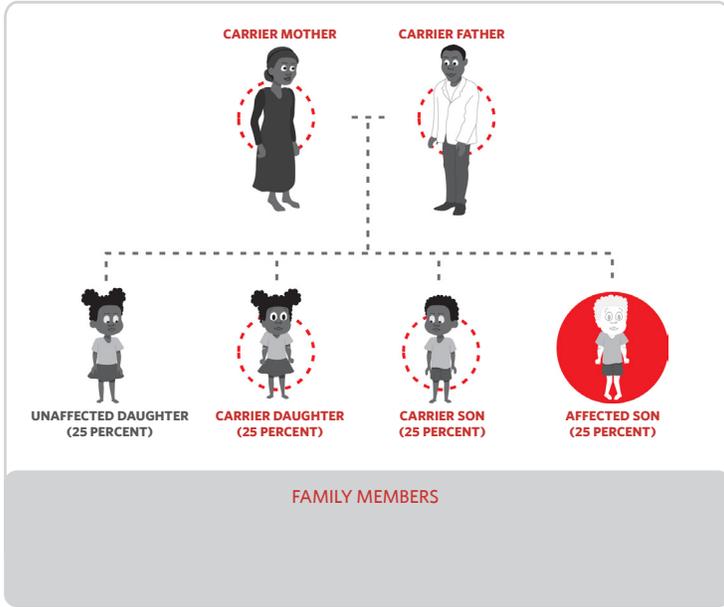
Little or no melanin (dark pigment), which is responsible for providing color to skin, hair, eyes, and the nerves in the eyes that are responsible for sight.

1 out of every 17,000 to 20,000 people has albinism globally. In African countries, 1 out of every 5,000 to 15,000 people has albinism; though in some populations, it is as high as 1 out of every 1,000 people. ^{1, 2, 3}

SIGNS AND SYMPTOMS ^{6, 7}



POSSIBLE CAUSES AND RISK FACTORS⁸



- Males or females may have the condition equally.
- If a child has the condition and the parents do not, both parents carry the genes for the condition.
- A child may or may not have family members with the condition.



REHEMA AND ALII

This brother and sister were born with albinism, although both parents are black. The father knew that he had a family history of albinism, but since he was educated about the condition, he did not view it as a problem. Today the children are enrolled in a mainstream school and protect their skin from the sun by wearing hats and sun lotions. Both of them are loved, well-cared for, and enjoy activities like any other child.

In other parts of the world, however, people with albinism live in dangerous circumstances. According to Amnesty International, in some parts of Africa, albino body parts are mistakenly thought to bring wealth and power. People with albinism are killed and their parts are sold for money. Others erroneously believe that sexual acts with a person with albinism will cure HIV and AIDS. To combat this negative stigma, albino rights groups are working to help others understand albinism and create a safer, more understanding environment.

Art Director: Amy Allaire | www.amyallaire.com
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INTERVENTIONS^{9,10}

Professional



EYEGASSES



SEE DOCTOR REGULARLY TO BE SURE THERE IS NO SKIN CANCER

Family/Community



ENROLL IN MAINSTREAM SCHOOL



PROTECT SKIN AND EYES FROM THE SUN USING CLOTHING, HATS, SUNGLASSES, AND CREAMS



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



JOIN/FORM A SUPPORT GROUP

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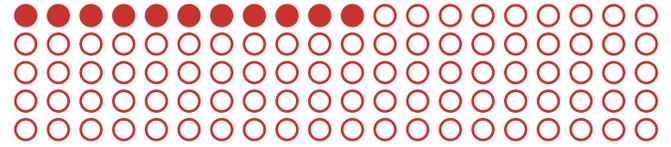
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ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)



7 out of every 100 children
18 and younger have ADHD.¹

DESCRIPTION ^{2, 3, 4}

Characterized by trouble focusing, difficulty controlling their actions, and seeming more active than others their age

SIGNS AND SYMPTOMS ^{5, 6, 7}

Many people exhibit the symptoms below at one time or another, but people with ADHD have some or all of these symptoms, which may interfere with how they function socially, at school, or in a job.



EASILY DISTRACTED



MOVE AROUND A LOT



MAKE SMALL MOVEMENTS WHILE SITTING



MAKE RASH DECISIONS



DIFFICULTY LISTENING



UNORGANIZED



COMPLETE TASKS LATE



FORGETFUL



TALKATIVE

POSSIBLE CAUSES AND RISK FACTORS ^{8,9}



FAMILY MEMBERS
with ADHD



DAMAGE
to certain parts of
brain before birth



PREGNANT MOTHER
SMOKING OR
DRINKING ALCOHOL



PREMATURE
child is born
too early

INTERVENTIONS ^{10,11}

Professional



MEDICATIONS



REGULAR CHECKUPS

Family/Community



LIMIT DISTRACTIONS



PHYSICAL ACTIVITY



KEEP REGULAR SCHEDULE



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



REWARD GOOD BEHAVIOR



JOIN/Form A SUPPORT GROUP



SIMONE BILES ^{12,13}

Simone Biles is an Olympic gymnast who won hearts across the country with her 2016 gymnastic performance. Her powerful tumblers and gravity-defying beam routines set hearts ablaze and earned her the 2016 Olympic individual all-around, vault, and floor gold medals.

After the Olympics were over, leaked drug tests from the Olympic committee showed that Biles tested positive for methylphenidate. This drug is also known as Ritalin. It's prescribed to many individuals with attention disorders. As Biles stated, "I have ADHD and I have taken medicine for it since I was a kid. Having ADHD, and taking medicine for it, is nothing to be ashamed of [and] nothing that I'm afraid to let people know."

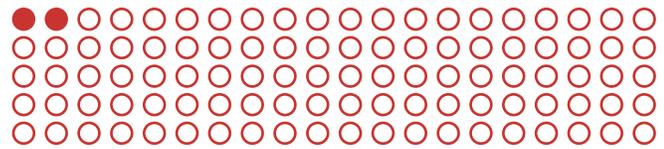
Art Director: Amy Allaire | www.amyallaire.com
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NOTES

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AUTISM SPECTRUM DISORDER



2 out of every 100 people have autism spectrum disorder.¹

DESCRIPTION ^{2,3,4}

Autism spectrum disorder (ASD) results in a broad range of characteristics that impact a person's social interactions, communication, behavior, emotions, senses, and thinking.

SIGNS AND SYMPTOMS ^{5,6,7}

Many people exhibit the symptoms below at one time or another, but people with ASD have some or all of these symptoms, which may interfere with how they function socially, at school, or at work. A child with ASD may have:

<p>CHALLENGE WITH LANGUAGE OR SPEECH</p>	<p>STRONG REACTIONS TO STIMULUS</p>	<p>A PREFERENCE TO PLAY ALONE</p>	<p>DIFFICULTY EXPRESSING EMOTION</p>	<p>ISSUES IGNORING SOMEONE TALKING TO HIM/HER</p>	
<p>DIFFICULTY KEEPING EYE CONTACT</p>	<p>A DISLIKE FOR BEING HUGGED</p>	<p>A DESIRE FOR CONSISTENT ROUTINE</p>	<p>EXTREME ATTACHMENT TO OBJECTS</p>	<p>REPETITIVE BEHAVIORS</p>	
<p>UNUSUAL SLEEP PATTERNS</p>	<p>INAPPROPRIATE LAUGHING OR CRYING</p>	<p>LIMITED FOOD PREFERENCES</p>	<p>LOTS OF ENERGY OR MOVEMENT</p>	<p>LEARNING CHALLENGES</p>	<p>HIGH INTELLIGENCE</p>

POSSIBLE CAUSES AND RISK FACTORS ⁸



BRAIN STRUCTURE
difference in brain structure and function from birth



FAMILY MEMBERS
who have ASD



POSSIBLE RISKS:
factors such as environment, infections, and parents' age

INTERVENTIONS ^{9,10}

Professional



MEDICATIONS FOR SYMPTOMS



SPEECH THERAPY

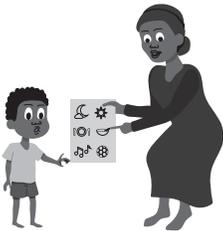


SPECIALIZED EDUCATION

Family/Community



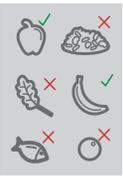
KEEP REGULAR SCHEDULE



COMMUNICATE WITH PICTURES OR GESTURES



HAVE A PLACE TO GO WHEN UPSET



LEARN FOOD PREFERENCES



KEEP FROM WANDERING TOWARD DANGER



DISTRACT FROM DANGEROUS ACTIVITY



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



DO NOT LOCK IN ROOM ALONE



AVOID CAUSES OF NEGATIVE BEHAVIOR



REWARD GOOD BEHAVIOR



JOIN/FORM A SUPPORT GROUP



BRIAN

When Brian was starting to show signs of autism, his family believed he was deaf. This was because he didn't have speech and didn't respond to people when they spoke to him. However, they later observed him humming songs he had heard, revealing he could hear after all. By the time Brian was six years old, he was diagnosed with autism.

With support from Kupenda/Kuhenza and teachers that understood his autism, Brian had access to the tools he needed to progress. When he first started school, he could not communicate his needs, focus, or interact with others. Now he can gesture to interact with others, has improved in his concentration, and enjoys playing with his peers.

Kuhenza/Kupenda also counseled Brian's family to help them understand his autism. Today they accept him for who he is and are very grateful for all he is able to do.

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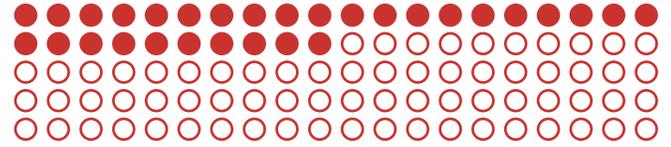
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10. "Autism Spectrum Disorder," Centers for Disease Control and Prevention.



BLINDNESS AND VISUAL IMPAIRMENT



3 out of every 10 people have a visual impairment and at least half of these cases are preventable.^{1,2}

DESCRIPTION^{3,4}

People with complete blindness cannot see anything, including light. Others might have some vision but not enough to successfully do daily activities at home, school, or work.

SIGNS AND SYMPTOMS^{5,6,7}

(People with blindness or visual impairment have some or all of these signs and symptoms.)



EYES DO NOT FOLLOW OBJECTS OR PEOPLE AS THEY MOVE



LOOK AT THINGS WITH ONE OR BOTH EYES PARTIALLY CLOSED



EYES MAY SEEM TO LOOK IN DIFFERENT DIRECTIONS FROM ONE ANOTHER



WHITE OR GRAYISH WHITE COLOR IN THE MIDDLE OF THE EYE



EYES THAT MOVE QUICKLY FROM SIDE TO SIDE OR UP AND DOWN



EYE PAIN

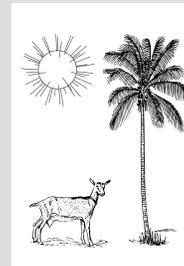


WATERY EYES



HEADACHES

EXAMPLES OF WHAT A PERSON WHO IS BLIND OR VISUALLY IMPAIRED SEES OR DOESN'T SEE⁸



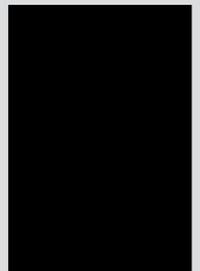
CHILD WITH NO EYE PROBLEMS



PARTLY BLIND



ONLY SEES LIGHT

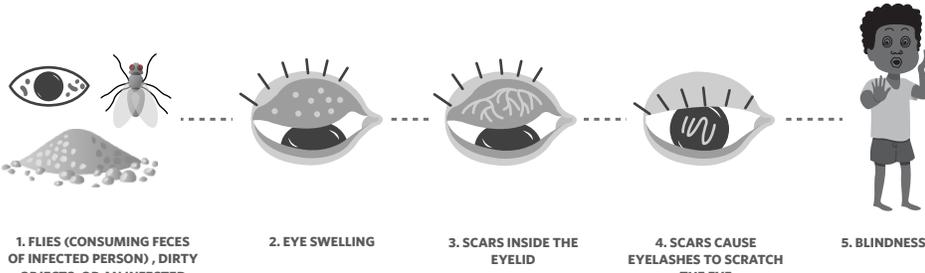


COMPLETELY BLIND

POSSIBLE CAUSES AND RISK FACTORS ^{9, 10, 11}

 <p>INFECTION like trachoma, measles, herpes, conjunctivitis, and parasites</p>	 <p>DRY EYE from lack of vitamin A found in milk, eggs, vegetables</p>	 <p>DAMAGE TO EYE from chemicals or object</p>	 <p>DIABETES inability to process sugar or starch without artificial help</p>	 <p>PARASITES that cause conditions like river blindness</p>	 <p>FAMILY MEMBERS with blindness</p>
--	--	--	---	--	--

THE LEADING CAUSE OF BLINDNESS WORLDWIDE



1. FLIES (CONSUMING FECES OF INFECTED PERSON) , DIRTY OBJECTS, OR AN INFECTED PERSON BRINGING BACTERIA TO EYES
2. EYE SWELLING
3. SCARS INSIDE THE EYELID
4. SCARS CAUSE EYELASHES TO SCRATCH THE EYE
5. BLINDNESS

Trachoma is a disease that can cause blindness and visual impairment in about 1.9 million people every year. Poor communities in rural areas of Africa, Central and South America, Asia, Australia, and the Middle East are most affected.

Poverty, poor sanitation habits, and overcrowded areas are common factors that encourage the spread of the disease.



ATHUMAN

Athuman is a 12 year old boy who is hard of hearing and has a visual impairment. He currently attends Kwale School for the Deaf. He understands tactile sign language and can follow instructions. He can also walk alone around the classroom and to the toilet. He is doing well and his teacher is planning to move him to the pre-vocational class.

At school, Athuman also participates in sporting activities such as acrobatics, track and field, and walking with guidance. He also took part in the national games and has been featured on the Kenyan television show "Able Differently."

At home, he likes discovering new places through touch and even climbs very tall trees. Although his parents separated for a while, they have now reunited. They love and accept their son, as does his whole community.

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INTERVENTIONS ^{12, 13, 14}

Professional



SURGERIES

SPECIALIZED EDUCATION

GLASSES FOR THOSE WHO HAVE SOME SIGHT

Family/Community



CANE OR STICK TO HELP HIM/HER GET AROUND

HELP FROM ANOTHER PERSON TO GET AROUND

HEALTHY DIET

JOIN/FORM A SUPPORT GROUP

NOTE: When interacting with the person who is blind, tell him/her what is happening around him/her and what you are going to do that involves him/her. (Example: Tell him/her that you are going to wipe his/her nose.)

INTERVENTIONS CONTINUED . . .

Family/Community



DO NOT MOCK OR STARE

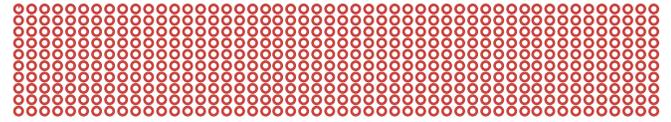
DO NOT ABUSE OR
PHYSICALLY PUNISH

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BRITTLE BONE DISEASE (OSTEOGENESIS IMPERFECTA)



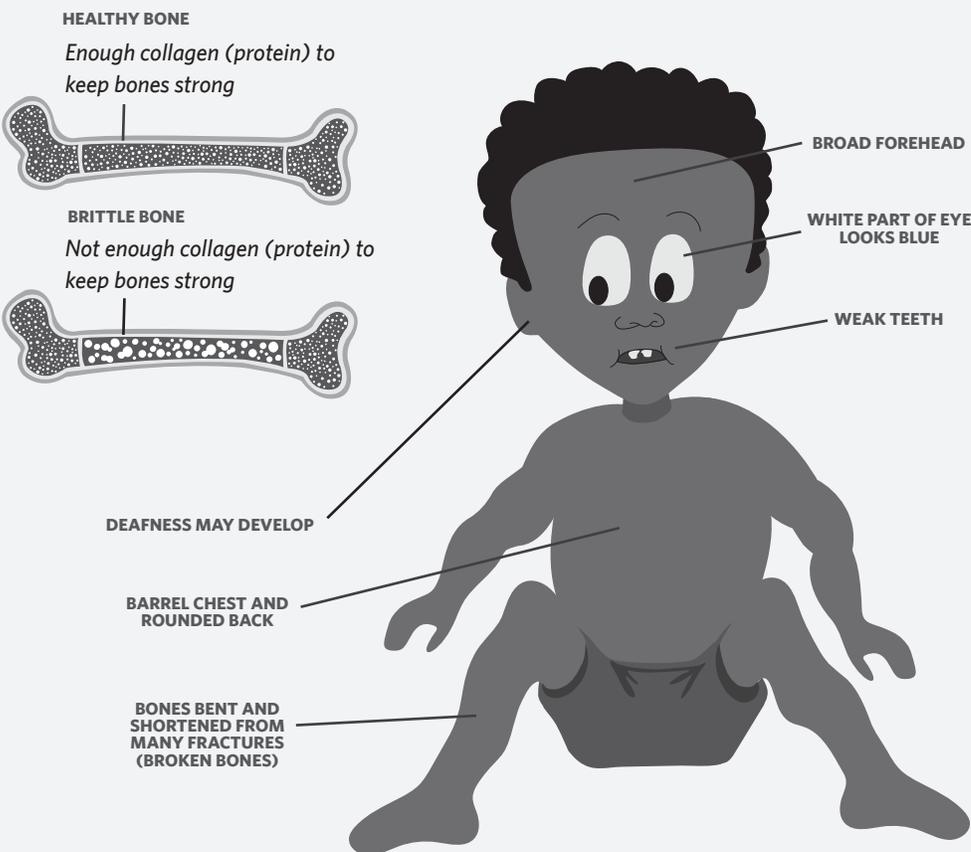
1 out of every 10,000 people have brittle bone disease.¹ One open dot = 10

DESCRIPTION^{2,3}

Brittle bone disease is a genetic disorder in which children are born with little to none of the proper protein (collagen) needed for healthy bones. This causes bones to be weak and break with little to no cause.

SIGNS AND SYMPTOMS^{4,5,6,7}

People with this condition may have some or all of these signs and symptoms.



BROKEN BONES WITHOUT CLEAR CAUSE



DELAYED SITTING, STANDING, CRAWLING, AND WALKING



HEARING LOSS (50%)



SHORTER THAN OTHERS THEIR AGE

POSSIBLE CAUSES AND RISK FACTORS ^{8,9}



FAMILY MEMBERS
with this condition (75%
chance of child having it)



DAMAGE TO THE GENES
information passed from
either parent to the child
during formation

INTERVENTIONS ^{10,11,12}

Note: There is no cure for this condition, but there are some interventions that can improve the life of a person with brittle bones.

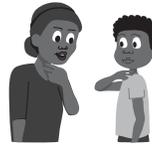
Professional



**MEDICATIONS
FOR SYMPTOMS**



**SURGERIES TO
SUPPORT BONES**



SPEECH THERAPY



PHYSICAL THERAPY

Family/Community



**TAKE TO DOCTOR
WHEN THERE ARE
BONE BREAKS**



HEALTHY DIET



**AVOID ACTIVITIES
THAT COULD CAUSE
BONE BREAKS**



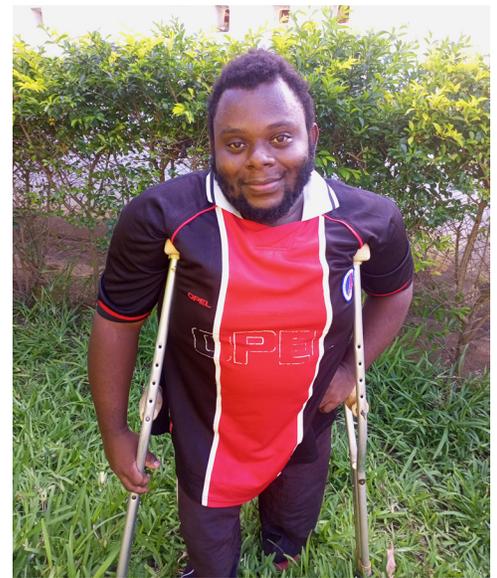
DO NOT MOCK OR STARE



**JOIN/FORM A
SUPPORT GROUP**



**DO NOT ABUSE OR
PHYSICALLY PUNISH**



CARLOS

Carlos is a young man living with brittle bone disease. Although he has five siblings, he is the only one with this condition.

His parents were concerned when Carlos experienced his first broken bone at one month old. As he was growing up, Carlos continued to break bones easily while playing or even sleeping.

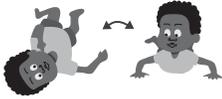
When he reached school age, he attended a mainstream school nearby. During his time there, he experienced several breakages which forced him to spend time in the hospital.

Despite these challenges, Carlos was still able to attend a mainstream high school. Afterwards, he went on to complete a computer course.

Due to the many breakages he experienced at a young age, Carlos is shorter in stature than the rest of his family. However, this did not limit his ability to receive an education and dream about his future!

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

Family/Community (For those who are unable or have difficulty moving on their own)



CHANGE THEIR POSITION OFTEN



ENSURE THEY HAVE CLEAN CLOTHES



BATHE THEM AFTER SOILING THEMSELVES



USE TOILET ADAPTATION



PROVIDE PAMPERS (NAPKINS)



PROVIDE ASSISTANCE DEVICES

NOTES

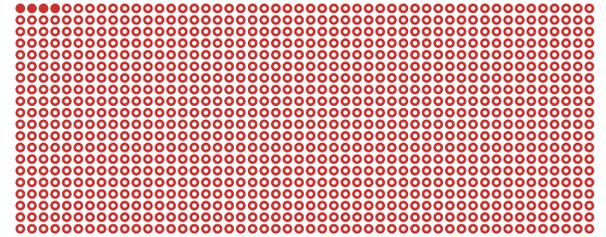
1. Surabhi Subramanian et al., "Osteogenesis Imperfecta," *StatPearls* (February 6, 2023). <https://www.ncbi.nlm.nih.gov/books/NBK536957/>.
2. Subramanian et al., "Osteogenesis Imperfecta."
3. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 126.
4. Subramanian et al., "Osteogenesis Imperfecta."
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6. Afsaneh Khetratal, "Types of Osteogenesis Imperfecta (OI): Brittle Bone Disease," News Medical, last modified December 22, 2022, <https://www.news-medical.net/health/Types-of-Osteogenesis-Imperfecta-%28OI%29-Brittle-Bone-Disease.aspx>.
7. "Osteogenesis Imperfecta: Overview," National Institutes of Health: Osteoporosis and Related Bone Diseases National Resource Center, last modified July 2019, <https://www.bones.nih.gov/health-info/bone/osteogenesis-imperfecta/overview>.
8. Werner, *Disabled Village Children*, 126.
9. "What Causes Osteogenesis Imperfecta (OI)?" National Institutes of Health, last modified December 20, 2021, <https://www.nichd.nih.gov/health/topics/osteogenesisimp/conditioninfo/causes#:~:text=Mutations%20in%20several%20genes%20can,collagen%20or%20too%20little%20collagen>.
10. Werner, *Disabled Village Children*, 126.
11. Subramanian et al., "Osteogenesis Imperfecta."
12. "What are the treatments for Osteogenesis Imperfecta (OI)?" National Institutes of Health, last modified December 20, 2021, <https://www.nichd.nih.gov/health/topics/osteogenesisimp/conditioninfo/treatments>.



CEREBRAL PALSY

DESCRIPTION ²

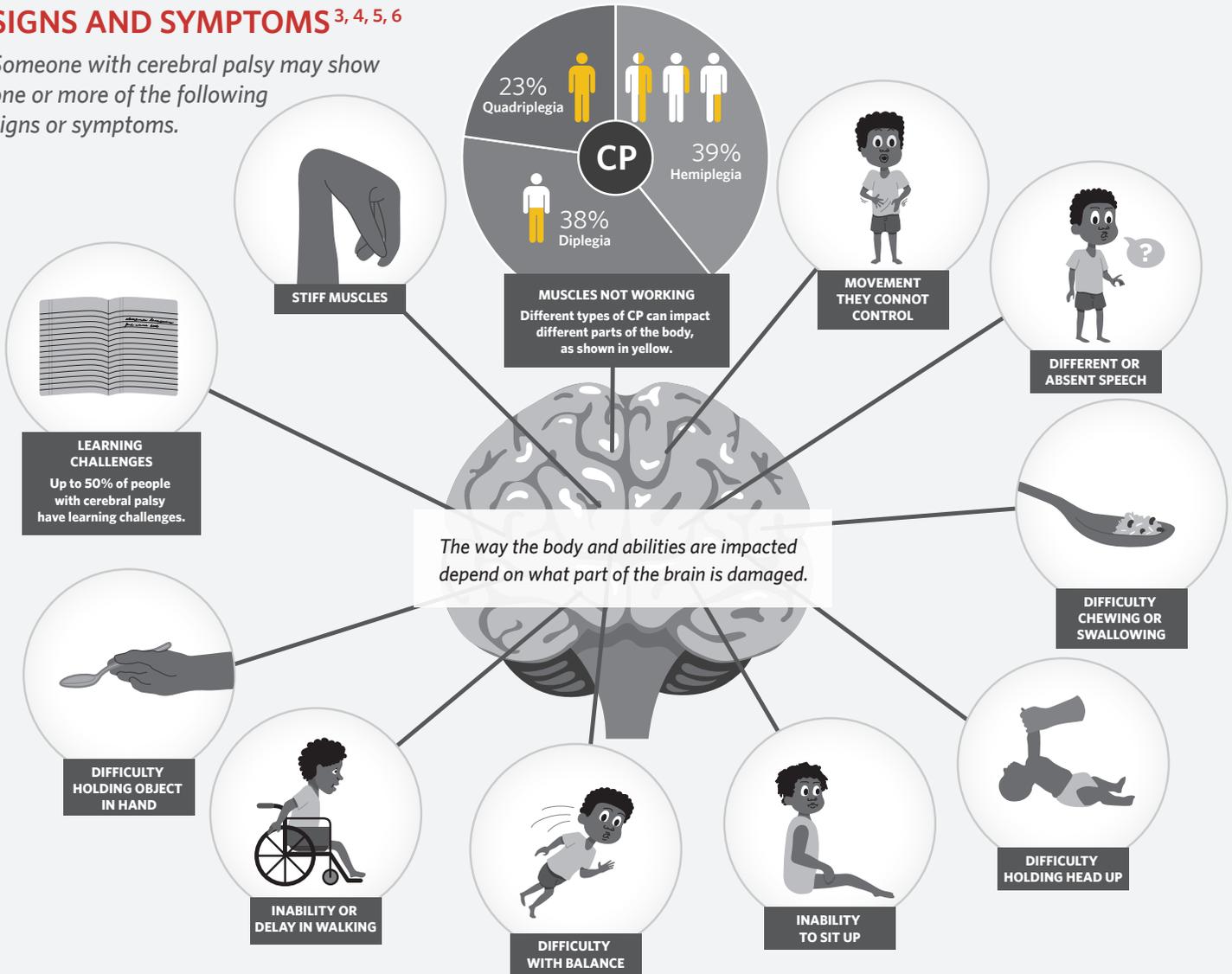
Cerebral palsy (CP) is caused by brain damage to children below the age of 5 that impacts their muscles and ability to move and balance. The damage to the brain does not get worse over time, but new challenges may occur as they age.



1-4 out of every 1,000 people have cerebral palsy.¹

SIGNS AND SYMPTOMS ^{3, 4, 5, 6}

Someone with cerebral palsy may show one or more of the following signs or symptoms.

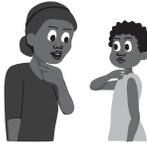


POSSIBLE CAUSES AND RISK FACTORS 7, 8, 9

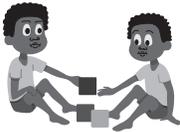
 <p>DAMAGE to certain parts of brain before or during birth or in early years</p>	 <p>OXYGEN DEPRIVATION before or during delivery or from other conditions</p>	 <p>PREMATURE BIRTH child is born too early</p>	 <p>INFECTION from diseases that damage the brain</p>	 <p>INJURY to the brain from accidents</p>
--	---	---	---	--

INTERVENTIONS 10, 11, 12, 13

Professional

 <p>MEDICATIONS</p>	 <p>SURGERIES</p>	 <p>PHYSICAL THERAPY</p>	 <p>SPEECH THERAPY</p>	 <p>SPECIALIZED EDUCATION</p>
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Family/Community

 <p>HEALTHY DIET</p>	 <p>DAILY PLAY</p>	 <p>HOME-BASED THERAPY</p>
 <p>DO NOT MOCK OR STARE</p>	 <p>DO NOT ABUSE OR PHYSICALLY PUNISH</p>	 <p>JOIN/FORM A SUPPORT GROUP</p>

Family/Community (For those with trouble swallowing)

(AROUND 30% OF CHILDREN WITH CEREBRAL PALSY MAY HAVE THIS PROBLEM)

<p>FEED THEM SMALL AMOUNT AT A TIME</p>  <p>MAKE SOFT FOOD</p>	 <p>FEED CHILD IN SEATED POSITION</p>
---	---



JEREMY

Jeremy has CP that limits his ability to move his arms and legs and speak clearly. When he was younger, his mother abandoned him because he had a disability.

Since he could not walk, his grandmother carried him everywhere on her back. Most people in Jeremy's community believed his CP was caused by a curse. They did not believe he would be successful in life. As a result, Jeremy lived in isolation from his community.

Fortunately, Jeremy's life was transformed when Kupenda/Kuhenza helped him to enroll in a school. There he received therapy services and an education. He also met many friends, including his best friend, Mohamed, who also has CP.

Jeremy is now a disability advocate in his community and works to protect other children with disabilities from abuse.

Thanks to therapy, he is also able to walk, though slightly imbalanced. Mohamed helps Jeremy to walk more steadily by letting him push his wheelchair.

Jeremy and Mohamed can always be found telling each other stories, though others may not understand their speech. They show the world the value of friendship and helping others.

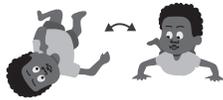
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

INTERVENTIONS CONTINUED . . .

Family/Community (For those who are unable or have difficulty moving on their own)



**ENSURE THEY HAVE
CLEAN CLOTHES**



**CHANGE THEIR
POSITION OFTEN**



**PROVIDE PAMPERS
(NAPKINS)**



USE TOILET ADAPTATION



**BATHE THEM AFTER
SOILING THEMSELVES**



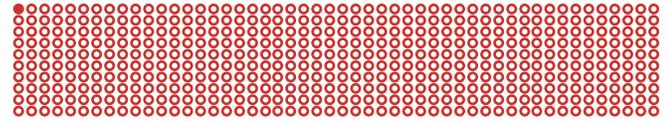
**PROVIDE ASSISTANCE
DEVICES**

NOTES

1. "Data and Statistics for Cerebral Palsy," Centers for Disease Control and Prevention, last modified December 31, 2020, <https://www.cdc.gov/ncbddd/cp/data.html>.
2. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention, last modified March 1, 2021, <https://www.cdc.gov/ncbddd/cp/features/cerebral-palsy-11-things.html>.
3. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
4. "What Is Cerebral Palsy?" Centers for Disease Control and Prevention, last modified September 2, 2021, <https://www.cdc.gov/ncbddd/cp/facts.html>.
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6. "Cerebral Palsy: Hope Through Research," NIH: National Institute of Neurological Disorders and Strokes, last modified September 29, 2021, <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Cerebral-Palsy-Hope-Through-Research>.
7. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 87-112.
8. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
9. "Cerebral Palsy: Hope Through Research," NIH: National Institute of Neurological Disorders and Strokes.
10. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
11. "What Is Cerebral Palsy?" Centers for Disease Control and Prevention.
12. "Cerebral Palsy: Hope Through Research," NIH: National Institute of Neurological Disorders and Strokes.
13. Werner, *Disabled Village Children*, 87-112.



CLEFT LIP AND PALATE



1 out of every 500 to 700 babies are born with cleft lip or palate.^{1,2}

DESCRIPTION ^{3, 4, 5}

Cleft (divided) lip and cleft palate are birth defects that occur when a baby's lip and/or top of the inside of the mouth (palate) don't completely form in a baby by the time he/she is born.

SIGNS AND SYMPTOMS ^{6, 7, 8}

These are the different forms of cleft lip and palate. A child can have a normal looking lip but have a cleft palate or can have a cleft lip without a cleft palate.



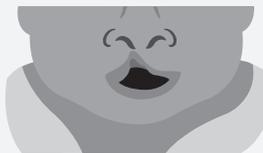
NORMAL LIP



UNILATERAL CLEFT LIP AND PALATE INCOMPLETE



BILATERAL CLEFT LIP AND PALATE INCOMPLETE



UNILATERAL INCOMPLETE



NORMAL PALATE



CLEFT LIP



BILATERAL CLEFT LIP



CLEFT PALATE



UNILATERAL CLEFT LIP AND PALATE



BILATERAL CLEFT LIP WITH FULL PALATE

OTHER SIGNS AND SYMPTOMS ^{9, 10, 11}

There is wide variation in the number, type, and severity of signs and symptoms people experience.



DIFFICULTY SWALLOWING



DIFFICULTY BREASTFEEDING



CRYING SOUNDS LIKE IT IS COMING FROM NOSE



HEARING LOSS



TEETH PROBLEMS

POSSIBLE CAUSES AND RISK FACTORS ^{12, 13, 14}



FAMILY MEMBERS
with cleft lip or
palate



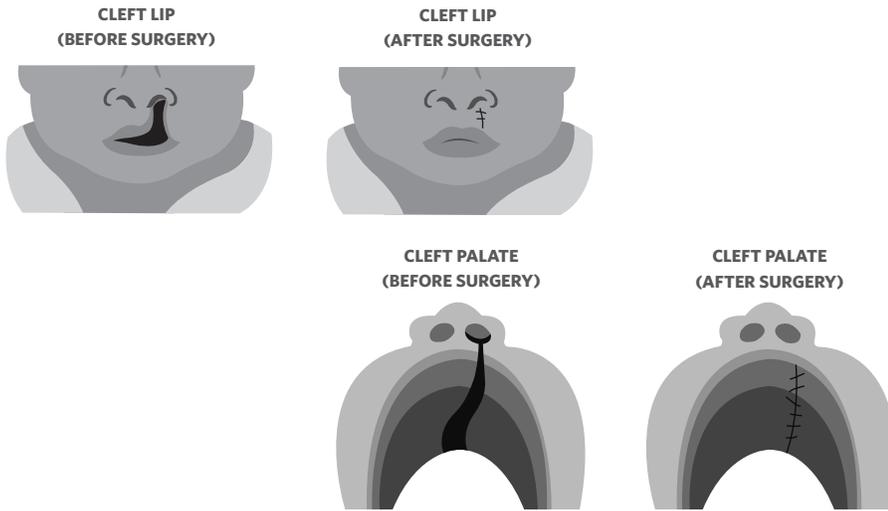
PREGNANT MOTHER
SMOKING OR
DRINKING ALCOHOL



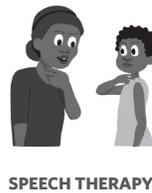
MANY UNKNOWN
CAUSES

INTERVENTIONS ^{15, 16}

Professional Interventions: Surgery



Additional Professional Interventions



Family/Community



SOMAYA ¹⁷

When Somaya was born with a cleft lip and palate, her father abandoned her. Her mother, Neny, however, never stopped praying for her daughter to be healed. Even when neighbors encouraged her to give Somaya away to an orphanage, Neny would not listen. "Somaya is a gift from God," she would say.

Somaya's lips made forming words nearly impossible. She had trouble eating and drinking. "She was always sick," Neny said. "She was always coughing." When it seemed all hope was lost, Somaya had surgery through an organization called Mercy Ships, where she met other families with cleft palates.

After Somaya's surgery, Neny couldn't stop smiling herself. "Now she is healthy!" she declared. "Now she can eat and drink normally. ... She says, 'Water, Mamma!'" As they prepared to return to their village, Neny couldn't wait to show her neighbors Somaya's sweet new smile. "They will be amazed to see her back with these lips," she said with a grin.

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

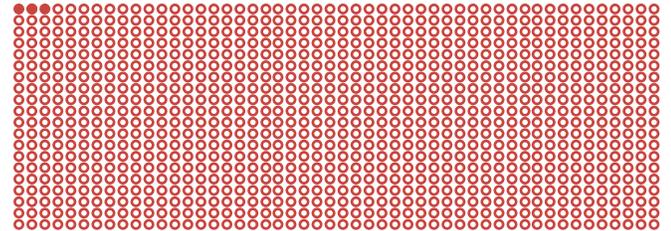
1. Alexis Caitlin Lanteri et al., "A Cross-Sectional Comparison of Cleft Lip Severity in 3 Regional Populations," *Eplasty* 12, no. 10 (February 3, 2012).
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3273313/#:~:text=While%20of%20children,every%20500%20to%20600%20births>.
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3. Werner, *Disabled Village Children*, 121.
4. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention, last modified December 16, 2022, <https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>.
5. Neelam Phalke and Joshua J. Goldman, "Cleft Palate," *StatPearls* (September 26, 2022).
<https://www.ncbi.nlm.nih.gov/books/NBK563128/>.
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8. Phalke and Goldman, "Cleft Palate."
9. Werner, *Disabled Village Children*, 121.
10. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
11. Phalke and Goldman, "Cleft Palate."
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13. "Cleft Lip and Palate," National Institute of Craniofacial Research, last modified January 2021, <https://www.nidcr.nih.gov/health-info/cleft-lip-palate>.
14. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
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16. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
17. Mercy Ships, "A Floating Hospital. A Second Chance," Stena Line, accessed July 3, 2023, <https://blog.stenaline.com/mercy-ships/a-floating-hospital-a-second-chance/>.



CLUBFOOT

DESCRIPTION ^{2, 3, 4}

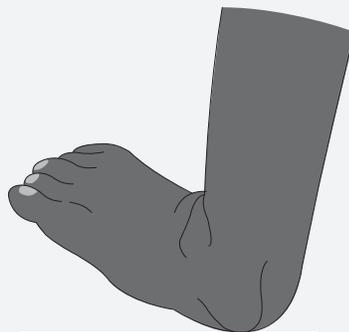
Clubfoot is a condition where one or both feet are in an uncommon position because tissues that connect muscles to bone in a baby's leg and foot are shorter than normal.



3 out of every 1,000 children are born with clubfoot or feet.¹

SIGNS AND SYMPTOMS ^{5, 6, 7}

One or both feet may look like any of these.



POSSIBLE CAUSES AND RISK FACTORS ^{8, 9, 10}



FAMILY MEMBERS
who have clubfoot

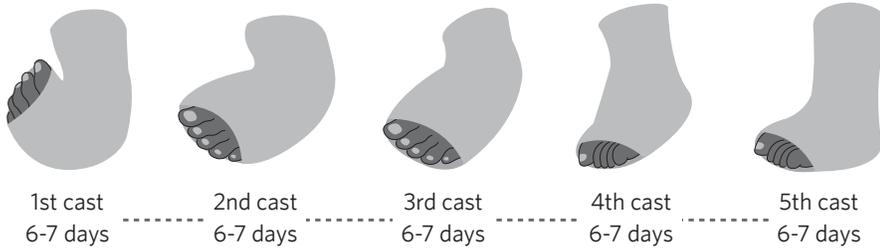


UNKNOWN CAUSES

INTERVENTIONS ^{11, 12, 13}

Professional Interventions: Casting

If caught early, medical professionals will often cast the impacted leg(s) to correct the clubfoot. This will vary depending on the severity.



Note: Family and community members should keep the cast dry and clean. They should also check the foot/feet every day for any dark coloring or coldness in the toes to make sure the cast is not too tight. Take the child to the doctor if there is a fever, foul odor, or liquid coming from the cast or rashes/redness around the cast.

Additional Professional Interventions



SURGERIES



REGULAR CHECKUPS

Family/Community



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



CANE OR STICK TO HELP THEM GET AROUND



JOIN/FORM A SUPPORT GROUP



JECINTA ¹⁴

Seventeen years ago when Jecinta was born, her mother noticed that her feet looked unusual. As Jecinta continued to mature, her condition deteriorated. Her two feet twisted in the wrong direction. Her gait was also affected; she fell almost every time she walked. Due to a lack of information and finances, the family did not receive any assistance.

Doctors informed Jecinta that she had clubfoot. The good news was that it could be corrected! Surgeons performed a surgery to correct and align her feet. The operation helped Jecinta move around without much difficulty and alleviated her pain. It also significantly boosted her self-esteem, which will, in turn, make her more likely to pursue her dreams.

Jecinta has now fully recovered thanks to CURE Kenya!

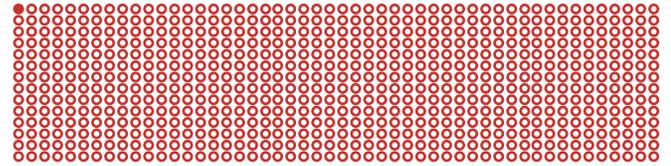
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

1. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 115.
2. Werner, *Disabled Village Children*, 115.
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<https://www.ncbi.nlm.nih.gov/books/NBK551574/>.
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<https://www.cdc.gov/ncbddd/birthdefects/surveillancemanual/chapters/chapter-4/chapter4.9a.html>.
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6. Barrie and Varacallo, "Clubfoot."
7. "Birth Defects Surveillance Toolkit," Centers for Disease Control and Prevention.
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14. "New Hope for Jecinta," CURE International, last modified June 6, 2019,
<https://cure.org/2019/06/new-hope-for-jecinta/>.



DOWN SYNDROME



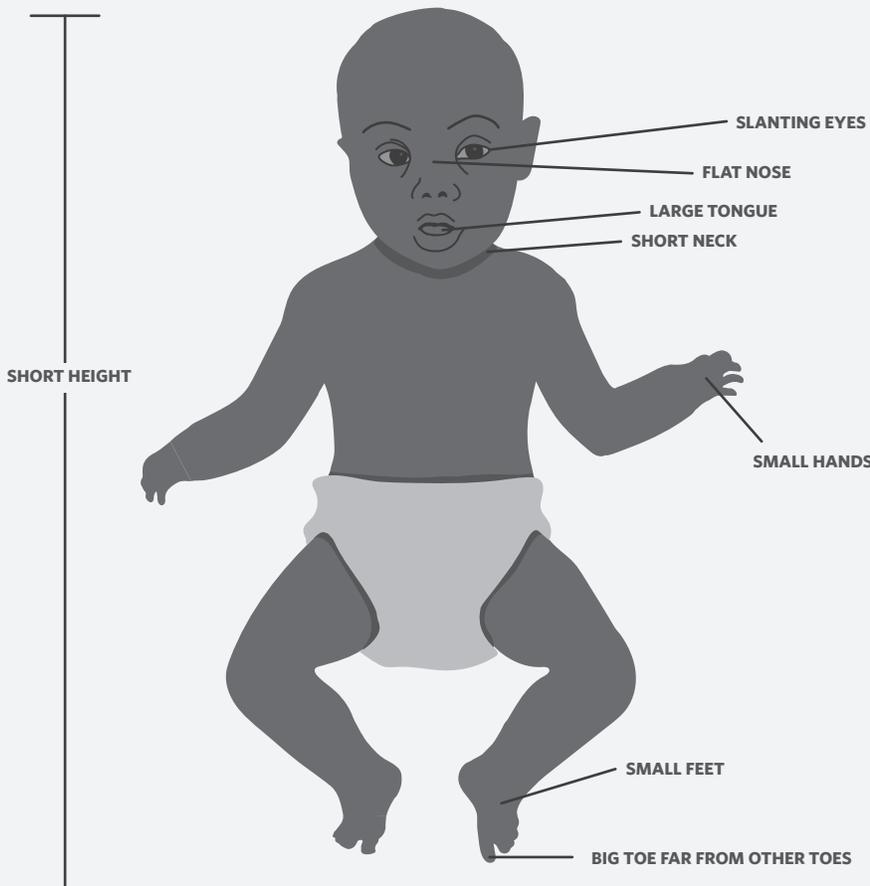
1 out of every 700 babies is born with Down syndrome.¹

DESCRIPTION ^{2, 3, 4}

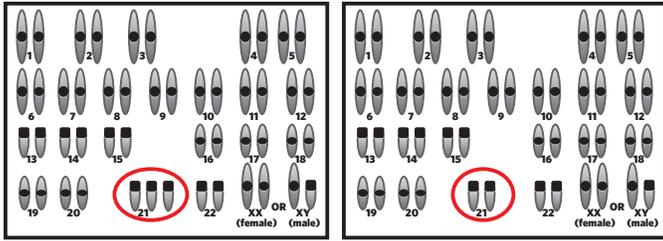
Down syndrome is the result of a specific extra chromosome (packet of information from the mother and father) that exists in a baby before birth. This condition results in lowered learning abilities and some physical differences and challenges.

SIGNS AND SYMPTOMS ^{5, 6, 7}

There is wide variation in the number, type, and severity of signs and symptoms people experience.



POSSIBLE CAUSES AND RISK FACTORS ^{8, 9, 10, 11}



EXTRA COPY OF THE 21ST CHROMOSOME
(packet of information from father or mother)

*Note: 50% to 80% of babies with Down syndrome are born to women under 35 years old, but there is a higher percentage of Down syndrome births to people under 20 and over 35 years. ^{12, 13, 14}

INTERVENTIONS ^{15, 16, 17}

Professional



HEARING AIDS



MEDICATION FOR SYMPTOMS



SURGERIES



SPEECH THERAPY

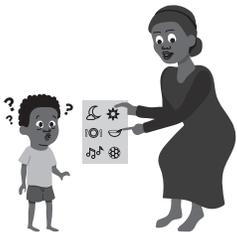


PHYSICAL THERAPY



SPECIALIZED EDUCATION

Family/Community



HAVE PATIENCE AS THEY LEARN THINGS SLOWER THAN OTHERS



DO NOT MOCK OR STARE

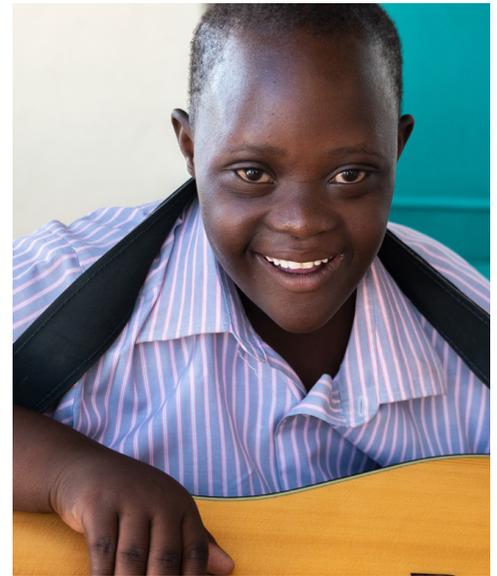


JOIN/FORM A SUPPORT GROUP



DO NOT ABUSE OR PHYSICALLY PUNISH

NOTE: There is no medication or medical procedure that can remove Down syndrome, but these interventions can improve a person's quality of life.



PETER

Peter is a 12-year-old with Down syndrome who lives on the coast of Kenya. Before he was born, his father, a pastor, thought disabilities were caused by witchcraft or were a punishment from God. Eventually, his father met other pastors who had learned that anyone can have a disability and that everyone is deserving of love. He also grew to recognize the importance of pastors sharing this message with others.

By the time Peter was born, his father accepted his son and taught his family and community to do the same. Today, Peter has a family that loves him and is part of a school that understands his needs. He enjoys music, telling jokes, and spending time with his friends. He is an example to others of what is possible when people with different types of abilities are given opportunities.

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

1. "Data and Statistics on Down Syndrome," Centers for Disease Control and Prevention, last modified June 28, 2023, <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html#:~:text=Down%20syndrome%20continues%20to%20be,in%20every%20700%20babies%20born.>
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4. "About Down Syndrome," National Institutes of Health, last modified June 20, 2018, <https://www.nih.gov/include-project/about-down-syndrome#:~:text=Down%20syndrome%20is%20a%20condition,a%20variety%20of%20birth%20defects.>
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6. Werner, *Disabled Village Children*, 279.
7. "About Down Syndrome," National Institutes of Health.
8. "What causes Down syndrome?" National Institutes of Health, last modified January 31, 2017, <https://www.nichd.nih.gov/health/topics/down/conditioninfo/causes#:~:text=Down%20syndrome%20is%20by,dis%20DJUHNGK%2Dshuhn.>
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17. "Facts about Down Syndrome," Centers for Disease Control and Prevention.



DWARFISM



Up to 1 out of every 15,000 children have some form of dwarfism. ¹ One open dot = 100

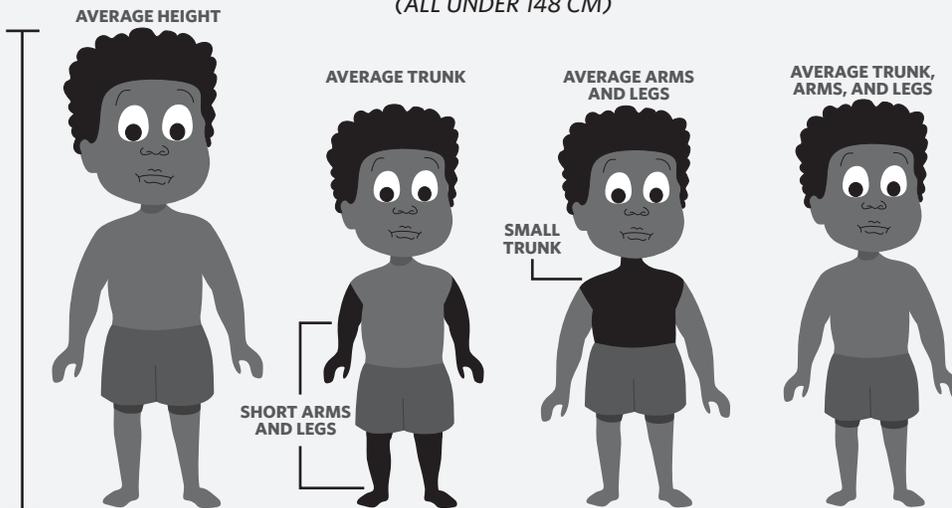
DESCRIPTION ^{2, 3, 4}

There are about 400 different conditions resulting in dwarfism. All conditions are characterized by a person reaching an adult height of less than 148 cm (4 ft 10 in).

SIGNS AND SYMPTOMS ^{5, 6, 7, 8}

(There is wide variation in the number, type, and severity of signs and symptoms people experience.)

BELOW ARE THREE OF THE MAIN CATEGORIES OF DWARFISM (ALL UNDER 148 CM)

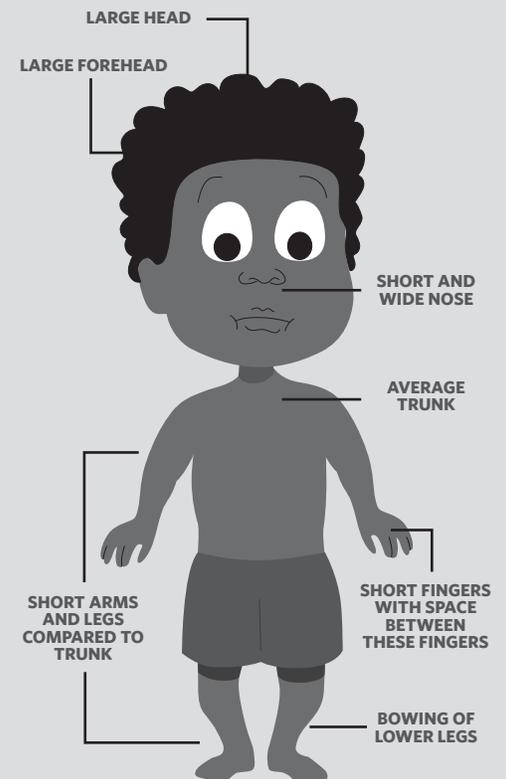


SOME HAVE BREATHING PROBLEMS, BACK PROBLEMS, OR HYDROCEPHALUS (FLUID AROUND THE BRAIN).



THE MOST COMMON TYPE OF DWARFISM IS CALLED ACHONDROPLASIA AND ACCOUNTS FOR 70% OF PEOPLE WITH DWARFISM. ⁹

ACHONDROPLASIA FEATURES



POSSIBLE CAUSES AND RISK FACTORS ^{10, 11}



MALNUTRITION

Pregnant mother or child not getting enough or the right types of food



FAMILY MEMBERS

who have dwarfism

INTERVENTIONS ^{12, 13}

Professional



SURGERIES (FOR BACK ISSUES, SEVERE BREATHING ISSUES, OR HYDROCEPHALUS)

Family/Community



ENROLL IN MAINSTREAM SCHOOL



DO NOT MOCK OR STARE



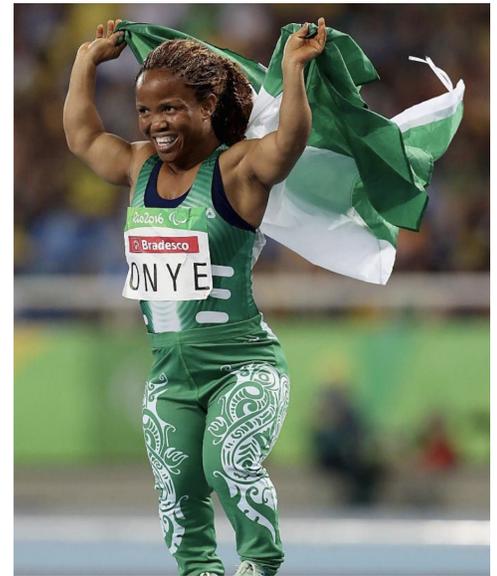
DO NOT ABUSE OR PHYSICALLY PUNISH



ENSURE PEOPLE WITH DWARFISM CAN REACH THINGS LIKE EVERYONE ELSE



JOIN/Form A SUPPORT GROUP



LAURITTA ONYE ^{14, 15}

Lauritta Onye is a Paralympian athlete with achondroplasia from Nigeria. With a history in acting, her life changed course when she pursued sports in 2007.

Competing in throwing events, she won silver at the 2011 All Africa Games. In 2015, she went on to set a new world record, earn the world title, and podium in the Rio Paralympic Games. She also became the first in her class to throw 8.40m to win Paralympic gold.

According to Onye, her disability does not prevent her from achieving. "I have determination in this; power and strength and determination in me. I can see the distance that I throw increase—look at what I threw in 2007 compared to 2011 and 2015. The more I train the more the distance that I throw is growing. I can't give up, I'm still winning," she said. Onye concluded "That's what I want - for me to be the champion. That's what pushes me, what inspires me. Determination keeps me going."

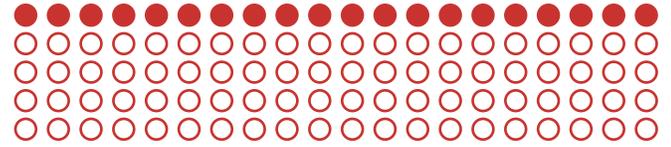
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

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DYSLEXIA



DESCRIPTION ^{2, 3, 4, 5}

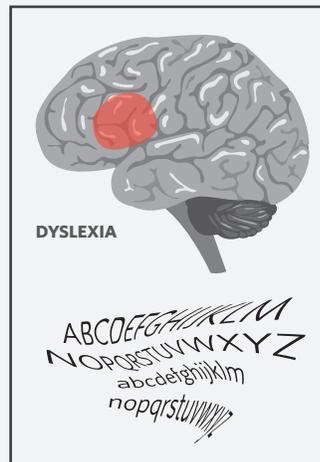
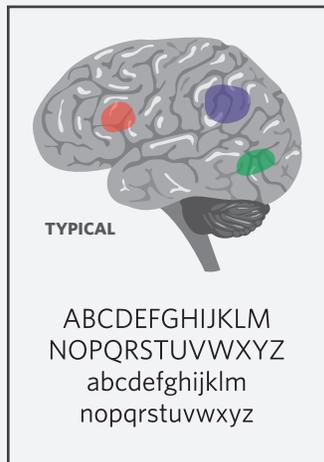
Difficulty reading, spelling, or understanding written words not connected to intelligence or lack of education

Up to **18** out of every 100 people have dyslexia.¹

SIGNS AND SYMPTOMS ^{6, 7, 8}

(There is wide variation in the number, type, and severity of signs and symptoms people experience.)

The red area is the part of the brain that connects sounds to letters. It is larger in dyslexic brains because they compensate for the less active areas (blue and green) responsible for memorizing words and learning new ones.



OTHER SIGNS AND SYMPTOMS

WITHOUT INTERVENTION INDIVIDUALS WITH DYSLEXIA COULD EXPERIENCE



WORRY



SADNESS



ANGER



DIFFICULTY READING OR DOING MATH COMPARED TO OTHERS THEIR AGE



AVOIDS READING



CHALLENGES WITH SPEECH



MEMORY PROBLEMS



TAKING LONGER THAN OTHERS TO FINISH SCHOOL WORK OR CHORES



CREATIVE THINKING

POSSIBLE CAUSES AND RISK FACTORS ^{9, 10, 11}



FAMILY MEMBERS
with dyslexia



BRAIN STRUCTURE
difference in area
connected to reading

INTERVENTIONS ^{12, 13, 14}

Family/Community



**DO NOT ABUSE
OR PHYSICALLY PUNISH**



**SPECIALIZED
EDUCATION**



**JOIN/FORM A
SUPPORT GROUP**



**REWARD GOOD
BEHAVIOR**



DO NOT MOCK OR STARE



WHOOPI ¹⁵

In her youth, Whoopi Goldberg struggled to learn and was labeled “dumb” and “lazy.” As a result, she dropped out of school and became involved in drugs..

When Goldberg realized she had dyslexia, it was lifechanging. Her mother told her that she wasn’t stupid and could be and do anything she wanted. She herself realized she couldn’t be stupid because, as she says, “If you read to me, I could tell you everything you read.” Her mother’s attitude, coupled with her own determination, took her off drugs and drove her to succeed.

Today Goldberg has an amazing career as an actress, comedian, television host, and author. Ultimately, she says thinking differently has helped her succeed.

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

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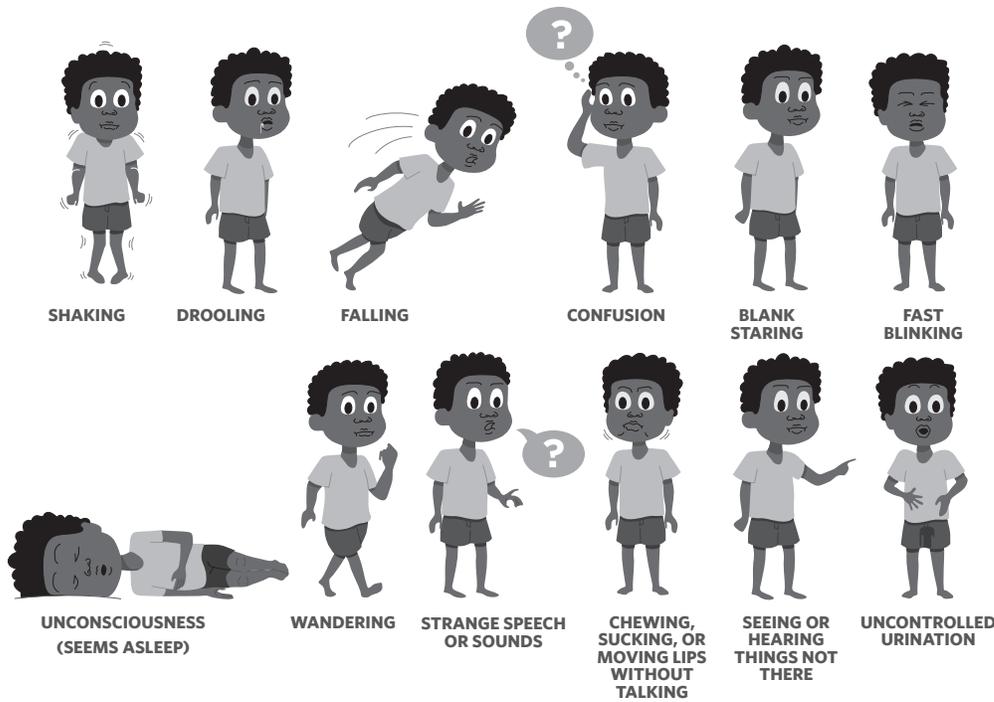
EPILEPSY

DESCRIPTION ^{2, 3}

Epilepsy is a disorder where there is a sudden change in normal brain activity which causes the person to have several seizures or “fits” over a long period of time.

SIGNS AND SYMPTOMS ^{4, 5, 6, 7, 8, 9}

Someone who is having a seizure may show one or more of the following symptoms before or during a seizure. Others may not show any signs before their seizure.



More **1** out of every 100 than people have epilepsy.¹

TRIGGERS FOR A SEIZURE

Avoiding these triggers may reduce the number of seizures a person with epilepsy experiences.



SEIZURES MAY

- Last for seconds or up to several minutes
- Lead to death or brain damage if they last longer than 30 minutes
- Not be remembered by the person who experiences them
- Cause memory loss overall, depending on the number and severity of the seizures
- Occur multiple times in a day or only once in a year (sometimes only every few years)
- Happen while the person is sleeping
- Stop when a child becomes an adult (true for half of people with epilepsy)

POSSIBLE CAUSES AND RISK FACTORS ^{10, 11, 12, 13}

 INFECTION from diseases that damage the brain	 INJURY to the head	 DISORDERS or disabilities that impact the brain	 OXYGEN DEPRIVATION to the brain	 FAMILY MEMBERS with epilepsy
--	---	--	--	--

NOTE: Epilepsy has biological causes that can be treated with medicine and is not the result of witchcraft or demons.

INTERVENTIONS ^{14, 15, 16}

Anti-seizure medication is the most effective treatment for people with epilepsy. If taken as directed by the doctor, medications may completely stop seizures for some people or reduce the frequency and severity of the seizures for others. There are also different kinds of medication. If one doesn't work, the individual should go back to the doctor to see if a different kind of medication may work better. Some people will need medicine their whole lives, while others may not need it as long.

Professional



MEDICATIONS



HELMET

Family/Community



HEALTHY DIET



TAKE MEDICINE AS DIRECTED



HAVE ENOUGH MEDICINE



ENSURE FAMILY IS TAKING THE CHILD FOR REGULAR DOCTOR VISITS



JOIN/FORM A SUPPORT GROUP



DO NOT ABUSE OR PHYSICALLY PUNISH



DO NOT MOCK OR STARE



HELP THE PERSON WHEN HE/SHE HAS A SEIZURE (SEE NEXT PAGE)



AVOID TRIGGERS (SEE PREVIOUS PAGE)



HANIFA

When Hanifa was three years old, she developed seizures due to a high fever from an unknown infection. Even after her fever went away, the seizures continued for years. Sometimes there were as many as seven seizures in a day.

Her family did not understand why she continued to have these attacks. Many people in their community believed that the symptoms were the result of an evil spirit and recommended she consult with local faith healers.

When Hanifa was put in touch with Kuhenza/Kupenda, however, local staff helped the family understand the biological cause of her disability and connected her to an epilepsy specialist who prescribed her appropriate medication. Today Hanifa has just a few mild seizures in a year. She is able to attend school and learn like anyone else.

Art Director: Amy Allaire | www.amyallaire.com
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Family/Community (During a seizure)

As soon as a person becomes aware that someone is going to have a seizure or is having a seizure, he or she should follow these steps.



MOVE ANY OBJECTS AWAY FROM THE PERSON

DO NOT PUT ANYTHING IN THE PERSON'S MOUTH



DO NOT HOLD THE PERSON DOWN

LAY THE PERSON ON HIS OR HER SIDE TO PREVENT CHOKING



RECORD HOW LONG THE SEIZURE LASTS AND HOW LONG THE PERSON IS UNABLE TO RESPOND



GIVE THE PERSON TIME
to relax after the seizure is over, as the person will likely be tired and confused.



CALL A MEDICAL PROFESSIONAL
if the person is unable to respond after 15 minutes. Tell him or her how long the seizure or unresponsiveness lasted.

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FETAL ALCOHOL SYNDROME DISORDERS (FASD)



1-5 out of every 100 children may have a fetal alcohol syndrome disorder in western countries, but research on this is limited in low-income countries.¹

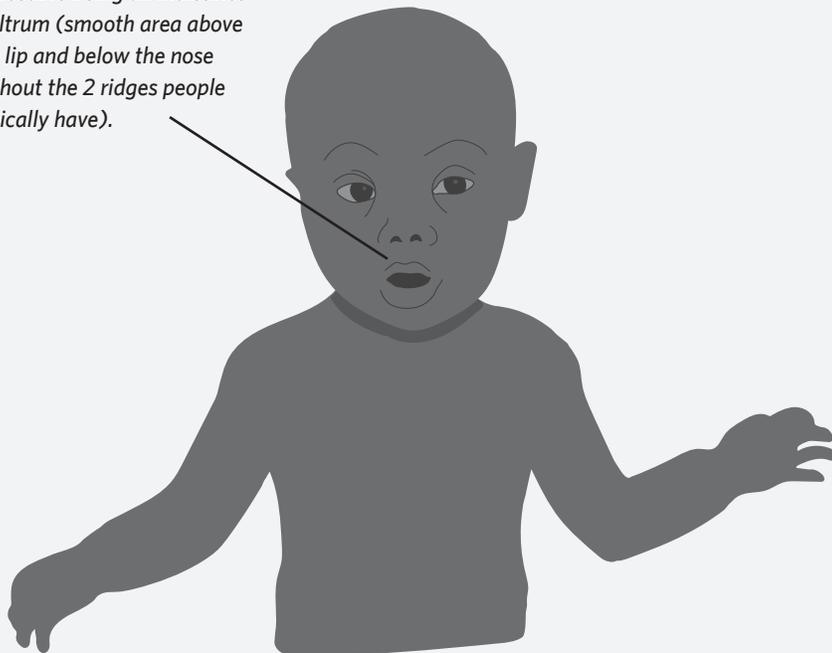
DESCRIPTION ^{2, 3}

A group of conditions that can occur in a person whose mother drank alcohol during pregnancy which may cause the child to have problems physically, behaviorally, and intellectually.

SIGNS AND SYMPTOMS ^{4, 5, 6}

(There is wide variation in the type and severity of symptoms people experience.)

Their faces have differences compared to children without FASD (photo), with the most noticeable being an indistinct philtrum (smooth area above the lip and below the nose without the 2 ridges people typically have).



LEARNING CHALLENGES



SPEECH CHALLENGES



RASH DECISION MAKING



MOVE AROUND A LOT



LOW BIRTH WEIGHT



PROBLEMS WITH HEART, KIDNEYS, AND VISION

POSSIBLE CAUSES AND RISK FACTORS ^{7, 8, 9, 10}



EXPOSURE
to alcohol during
pregnancy

INTERVENTIONS ^{11, 12}

Professional



MEDICATIONS



SPECIALIZED COUNSELING



**SPECIALIZED
EDUCATION**

Family/ Community



**JOIN/FORM A
SUPPORT GROUP**



**DO NOT ABUSE OR
PHYSICALLY PUNISH**



**REWARD GOOD
BEHAVIOR**



**DO NOT MOCK
OR STARE**



ANDREW ^{13, 14, 15}

Andrew Peterson was born after months in the womb soaking up the alcohol his mother drank.

He was found alone in his mother's home at three weeks old. Andrew would grow into a 5-year-old who didn't run, didn't laugh easily, and didn't understand the world around him. In addition, kids made fun of him in school.

Eventually, Peterson grew to be an athlete—an athlete that won 50 gold medals from state competitions and 4 golds from national competition.

Today he talks to others about having Fetal Alcohol Syndrome, his years of physical therapy, and about how he joined the cross-country team and won gold medals. But the greatest honor, he tells the students, is to have people's respect.

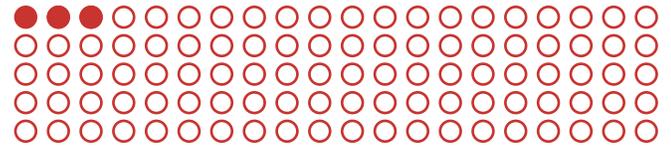
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

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GENERALIZED ANXIETY DISORDER (GAD)



Up to **1** child or **3** adolescents out of every 100 experience generalized anxiety disorder (GAD). GAD is more common in females than in males.^{1,2}

DESCRIPTION^{3,4}

People with generalized anxiety disorder (GAD) experience persistent and excessive worry about aspects of everyday life and events that is difficult to control for at least 6 months.

SIGNS AND SYMPTOMS^{5,6,7,8}

There is a wide variation in the type and severity of symptoms people experience.



EXCESSIVE ANXIETY OR WORRY



BEING TIRED



INABILITY TO RELAX



TROUBLE CONCENTRATING AND MAKING DECISIONS



UNEXPLAINED NEGATIVE EMOTIONS (FEAR, SADNESS, OR IRRITABILITY)



PHYSICAL SYMPTOMS (SUCH AS MUSCLE PAIN, HEADACHES, STOMACH PROBLEMS, SHAKING, OR SWEATING)



UNUSUAL SLEEP PATTERNS



PROBLEMS WITH BOWEL AND BLADDER CONTROL



FEARING SOMETHING BAD WILL HAPPEN



EASILY STARTLED



LIGHTHEADEDNESS OR BEING OUT OF BREATH



DIFFICULTY SWALLOWING



ABUSING DRUGS/ALCOHOL

POSSIBLE CAUSES AND RISK FACTORS ^{9, 10}

 <p>BRAIN CHEMISTRY</p>	 <p>FAMILY MEMBERS with anxiety</p>	 <p>POSSIBLE RISKS: physical conditions which affect hormones or other long-term illnesses or disease</p>	 <p>LOSS, TRAUMA, OR STRESS</p>	 <p>ABUSING DRUGS, ALCOHOL, OR MEDICATION</p>
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INTERVENTIONS ^{11, 12}

Professional



Family/Community



MARCUS ^{13, 14}

Marcus Morris grew up in a neighborhood filled with gang violence, which gave him a lot of anxiety.

Marcus stated, "Honestly, I didn't feel like I could trust anybody—not even the people in my neighborhood, who I knew my whole life." The one thing he loved was playing basketball with his twin brother. As an adult, Marcus joined the NBA but increasingly struggled with feeling anxious. At one point, he even turned to sleeping pills and marijuana but did not find relief. Eventually Marcus found support by seeing a counselor and practicing meditation. As a result, Marcus states that he feels calmer, happier, and more productive. Today Marcus plays as a power forward for the Boston Celtics.

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Note: The text, graphics, and images contained in this guidebook are for informational purposes only. None of the material in this book is intended to be a substitute for professional medical advice or diagnosis.

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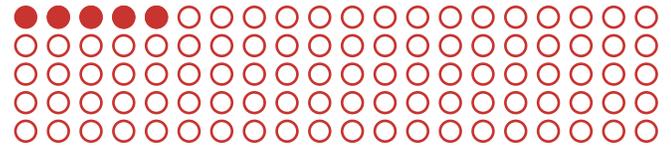
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HEARING LOSS OR DEAFNESS



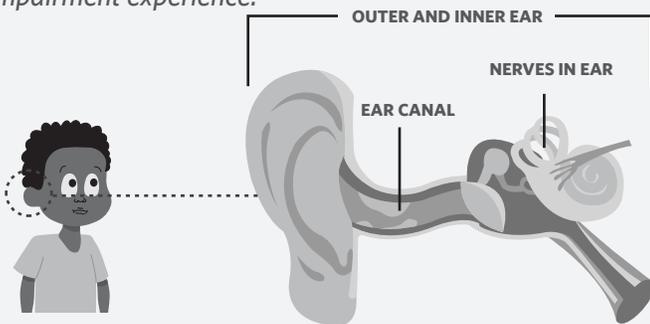
5 out of every 100 people have significant hearing loss around the world. 60% of cases in children could be prevented.¹

DESCRIPTION^{2,3}

Inability to hear the same level or type of sound as people without hearing loss, typically impacting the ability to verbally communicate.

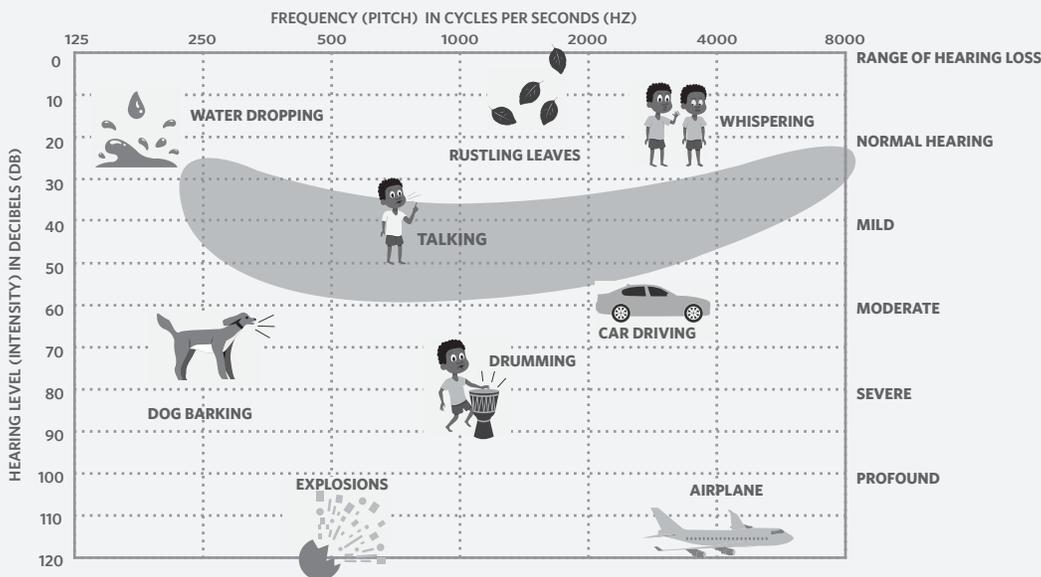
SIGNS AND SYMPTOMS^{4,5,6,7,8}

There is variation in the types and levels of sounds people with hearing impairment experience.



There are three types of hearing loss

1. Damage or blockage (such as ear wax) to the ear canal, which can often be repaired
2. Damage to the nerves in the ear, which is the most common type of hearing loss and typically cannot be repaired
3. Damage to the nerves and the ear canal

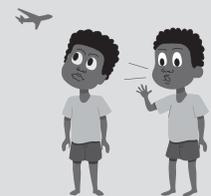


This chart shows the sounds people can hear with different levels of hearing loss. This is the typical way to classify hearing loss, but there are some people who only hear high sounds (like birds) but not low sounds (like trucks).

OTHER SIGNS AND SYMPTOMS



DOES NOT TURN TO THE SOURCE OF A SOUND OR REACT TO LOUD NOISES



RESPONDS TO SOME TYPES OF SOUNDS BUT NOT OTHERS



CHALLENGE WITH LANGUAGE OR SPEECH



TROUBLE UNDERSTANDING PEOPLE TALKING

POSSIBLE CAUSES AND RISK FACTORS ^{9, 10, 11}

 <p>FAMILY MEMBERS with hearing loss</p>	 <p>INJURY to the brain from accidents</p>	 <p>PROBLEMS during birth</p>	 <p>INFECTION in child or mother (before birth)</p>
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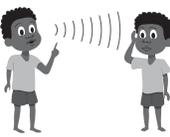
INTERVENTIONS ^{12, 13, 14}

Interventions may be different depending on the severity of hearing loss.

Professional

 <p>HEARING AIDS</p>	 <p>VISIT A HEARING SPECIALIST</p>	 <p>SPEECH THERAPY</p>	 <p>ENROLL IN SIGN LANGUAGE CLASS</p>
--	--	--	---

Family/Community

 <p>FACE PERSON WHEN SPEAKING TO HIM/HER</p>	 <p>SPEAK CLEARLY WITHOUT BACKGROUND NOISE</p>	 <p>FAMILY AND COMMUNITY SHOULD LEARN SIGN LANGUAGE</p>
 <p>JOIN/FORM A SUPPORT GROUP</p>	 <p>DO NOT MOCK OR STARE</p>	 <p>DO NOT ABUSE OR PHYSICALLY PUNISH</p>



HASSAN

Hassan is a 23-year-old young man with little hearing from the time he was a baby. His family did not believe someone who was deaf could be educated and kept him at home to tend to the goats. The director of Kuhenza visited Hassan's family many times to convince them that he was able to go to school.

Eventually, Hassan attended classes and thrived. Even though he started school at an older age than his peers, he learned sign language and other subjects quickly. He is now doing well in his second year of high school and continues to win running races and soccer at the national level.

One of Hassan's most impressive accomplishments was reaching the top of Mount Kilimanjaro and starring in a documentary about it. The boy who was told he had limited options for his future is now a local hero.

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Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

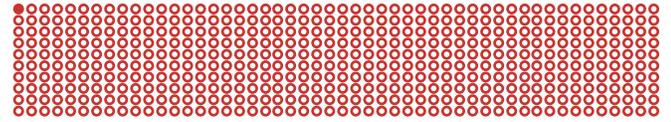
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HYDROCEPHALUS

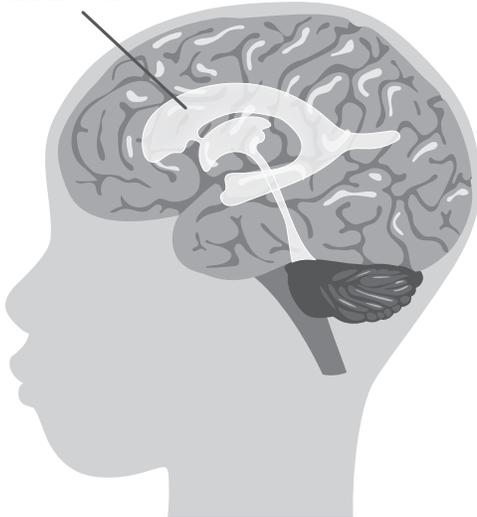
DESCRIPTION ^{3, 4, 5}

Extra fluid on the brain, typically in an infant, resulting in a larger-than-average head size. ^{3,4,5}



1 out of every 500 children develop hydrocephalus before the age of 2, though it is more common in low-income countries. ^{1,2}

NORMAL SPACE



ENLARGED SPACE



These two graphics depict the increasing buildup of fluid in spaces of the brain as well as the subsequent head size of a child with hydrocephalus, compared to a child without hydrocephalus.

SIGNS AND SYMPTOMS ^{6, 7, 8, 9, 10}

People with hydrocephalus have several symptoms that differ in severity from one person to another.



HEADACHE



DIZZINESS



STOMACHACHE



VOMITING



DIFFICULTY SEEING



SLEEPINESS



EYES ALWAYS LOOKING DOWN



LEARNING CHALLENGES



SEIZURES (FITS)



INABILITY OR DIFFICULTY WALKING



OTHER DISABILITIES LIKE SPINA BIFIDA

POSSIBLE CAUSES AND RISK FACTORS ^{11, 12, 13}

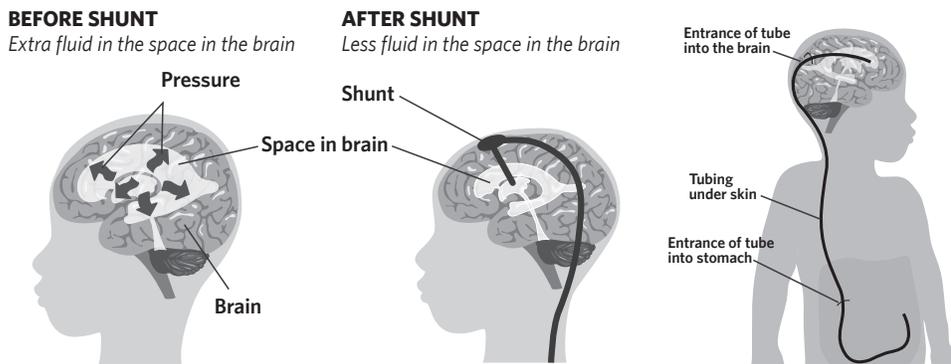
					
INFECTION from diseases that damage the brain	SPINA BIFIDA	TUMORS in the brain	PREMATURE child is born too early	PROBLEMS during birth	INJURY to the brain from accidents

INTERVENTIONS ^{14, 15, 16}

Professional Interventions: Inserting a shunt

A doctor trained in hydrocephalus may decide it is best to insert a tube (shunt) in the brain. This tube will drain the fluid from the brain to the stomach, heart, or lining of the lungs and be absorbed by the body.

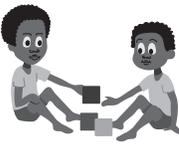
*This intervention may be necessary to prevent death or increased damage to the brain.



Additional Professional Interventions

				
MEDICATION TO HELP WITH THE PAIN	SPECIALIZED EDUCATION	SPEECH THERAPY	PHYSICAL THERAPY	REGULAR CHECKUPS

Family/Community

			
KEEP SHUNT SITE CLEAN	ENSURE THE FAMILY IS TAKING THE CHILD FOR REGULAR DOCTOR VISITS AFTER SHUNT IS PUT IN	HOME-BASED THERAPY	DAILY PLAY



JUSTINE

Justine developed hydrocephalus after coming down with an infection at 6 months old. The pain caused him to cry most of the time. His parents thought he would surely die, so they took him to local healers.

The condition continued to get worse until Kuhenza/Kupenda referred him to Bethany Kids Kijabe Hospital. Doctors there inserted a shunt into his head to drain excess fluid from around his brain.

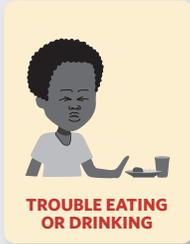
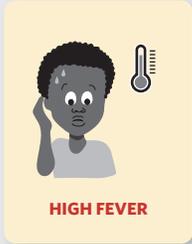
Eventually, Justine was able to walk on his own at 4 years old. Although he was delayed in his early development, physical therapy and the support of his family helped him significantly.

Today Justine is 9 years old and enrolled in a mainstream school in his community, like any other child his age. He has many friends and loves his life!

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

SIGNS OF INFECTION

Watch for signs of infection and visit a doctor if any of these symptoms arise.



INTERVENTIONS CONTINUED . . .

Family/Community



HEALTHY DIET



JOIN/Form A SUPPORT GROUP



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH

Family/Community (For those who are unable or have difficulty moving on their own)



CHANGE THEIR POSITION OFTEN



ENSURE THEY HAVE CLEAN CLOTHES



BATHE THEM AFTER SOILING THEMSELVES



USE TOILET ADAPTATION



PROVIDE PAMPERS (NAPKINS)



PROVIDE ASSISTANCE DEVICES

NOTES

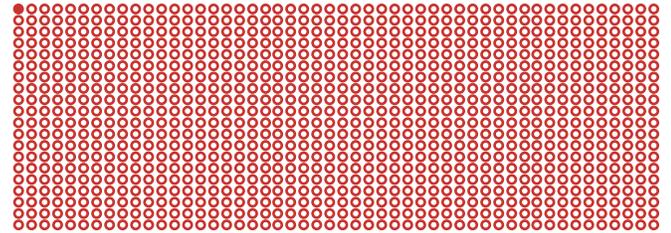
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- Werner, *Disabled Village Children*, 168-169.



LIMB LOSS OR REDUCTION

DESCRIPTION ^{2,3}

Characteristics of limb loss or reduction include limbs that are either partially or entirely missing or deformed.

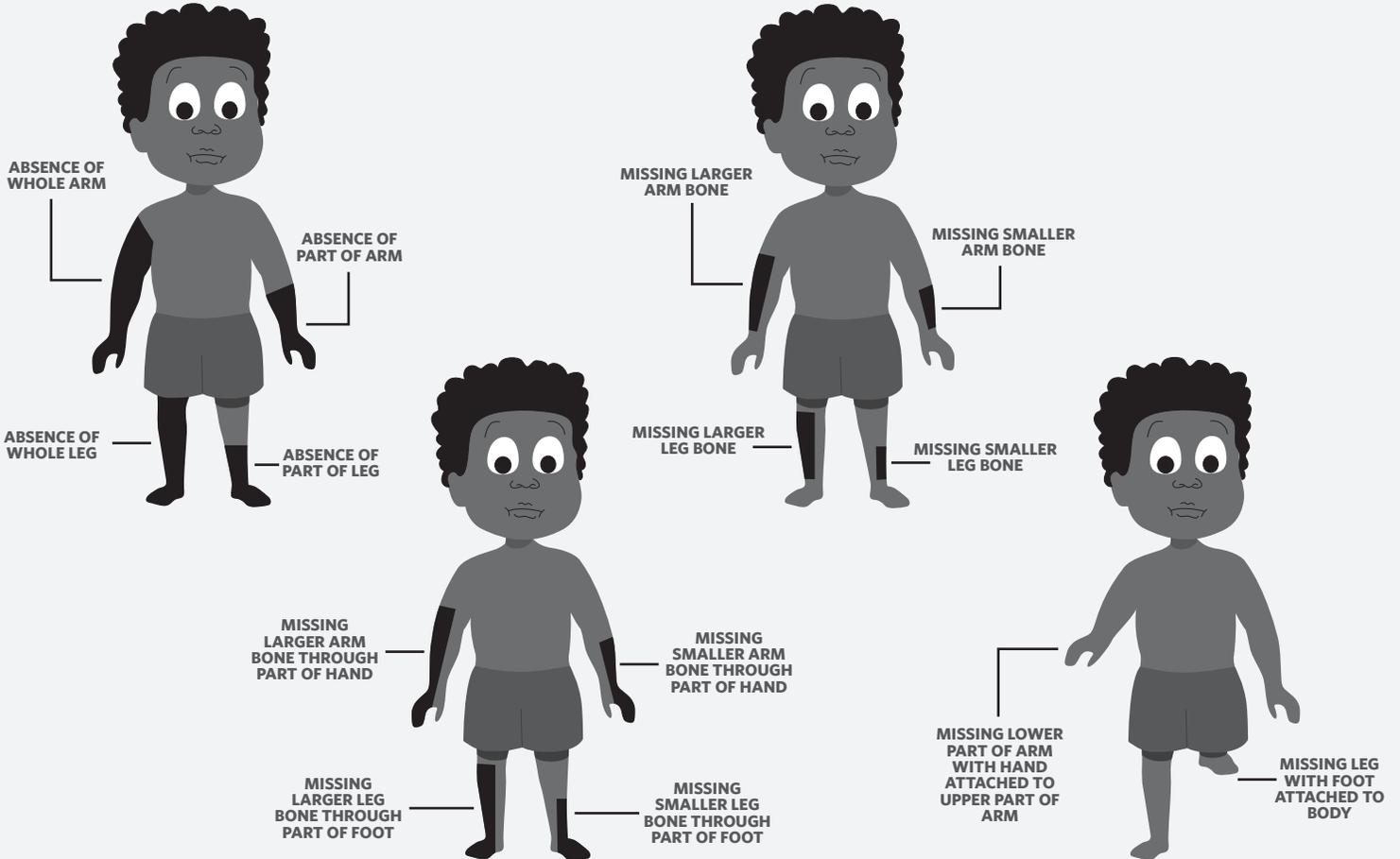


Up **1** out of every 1,900 children are born with one or more limbs missing or different from others. (This does not include those with limb differences acquired after birth.)¹

SIGNS AND SYMPTOMS ^{4,5,6}

(People may be affected in one or multiple areas of the arms, legs, hands, or feet.)

COMMON KINDS OF MISSING OR DIFFERENTLY FORMED ARMS AND LEGS:



POSSIBLE CAUSES AND RISK FACTORS ⁷



FAMILY MEMBERS
who have limb loss
or reduction



**MANY UNKNOWN
CAUSES**

INTERVENTIONS ^{8,9}

Professional



ARTIFICIAL LIMBS
(SOME CHILDREN MAY PREFER
NOT TO USE THEM)



**PROVIDE ASSISTANCE
DEVICES**



**PHYSICAL
THERAPY**

Family/Community



**ENROLL IN
MAINSTREAM
SCHOOL**



**JOIN/FORM A
SUPPORT GROUP**



**DO NOT MOCK
OR STARE**



**DO NOT ABUSE OR
PHYSICALLY PUNISH**



JOYCE

When Joyce was born, her mother wondered what she had done wrong to have a child born without a hand.

She questioned whether God was punishing her for something. Her parents didn't know what to do or where to turn for help. A child with a disability was viewed as a source of shame and a disgrace to the family. Eventually, the midwife who delivered Joyce brought the family to the Kupenda Center. There she met the Kenya director and a pastor as well as the U.S. Director, Cynthia, who was also born without a hand. Cynthia demonstrated that, although she did not have a hand, she was not limited academically, physically, or socially. In fact, Cynthia's condition inspired her to create Kupenda, an organization that helps thousands of children with disabilities. After many interactions with Cynthia, Joyce is now fully included in her village like any other child. Today she can do activities like other girls in her community, such as carrying water on her head and attending mainstream school where she is at the top of her class. Joyce continues to thrive and has gone on to influence people around the world as a featured child in the book, "An Unlikely Gift," a story about Kupenda's formation.

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

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MAJOR DEPRESSION



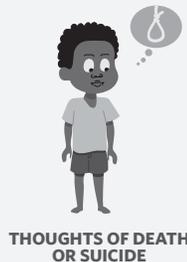
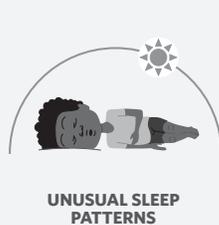
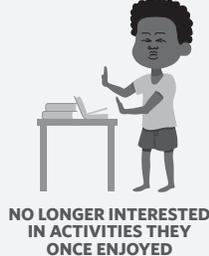
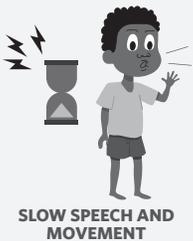
7 out of every 100 people experience major depression at some point in their life.¹

DESCRIPTION ^{2, 3, 4, 5}

A person with this disorder has feelings of sadness that get in the way of eating, sleeping, working, or doing normal daily activities on most days for at least two weeks at a time.

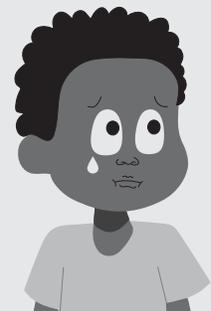
SIGNS AND SYMPTOMS ^{6, 7, 8, 9}

There is a wide variation in the type and severity of symptoms people experience, but people with major depression have 5 or more of the following symptoms.



STIGMA OF DEPRESSION ¹⁰

There are many negative cultural views associated with depression. These attitudes may make someone feel embarrassed or ashamed to be who they are and/or to seek help. Depression affects people regardless of their age, appearance, or success in life. It is a disease that is not always possible for a person to control. People with depression should receive help and compassion just like people with any other illness.



POSSIBLE CAUSES AND RISK FACTORS ^{11, 12}



BRAIN CHEMISTRY



FAMILY MEMBERS
with depression



MAJOR LIFE CHANGES
(new job or home)



LOSS OR TRAUMA



ILLNESSES OR MEDICATIONS
that affect the brain

INTERVENTIONS ^{13, 14}

Professional



Family/Community



KERRY ^{15, 16}

Kerry Washington, an American actress, hasn't been shy about her past battle with depression.

In an interview with Essence magazine, she disclosed that much of her college experience revolved around a depression that including an "abusive relationship with food and exercise." "I used food as a way to cope," she said. "It was my best friend." It was only when a dance teacher intervened that Washington began what would become years of therapy and was finally able to end her routine of "eat, pass out, exercise for hours, feel guilty." More recently, Washington has worked closely with figures like Michelle Obama and Sarah Jessica Parker to call attention to the issue of depression, especially as it affects veterans. As she told Glamour magazine, "I think it's really important to take the stigma away from mental health."

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

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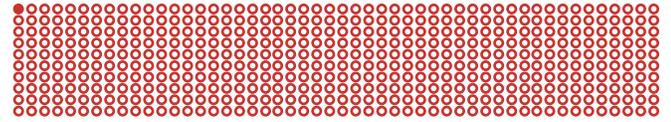


MICROCEPHALY

WITHOUT MICROCEPHALY



WITH MICROCEPHALY



2-12 babies out of every 10,000 live births are born with microcephaly. There is likely a higher occurrence in areas where disease and poverty rates are high. ¹

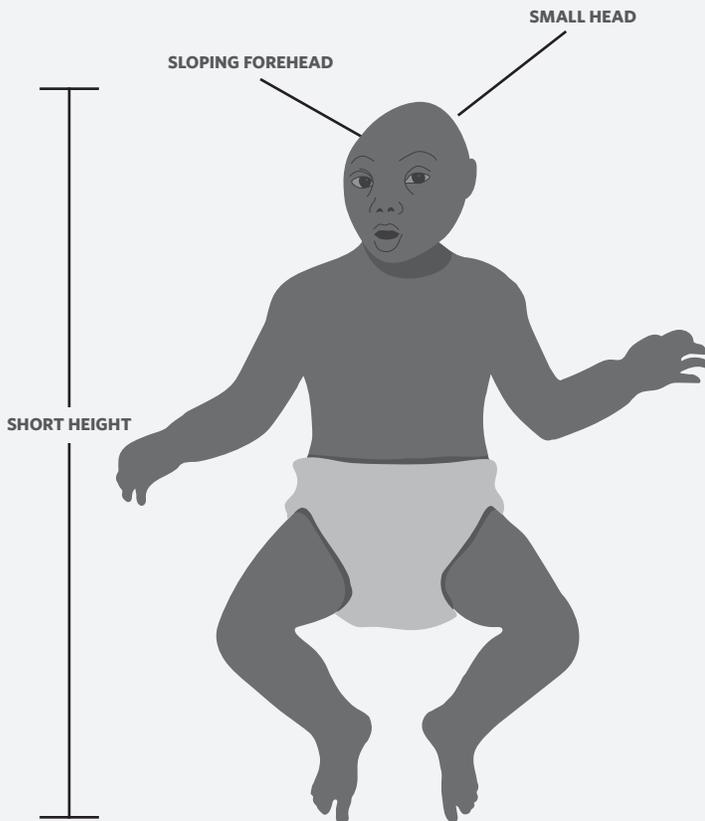
One open dot = 10

DESCRIPTION ^{2, 3, 4, 5}

Microcephaly is a condition where a baby has a head and brain size much smaller than other children of the same age and sex.

SIGNS AND SYMPTOMS ^{6, 7, 8, 9, 10, 11}

There is wide variation in the type and severity of symptoms people experience.



SPEECH CHALLENGES



LEARNING CHALLENGES



DIFFICULTY WITH BALANCE



DELAYED SITTING, STANDING, CRAWLING, AND WALKING



VISION PROBLEMS



HEARING PROBLEMS



SEIZURES (FITS)



DIFFICULTY SWALLOWING

POSSIBLE CAUSES AND RISK FACTORS ^{12, 13}



INFECTION
during pregnancy



MALNUTRITION
pregnant mother or child not getting enough food or nutrients



EXPOSURE
to alcohol or drugs during pregnancy



OXYGEN DEPRIVATION
during pregnancy or delivery



FAMILY MEMBERS
with microcephaly



DISABILITIES
like Down syndrome

INTERVENTIONS ^{14, 15}

Professional



MEDICATION FOR SYMPTOMS



SPECIALIZED EDUCATION



SPEECH THERAPY



PHYSICAL THERAPY

Family/Community



HEALTHY DIET



DAILY PLAY



HOME-BASED THERAPY



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



JOIN/FORM A SUPPORT GROUP



CHARO FAMILY

Kadzo was told she had children with microcephalus because demons came upon her when she was pregnant. She tried going to local healers for help but was unsuccessful. She was isolated and in such despair that she wanted to take her own life.

Participating in a parent workshop sponsored by Kupenda/Kuhenza showed her that she was not alone. She also discovered the true biological causes of her children's microcephaly.

Today, her sons are in school and Kadzo is the leader of a parent support group. She spends her time teaching other families that their children with disabilities can go to school and be a part of the community, too.

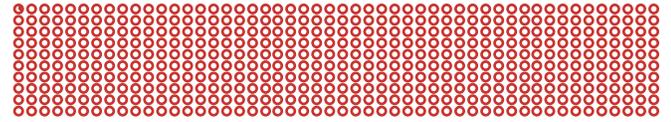
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

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MUSCULAR DYSTROPHY



One open dot = 10

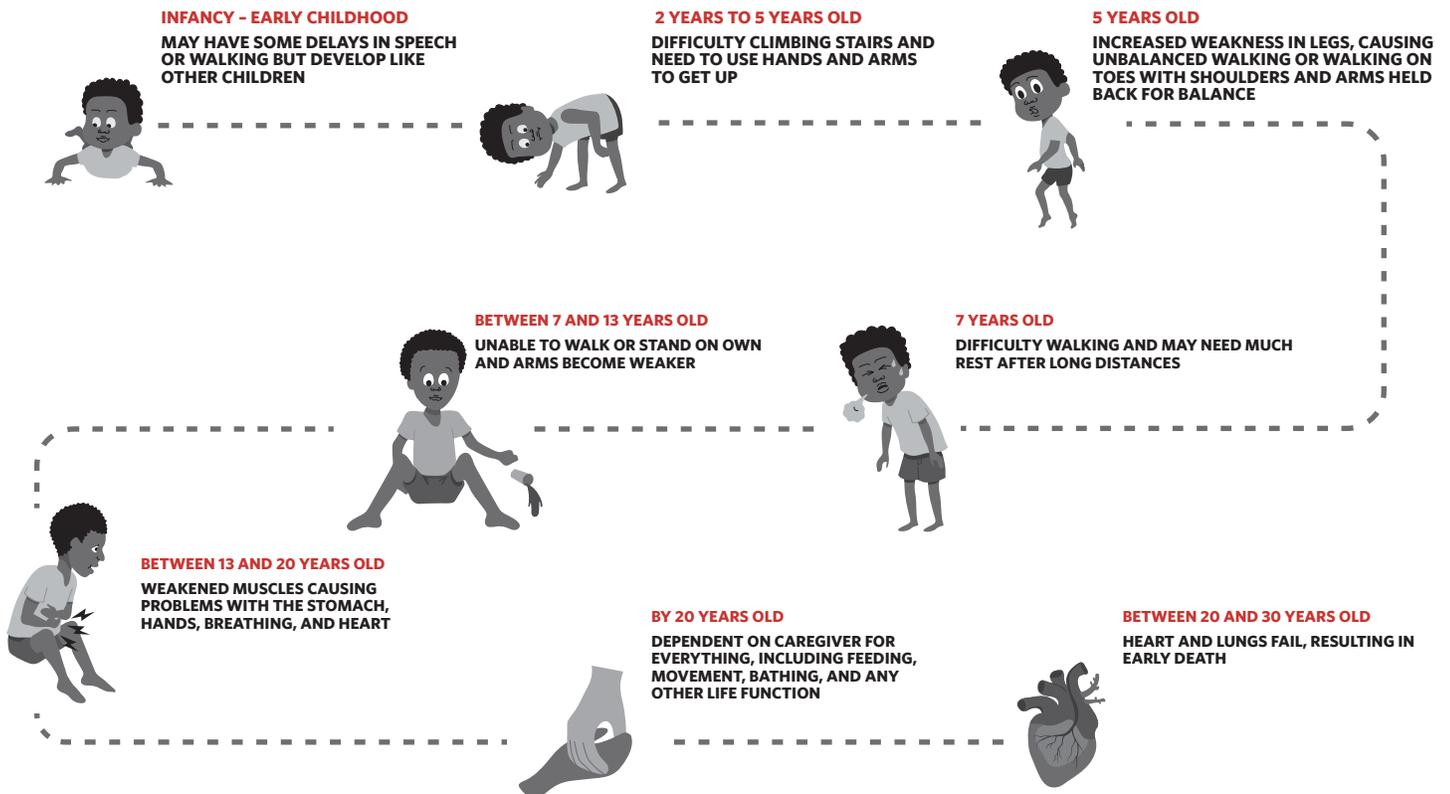
1 out of every 5,600 to 7,700 people have Duchenne's form of muscular dystrophy.¹

DESCRIPTION^{2, 3, 4}

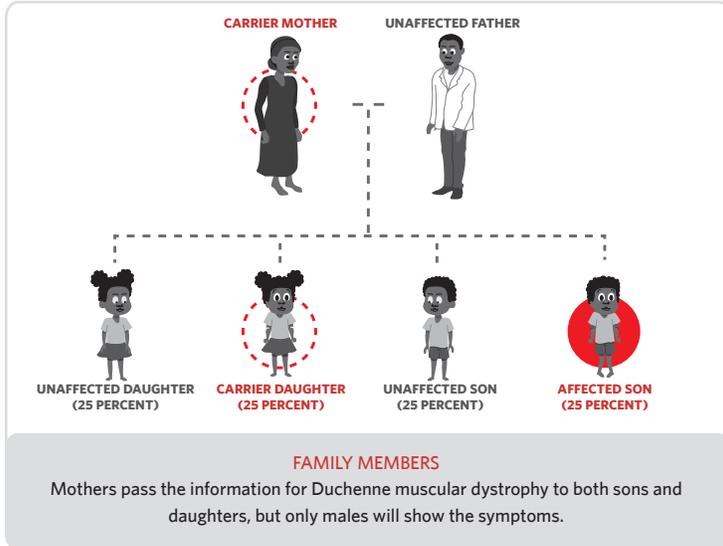
A group of inherited diseases that cause the muscles to become weaker over time, eventually limiting the use of arms and legs in addition to weakening the lungs and heart. There are several types of muscular dystrophy, but Duchenne's is the most common and severe. Becker's is similar, but symptoms usually show up in the teen years.

SIGNS AND SYMPTOMS^{5, 6, 7}

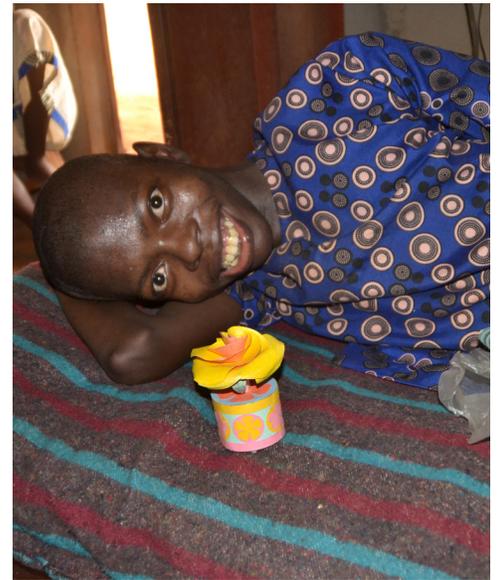
Depending on the type of muscular dystrophy, children can show symptoms as early as 2 and as late as 25-years old. Before the onset of symptoms, they develop like any other child. Duchenne muscular dystrophy is the most common type, with clear signs occurring sometime between 7-12 years. Duchenne's is what is detailed below.



POSSIBLE CAUSES AND RISK FACTORS ^{8,9}



- Only males have the condition
- Mothers carry information (genes) for the condition but do not have it themselves (carrier)
- May have family members with the condition
- May occur without any family members having it



GERALD

As a young child, Gerald was able to run around his village. By the age of 6, however, he was struggling to walk. By the age of 10, he was in a wheelchair. As his condition got worse, his family was ridiculed, accused of witchcraft, and threatened with harm.

Often, others did not realize that Gerald was intelligent and loved to learn. Although he studied and took exams while lying down, his scores were at the top of the class.

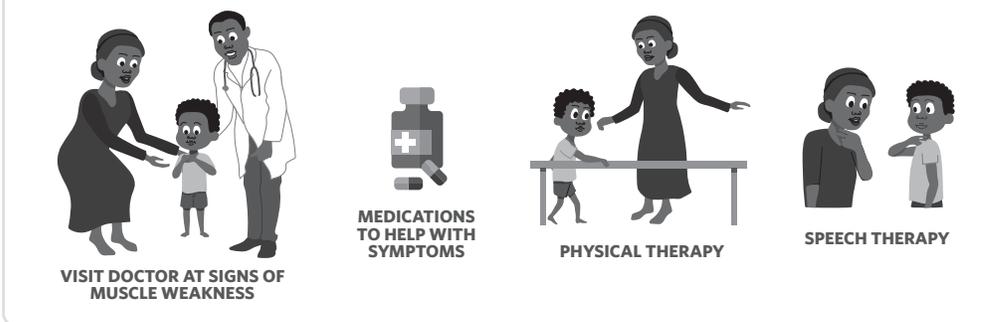
Kupenda/Kuhenza educated his community about muscular dystrophy and how it would eventually take his life. His community began assisting him to get to and from school and aided his family with household chores.

In January of 2021, Gerald died in his early twenties, as is common for people with muscular dystrophy. He died surrounded by love.

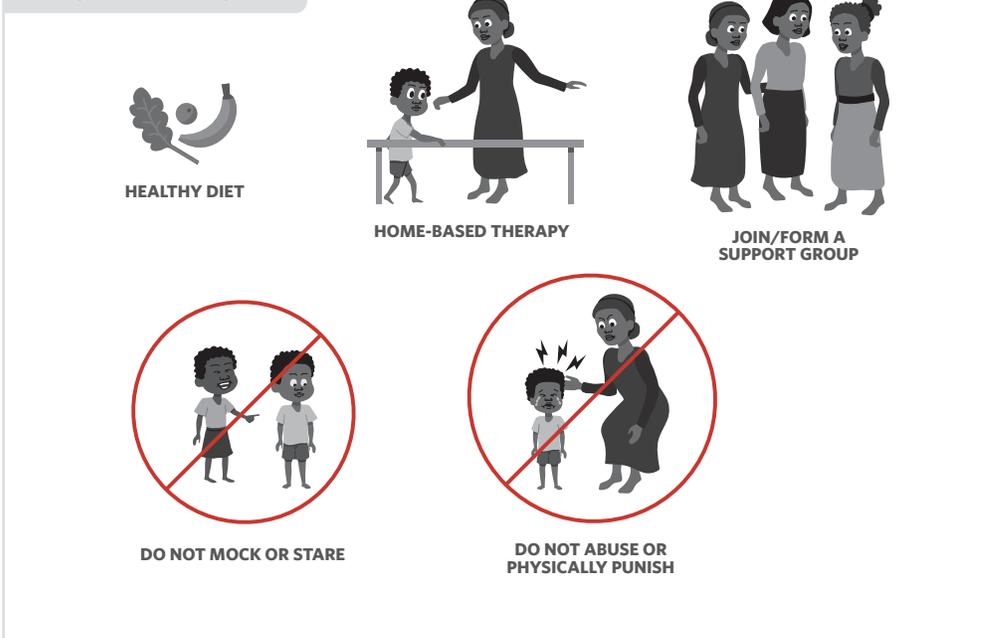
Art Director: Amy Allaire | www.amyallaire.com
 Graphic Designer: Siwen Tao | www.siwentao.com

INTERVENTIONS ^{10, 11, 12, 13}

Professional



Family/Community



Kuhenza for the Children

Tel: +254-733-316584 | kuhenza@kuhenza.org | www.kuhenza.org | PO Box 9, Gede, Killifi, Kenya 80208

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INTERVENTIONS CONTINUED . . .

Family/Community (For those who are unable or have difficulty moving on their own)



CHANGE THEIR POSITION OFTEN



ENSURE THEY HAVE CLEAN CLOTHES



BATHE THEM AFTER SOILING THEMSELVES



PROVIDE PAMPERS (NAPKINS)



PROVIDE ASSISTANCE DEVICES



USE TOILET ADAPTATION DEVICES

NOTES

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OBSESSIVE-COMPULSIVE DISORDER (OCD)



Up **2** out of every 100 people have OCD, with females 1.6 to **2** times more likely to have OCD than males.^{1,2,3}

DESCRIPTION ^{4,5,6}

People with OCD have repeated thoughts and/or actions for more than 1 hour a day that cause significant distress and interference with daily life. Symptoms usually occur between the ages of 7 and 12 or the late teenage years and adulthood and may worsen over time, particularly during periods of stress.

SIGNS AND SYMPTOMS ^{7,8,9}

There is a wide variation in the type and severity of symptoms people experience.

Repetitive thoughts one cannot control about topics such as:



GERMS OR BECOMING DIRTY (BY SHAKING HANDS OR TOUCHING CERTAIN OBJECTS)



FORGETTING, LOSING, OR MISPLACING SOMETHING



ANGRY THOUGHTS ABOUT LOSING CONTROL AND HARMING ONESELF OR OTHERS



HAVING THINGS IN PERFECT ORDER

Repetitive actions one feels they need to do, such as:



EXCESSIVE CLEANING OR HANDWASHING



ORDERING ITEMS IN A PARTICULAR WAY



REPEATEDLY CHECKING THINGS (DOOR BEING LOCKED OR LIGHTS TURNED OFF)



COMPULSIVELY COUNTING



PRAYING OR REPEATING WORDS SILENTLY

POSSIBLE CAUSES AND RISK FACTORS ^{10, 11, 12}



BRAIN STRUCTURE DIFFERENCES



FAMILY MEMBERS with OCD



VIOLENCE OR TRAUMA

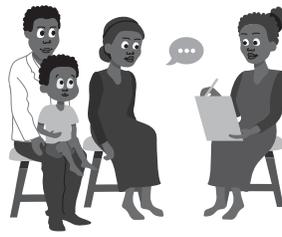


INFECTION from diseases that damage the brain

Note: Some disabilities, like autism, also show symptoms of OCD.

INTERVENTIONS ^{13, 14}

Professional



Family/Community



**Note: Family and community members should be sure to monitor any changes in a person with OCD who begins taking medication and report any negative impacts to a medical professional.*



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HOWIE ^{15, 16}

When Howie Mandel was growing up, he often felt isolated by his OCD and had an unhealthy fear of germs. In fact, he refused to touch his shoelaces to tie them because he thought they were dirty. Even as an adult, Howie prefers not to wear shoes with laces. He also chooses to be bald because it feels “cleaner.”

In one instance, Howie recalled having difficulty leaving his own home. He stated, “I don’t think I locked the door. I just kept going back to the door. And I couldn’t stop myself from checking and checking.” Ultimately, Howie Mandel checked the lock 32 times before he was able to move on.

Today Howie regularly takes medication and meets with a counselor, which have allowed him to succeed as a famous comedian, actor, father, husband, and friend.

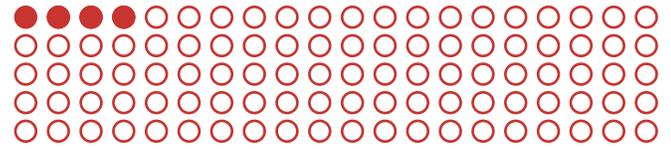
Art Director: Amy Allaire | www.amyallaire.com
 Graphic Designer: Siwen Tao | www.siwentao.com

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POST-TRAUMATIC STRESS DISORDER (PTSD)



4 out of every 100 people have post-traumatic stress disorder at some point in their lives, though data is not readily available. Low-income countries are likely to have higher rates due to increased exposure to traumatic situations.^{1,2}

DESCRIPTION 4, 5, 6

Post-traumatic stress disorder (PTSD) is an emotional and/or physical response to witnessing or experiencing one or more traumatic events. PTSD causes a person to continue to re-experience the event, avoid reminders of the event, and experience heightened distress and interference with daily life, work, school, or relationships with others for at least one month or more.

People typically exhibit signs of PTSD within months after the traumatic experience, but some may not show symptoms until years later. Some people recover from PTSD within months while others deal with it for a lifetime.

Note: Experiencing distress or other mental health difficulties after a potentially traumatic event is common but does not necessarily mean someone is experiencing PTSD.

SIGNS AND SYMPTOMS 6, 7, 8, 9

There is a wide variation in the type and severity of symptoms people experience.



FLASHBACKS



RECURRING MEMORIES/DREAMS



DISTRESSING THOUGHTS



PHYSICAL SYMPTOMS (SUCH AS MUSCLE PAIN, HEADACHES, OR STOMACH PROBLEMS)



AVOIDANCE OF TRAUMA REMINDERS



EASILY STARTLED



TROUBLE CONCENTRATING AND MAKING DECISIONS



UNUSUAL SLEEP PATTERNS



EASILY ANGERED OR ANNOYED



MEMORY PROBLEMS ABOUT TRAUMA



NEGATIVE THOUGHTS OF ONESELF/WORLD



DIFFICULTY FEELING HAPPY/SATISFIED



NEGATIVE EMOTIONS (ANGER/FEAR/GUILT/SHAME)



NO LONGER INTERESTED IN ACTIVITIES THEY ONCE ENJOYED

SIGNS AND SYMPTOMS CONTINUED ...



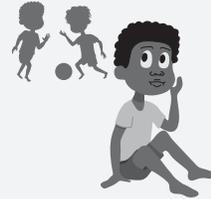
FEELING ALONE



SEEING/HEARING THINGS NOT THERE



ABUSING DRUGS/ALCOHOL



SOCIAL WITHDRAWAL

Note: Symptoms for children, particularly those under 6 years old, may be different than those who are older, including:



PROBLEMS WITH BOWEL AND BLADDER CONTROL



DIFFICULTY COMMUNICATING



ACTING OUT THE TRAUMA DURING PLAYTIME



CLINGINESS TO A PARENT OR ADULT

Note: Approximately 50% of people with PTSD often have major depression.

POSSIBLE CAUSES AND RISK FACTORS 10, 11



VIOLENCE OR TRAUMA



WITNESSING ANOTHER PERSON GET HURT OR DIE



FEELING HORROR, HELPLESSNESS, OR EXTREME FEAR



MAJOR LIFE CHANGES (loss of a loved one or job, injury, etc.)



LITTLE SOCIAL SUPPORT after the trauma



FAMILY MEMBERS with mental illness



OTHER MENTAL ILLNESS which increase the risk of PTSD



GENETICS which increase the risk of PTSD

Note: Anyone can develop PTSD at any time, but one person may experience the same event as another and only one ends up with PTSD.



NADIYA 14, 15

Nadiya experienced a number of challenging symptoms growing up, including panic attacks and voices in her head telling her negative things.

Later, when she learned she had PTSD, she realized that this was due to trauma she experienced in her childhood, including sexual assault by a relative and bullying, where others pulled her hair out, slammed her fingers in doors, and flushed her head down the toilet. Complicating matters, Nadiya also experienced the stress of her younger siblings being seriously ill while she was growing up. At one point, Nadiya even considered killing herself but decided not to when she discovered her mother was pregnant.

Today Nadiya is a famous cook doing television shows. She is also married with three children.

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

INTERVENTIONS ^{12, 13}

Professional



MEDICATIONS



SPECIALIZED COUNSELING

Family/Community



HAVE ENOUGH MEDICINE



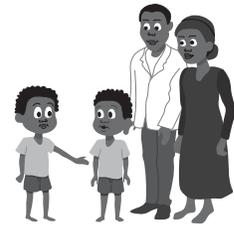
PROVIDE A SAFE PLACE AWAY FROM TRAUMA



TAKE MEDICINE AS DIRECTED



EXERCISE



SPEND TIME WITH FRIENDS OR FAMILY



MAKE A PLAN TO DO SMALL TASKS EACH DAY



EDUCATE FAMILY AND OTHER SUPPORTIVE PEOPLE ON THE CONDITION



DO NOT ABUSE OR PHYSICALLY PUNISH



DO NOT MOCK OR STARE



JOIN/Form A SUPPORT GROUP

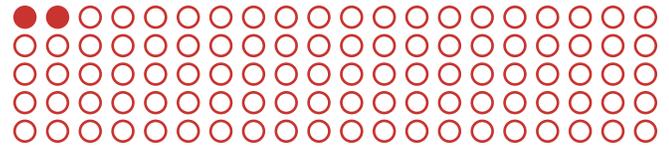
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REACTIVE ATTACHMENT DISORDER (RAD)



Up **2** out of every 100 people have reactive attachment to disorder (RAD).¹

DESCRIPTION ²

A child with reactive attachment disorder (RAD) has difficulty forming healthy attachments and emotional bonds with parents or caregivers, often due to neglect in infancy. Someone with RAD may first show signs and symptoms between the ages of 9 months and 5 years.

SIGNS AND SYMPTOMS ^{3, 4, 5, 6}

There is a wide variation in the type and severity of symptoms people experience.

- UNEXPLAINED NEGATIVE EMOTIONS (FEAR, SADNESS, OR IRRITABILITY)**
- DOES NOT SEEK/ACCEPT COMFORT FROM CAREGIVERS**
- SOCIAL WITHDRAWAL**
- LEARNING CHALLENGES**
- DOES NOT REACH OUT WHEN PICKED UP**
- ANGRY AND DISRUPTIVE BEHAVIOR**
- OFTEN DOES NOT SHOW POSITIVE EMOTION**
- DEPRESSION**

Note:⁷



STAGES OF ATTACHMENT

- Pre-attachment: Birth to 6 Weeks**
Baby shows no particular attachment to specific caregiver
- Indiscriminate: 6 Weeks to 7 Months**
Infant begins to show preference for primary and secondary caregivers
- Discriminate: 7+ Months**
Infant shows strong attachment to one specific caregiver
- Multiple: 10+ Months**
grows bonds with other caregivers

POSSIBLE CAUSES AND RISK FACTORS ^{8, 9}



CONTINUOUS UNMET NEEDS
(physically, socially, or emotionally)



REPEATED CHANGES IN CAREGIVERS



MENTAL ILLNESS IN CAREGIVER



ABUSE BY CAREGIVER



LIVING SITUATION
(too few adults for number of children)

INTERVENTIONS ^{10, 11}

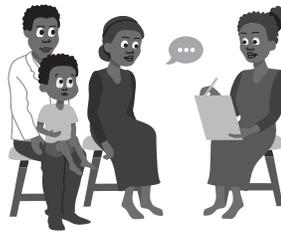
Professional



ATTEND A PARENTING SKILLS TRAINING



SPECIALIZED EDUCATION (IF NEEDED)



SPECIALIZED COUNSELING

Family/Community



PROVIDE A SAFE PLACE AWAY FROM ABUSE/NEGLECT



EDUCATE FAMILY AND OTHER SUPPORTIVE PEOPLE ON THE CONDITION



DO NOT ABUSE OR PHYSICALLY PUNISH



DO NOT MOCK OR STARE



JOIN/FORM A SUPPORT GROUP

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GINA ^{12, 13}

Gina Heumann adopted a son with a history of neglect since birth. For 12 years, she and her family feared much of his behavior. Gina stated, "I became afraid of my own child. ... He often told me he wished I were dead."

Although she spent years seeking help, her son was repeatedly misdiagnosed by therapists. Eventually, when he assaulted a teacher, he was taken away by police and they finally learned he had RAD.

With the right interventions, today Gina's son is now thriving. He is in high school and achieving things she never thought possible. Today Gina speaks to others about her experience, is an award-winning adoption advocate, and is a best-selling author.

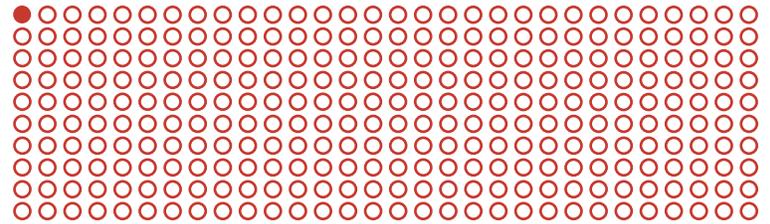
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

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SCHIZOPHRENIA



1 out of every 300 people has schizophrenia.¹

DESCRIPTION^{2,3}

People with schizophrenia experience disruptions in the way they perceive reality, impacting how they think, feel, and behave. This condition lasts for at least a month and usually starts between the late teens to early 30s.

SIGNS AND SYMPTOMS^{4,5,6,7}

There is a wide variation in the type and severity of symptoms people experience.



SEEING OR HEARING THINGS NOT THERE



BELIEVE THINGS THAT ARE NOT TRUE (WHO/ WHERE THEY ARE)



SHOW LITTLE EMOTION



FEELING SAD



UNUSUAL SLEEP PATTERNS



ANGRY AND DISRUPTIVE BEHAVIOR



STRANGE SPEECH OR SOUNDS



EASILY DISTRACTED



SOCIAL WITHDRAWAL



UNUSUAL MOVEMENTS



DIFFICULTY LISTENING



LAUGH FOR NO REASON



FORGETFUL



DIFFICULTY THINKING AND MAKING DECISIONS

POSSIBLE CAUSES AND RISK FACTORS ^{8,9}

 BRAIN CHEMICAL DIFFERENCES	 FAMILY MEMBERS with schizophrenia	 DIFFICULT ENVIRONMENT	 INFECTION
 OXYGEN DEPRIVATION during delivery	 PREMATURE BIRTH	 TRAUMA during childhood	



TANARA ^{12,13}

Tanara was always a peaceful person. That’s why, at age 24, her family was surprised when she got into a fight with a neighbor over a parking spot and was sent to jail.

Soon after, she also began experiencing other strange symptoms, including feeling paranoid and seeing and hearing things that weren’t there. Eventually, she didn’t even want to get dressed or get out of bed.

At first, she was reluctant to tell her doctors about what she was experiencing. When she finally did, however, she was able to receive the medication and counseling she needed. Now Tanara’s schizophrenia symptoms are under control, and she has regained her interest in the things she used to enjoy.

Today Tanara helps others who struggle with mental health illnesses so that they can grow in confidence and pursue their goals.

INTERVENTIONS ^{10,11}

Professional



MEDICATIONS



SPECIALIZED COUNSELING

Family/Community



TAKE MEDICINE AS DIRECTED



HAVE ENOUGH MEDICINE



EDUCATE FAMILY AND OTHER SUPPORTIVE PEOPLE ON THE CONDITION



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



JOIN/FORM A SUPPORT GROUP

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NOTES

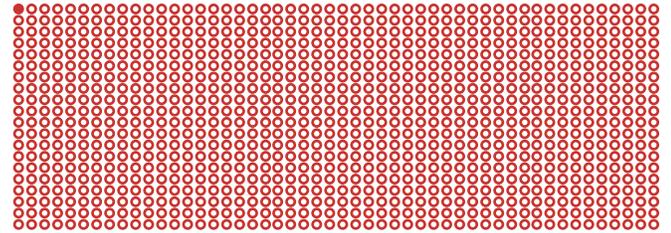
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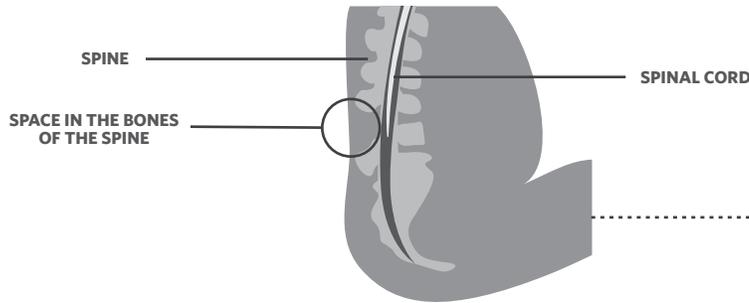
SPINA BIFIDA (SB)

DESCRIPTION ^{4, 5, 6}

Spina Bifida (SB) is a condition where there is a hole in the backbone that often causes damage to the spine and nerves in the back.

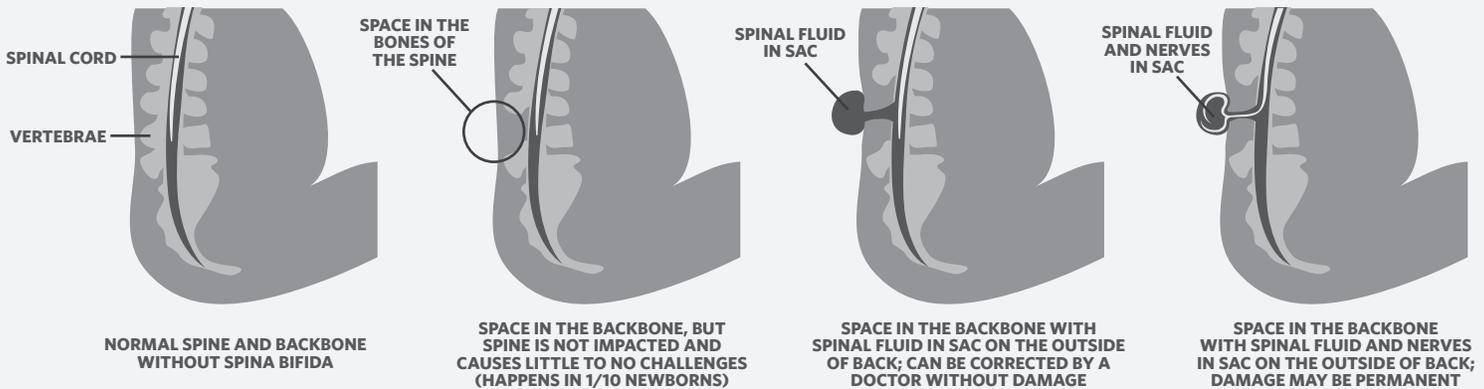


1 out of every 1,000 infants is born with disabling spina bifida (SB). ^{1, 2, 3}



SIGNS AND SYMPTOMS ^{7, 8, 9}

There is wide variation in the type and severity of symptoms people experience.



Abilities are determined by the type of SB as well as the size and location of the hole in the back.



DELAYED SITTING, STANDING, CRAWLING, AND WALKING



DIFFICULTY WITH BALANCE



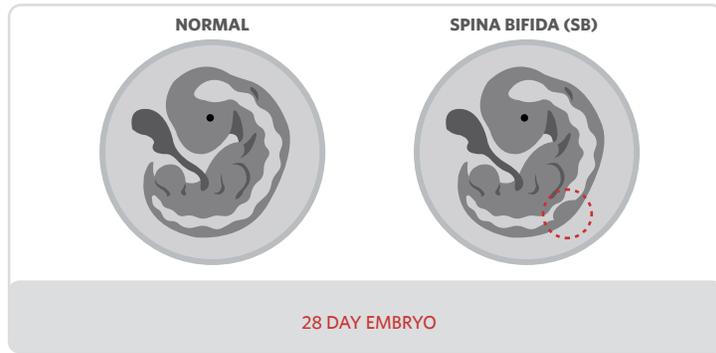
HYDROCEPHALUS (FLUID ON THE BRAIN)



PROBLEMS WITH BOWEL AND BLADDER CONTROL

POSSIBLE CAUSES AND RISK FACTORS ^{10, 11, 12}

The reason for spina bifida is unknown.



During the first weeks of pregnancy, the hole forms for unknown reasons. This is before most women know they are pregnant.

INTERVENTIONS ^{13, 14, 15}

The type of intervention depends on the severity and location of the hole in the spine. They may or may not benefit from...

Professional



Family/Community (For those who are unable or have difficulty moving on their own)



BULELWA ¹⁶

Bulwewa was born in 1975 with spina bifida. She attended a primary school for special needs but later attended a mainstream high school. She completed an executive secretarial course at K Commercial College and is now a chief administrator in the information systems department at Transnet in Saldanha Bay. In 1998, Bulelwa gave birth to a baby boy, who is now 16 years old.

For most of her life, Bulwewa walked with the aid of crutches, until a hip injury in 2009 forced her to use a wheelchair. She concludes, "My spina bifida is not an obstacle on living my life and reaching for my dreams. Whatever I do, my mother supports me, she believes in me, gives me space, and allows me to fall."

Art Director: Amy Allaire | www.amyallaire.com
 Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

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SPINAL CORD INJURY



1 out of every 15,000 people has a spinal cord injury.¹

One open dot = 100

DESCRIPTION ^{2, 3, 4, 5}

A spinal cord injury is damage to the bundle of nerves that carry messages between the brain and the rest of the body. This results in temporary or permanent changes to a person's ability to move or feel. The location and severity of the injury determines the particular areas of the body that will be affected.

SIGNS AND SYMPTOMS ^{6, 7, 8}

(The function and pain of a spinal cord injury depend on where and how much the nerve has been damaged.)

SPINAL CORD INJURIES AND EFFECT
(The higher the injury in the spine, the more severe the effect.)



- No feeling or ability to move below the neck
- Trouble breathing
- No urine or bowel control



- Full use of arms and hands
- No feeling or movement below the chest
- No urine or bowel control



- Full use of arms and hands
- No feeling or movement below the waist
- No urine or bowel control



- Full use of arms and hands
- No feeling or movement below the waist
- Some have urine or bowel control while others do not

POSSIBLE CAUSES AND RISK FACTORS ^{9, 10}



INFECTION
from diseases that impact the spine
(ex.: meningitis or polio)



INJURY
to the spine

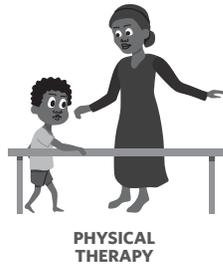


PROBLEMS
with bones growing incorrectly and damaging the spine

INTERVENTIONS ^{11, 12, 13}

When an injury does not fully disconnect the spinal cord, there is more function and potential for improvement over time. However, when a spinal cord injury completely cuts the nerves, it cannot be repaired.

Professional



Family/Community



STEPHEN

At ten years old, Stephen Kitsao was paralyzed from the waist down when he fell from a coconut tree. His community told him his disability was a curse, and that he would never accomplish anything.

According to Stephen, "The doctors had said that I would not walk again. This means that I was not going to school and play[ing] with my friends like before. I started asking myself hard questions. Having found no answers, I slowly found myself in a state of denial which would last for some time. During this state, I would remain indoors and even refuse to eat my food. Life had no meaning to me."

In spite of negative stigmas in his community about disability, Stephen's family worked hard to connect him to the right resources and medical treatment. When they found Kupenda/Kuhenza, Stephen was able to receive a wheelchair, medical care, schooling, and counseling.

With this support, Stephen went on to earn a scholarship to Kenyatta University. There he excelled in his studies and majored in special needs education and journalism. With this new skill set as well as his own experiences, Stephen hopes to improve the lives of others.

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Kuhenza for the Children

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INTERVENTIONS CONTINUED . . .

Family/Community (For those who are unable or have difficulty moving on their own)

Most people with a spinal cord injury have difficulty moving on their own. Depending on the severity of their condition, they may need some of these supports:



**ENSURE THEY HAVE
CLEAN CLOTHES**



**CHANGE THEIR
POSITION OFTEN**



**PROVIDE PAMPERS
(NAPKINS)**



USE TOILET ADAPTATION



**BATHE THEM AFTER
SOILING THEMSELVES**



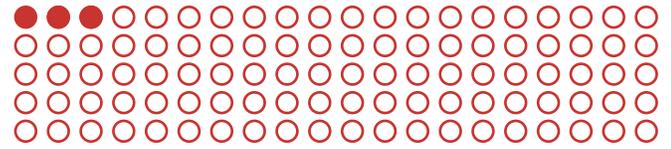
**PROVIDE ASSISTANCE
DEVICES**

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8. "Spinal Cord Injury," National Institute of Neurological Disorders and Stroke.
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SPINE CURVATURE DISORDERS



Up **3** out of every 100 people have some kind of spine to curvature disorder.¹

DESCRIPTION ^{2,3}

An irregular curvature of the spinal column that can create a C or S shape (Scoliosis), a curve in the lower back towards the front of the body (Lordosis), or a more than 50% curvature or hump in the upper back (Kyphosis).

SIGNS AND SYMPTOMS ^{4,5}

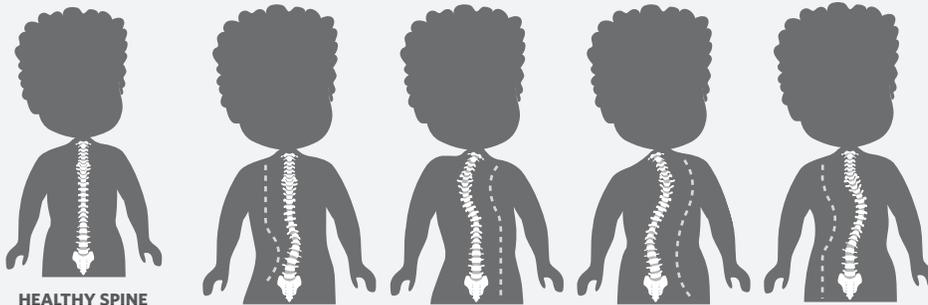
(There is wide variation in the number, type, and severity of signs and symptoms people experience.)

MAIN TYPES OF SPINE CURVATURE DISORDERS:

SCOLIOSIS

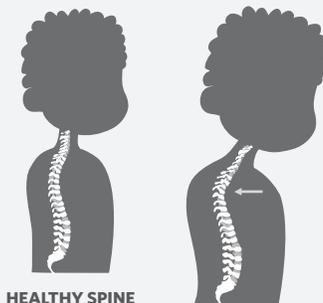
A 'C' or 'S' curvature of the spine causing uneven shoulders, hips, and leaning to one side

(Rotoscoliosis includes a sideways curvature as well as a strong degree of rotation or twist.)



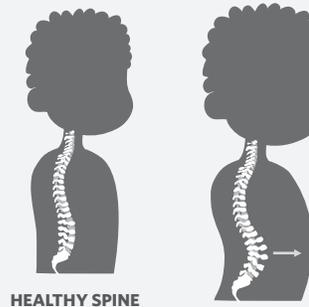
KYPHOSIS

An excessive curvature between the shoulders causing a hunching of the back



LORDOSIS

Increased inward curvature of the lower part of the spine



BACK PAIN



BREATHING PROBLEMS

POSSIBLE CAUSES AND RISK FACTORS ^{6,7}



FAMILY MEMBERS
with spine differences



MANY UNKNOWN CAUSES
The causes of most spine deformities are unknown.



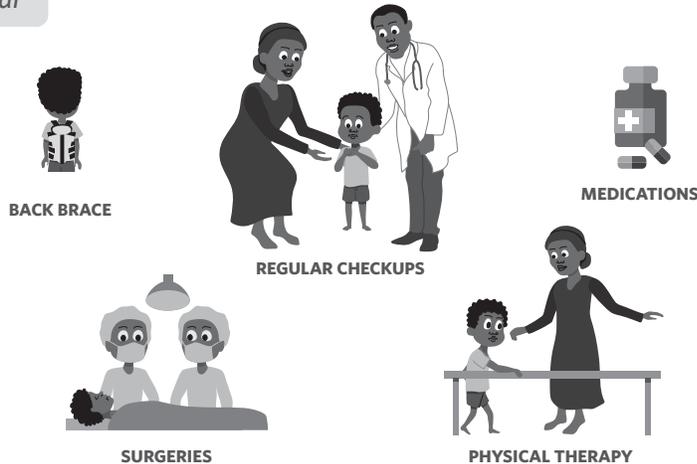
INFECTION
from diseases that impact the spine (tuberculosis, etc.)



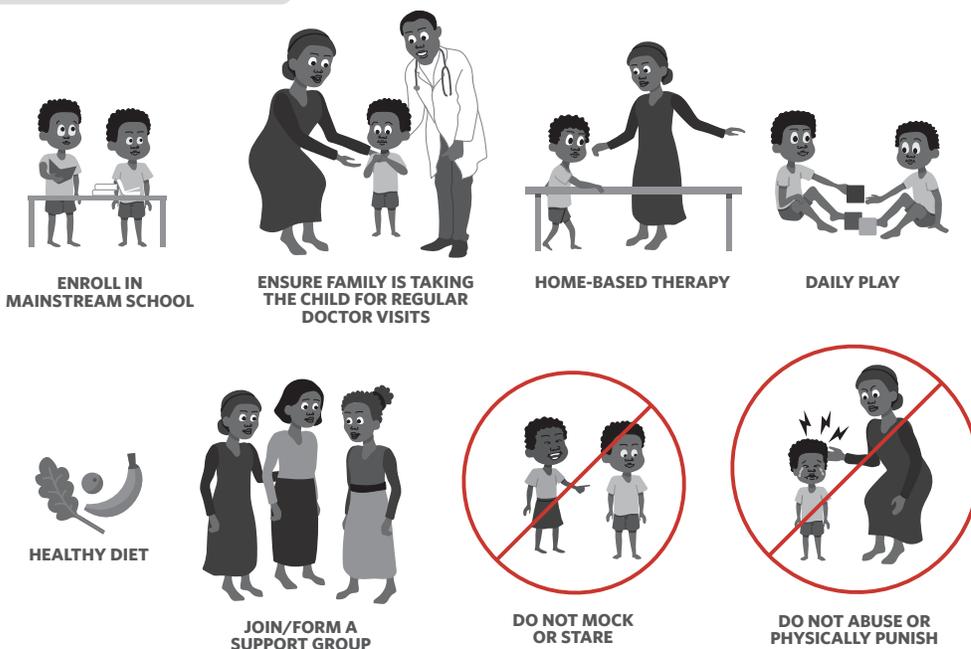
OTHER CONDITIONS
impact the spine like cancer, dwarfism, spina bifida, broken bones, muscular dystrophy, bone disease, etc

INTERVENTIONS ^{8,9,10}

Professional



Family/Community



NEEMA

Neema is a 23-year-old young woman who developed kyphoscoliosis at a young age.

As her spine started to curve, she developed a hunching of her upper back that affected the alignment of her shoulders and hips. Since her challenges were discovered later in life, surgical interventions were too risky to her mobility. However, her condition did not prevent her from finishing secondary school and looking into her next steps for education.

Today Neema enjoys being active in her community, where she is loved and accepted for her kindness and determination.

Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

NOTES

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TOURETTE SYNDROME



DESCRIPTION ^{2,3}

This condition typically starts to appear between 5 to 10 years old and is characterized by tics, which are repeated involuntary movements or sounds.

1 out of every 162 people have this syndrome.¹

SIGNS AND SYMPTOMS ^{4,5,6}

(There is wide variation in the type and severity of symptoms people experience.)

REPEATED BODY MOVEMENTS LIKE:



SHRUGGING SHOULDERS



INCREASED BLINKING



NECK STRETCHING

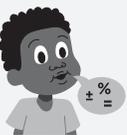


MOUTH MOVEMENT



SPITTING

REPEATED SOUNDS LIKE :



WORDS OR PHRASES



HUMMING



GRUNTING



SMELLING



COUGHING NOT RELATED TO ILLNESS

Note: For some with Tourettes, their tics may include inappropriate words, phrases, or gestures that seem rude, but the person is not in control of these tics.

TRIGGERS ^{7,8}

Avoiding these triggers may reduce the amount of tics a person with tourette's experiences.



STRESS



BEING TIRED



BEING EXCITED



ILLNESS

POSSIBLE CAUSES AND RISK FACTORS ^{9, 10}



FAMILY MEMBERS

about 50% of parents who carry the information for this disorder pass it on to their children



INFECTION

in child or mother (before birth)



PREMATURE

child is born too early



PROBLEMS

during birth

INTERVENTIONS ^{11, 12}

Professional

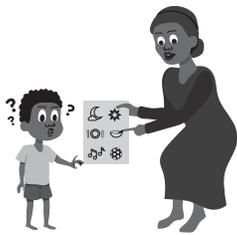


MEDICATIONS



BEHAVIOR THERAPY

Family/Community



PATIENCE AND UNDERSTANDING



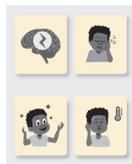
ENROLL IN MAINSTREAM SCHOOL



EDUCATE OTHERS (COMMUNITY, TEACHERS, ETC.) ON THE CONDITION



JOIN/Form A SUPPORT GROUP



AVOID TRIGGERS (SEE PREVIOUS PAGE)



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



MIKE ¹³

“My name is Mike Higgins and I am a father, a pastor, a husband, a dean of students of a seminary, a minister, a full colonel in the United States Army, and I have Tourette syndrome.

The first time I heard the word, ‘Tourette syndrome,’ from the doctor I had no idea what he was talking about. I had never heard of it. I didn’t know anybody who had ever heard of it before. There were a lot of days as a 12 year-old when I would lay in bed and think about what was happening to me that I could not control. It caused me to wonder, ‘Why was I born like this?’

I think that I was not diagnosed until I was 28 years old because our family doctors didn’t know about Tourette syndrome. Finally, I met a neurologist who asked me if anybody in my family had ever had this. I told him that my grandfather did. And he said, ‘I think I know what you have.’

I didn’t think that I was ever going to be married because it seemed like it was hard enough to just be single with Tourette syndrome. But in my family life now, it’s just who I am.”

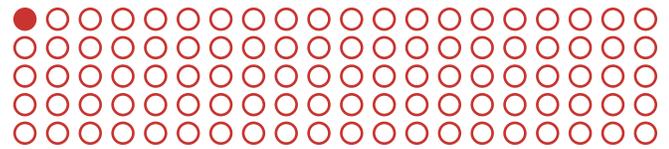
Art Director: Amy Allaire | www.amyallaire.com
Graphic Designer: Siwen Tao | www.siwentao.com

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TRAUMATIC BRAIN INJURY (TBI)



Up **1** out of every 100 people have to a TBI.^{1,2}

DESCRIPTION^{3,4}

A brain injury caused by an external blow/trauma to the head that ranges from mild to severe and can result in permanent disabilities and even death.

SIGNS AND SYMPTOMS^{5,6,7}

There is a wide variation in the type and severity of symptoms people experience. Some symptoms may appear right away, while others may develop over time.



TROUBLE EATING / DRINKING



SEIZURES (FITS)



UNUSUAL SLEEP PATTERNS OR DIFFICULTY WAKING UP



HEADACHE



NAUSEA OR VOMITING



LEARNING CHALLENGES



MOOD CHANGES OR SWINGS



DIFFICULTY PAYING ATTENTION



NO LONGER INTERESTED IN ACTIVITIES/TOYS ONCE ENJOYED



DIFFICULTY SEEING



RINGING IN EARS



BAD TASTE IN MOUTH



IRRITABILITY/CRYING CONTINUOUSLY



LOSS OF BALANCE/ UNSTEADY WALKING



LOSS OF A SKILL (SUCH AS TOILETING)



LIMITED OR NO SPEECH



LIMITED OR NO MOVEMENT

Note: Some TBIs may go away after time, while others exist for the person's lifetime, though some symptoms may improve.

POSSIBLE CAUSES AND RISK FACTORS ⁸

Note: Each of the following causes of a TBI involve a blow/trauma to the head.



FALLS



VEHICLE ACCIDENTS



INJURIES



PHYSICAL VIOLENCE



EXPLOSIONS/ BLASTS

INTERVENTIONS ^{9,10}

Professional



MEDICATIONS



SPECIALIZED EDUCATION (IF NEEDED)



REGULAR CHECKUPS



SPECIALIZED COUNSELING



PHYSICAL THERAPY (IF NEEDED)



SPEECH THERAPY (IF NEEDED)

Note: A medical professional should be seen as soon as possible after the injury to assess the damage to the brain.

Family/Community



TAKE MEDICINE AS DIRECTED



HAVE ENOUGH MEDICINE



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



JOIN/FORM A SUPPORT GROUP

Note: The text, graphics, and images contained in this guidebook are for informational purposes only. None of the material in this book is intended to be a substitute for professional medical advice or diagnosis.



MARTIN ^{11,12}

Following a car accident in Kenya in 2012, Rev. Martin Mangi was in a coma for three months and was unable to speak for 13 months. He also experienced challenges with his balance and vision as well as with emotional outbursts of violence and anxiety. His friends and family worried he would never fully recover.

Eventually, Martin traveled to the US and began working with physical, occupational, speech, and recreation therapists.

“After a week, there was a change in his speech,” Margaret says. “Everyone could hear it. And he continued to improve steadily. Also, there was gradual changes in his walking and standing, too. The therapy ... was really specialized and focused, and the therapists were very positive and friendly. They gave him a lot of hope.”

Martin has since returned to Kenya and continues to improve. Today he continues physical therapy, can walk four miles a day, and has learned to feed himself easily.

Art Director: Amy Allaire | www.amyallaire.com
 Graphic Designer: Siwen Tao | www.siwentao.com

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