

Let's Talk

ABOUT CIDP

LET'S TALK ABOUT CIDP HAS BEEN VALIDATED BY THE
HOSPITAL FOR SICK CHILDREN (SICKKIDS) NEUROMUSCULAR TEAM

You've just been diagnosed with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

You probably have lots of questions and that's okay! All kids with CIDP have questions. With the right medicine and care, many kids with CIDP start to feel better and stronger. Sometimes the illness can even go away. Reading this with your family can help you understand what's happening in your body and work through your questions. The most important part to remember is that having CIDP doesn't change who you are. You're still the same lovable you!

Highlights

- What is CIDP?
- Treatment
- Your team
- Symptoms
- Words to help



What is CIDP?

CIDP is a bit like having a problem with the wires in your body. Your nerves act like wires that help your brain send messages to your muscles and help you feel things. Nerves are covered with a special coating, kind of like the plastic coating on a wire, that helps send the messages. With CIDP, the body's defence system (the immune system) gets mixed up and accidentally attacks this coating. The messages don't travel properly which can make your muscles feel weak and your skin might feel numb, hot or tingly.

More Details

Nerves are like wires:

- Nerves send messages from your brain to your body, telling your muscles to move and carrying information about how things feel (like if something is hot or cold, or if you're touching something soft or hard). You have two types of nerves, ones that talk to your muscles and ones that let you feel things.

Myelin is the insulation (like wearing a winter coat):

- Nerves have a special coating called myelin that helps the messages travel quickly and smoothly.

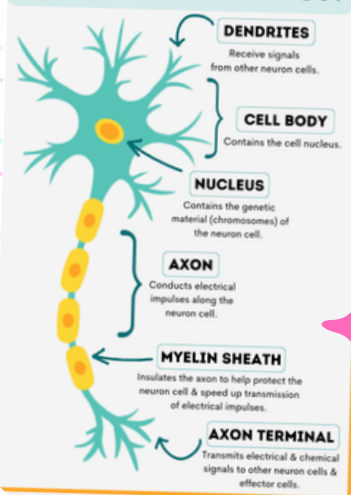
CIDP is like a mix-up:

- In CIDP, the body's defense system (the immune system) mistakenly attacks the myelin. This is called demyelination.

Weakness and numbness:

- When myelin is damaged, the messages can't travel the right way and that can make your muscles feel weak, tingly or numb.

PARTS OF A NEURON



Neuron

Possible symptoms

- weak arms and legs
- losing your balance
- fatigue
- trouble concentrating
- tingling, strange feelings



SYMPTOMS

You may be having trouble doing everyday things like getting dressed, making a snack, or playing your favourite sport or game. Your body might just feel different. These are called symptoms. There are many different kinds of symptoms.

Some of these symptoms are invisible to others. That's why it is so important to talk about how you're feeling.



More Details

Weak arms and legs:

- Your arms and legs feel very tired, as if there were weights tied to them.

Losing your balance:

- You might lose your balance, or fall over. It can be hard to walk in a straight line.

Fatigue - like being tired:

- Fatigue is like being tired but having a nap or rest doesn't make it better. You can feel fatigue at anytime, even after a long sleep.

Having trouble concentrating:

- Sometimes CIDP can make it hard to pay attention or remember things.

Tingling, strange feelings:

- When myelin is damaged, this can cause tingling, burning, numbness and strange feelings - kind of like the feeling when your hand or foot falls asleep.



I feel strange

Possible treatments

- IVIG (Immunoglobulin)
- Plex
- Corticosteroids or other Immunosuppressants

Treatments can be different for every patient.

TREATMENTS USED TO HELP

IVIG (Immunoglobulin):

- IVIg is made from protein (antibodies) from healthy donors and is usually given every few weeks. IVIg can help by blocking the immune system's attack on the nerves.

Plex or also known as Plasmapheresis:

- Plex is a process that cleans your blood. It takes out the harmful antibodies and then puts your cleaned blood back in your body.

Corticosteroids:

- These medications can reduce swelling (inflammation) in the body and calm the immune system. They are often used with IVIg or as a second option if IVIg isn't enough.

Let's Meet Some People

THAT WILL HELP

These are just a few that might be on your team

Neuromuscular Neurologist

This is a very special doctor that knows a lot about nerves and muscles.



Nurse Practitioner

A highly trained nurse who can do many of the same things as a doctor and helps people stay healthy or get better.

Nurse

This is a person who works with doctors and other healthcare professionals to take care of people who need help.

Physiotherapist

This specialist will use exercises, games, and special activities to help kids get stronger, move better, and feel more confident doing the things they love.



Occupational Therapist

This is a specialist who uses fun activities to help kids get better at every day things, like getting dressed and opening jars, so they feel more confident doing these tasks on their own.

Social Worker or Psychologist

This a person who talks with kids to help them understand their feelings. They teach kids tricks that help make everyday life a little easier.

How Does It Hurt

WORDS TO HELP

Sore

- achy
- dull
- low
- tender

Sharp

- stings
- shooting
- poking
- stabbing

Pounds

- throbbing
- cramping
- pulsing
- spasms
- beating like a heartbeat

Pressure

- squeezing
- heavy
- crushing
- squished
- like a hug

Temp

- warm
- hot
- burning
- cold
- freezing

Feels

- tingly
- tender
- numb
- scratchy

How long?

- sudden
- quick
- spreading
- long
- doesn't stop

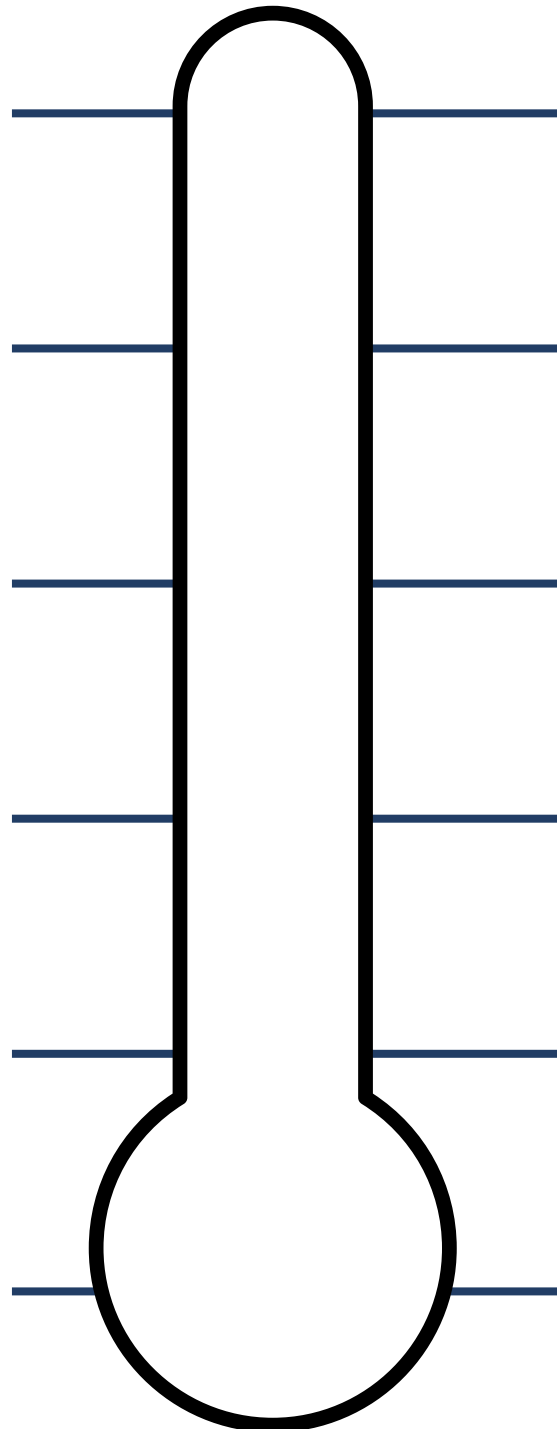
Tiring

- wears me out
- need to rest
- don't want to/
can't move



Pain / Symptoms Thermometer

How is your pain / symptoms today?
Print and have available to be coloured.



**The worst
pain**

Horrible pain

A lot of pain

Some pain

**A tiny bit of
pain**

**No pain, I feel
great**

Symptom/Pain Chart



None - 0

This chart can be used for pain or a specific symptom.

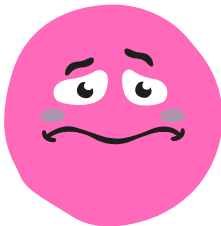


A little 1-2

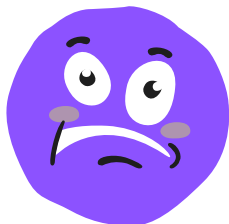
Have a look at how does it hurt - words that help page.



Some 3-4



A lot 5-6



Horrible 7-8



The Worst 9-10

Did you know that a turtle is our mascot?

The turtle is a perfect symbol

- Slow and steady progress
- Strength and patience
- Hope and determination



GBS/CIDP
Foundation of Canada



Fondation canadienne du
SGB/PDIC

GBS/CIDP WORD SEARCH

We get better slowly but surely.



B	A	L	A	N	C	E	T	E	M	P	B	I	C	S
I	C	G	G	R	E	E	N	H	O	U	S	E	A	U
O	M	Y	E	L	E	N	S	H	E	A	T	H	R	S
P	H	Y	S	I	C	A	L	T	H	E	R	A	P	Y
I	P	L	A	S	M	A	E	X	C	H	A	N	G	E
V	G	P	S	P	I	N	A	L	T	A	P	R	R	I
I	I	L	S	E	E	O	F	T	E	T	G	O	T	N
G	C	A	T	I	N	G	L	I	N	G	Y	M	Y	E
T	A	N	L	E	P	E	A	S	A	I	E	E	T	U
P	U	E	A	W	E	A	K	N	E	S	S	N	I	R
D	F	R	C	A	C	P	O	V	I	A	F	T	A	O
I	E	O	T	R	E	F	L	E	X	E	S	A	G	L
R	F	L	C	L	C	O	C	C	I	M	C	L	B	I
A	X	O	N	E	E	N	E	R	V	E	I	I	S	G
T	F	G	C	L	C	L	F	C	Y	M	E	S	S	I
T	I	M	M	U	N	E	S	Y	S	T	E	M	O	S
O	E	S	P	O	L	C	I	D	P	N	T	D	L	T
N	U	R	S	E	C	O	F	A	T	I	G	U	E	Y

GBS

CIDP

NERVE

TURTLE

IVIG

IMMUNE SYSTEM

PLASMA EXCHANGE

REFLEXES

NURSE

AXON

MYELIN SHEATH

SPINAL TAP

WEAKNESS

BALANCE

FATIGUE

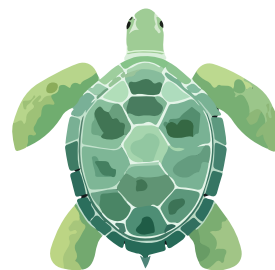
NEUROLOGIST

TINGLING

PHYSICAL THERAPY

GBS/CIDP CROSSWORD PUZZLE

We get better slowly but surely.

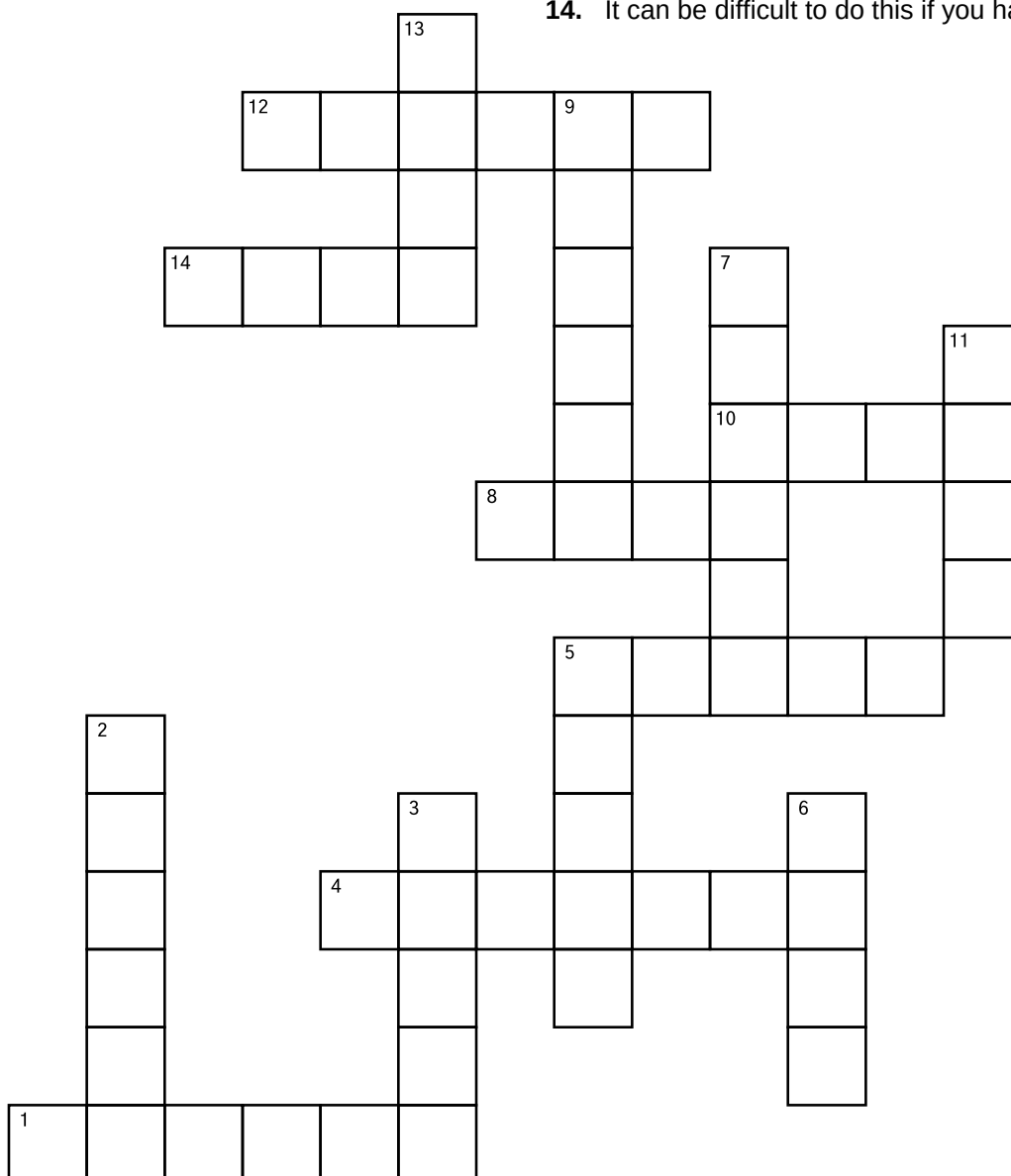


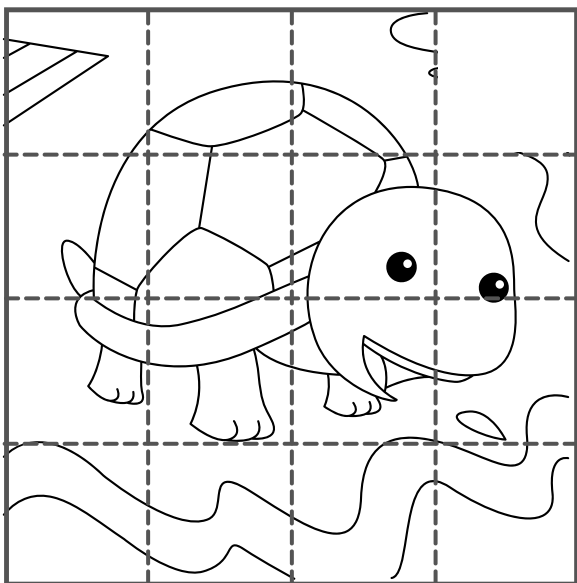
Down:

2. Our mascot, we get better slowly but surely.
3. These might have trouble holding things with CIDP.
5. What do doctors do to help people with CIDP?
6. It's important to get plenty of this if you have CIDP.
7. Who helps treat CIDP?
9. This system in the body is involved in CIDP.
11. These might feel heavy or hard to move with CIDP.
13. Feeling this way can be a symptom of CIDP.

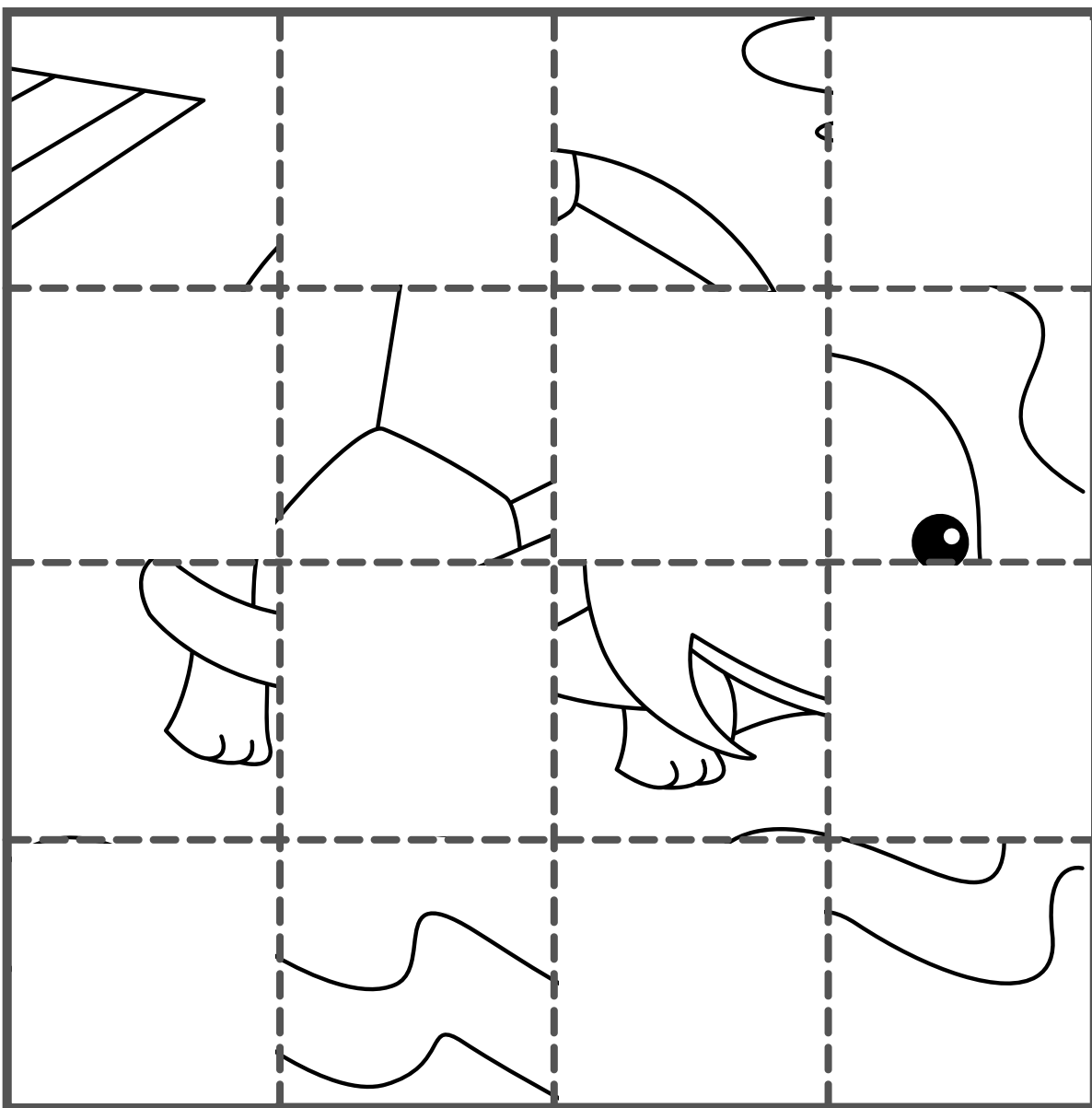
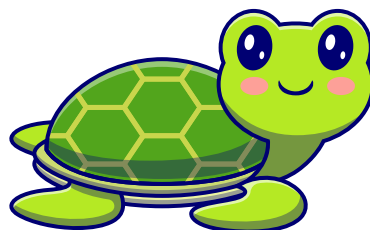
Across:

1. What part of the body does CIDP affect?
4. People with CIDP might have trouble with this.
5. You might feel this way if you have CIDP.
8. This part of the body might feel tingly due to CIDP.
10. People with CIDP receive this from their loved ones.
12. The special coating on your nerves.
14. It can be difficult to do this if you have CIDP.



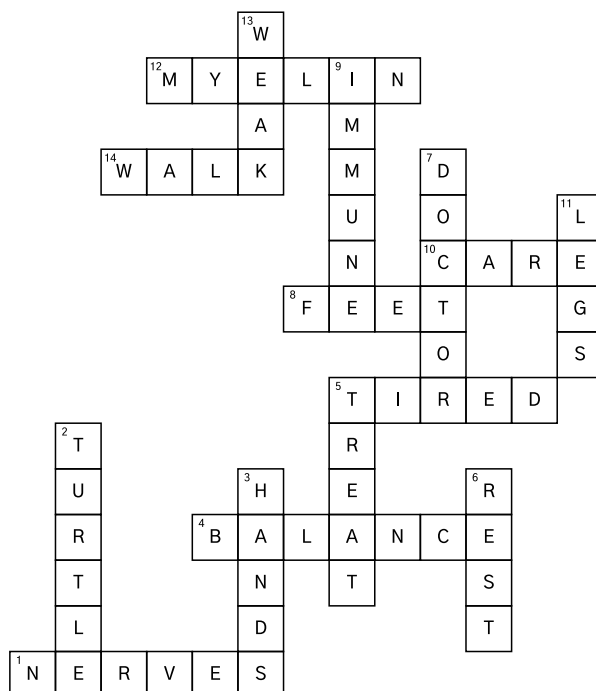
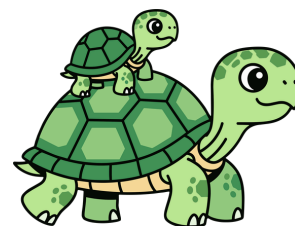


Can you
finish the
drawing?





GBS/CIDP ANSWER KEY



B A L A N C E T E M P B I C S
 I C G G R A E N H O U S E A U
 O M Y E L E N S H E A T H R S
 P H Y S I C A L T H E R A P Y
 I P L A S M A E X C H A N G E
 V G P S P I N A L T A P R R I
 I I L S E E O F T E T G O T N
 G C A T I N G L I N G Y M Y E
 T A N L E P E A S A I E E T U
 P U E A W E A K N E S S N I R
 D F R C A C P O V I A F T A O
 I E O T R E F L E X E S A G L
 R F L C L C O C C I M C L B I
 A X O N E E N E R V E I I S G
 T F G C L C L F C Y M E S S I
 T I M M U N E S Y S T E M O S
 O E S P O L C I D P N T D L T
 N U R S E C O F A T I G U E Y