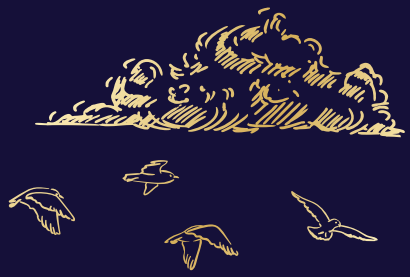


A BEAR WHO TOOK HIS TIME

THE MYASTHENIA GRAVIS EDITION

Adapted from the original
Winnie-the-Pooh

BY A.A. MILNE

This special centennial chapter edition of Winnie-the-Pooh was created in collaboration with Canadians living with myasthenia gravis (MG), and the patient advocacy group Muscular Dystrophy Canada.

Inspired by Christopher Robin Milne, who lived with MG and was the son of A.A. Milne, this adaptation brings these two worlds together through the eyes of one of literature's most beloved characters. Winnie-the-Pooh navigates living with MG, offering a gentle glimpse into what life can be like for people living with a rare, chronic, neuromuscular disease that causes fluctuating muscle weakness and fatigue that can affect everyday activities such as speaking, swallowing, moving, and even breathing.

- Muscular Dystrophy Canada

Part of a broader disease awareness campaign recognizing the many faces of MG, this adaptation seeks to spark meaningful conversations and deepen understanding of a disease that may not always be visible to others.

Thank you to the Canadians living with MG who generously shared their experiences and insights and for their collaboration in bringing this project to life.

A BEAR WHO TOOK HIS TIME

THE MYASTHENIA GRAVIS EDITION

WINNIE-THE-POOH

WE ARE INTRODUCED TO WINNIE-THE-POOH AND SOME BEES, AND THE STORY BEGINS

HERE is Edward Bear, coming downstairs now, bump, bump, bump, on the back of his head, behind Christopher Robin. It is, as far as he knows, the only way of coming downstairs **these days, because his muscles do not always do what he asks of them. With Myasthenia Gravis (MG), even something as ordinary as stairs can feel like a great expedition, especially when tiredness decides to visit.** But sometimes he feels that there really is another way, if only he could stop bumping for a moment, **rest a while** and think of it. And then he feels that perhaps there isn't, **at least not today**. Anyhow, here he is at the bottom, and ready to be introduced to you: Winnie-the-Pooh.

When I first heard his name, I said, just as you are going to say, "But I thought he was a boy?"

"So did I," said Christopher Robin.

"Then you can't call him Winnie?"

"I don't."

"But you said——"

"He's Winnie-ther-Pooh. Don't you know what '*ther*' means?"

"Ah, yes, now I do," I said quickly; and I hope you do too, because it is all the explanation you are going to get.

Sometimes Winnie-the-Pooh likes a game of some sort when he comes downstairs **– on days when his strength is with him and his arms and legs feel steady enough to manage it.** And sometimes, **when his MG makes him tired and his muscles won't quite cooperate,** he likes to sit quietly in front of the fire and listen to a story. This evening——

"What about a story?" said Christopher Robin.

"*What* about a story?" I said.

"Could you very sweetly tell Winnie-the-Pooh one?"

"I suppose I could," I said. "What sort of stories does he like?"

"About himself. Because he's *that* sort of Bear."

Oh, I see."

"So could you very sweetly?"

"I'll try," I said.

So I tried.

Once upon a time, a very long time ago now, about last Friday, Winnie-the-Pooh lived in a forest all by himself under the name of Sanders.

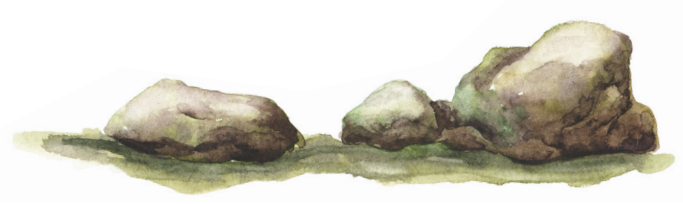
("What does 'under the name' mean?" asked Christopher Robin.

"It means he had the name over the door in gold letters, and lived under it."

"Winnie-the-Pooh wasn't quite sure," said Christopher Robin.

"Now I am," said a growly voice.

"Then I will go on," said I.)



One day when he was out walking, **taking his time as he went, because walking sometimes took more out of him than it used to – as is often the way with his particular illness – an ordinary walk can become quite the challenge –** he came to an open place in the middle of the forest, and in the middle of this place was a large oak-tree, and, from the top of the tree, there came a loud buzzing-noise.

Winnie-the-Pooh sat down at the foot of the tree, put his head between his paws and began to think, **slowly and very carefully, because his brain had been feeling particularly foggy today, the sort of exhausted feeling MG can bring, where thoughts take longer to line themselves up and things seem muddled.**

He sat quietly for a moment to gather all the thoughts properly, just to make sure they were all in the right place.

First of all he said to himself:

"That buzzing-noise means something. You don't get a buzzing-noise like that, just buzzing and buzzing, without its meaning something. If there's a buzzing-noise, somebody's making a buzzing-noise, and the only reason for making a buzzing-noise that *I* know of is because you're a bee."

Then he thought another long time, and said: "And the only reason for being a bee that I know of is making honey."

And then he got up, and said: "And the only reason for making honey is so as I can eat it." So he began to climb the tree, **slowly, and with more effort than he had at first expected, because even when you are determined, MG does not always agree with your plans. He stopped once or twice to catch his breath, taking it at a pace he felt was quite alright, paw by paw.**

He climbed and he climbed and he climbed, and as he climbed he sang a little song to himself. It went like this:

Isn't it funny
How a bear likes honey?
Buzz! Buzz! Buzz!
I wonder why he does?

Then he climbed a little further ... and a little further ... and then just a little further. By that time he had thought of another song.

It's a very funny thought that, if Bears were Bees,
They'd build their nests at the *bottom* of trees.
And that being so (if the Bees were Bears),
We shouldn't have to climb up all these stairs.

He was getting rather tired by this time, **much more tired than he had thought, the kind of sudden heavy fatigue that arrives without asking and makes your**

muscles feel like they belong to somebody else. So he paused on a branch to rest his muscles a while before going on, because it seemed the sensible thing to do, so that is why he sang a **Rather Tired Song.** He was nearly there now, and if he just stood on that branch ...

Crack!

"Oh, help!" said Pooh, as he dropped ten feet on the branch below him.

"If only I hadn't——" he said, as he bounced twenty feet on to the next branch.

"You see, what I meant to do," he explained, as he turned head-over-heels, and crashed on to another branch thirty feet below, "what I meant to do——"

"Of course, it *was* rather——" he admitted, as he slithered very quickly through the next six branches.

"It all comes, I suppose," he decided **a little wearily,**

as he said good-bye to the last branch, spun round three times, and flew gracefully into a gorse-bush,

"it all comes of *liking* honey so much. Oh, help!"

He crawled out of the gorse-bush, brushed the prickles from his nose, and began to think again, **taking a moment longer, because it was not always easy to think quickly after such a tumble, especially when his illness makes recovery a lot longer than it does for most.** And the first person he thought of was Christopher Robin.

("Was that me?" said Christopher Robin in an awed voice, hardly daring to believe it.

"That was you."

Christopher Robin said nothing, but his eyes got larger and larger, and his face got pinker and pinker.)

So Winnie-the-Pooh went round to his friend

Christopher Robin who lived behind a green door in another part of the forest, **because sometimes Pooh found it was easier to ask his friend for help than to manage everything alone, especially when your body has already done quite enough for one day.**

"Good morning, Christopher Robin," he said.

"Good morning, Winnie-*the*-Pooh," said you.

"I wonder if you've got such a thing as a balloon about you?"

"A balloon?"

"Yes, I just said to myself coming along: 'I wonder if Christopher Robin has such a thing as a balloon about him?' I just said it to myself, thinking of balloons, and wondering."

"What do you want a balloon for?" you said.

Winnie-the-Pooh looked round to see that nobody

was listening, put his paw to his mouth, and said in a deep whisper: "*Honey!*"

"But you don't get honey with balloons!"

"*I* do," said Pooh.

Well, it just happened that you had been to a party the day before at the house of your friend Piglet, and

you had balloons at the party. You had had a big green balloon; and one of Rabbit's relations had had a big blue one, and had left it behind, being really too young

to go to a party at all; and so you had brought the green one *and* the blue one home with you.

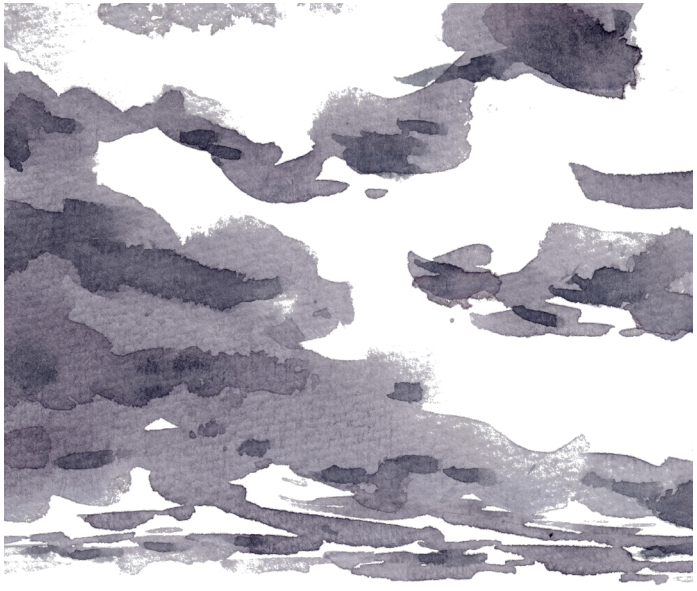
"Which one would you like?" you asked Pooh.

He put his head between his paws and thought very carefully **because his eyes had become heavy after the tumble and he had started seeing two things when there ought to have been one.**

"It's like this," he said.

"When you go after honey with a balloon, the great thing is not to let the bees know you're coming... **and also to have a plan, because things do not always work out the first way you think they will." Pooh had become particularly talented at having multiple plans since his diagnosis as he learnt that sometimes things are far more difficult than they first appeared.**

"Now, if you have a green balloon, they might think you were only part of the tree, and not notice you,



and, if you have a blue balloon, they might think you were only part of the sky, and not notice you, and the question is: Which is most likely?"

"Wouldn't they notice *you* underneath the balloon?" you asked.

"They might or they might not," said Winnie-the-Pooh.

"You never can tell with bees."

He thought for a moment and said: "I shall try to look like a small black cloud. That will deceive them."

"Then you had better have the blue balloon," you

said; and so it was decided.

Well, you both went out with the blue balloon, and you took your gun with you, just in case, as you always did, and Winnie-the-Pooh went to a very muddy place that he knew of, and rolled and rolled until he was black all over; and then, when the balloon was blown up as big as big, and you and Pooh were both holding on to the string, you let go suddenly, and Pooh Bear floated gracefully up into the sky, and stayed there—level with the top of the tree and about twenty feet away from it.

"Hooray!" you shouted.

"Isn't that fine?" shouted Winnie-the-Pooh down to you.

"What do I look like?"

"You look like a Bear holding on to a balloon," you said.

"Not," said Pooh anxiously,

"—not like a small black cloud in a blue sky?"

"Not very much."

"Ah, well, perhaps from up here it looks different. And, as I say, you never can tell with bees."

There was no wind to blow him nearer to the tree, so there he stayed. He could see the honey, he could smell the honey, but he couldn't quite reach the honey, **not as easily as he felt he ought to be able to, which was a little disappointing.**

After a little while he called down to you.

"Christopher Robin!" he said in a loud whisper.

"Hallo!"

"I think the bees *suspect* something!"

"What sort of thing?"

"I don't know. But something tells me that they're *suspicious*!"

"Perhaps they think that you're after their honey."

"It may be that. You never can tell with bees."

There was another little silence, and then he called down to you again.

"Christopher Robin!"

"Yes?"

"Have you an umbrella in your house?"

"I think so."

"I wish you would bring it out here, and walk up and down with it, and look up at me every now and then, and say 'Tut-tut, it looks like rain.' I think, if you did that, it would help the deception which we are practising on these bees."

Well, you laughed to yourself, "Silly old Bear!" but you didn't say it aloud because you were so fond of him, and you went home for your umbrella.

"Oh, there you are!" called down Winnie-the-Pooh, as soon as you got back to the tree.

"I was beginning to get anxious. I have discovered that the bees are now definitely Suspicious."

"Shall I put my umbrella up?" you said.

"Yes, but wait a moment. We must be practical. The important bee to deceive is the Queen Bee. Can you see which is the Queen Bee from down there?"

"No."

"A pity. Well, now, if you walk up and down with your umbrella, saying, 'Tut-tut, it looks like rain,' I shall do what I can by singing a little Cloud Song, such as a cloud might sing.... Go!"

So, while you walked up and down and wondered if it would rain, Winnie-the-Pooh sang this song:

How sweet to be a Cloud
Floating in the Blue!
Every little cloud
Always sings aloud.

"How sweet to be a Cloud
Floating in the Blue!"
It makes him very proud
To be a little cloud.

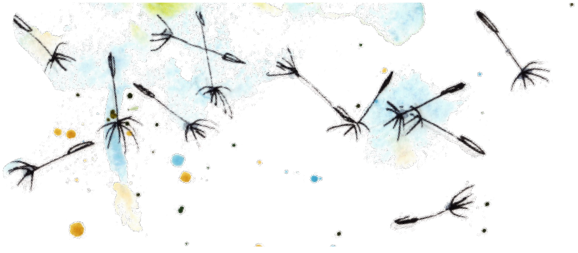
The bees were still buzzing as suspiciously as ever. Some of them, indeed, left their nests and flew all round the cloud as it began the second verse of this

song, and one bee sat down on the nose of the cloud for a moment, and then got up again.

"Christopher—*ow*!—Robin," called out the cloud.

"Yes?"

"I have just been thinking – **which today is taking a little longer for me than usual on the account of the tiredness**—and I have come to a very important decision. *These are the wrong sort of bees.*"



"Are they?"

"Quite the wrong sort. So I should think they would make the wrong sort of honey, shouldn't you?"

"Would they?"

"Yes. So I think I shall come down."

"How?" asked you.

Winnie-the-Pooh hadn't thought about this. If he let go of the string, he would fall—*bump*—and he didn't like the idea of that. **It already happened too often. But his arms felt as if someone had tied sandbags to them and it was getting harder and harder to keep them lifted.** So he thought for a long time, and

then he said:

"Christopher Robin, you must shoot the balloon with your gun. Have you got your gun?"

"Of course I have," you said. "But if I do that, it will spoil the balloon," you said.

"But if you *don't*," said Pooh,

"I shall have to let go, and that would spoil *me*, **and I don't think I've quite the strength for that today."**

When he put it like this, you saw how it was, **and you were adamant to help your friend in need,** you

aimed very carefully at the balloon, and fired.

"*Ow!*" said Pooh.

"Did I miss?" you asked.

"You didn't exactly *miss*," said Pooh, "but you missed the *balloon*."

"I'm so sorry," you said, and you fired again, and this time you hit the balloon, and the air came slowly out, and Winnie-the-Pooh floated down to the ground.

But his arms were so stiff from holding on to the string of the balloon all that time that they stayed up straight in the air for more than a week, and whenever a fly came and settled on his nose he had to blow it off, **because MG sometimes meant that when he used his strength for too long, it took a while to come back again.**

And I think—but I am not sure—that *that* is why he was always called Pooh.

"Is that the end of the story?" asked Christopher Robin.

"That's the end of that one. There are others."

"About Pooh and Me?"

"And Piglet and Rabbit and all of you. Don't you remember?"

"I do remember, and then when I try to remember, I forget."

"That day when Pooh and Piglet tried to catch the Heffalump——"

"They didn't catch it, did they?"

"No."

"Pooh couldn't, because, **he was having one of those very foggy, tired thinking kind of days. It was such a tiredness that even remembering what you wanted to remember seemed to wonder off to someplace else.** Did *I* catch it?"

"Well, that comes into the story."

Christopher Robin nodded.

"I do remember," he said, "Only Pooh doesn't very well, so that's why he likes having it told to him again. Because then it's a real story and not just a remembering, **especially on days when tiredness makes remembering feels harder than it normally does."**

"That's just how *I* feel," I said.

Christopher Robin gave a deep sigh, picked his Bear up by the leg, and walked off to the door, trailing Pooh behind him. At the door he turned and said, "Coming to see me have my bath?"

"I might," I said.

"I didn't hurt him when I shot him, did I?"

"Not a bit."

He nodded and went out, and in a moment, I heard Winnie-the-Pooh—*bump, bump, bump*—going up the stairs behind him, **a little more slowly this time, because on such tired days, MG asks you to take the stairs one careful bump at a time.**

END OF CHAPTER

About Myasthenia Gravis

Myasthenia gravis (MG) is a rare, chronic autoimmune neuromuscular disorder that causes muscle weakness and fatigue. [1,2] The condition occurs when the body's immune system mistakenly attacks the communication point between nerves and muscles, making it more difficult for muscles to respond to signals from the brain. [1,2]

MG affects the voluntary muscles used for many everyday activities, including speaking, chewing, swallowing, facial expressions, moving, and breathing. Symptoms often fluctuate throughout the day and can vary significantly from person to person. [1,2]

There are two main forms of MG: ocular MG, which primarily affects the muscles that control the eyes and eyelids, and generalized MG, which affects multiple muscle groups throughout the body. [4]

Common symptoms may include: [1]

- Drooping eyelids
- Double or blurred vision
- Difficulty speaking or swallowing
- Weakness in the arms, hands, legs, or neck
- Fatigue that worsens with activity
- Shortness of breath in more severe cases

Because many symptoms can resemble those of other conditions, obtaining an accurate diagnosis can sometimes be challenging. [5]

Although there is currently no cure for myasthenia gravis, advances in treatment are helping many Canadians better manage their symptoms and continue participating in the activities that matter most to them. [6]

In Canada, MG is estimated to affect approximately 30 people per 100,000, with women more commonly diagnosed at younger ages and men more commonly diagnosed later in life. [3]

To learn more about myasthenia gravis and support available for Canadians living with the condition, visit Muscular Dystrophy Canada.

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