

Crystals in my eyes

This booklet
belongs to



In her office,
Ben's doctor
is telling
him all about
cystinosis.

"Your body is made
up of many many
tiny cells," she
explained.

"You can think of
cells as being like
tiny little bodies, so small you can't see them,
but there are lots and lots of them. All grouped
together your cells
make up your organs,
including your heart
and stomach and eyes,
and the rest of your
body."

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N L T A V R
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"In cystinosis, some of the cells don't work properly. Little crystals start to build up in the cells. Your pills dissolve the crystals in the cells in the same way as tea dissolves sugar crystals.

This treatment will protect your organs from the crystals. But it can't get into your eyes. So we need to find a different way to protect your eyes. I know someone who can help you. It is the owl who lives in the bottom of the woods"

On his way to school the same day, Ben thought about what the doctor had told him.

*L*ike every afternoon after school, the children were playing together and laughing. But when the sun came out Ben started to squint and blink. So he puts on a pair of sunglasses.

"What are you doing?"
said Timothy,
the timid fox, surprised.

"My eyes hurt,"
said Ben and started
to cry.





"What's the matter?"
asked Sophie the deer,
concerned.

*"The doctor told me I've got
cystinosis,"* Ben said.

"What's that?" asked Timothy.

*"It's a disease. I get crystals in my
body and also in my eyes. That's why
I need sunglasses."*

"Wow, crystals? I can't see any," said Sophie,
looking with curiosity into Ben's eyes.

*"You can't see them. But they are damaging
my eyes. I might go blind,"* He replied.

"Like the grumpy old magpie?"

Sophie carried on, *"He's always in such a bad
mood!"*

Timothy, who had been listening in, asked:

"How can you treat that cyst-a-thing?"



"The doctor told me that the owl who lives in the bottom of the woods will show me what to do," said Ben. *"I need your help, because I've never been there before, I might get lost!"* he added.

"Well we'll all go!" Said Sophie.

"Can I come too?" Timothy asked nervously, not at all sure if they meant him too.

"Of course you can come with us!" said Sophie and Ben together.



The friends faced many dangers in the woods. They were chased by wolves. And then they were attacked by bats.

And after a short break to catch their breath and so that Ben could take a sip of water and swallow his pills, they had to swing across a raging river.





*F*inally, the friends found the owl.

"Please Mr Owl" asked Sophie politely,
"can you help us?"

Ben said,
"I've got cystinosis. Can you help me save my eyes? Please say you can, we've come so far."

"My little friends, because you've been so brave, you supported each other and you didn't turn back when things were scary, I will tell you what I know," the wise owl replied.



"It's really simple. You just need to take these special drops every day. If you put those drops in your eyes they will dissolve the crystals. But you must remember to do this regularly every day. It is important for your eyes. If you do it right, you won't end up like the grumpy old magpie. He has cystinosis too, but he never put the drops in like he was supposed to. He said the drops made his eyes itch and sting. Eventually his eyes got damaged and he couldn't see properly anymore. But it won't happen to you if you put the drops in your eyes regularly every day."





But Ben was still not sure. "*How will I remember to do that?*" he asked.

"*Oh that's easy,*" said the owl, with a smile, "*you just have to put a drop into each of your eyes at regular times of the day, like at breakfast, lunch, your afternoon break and at supper time. Your parents and teachers will help you to remember and do it properly.*"



"*We can help too!*" said Sophie and Timothy proudly.

"*You see, I'm sure that with the help of your family and your friends, you will have no problem taking those drops,*" said the owl.



"Thank you Mr Owl!" the friends chorused,
and hurried home.



And that's how Ben could carry on jumping,
running and playing with his friends.

To dissolve the crystals in your eyes, you need to put one drop in each of your eyes regularly every day.

